Rehabilitation of Pediatric-Onset Spinal Cord Injury

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Key Points

Functional electrical stimulation and implantable, percutaneous electrical stimulation, while shown to have a functional impact on standing and swing-thru gait and even with greater satisfaction than knee-ankle foot orthoses, other barriers persist and neither approach has been effectively translated to clinical practice and home use.

The use of orthotics and assistive devices has been described according to who, what, when and sustained use or abandonment by adolescence due to convenience of mobility, e.g., wheelchair. Parapodiums appear favored in early childhood, with progression to knee-ankle-foot orthoses and reciprocating gait orthoses with advancing age and abandonment in adolescence for wheeled mobility. No distinct orthotic is recommended but instead individualized care. The use of braces does not lead to walking without braces.

The use of a treadmill in the context of restorative activity-based locomotor training has demonstrated benefit in those with incomplete spinal cord injury (SCI), though a variety of training approaches and delivery of training has been reported.

The term “treadmill training” is insufficient to use for classifying and intervention comparison. The principles guiding clinical decision-making using this tool, the overall goal and intent, and the “how” behind progression are key to understanding each intervention regardless of commonality in the selected equipment used for delivery.

There has been limited achievement of walking in pediatrics with complete SCI, thus research should advance this agenda.

Most of the pediatric literature for rehabilitation of standing/walking has been case studies and small n studies.

Trunk control after pediatric SCI can be improved via activity-based locomotor training in children with acute (< 1-year post-SCI) and chronic SCI (> 1-year post-SCI).

While greater rigor in pediatric research is recommended, e.g., inclusion of blinded assessors, the limited population numbers and particularly limited availability in one geographic location and its heterogeneity of etiology, presentation, and impairment level provide challenges to the use of the randomized clinical trial design. Other designs, including within subjects (subjects as own control), wait-list design, or adaptive designs should be considered alternatively and as informative, especially when examining interventions in children with chronic SCI. Small “n” studies in children with chronic SCI often provide the needed pilot work to direct a larger study of mechanisms and efficacy. This is especially true when the intended goal, e.g., recovery of walking, is clearly absent in those with chronic SCI and complete SCI.

Walking outcome measures mirror the use of compensation-focused interventions targeting function and independence with use of braces and equipment due to paralysis providing external support.

Measures that disallow compensation focus on “how” a movement or task, such as sitting upright, standing, or walking is performed to denote progress and align with the use of recovery-focused therapies.

Evidence on upper extremity function for children with tetraplegia is limited to low level studies on finite topics. The body of literature lacks the breadth of interventions and careful measurement of function present in the adult literature.

Functional electrical stimulation is effective at improving upper extremity movement efficiency, consistency, and strength. Performance of skilled tasks is better with functional electrical stimulation as compared to tenodesis alone. functional electrical stimulation may be used in combination with tendon transfers to build more options for movement, where there previously was none.

Children who participated in functional electrical stimulation therapies reported greater confidence in movement and resulting enhancements in quality of life (Davis et al. 1997; Mulcahey et al. 1997; Mulcahey MJ, 1997; Mulcahey et al. 1994; Smith et al. 1994; Smith et al. 1996, 2001; Smith et al. 1992; Triolo et al. 1994).

Tendon transfers are useful in restoring both proximal functions, like elbow extension, and distal skill, like lateral pinch. Good surgical candidates have strong redundant functions. There is little consensus on priorities, approaches, and post-operative care (Davis et al. 1997; Mulcahey et al. 1999a; Mulcahey et al. 1995; Vova & Davidson, 2020).

Nerve transfers are useful for multi-step reanimation of the upper extremity following SCI. These require intervention earlier post injury. There is little consensus on priorities, approaches, and post-operative care (Vova & Davidson, 2020)

There is level 5 evidence that the typical manual wheelchair propulsion stroke patterns used by children with SCI varies across subjects.

There is level 4 evidence that a wheelchair training program may improve measured manual wheelchair propulsion efficiency.

There is very little data regarding frequency, management and outcomes of late neurologic decline in pediatric SCI. Given the potential implications of these conditions, neurologic function in individuals with chronic SCI should be monitored.

Both nociceptive and neuropathic pain are common consequences of pediatric SCI.

There is inadequate evidence to guide pain management for patients with pediatric SCI, resulting in providers relying on available data regarding pain management in children without SCI.

Spasticity may be associated with tetraplegia, lower American Spinal Injury Association motor scores, and lower total and motor Functional Independence Measure scores in individuals with pediatric-onset SCI.

Measures of spasms (Spasm Score and Spasm Frequency Scale) and muscle tone (Ashworth scale/Modified Ashworth scale) are commonly used to evaluate spasticity in the pediatric SCI population.

Intrathecal baclofen and selective dorsal rhizotomy may be effective in managing spasticity in children with SCI.

Systematic, controlled studies are needed to drive clinical practice, guideline development, and the most optimal method for treating spasticity in the pediatric SCI population.

Only a few studies have prospectively assessed the body mineral density and body mineral content changes following onset of sickle cell disease related neurologic deficit. Findings from those studies seem to confirm significant bone loss occurring shortly (first year or so) following injury at the sub-lesional level (as opposed to adults with SCI, where bone loss has been documented for ≥ 5 years post injury).

The bone loss in the pediatric population is ameliorated by weight bearing and possibly spasticity and functional electrical stimulation usage. Age related bone accrual appears to resume after the first year post injury, but body mineral density and body mineral content post SCI does not achieve age and sex matched able body values. Bone and muscle mass appear to be closely correlated.

As for heterotopic ossification in pediatric onset SCI, it is rarer than in adults, is mainly diagnosed by clinical onset of range of motion limitation and should probably not undergo resection surgery. Like in the adult individuals with sickle cell disease related paralysis, it is more common in higher (cervical, upper thoracic) injuries. Presence of a focal trigger factor (pressure injuries, trauma, including iatrogenic) increases the risk of occurrence.

Hypercalcemia of immobility occurs early (up to 6 months) post injury mostly in children, adolescents and young adults and is clinically manifested with mainly GI abnormalities (nausea, vomiting, abdominal pain, etc.); intravenous pamidronate (with or without hydration) is effective in restoring calcium levels.

Bone metabolic changes post spinal cord dysfunction (SCD) related pediatric paralysis onset could benefit from prospective, multi-centered studies to better inform the field.

All individuals with pediatric onset SCI are at significantly increased risk of scoliosis, especially if the injury occurs at a younger age. In particular, those with injuries occurring prior to skeletal maturity are at much greater risk of developing scoliosis, of rapid curve progression and of requiring surgical intervention.

Bracing for scoliosis in this population may be beneficial, particularly in younger, skeletally immature patients with smaller curves (either to prevent surgery or to delay it until skeletal maturity). The role of bracing for older patients with larger curves (>40 degrees) is limited.

Hip displacement is more common in individuals injured at a younger age and with a longer duration of SCI. The implications and management of hip displacement in pediatric SCI are unclear.

Contractures and fractures are both common complications of pediatric SCI but little is known about targeted intervention in this specific population.

The neurogenic bowel management in pediatric population with SCI is important for long term medical management and quality of life.

In view of the fact that neurogenic bowel is a significant contributor to quality of life in individuals with SCI and its’ manner of performance changes along neurodevelopmental and disease chronicity lines, it is imperative that we summarize the current knowledge and develop research strategies that can optimize gastro-intestinal function lifelong when neurogenic dysfunction ensues.

Preservation of renal function is the most important objective of any long-term treatment plan in children with SCI/D (spinal cord injury/dysfunction).

Continence and bladder management status does not significantly correlate with neurological level of lesion.

Personalized, long-term neuro-urologic care is necessary in individuals with pediatric onset neurologic upper and lower urinary tract dysfunction.

SCI related paralysis is a risk factor for venous thromboembolism occurrence, especially in adolescents and young adults.

Preventions and treatment of venous thromboembolism in this population is highly individualized and, in most cases, left to the treating clinician’s decision and there is no pediatric specific mechanical or pharmacologically proven intervention

Venous thromboembolism diagnosis is clinically based not on active screening and the role of active screening is not known in this population; older kids are found to have more venous thromboembolism but that could also be related to them being more actively screened in adult trauma hospital protocols.

Children with traumatic SCI might have associated risk factors for venous thromboembolism, like central venous catheter, long bone fractures, vascular injuries, higher injury severity scores, etc.).

Children with SCI/D paralysis consistently exhibit body composition and metabolic changes that predispose to poor cardiovascular health

There is no exercise/therapeutic intervention that has been proven to consistently/predictably improve cardiovascular profile in this population.

The prevalence of autonomic dysreflexia in the pediatric SCI population is around 50%, which is comparable to that in the adult SCI population.

Complete injuries, traumatic injuries, and older may be linked to higher risk of autonomic dysreflexia in children with SCI.

Respiratory comorbidities in children with SCI are common and require hospitalized care.

Lung volumes and generated airway pressures depend on age and level and severity of injury.

Pulmonary hygiene, management of anxiety and learning alternative methods of breathing that can offer ventilator free time play important role in the long term management of respiratory dysfunction associated with SCI.

Pressure injuries are the most common and impactful skin complications of SCI. Risk factors may include previous pressure injury, male gender, non-white race, non-sports related injury, motor severity, functional independence measure score, smoking and spasticity.

Latex allergy may occur at a higher rate amongst people with pediatric SCI than in the general population.

Individuals with pediatric-onset SCI have similar levels of depression, anxiety, and life satisfaction compared to the general population; however, the quality of life of children with SCI and adults with pediatric-onset SCI is significantly lower than that of individuals without disabilities.

Various demographic and clinical factors, such as age, duration of injury, level of participation, caregiver characteristics, and employment status, have been identified as predictors of depression, anxiety, life satisfaction, and quality of life in individuals with pediatric-onset SCI.

Active coping strategies may help offset the adverse psychosocial impact of SCI in the pediatric SCI population.

More intervention studies addressing the psychosocial consequences of pediatric-onset SCI, especially controlled studies, are needed in the future.

Evidence for play and participation after pediatric onset SCI is limited to observational studies, descriptive cohorts, and small or single case reports. There have been no interventional studies to date, as assessed by this committee.

Persons with pediatric-onset SCI are more likely to report greater functional independence, less pain, and less comorbidities requiring medical intervention as compared to persons with adult-onset SCI. Additionally, they are more likely to participate in moderate to heavy physical activity and a greater variety of social and occupational activities.

Children with paraplegia (all American Spinal Injury Association impairment scale) and American Spinal Injury Association impairment scale D tetraplegia participate in a greater variety of activities at higher intensities than persons with tetraplegia (American Spinal Injury Association impairment scale ABC), but at the same frequency; satisfaction with participation is equally high across both groups.

Greater variety in location of participation (i.e., away from home) and peer group positively impacts quality of life, after controlling for age, sex, level of injury and chronicity.

More than half of caregivers report at least one obstacle limiting their child's participation. Community and disability-related factors are the most likely obstacles to be reported. Obstacles are more likely to be reported for younger children and children in more rural settings.

Persons with pediatric-onset SCI are more likely to participate in informal activities, than formal activities. Satisfaction with participation in these activities is more likely to be higher in younger children, females, and children with paraplegia.

Children with SCI who have a greater variety of social activities are more likely to report greater participation, less depression, and higher quality of life.

Experts in the field has identified the process of re-entry to school the main issue for children and adolescents with SCI.

However, evidence in this field is lacking, which highlight the need of more and methodological sound research. School settings and programs, study populations need to be defined. Outcome measures need to be validated and standardized.

There is a challenge in obtaining good quality data due to the relatively low incidence of pediatric SCI, which calls for more multicentre studies nationally and internationally to direct best practice.

Despite their high educational attainment, the employment rate of individuals with pediatric-onset SCI is considerably lower than that of the general population.

High level of education, high household income, functional independence, community mobility, and active community participation facilitate employment in individuals with pediatric-onset SCI; high injury severity and frequent occurrence of health complications hinder employment in this population

While the existing observational studies offer valuable insight into the facilitators and barriers of employment in individuals with pediatric onset SCI, high-quality intervention studies are needed in this area.

Future research needs to explore the roles of environmental factors in shaping employment outcomes in individuals with pediatric-onset SCI.

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1 Introduction

Although relatively rare, pediatric-onset spinal cord injury (SCI) has pervasive and long-lasting impact on various aspects of an individual's life. Management of pediatric SCI calls for a physiologically-centred and developmentally-based approach; depending on their developmental stages and specific skills, those with childhood-onset SCI may require habilitation (i.e. learning a skill for the first time) or rehabilitation (i.e. re-development of a skill that was learnt prior to the onset of SCI) (Hayton & Dimitriou, 2019; Miller et al. 2011). For children and adolescents with SCI, the inherent growth and development taking place during childhood and adolescence come with SCI-related complications and manifestations that are distinct from those experienced by the adult SCI population. Therefore, evidence-based research focusing specifically on children and adolescents with SCI is needed to guide clinical practice in the pediatric SCI rehabilitation setting. This chapter aims to examine current scientific literature on factors of importance for rehabilitation/habilitation for individuals with pediatric-onset SCI. Gaps within the body of work on pediatric SCI rehabilitation/habilitation will also be discussed.

2 Methods

2.1 Literature Search Strategy

The research team conducted a systematic review of the evidence following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Page et al. 2021). A literature search was performed using five scholarly databases, including PubMed, MEDLINE, CINAHL, EMBASE, and PsychINFO. The search strategy involved two constructs: SCI and pediatrics. The search included full-length journal articles published in English language up to the end of December 2020. Any duplicates were removed.

2.2 Study Selection and Data Synthesis

Each article was assessed for relevance by two independent reviewers. The studies were included if 1) ≥50% of the study participants had experienced a traumatic SCI and non-traumatic acquired SCI; 2) participants' age of onset of SCI was between 0-21 years; and 3) they examined factors of importance for rehabilitation/habilitation post-SCI (i.e., primary and/or secondary complications) descriptively or via an intervention. The review included all research designs, with the exception of general, non-systematic, reviews. Case reports must have reviewed a specific rehabilitation/habilitation management topic in order to be included for review.

Studies were excluded if they 1) included a sample with predominately non-traumatic, congenital SCI (e.g., spina bifida); 2) represented conference proceedings, program reviews/descriptions (without a study sample), continuous learning/education modules, or clinical practice guidelines; 3) focused on the following topics: a) acute care management and spine stability; b) diagnostic and radiological imaging, or c) psychometrical property analyses; and 4) did not report all necessary details for the reviewer to determine if they met the inclusion criteria (e.g., etiology, age, etc.).

Relevant information from each included study was extracted by two reviewers and summarized in tabular form. This includes: author(s), year of publication, country of origin, study design, sample size, subject characteristics (e.g., age, gender, injury etiology, level of injury, severity of injury, time since injury), area of impairment targeted by rehabilitation/habilitation, intervention (if applicable), outcome measures, and results.

3 Direct Consequences of SCI

3.1 Lower Extremity

Cervical, thoracic, and/or lumbo-sacral SCI, regardless of age at injury, often results in trunk and lower extremity paralysis and/or weakness. The resulting functional impacts include a spectrum of limitations of trunk control and balance, standing, transferring and walking. The approach to these impairments and their functional impact has primarily involved the introduction of braces and assistive devices to compensate for paralysis/weakness, achieving functional alternatives for the tasks of upright trunk posture, standing, and walking. This treatment approach is consistent with the assumption that the impairments and functional impact of SCI are permanent. Recent evidence, however, points towards some potential for partial functional recovery below the level of the spinal cord lesion. From this vantage point, physical rehabilitation extends to recovery-based strategies tapping into the intrinsic biology of the neuromuscular system to partially restore its capacity for motor control.

The “Lower Extremity and Trunk” evidence for Spinal Cord Injury Research Evidence is presented relative to three therapeutic goals: 1) Trunk control, 2) Standing, and 3) Walking. The literature is further presented within the context of two rehabilitation approaches: 1) compensation (i.e., development of new adaptive behaviours, use of devices/equipment) and 2) restoration (or recovery). Both perspectives have guided the development and use of outcome measures and therapeutic interventions to achieve the goal of improved function. Accordingly, the tables of evidence for lower extremity and trunk outcome measures and interventions for the goals of standing, walking, and trunk upright posture are organized to differentiate the “solutions” as either 1) compensation strategies to achieve functional alternatives or 2) restorative interventions to achieve neuromuscular capacity supporting typical functional behaviors to stand, walk, and maintain an upright trunk posture. Defining the parameters of performance for each goal is critical to compare the intervention strategies.

Table 1. Studies Assessing Measurement of Compensatory Strategies for Lower Limb for Pediatric-Onset SCI

Main Outcomes	Author, Year Country Study Design Sample Size	Study Characteristics	Results
	TRUNK		
Cobb Angle	Mulcahey et al. (2013) USA Observational N=217	**Population:** 13.2±4.9yr.; Gender: males=127, females=90; Level of injury: Not reported; Level of severity: AIS A=105, B=45, C=30, D=21, Missing=16; Time since injury=4.2±3.7 yr. **Intervention:** None – observational, participants evaluated using the testing guidelines of the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) to determine predictors of worse curve and spinal fusion in neurological scoliosis. *All participants had neuromuscular scoliosis and 24 of the 217 participants underwent spinal fusion due to their progressive neuromuscular scoliosis. **Outcome Measures:** ISNCSCI classification, Cobb angle, motor score.	1. Age of injury (p<0.0001) and AIS classification (p<0.0095) were the only significant predictors of worse curve when grouped as an entire sample 2. Risk of spinal fusion increased by 11% for every yr. decrease in age at injury 3. Sex, motor score, and neurological level were not predictors of worse curve of spinal fusion 4. Subjects injured before the age of 12 were 3.7 times more likely to require a spinal fusion than those injured after age 12 (95% CI, 0.31-44.64)
ISNCSCI	Mulcahey et al. (2011) USA Repeated Measures N=236	**Population:** Mean age=14.5±4.2yr.; Gender: males=109, females=72; Level of injury: Not reported; Level of severity: Complete=97, Incomplete=84; Time since injury=5.0±4.4yr. **Intervention:** None – observational, participants given the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) to test interrater reliability. Subjects underwent 4	1. No child under 6 was able to complete the INSCSCI in its entirety. 2. 3 of the 18 participants in the 0-5-yr. age group the PP(n=2) and motor examinations (n=3). 3. 9 of the 42 participants in the 6-11-yr. age group were unable to complete the entire examination, thus most children 6 yr and older can comprehend the directions for, and participate in the INSCSCI examinations.

		examinations by 2 raters: sensory tests (in prick (PP) and light touch (LT)), a motor test (upper and lower extremity motor test (UEM and LEM respectively), and a test of anal sensation (AS) and anal contraction (AC). **Outcome Measures:** 2-way general linear model analysis of variance, interclass correlation coefficients (ICCs) and 95% confidence intervals.	4. Interrater reliability for each variable (PP, LT, TM, UEM, LEM, AS and AC) in all 3 age groups was high (ICC: 0.93-0.99) except for AC in the 12-15-yr. age group which showed moderate reliability (ICC=0.88). 5. ICC values for S4-5 dermatome PP and LT were all higher than 0.75, indicating moderate interrater reliability across each age group when examined as a function of age. 6. When analyzed as a function of type of injury (tetraplegia/paraplegia), interrater reliability at each age group was moderate to high (ICC: 0.89-0.99). 7. Interrater reliability for classification of severity and type of injury was high (ICC≥0.92 and ICC≥0.92 respectively).
	STAND		
PEDI SCIM	(Altizer et al. 2017) USA Case Report N=1	**Population:** 23 mo, female, T10 AIS A SCI. **Intervention:** Overground supported stepping intervention using a dynamic gait trainer. **Outcome Measures:** Paediatric Evaluation of Disability Inventory (PEDI), Spinal Cord Independence Measure (SCIM), Gross Motor Function Measure (GMFM-66), Developmental Profile (DP-3), Support Walker Assessment Ambulation Performance Scale (SWAPS), 6-Minute Walk Test (6MWT).	1. PEDI score improved by 6 points (60%) from age 36-54mo. and by 18 points (75%) from age 54-72mo. 2. SCIM score improved over the 3 yr. of intervention (36mo. – 19; 54mo. – 31; 72mo. – 43) but remained well below the median adult score for those with injury at T10 of 63 3. GDFM-66 score improved minimally over 3 yr of intervention 4. DP-3 score demonstrated a continued motor deficit in comparison to age, but also shows progress in physical skills 5. 6MWT change from 54-72mo. was double what was expected from documentation in literature for her age and level of SCI.

PEDI	(Choksi et al. 2010) Observational USA N=32	**Population:** Mean age 10.6±6.2 (1-19) yr; Injury Etiology: Traumatic=24, Non-traumatic=8; Level of Injury: Cervical=18, Thoracolumbar=14. **Intervention:** Inpatient rehabilitation physiotherapy and occupational therapy (3 hr/day). **Outcome Measures:** Pediatric Evaluation of Disability Inventory (*mobility* and *self-care*) via Functional Skills and Caregiver Assistance scales).	1. PEDI mobility (functional skills): ↑24.0±14.7 2. PEDI mobility (caregiver assistance): ↑26.1+21.5 3. All children improved or showed no change on walking-related PEDI items: - Indoor locomotion methods: 8/21 ↑ - Indoor locomotion distance/speed: 11/21 ↑ - Indoor locomotion pulls/carries: 13/21 ↑ - Outdoor locomotion methods: 1/21 ↑ - Outdoor locomotion distance/speed: 12/21↑ - Outdoor locomotion surfaces: 12/21↑
Time using FES	(Moynahan, Mullin, et al. 1996) USA Observational N=5	**Population:** Age: 18.4±1.1 yr; Gender: males=2, females=3; Level of Injury: T4 (n=2), T5 (n=1), T8 (n=1), T11 (n=1); Severity of Injury: AIS A; Orthotics Use: Molded Shoe Insert=4, Ankle Foot Orthosis [AFO]=1. **Intervention:** Hybrid system of implanted Functional Electrical Stimulation [FES] (pulse duration 0-150µsec, frequency 0-50 Hz) with wearable AFO. After implantation, participants completed training for standing and mobility. **Outcome Measures:** Patterns of home and community FES use; barriers and facilitators of use. Assessed every 1-4 wk for 1 yr.	1. The frequency of donning the system ranged 23%-34% of the days surveyed; this is equivalent to donning the system once every 3 to 4 days. 2. The two most common standing activities were "one-handed activities (e.g., painting furniture, changing a car's air filter, pushing a sibling on a swing-set) or reaching" and "standing for exercise or to stretch," accounting for 62% of all reported standing activities across subjects. 3. Maneuvering" was typically performed in areas of the house that were easily accessed by wheelchair. 4. The FES system was used to perform swing-to gait with their walkers around the house, sometimes transferring to other seats. 5. "Standing with others" included showing friends or family standing ability, to take pictures or for hugging. 6. "Transfers" (e.g., for weighing or to transfer into a car) were not widely performed.

			7. "Motivators" for FES use included: being able to do things that would be difficult/impossible otherwise, perceiving a healthful benefit from exercise/standing, having a sense of well-being, and feeling an obligation to stand as a member of the research study. 8. "Barriers" included: not having time to stand or exercise, having difficulty seeing opportunities and reluctant to wear it all day.
Time to complete tasks	(Betz et al. 2002) USA Case Report N=1	**Population:** 13 yr, male, T8 SCI. **Intervention:** Lower extremity implanted Functional Electrical Stimulation (FES) with a Knee Ankle Foot Orthoses (KAFO). **Outcome Measures:** Completion of eight upright mobility activities, scored based on completion time and level of independence: donning, stand and reach, high transfer, bathroom, floor to stand, 6-meter walk test (6MWT), stair ascent, stair descent.	1. Across all time periods, the subject required less time to don the FES system ($P<0.0001$) and to complete the high reach ($P<0.0001$), high transfer ($P<0.0001$), and 6MWT ($P=.006$) compared with KAFO 2. More time was needed to complete the floor-to-stand activity for FES compared to KAFO ($P=0.0001$) 3. No time differences were seen between FES and KAFO for the inaccessible bathroom transfer ($P=0.507$) and ascending ($P=0.753$) and descending stairs ($P=0.164$) 4. Subject was able to more quickly complete the sit-to-stand transition ($P<0.0001$), reach for a videotape on a high shelf ($P<0.0001$), and return to sitting in the wheelchair ($P<0.0001$) when using FES 5. Subject preferred FES to KAFO for all activities but floor-to-stand at 2-yr. follow-up
FIM	(Bonaroti et al. 1999b) USA Pre-Post N=5	**Population:** Age: 9 yr.(n=2), 10 (n=1), 18 yr.(n=2); Gender: males=4, females=1; Etiology: Traumatic SCI=4, Non-Traumatic SCI=1; Level of Injury: cervical=2,	1. When comparing the upright mobility activities between using FES versus LLB, subjects required equal (70%) or less (24%) assistance

		thoracic=3; Severity of Injury: Paraplegia=5. Bracing for Standing & Therapy: Knee Ankle Foot Orthoses [KAFO]=5. **Intervention:** Hybrid system of implanted Functional Electrical Stimulation [FES] (pulse duration 0-150µsec, frequency 0-50 Hz) with wearable Ankle Foot Orthoses (AFO). After implantation, participants completed FES strengthening followed by sit/stand exercise, and then upright mobility training for 4 weeks. **Outcome Measures:** Completion of eight upright mobility activities, scored based on completion time and level of independence with FES versus Long Leg Braces (LLB): donning, stand and reach, high transfer, floor to stand, 6-meter walk test (6MWT), toilet transfer.	when using FES compared with using LLB 2. One subject had greater independence using LLB for the *floor to stand* transfer 3. One subject had greater independence using LLB for the 6MWT 4. For each activity in which FES provided greater independence, subjects improved from requiring contact assistance (3 or 4) while using LLB to not needing contact assistance (5 or 6) while using FES 5. There were two subjects who required minimal contact assist (4) with LLB but were independent with FES (6), both for the *stand and reach* activity, and six instances in which minimal (4) or moderate (3) contact assistance was required with LLB and no contact assistance (5) was required using FES 6. Two activities, *stand and reach* and *high transfer,* were performed significantly faster with FES 7. When subjects were asked which mode of standing, they preferred: • FES 62% of the time • LLB 27% of the time • No preference 11% of the time
FIM, FST	(Bonaroti et al. 1999a) USA Case Report N=1	**Population:** 11 yr, T10 AIS A SCI **Intervention:** Functional electrical stimulation, Knee Ankle Foot Orthoses **Outcome Measures:** Functional Independence Measure (FIM) and time to completion during upright mobility activities: donning, high transfer, toilet transfer, floor-to-standing transfer, ascend/descend stairs.	1. FIM measurements of bathroom transfer and descending stairs completed significantly faster with KAFO ($p<0.001$ and $p=0.04$ respectively) 2. For the remaining activities there was a trend towards faster completion times with FES, but this was not statistically significant (donning: $p=0.28$; high transfer: $p=0.36$; floor

			transfer: p=0.67; ascending stairs: p=0.32) 3. While performing the 10 subset activities of the FST, the subject displayed no significant differences in completion times between the 2 modes 4. Subject was significantly more stable in the static position using KAFO (p=0.03) whereas in dynamic testing subject was slightly more stable using FES, but was not statistically significant (p=0.7) 5. Ambulation velocity was significantly faster using FES during the 100 feet ambulation (p<0.001) and maximum ambulation (p<0.001) test but not during energy expenditure testing (p=0.13)
	GAIT		
Gait Speed	(Behrman et al. 2008) USA Case Report N=1	**Population:** 4.5 yr, male, C8 AIS C traumatic SCI, 16 mo post-injury. **Intervention:** Body weight support, overground walking. **Outcome Measures:** American Spinal Injury Association Impairment Scale (AIS), Lower extremity motor score (LEMS), gait speed, walking independence, walking index for spinal cord injury II (WISCI-II), number of steps.	1. AIS score remained the same after session 74 2. LEMS score remained at 4/50 at session 74 3. From session 51 to 76 gait speed increased from 0.19m/s to 0.29m/s 4. From session 51 to 76 fastest walking speed increased from 0.3m/s to 0.48m/s 5. WISCI score increased from 0/20 to 13/20 6. At session 33 the child showed multiple non-cued steps 7. From session 49 to 74 the child increased from 926 steps per day to 2488 steps per day
Gait Speed	(Betz et al. 2002) USA Case Report N=1	**Population:** 13 yr, male, T8 SCI. **Intervention:** Lower extremity implanted Functional Electrical Stimulation (FES) with a Knee Ankle Foot Orthoses (KAFO).	1. Across all time periods, the subject required less time to don the FES system (P<0.0001) and to complete the high reach (P<0.0001), high transfer (P<0.0001), and 6MWT (P=.006) compared with KAFO

		Outcome Measures: Completion of eight upright mobility activities, scored based on completion time and level of independence: donning, stand and reach, high transfer, bathroom, floor to stand, 6-meter walk test (6MWT), stair ascent, stair descent.	2. More time was needed to complete the floor-to-stand activity for FES compared to KAFO (P=0.0001) 3. No time differences were seen between FES and KAFO for the inaccessible bathroom transfer (P=0.507) and ascending (P=0.753) and descending stairs (P=0.164) 4. Subject was able to more quickly complete the sit-to-stand transition (P<0.0001), reach for a videotape on a high shelf (P<0.0001), and return to sitting in the wheelchair (P<0.0001) when using FES 5. Subject preferred FES to KAFO for all activities but floor-to-stand at 2-yr. follow-up
Gait Speed	(Johnston et al. 2005) USA Post Test N=3	Population: Age: 17-21; Gender: males=3; Level and Severity of Injury: Motor complete T3-T8; Time since injury: 1.0-1.5 yr; Intervention: Functional electrical stimulation (FES) consisting of 22-channel implant stimulator, extension leads and epineural electrodes. Leads emanating from the stimulator include two tresses of nine leads each for stimulation of lower extremity muscles and one tress of four leads for stimulation for bladder and bowel function (parameters: 0.2–8 mA amplitude, 25–600 ms pulse duration, 2–500 Hz pulse frequency per channel). After implantation and immobilization participants completed exercise phase (FES strengthening) followed by lower extremity conditioning, standing and	1. Three of the 52 electrodes placed for lower extremity stimulation experienced changes in the responses of the muscles. 2. Two subjects used a walker with wheels to perform the mobility activities and one subject used forearm crutches. 3. None of the subjects required physical assistance to complete the activities but two required supervision. 4. One individual could not ascend/descend stairs as it was felt to be unsafe for him; several activities could not be performed by another subject secondary to complaints of shoulder pain related to poor scapular muscle control. 5. All subjects reported preferring a swing through pattern for walking as they felt it was faster; two subjects could ambulate up to 20 feet and the third subject up to 75 feet.

		upright mobility training (13 wk). **Outcome Measures:** Completion of eight upright mobility activities, scored based on completion time and level of independence: donning, stand and reach, high transfer, bathroom, floor to stand, 6-minute walk test (6MWT), stair ascent, stair descent.	6. Just one subject demonstrated positive neuromodulation effects of the bladder; stimulation suppressed reflex bladder contractions acutely thereby reducing vesical pressure. 7. For one subject, low frequency stimulation significantly increased rectal and anal sphincter pressure which reduced time to defecate; compared to bowel management without stimulation, the patient reported greater satisfaction with stimulation.
Gait Speed, TUG, WISCI II	(O'Donnell & Harvey, 2013) Australia Case Report N=1	**Population:** 17 yr, male, T6 AIS C traumatic SCI, 16 mo post injury. **Intervention:** Body weight support treadmill training, overground walking **Outcome Measures:** Lower extremity motor score (LEMS), Walking index for spinal cord injury (WISCI II), 6-minute walk test (6MWT), 10-meter walk test (10MWT), Timed up and go (TUG), Pediatric Quality of Life Inventory (PedsQL).	1. LEMS score improved from 16 to 17 from pre- to post-training and from 17 to 18 from post-training to follow-up 2. WISCI score improved from 6 to 9 from pre- to post-training and remained at 9 at follow-up 3. 6MWT score improved from 67m (1 rest) at pre-training to 76m (no rests) at post-training and further improved to 80m (no rests) at follow-up 4. 10MWT score improved from 32.2s at pre-training to 30.3s at post-training but declined to 33.6s at follow-up 5. TUG score improved from 44.6s at pre-training to 40.1s at post-training but declined to 42.0s at follow-up, remaining improved compared to pre-training 6. Overall PedsQL score improved from 38/92 at pre-training to 23/92 at post-training and remained at 23/92 at follow-up
Years using device	(Vogel & Lubicky, 1995) USA Observational N=39	**Population:** (Parapodium) Age (at injury)=3.2yr. (range birth-9yr.); Gender: males=15, females=11; Level and severity of injury: T1-T4	1. No patients in either group were community ambulators 2. Among the 20 children that began using parapodia at

	N(Parapodium)=26 N(RGO)=13 RGO – Reciprocating Gait Orthoses	paraplegia=7, Tetraplegia=6, Not reported=13; Time since injury: Not reported. (RGO) Age at injury= 8.1yr. (range birth-15yr.); Gender: males=5, females=8; Level and severity of injury: T4 paraplegia=1, Tetraplegia=0, Not reported=12; Time since injury: Not reported. **Intervention:** Chart review of parapodium and RGO users. **Outcome Measures:** Post-orthotic use outcomes.	less than 6yr., 12 were household ambulators 3. All 6 children who began using parapodia after 6yr. old were therapeutic ambulators 4. Among children that initially used RGOs, 2 were household ambulators and the remaining 11 were all therapeutic ambulators 5. Of the 26 children in the parapodium group, four were lost to follow-up or died after a mean of 3.7 yr. of orthotic use, 12 continued to use their parapodia with a mean follow-up of 3.4 yr., and 10 stopped using their parapodia after 2.2 vr. on average 6. 12 children who continued to use their parapodium. the mean age at injury was 2 1/2 yr., mean age at initiation of parapodium use was 3.7 yr., and their mean age at current follow-up was 7.1 yr. 7. For the 10 children who had discontinued use of their parapodium, the mean age at injury was 5 yr., mean age at initiation of orthotic use was 5.7 yr., and mean age at discontinuation of parapodium use was 7.9 yr. 8. Among the 13 children who initiated their orthotic use with RGOS, three were lost to follow-up after using their RGOs for an average of 2 1/2 yr., two are still using RGOs and 8 have stopped using them 9. The two children still using them were approximately 2 1/2 yr. old when injured and began orthotic use at three and 3 1/2 yr. of age, each has been followed for 1 1/2 yr. 10. The eight individuals who discontinued RGO use were on average 10.8 yr. old at the

			time of their injury, began using the RGO at a mean age of 12 1/2 yr. and stopped using their RGOs at a mean age of 16.7 yr. 11. Of the eight individuals who discontinued RGO use seven did not progress to another orthotic device and one teenager with T10 paraplegia progressed to a knee ankle foot orthosis (KAFO) which she used sporadically for 1 1/2 yr.
Time to complete task, WeeFIM	(Johnston et al. 2003) USA Pre-Post N=9	**Population:** Age: 12.7±5.2 yr (range 7-20 yr); Level and Severity of Injury: C7 tetraplegia (n=1), T1-11 paraplegia (n=8); Long Leg Bracing [LLB] Used: Knee Ankle Foot Orthoses [KAFO] (n=2), Hip Knee Ankle Foot Orthoses [HKAFO] (n=2), Reciprocating Gait Orthoses [RGO] (n=5). **Intervention:** Lower extremity Functional Electrical Stimulation (FES) implant which delivered a balanced asymmetrical biphasic waveform with pulse duration up to 200 msec, 20 Hz frequency, and 20 mA current. Bilateral ankle foot orthoses (AFO) set in zero degrees of dorsiflexion were worn when ambulating with the FES system. After implantation and immobilization participants did 2-4 wk of FES strengthening followed by standing and walking exercise, and upright mobility training. **Outcomes:** Completion of eight upright mobility activities, scored based on completion time and level of independence: donning, stand and reach, high	1. Two subjects did not complete training and were not included for analysis. 2. 12/72 originally implanted electrodes required revision primarily due to inadequate force production. 3. Subjects completed four activities more quickly when using FES as compared to LLB: donning (p=0.0026), stand and reach (p=0.0012), high transfer (p=0.0009), bathroom (p=0.0164). 4. Subjects completed five activities with less assistance when using FES as compared to LLB: donning (p=0.0001), stand and reach (p=0.0036), high transfer (p=0.0191), bathroom (p=0.0006), and floor to stand (p=0243). 5. No activity required more time or more assistance to complete with FES as compared to LLB. 6. Subjects reported preferring FES for 87.5% of the activities, LLB for 3.6% of the activities, and showed no preference for 8.9% of the activities.

		transfer, bathroom, floor to stand, 6-meter walk test (6MWT), stair ascent, stair descent.	
Time to complete task, TUG	(Johnston et al. 2005) USA Post Test N=3	**Population:** Age: 17-21; Gender: males=3; Level and Severity of Injury: Motor complete T3-T8; Time since injury: 1.0-1.5 yr; **Intervention:** Functional electrical stimulation (FES) consisting of 22-channel implant stimulator, extension leads and epineural electrodes. Leads emanating from the stimulator include two tresses of nine leads each for stimulation of lower extremity muscles and one tress of four leads for stimulation for bladder and bowel function (parameters: 0.2–8 mA amplitude, 25–600 ms pulse duration, 2–500 Hz pulse frequency per channel). After implantation and immobilization participants completed exercise phase (FES strengthening) followed by lower extremity conditioning, standing and upright mobility training (13 wk). **Outcome Measures:** Completion of eight upright mobility activities, scored based on completion time and level of independence: donning, stand and reach, high transfer, bathroom, floor to stand, 6-meter walk test (6, stair ascent, stair descent;	1. Three of the 52 electrodes placed for lower extremity stimulation experienced changes in the responses of the muscles. 2. Two subjects used a walker with wheels to perform the mobility activities and one subject used forearm crutches 3. None of the subjects required physical assistance to complete the activities but two required supervision. 4. One individual could not ascend/descend stairs as it was felt to be unsafe for him; several activities could not be performed by another subject secondary to complaints of shoulder pain related to poor scapular muscle control. 5. All subjects reported preferring a swing through pattern for walking as they felt it was faster; two subjects could ambulate up to 20 feet and the third subject up to 75 feet 6. Just one subject demonstrated positive neuromodulation effects of the bladder; stimulation suppressed reflex bladder contractions acutely thereby reducing vesical pressure 7. For one subject, low frequency stimulation significantly increased rectal and anal sphincter pressure which reduced time to defecate; compared to bowel management without stimulation, the patient reported greater satisfaction with stimulation.

WeeFIM, WISCI II	(Prosser, 2007) USA Case Report N=1	**Population:** 5 yr.10 mo, female, C4 AIS A SCI and mild traumatic brain injury. **Intervention:** Locomotor training including body weight support treadmill training, overground walking, inpatient rehabilitation with aquatic therapy. **Outcome Measures:** Functional Independence Measure for Children II (WeeFIMII), Walking Index for Spinal Cord Injury II (WISCI II).	1. WeeFIM score improved from 5/35 to 21/35 over 5 months of locomotor training 2. WISCI score improved from 0 to 12 over 5 months of locomotor training 3. At home, she walked the majority of the time and walked up the stairs to her bedroom with a handrail and minimal assistance
WISCI II	(Fox et al. 2010) USA Case Report N=1	**Population:** 3.5 yr, male, C8 AIS C SCI. **Intervention:** Description of child's walking function and musculoskeletal growth and development during the 2 yr after locomotor training **Outcome Measures:** Walking Index for Spinal Cord Injury II (WISCI II), gait speed, cadence, step length, stride length, daily steps activity at home and in the community, musculoskeletal growth and development, gross motor function measure (GMFM-66).	1. Walking independence remained unchanged with WISCI score staying at 13/20 as he still used a reverse rolling walker to ambulate 2. Fastest gait speed increased from 0.45m/s at baseline (1 month post LT) to 0.67m/s at 2 yr. follow-up • After 2 yr., gait pattern was improved • Able to generate reciprocal stepping with noticeable absence of shoulder and trunk compensations, particularly on his left side • Despite being able to step reciprocally, he could not walk backwards, side step, or maintain balance without upper-extremity support 3. Cadence increased from 63.35 steps/min at baseline to 70.75 steps/min at 2 yr follow-up 4. Step length increased in both legs: • Left leg: increased from 42.25 cm at baseline to 51.31 cm at 2 yr follow-up • Right leg: increased from 44.07 cm at baseline to

			63.55 cm at 2 yr follow-up 5. Stride length increased in both legs: - Left leg: increased from 85.95cm at baseline to 114.79cm at 2 yr follow-up - Right leg: increased from 87.19cm at baseline to 114.47cm at 2 yr follow-up 6. Daily steps increased from about 1600 steps/day at baseline to 3000 steps/day at 2 yr follow-up 7. Over the 2-yr. period the child was not diagnosed with scoliosis, but mild coxa valga was noted at both hip joints and radiology reports indicated all findings stable 8. GMFM-66 scores remained stable over the 2-yr period

Table 2. Studies Assessing Interventions for Compensatory Strategies for Lower Limb for Pediatric-Onset SCI

Main Outcomes	Author, Year Country Study Design Sample Size	Study Characteristics	Results
	TRUNK		
TLSO Brace	Sison-Williamson et al. (2007) USA "With-and-without intervention quasi-experimental" N=20	**Population:** Mean age=10.9±2.9; Gender: males=10, females=10; Level of injury: C7-L1; Level of severity: AIS A=18, B=0, C=2, D=0; Time since injury: Not reported. **Intervention:** Upper extremity motion analysis – tested in and out of thoracic lumbar sacral orthoses (TLSO) brace. **Outcome Measures:** Reach volume (in and out of TLSO brace)	1. Reachable workspace volumes were significantly greater for the non-TLSO brace condition compared to the TLSO condition (p=0.0002) 2. Anterior posterior and medial lateral ranges of reach were statistically greater in the non-TLSO condition (p=0.002 and p=0.01, respectively). 3. Nondominant hand medial lateral reaches were statistically greater in the non-TLSO brace condition (p=0.03) 4. Dominant hand anterior posterior reaches were statistically greater in the non-TLSO condition (p=0.009).

Scoliosis/ Spinal Fusion	Mehta et al. (2004) USA Case Control N=123	**Population:** Mean age=7.4yr; Gender: males=69, females=54; Level of injury: cervical=69, thoracic=54; Severity of Injury: AIS A=71, B=49, C=1, D=2; Mean time since injury=2.1yr. **Intervention:** Patient records from January 1996 to December 2001 from the Shriners Hospitals for Children-Philadelphia were retrospectively reviewed. Patients were divided into 5 groups based on their radiographic curve severity at presentation (group I: patients with < 1 Ü0 of scoliosis; group II: 11 ° to 20°; group III: 21 ° to 40°; group IV: 4 1 ° to 50°; group V: > 5 1° of curvature). Each group was then subdivided into a group that was managed with prophylactic bracing and a group that was not braced. **Outcome Measures**: Completion of bracing regimen, surgery, or cessation of growth.	At follow-up (range 2-13 yr), 95% of patients had developed scoliosis; surgical stabilization was required in 65% of the total sample. Group I (initial curve <10°; n=42) 1. 29 of the patients in this group were braced, and 13 who were not. 2. Of the braced group, 13 (45%) went on to surgery, whereas 10 (77%) of the non-braced group had surgical correction (p=0.03). 3. Of the patients who were initially braced, the average time to surgery was 8.5 yr, whereas that for the non-braced group was 4.2 yr (p=0.002). 4. There was no significant difference between time to surgery for the braced and non-braced patient groups at higher (>20°) initial curve presentations. Group II (Initial curve 11 ° to 20°; n=25) 1. Eighteen (72%) patients in this group were braced and 72 8%) were not braced. 2. Nine of the 18 children in the braced group (50%) required surgery at 6.8 years after initial presentation, whereas 6 of 7 of the nonbraced group (86%) required surgery at 3.7 years after presentation. 3. The difference between the rate of surgery (p=0.04) and the length of time to surgery (p=0.008) in the braced vs nonbraced group was statistically significant, whereas the curve at the time of surgery was not (p=0.52). Group III (Initial curve 21 ° to 40°; n=28) 1. Of the 20 (61%) children initially braced in this group, 1

			2 (60%) went on to have surgery at 4.2 years after presentation, whereas 8 (40'7'o) did not require surgery. 2. Of the 8 children (3 9%) who were not braced, 6 (7 5%) went on to surgical correction at 3.2 years after presentation. 3. While there was no statistical difference for time to surgery between the braced and nonbraced patients in group III (p=0.3 6), there was a trend toward less surgical intervention in the braced patients (p=0.08). Group IV (Initial curve > 41 ° but < 50°; n=16) & Group V (curves > 51 ° at presentation; n=12) 1. In Group IV, one patient (6%) was not braced and proceeded to surgery, whereas 15 (94%) were braced, of which 12 (80%) went on to have surgical correction of their deformity. 2. In Group V, ten patients (83%) were braced and 2 (17%) were not braced; surgical correction of the spine was performed on 8 children (80%) in the braced group and both children (100%) in the nonbraced group. 3. In group IV and V, There was no significant difference between time to surgery for the braced and non-braced patient groups.
TLSO Brace	Chafetz et al. (2007) USA Prospective Controlled Trial N=14	**Population:** Mean age:10.8±2.4yr; Gender: males=7, females=7; Level of injury: C1-C7=1, T1-T12=13; Severity of injury: Not reported; Time since injury: Not reported. **Intervention:** Children with spinal cord injuries (SCI) completed the activities of the functional	1. For each of the activities of the TMT, subjects were slower when wearing the TLSO. For those wearing a TLSO, there was a noticeable 26% increase in time for donning a shirt (13.6±4.3s to 17.1±8.0s), and a 21% increase in time for donning pants (40.0±8.6s to 48.2±12.8s) (p<0.01)

		activities scale (FAS) and repetitive timed motor tests (TMT) while wearing a thoracolumbosacral orthosis (TLSO) and without a TLSO. Subjects were asked their preference for wearing or not wearing the TLSO during each of the activities. **Outcome Measures:** Timed motor test (TMT), functional activities scale (FAS).	2. For FAS, wearing a TLSO did not impact the activities of eating, grooming, wheelchair propulsion, curb management, or transitioning from sitting at the edge of a bed to a supine position 3. The only statistically significant difference was for upper-body dressing, with the activity scoring lower when the subject was wearing a TLSO (p<0.01) 4. Preference for not wearing a TLSO was significantly different (p<0.05) for lower-body dressing, reaching for the floor, and transitioning from a supine position to sitting at the edge of the bed
Scoliosis/ Spinal Fusion	Mulcahey et al. (2013) USA Cross-Sectional N=217	**Population:** 13.2±4.9yr.; Gender: males=127, females=90; Level of injury: Not reported; Level of severity: AIS A=105, B=45, C=30, D=21, Missing=16; Time since injury=4.2±3.7yr. **Intervention:** None – observational, participants evaluated using the testing guidelines of the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) to determine predictors of worse curve and spinal fusion in neurological scoliosis. *All participants had neuromuscular scoliosis and 24 of the 217 participants underwent spinal fusion due to their progressive neuromuscular scoliosis. **Outcome Measures:** ISNCSCI classification, Cobb angles, motor score.	1. Age of injury (p<0.0001) and AIS classification (p<0.0095) were the only significant predictors of worse curve when grouped as an entire sample 2. Risk of spinal fusion increased by 11% for every yr. decrease in age at injury 3. Sex, motor score, and neurological level were not predictors of worse curve of spinal fusion 4. Subjects injured before the age of 12 were 3.7 times more likely to require a spinal fusion than those injured after age 12 (95% CI, 0.31-44.64)

Scoliosis/ Spinal Fusion	Schottler et al. 2012 USA Cross-Sectional N=159	**Population:** Median Age: 2yr (age range: 0-5yr); Gender: males=92, females=67; Level of severity: Paraplegia=100 (incomplete=33, complete=64, unknown=3), Tetraplegia=52 (incomplete=23, complete=24, unknown=5), Not reported=7; Time Since Injury=Not reported **Interventions:** **Outcome Measures:** Complications (i.e., scoliosis, hip dysplasia, latex allergies, autonomic dysreflexia, pressure ulcers, spasticity, deep venous thrombosis, and kidney stones), demographic and injury-related factors (i.e., age at injury, etiology, level of injury, American Spinal Injury Association Impairment Scale (AIS), and SCIs without radiological abnormalities (SCIWORA))	1. Ninety-six percent of participants developed scoliosis, 57% had hip dysplasia, and 7% had latex allergy. 2. Median age of initiating wheelchair use was 3 years 4 months (range 1y 2mo–12y 5mo). 3. Twenty-four participants were community ambulators, and they were more likely to have AIS D lesions and less likely to have skeletal complications.
	STAND		
FES	(Johnston et al. 2003) USA Pre-Post N=9	**Population:** Age: 12.7±5.2 yr (range 7-20 yr); Level and Severity of Injury: C7 tetraplegia (n=1), T1-11 paraplegia (n=8); Long Leg Bracing [LLB] Used: Knee Ankle Foot Orthoses [KAFO] (n=2), Hip Knee Ankle Foot Orthoses [HKAFO] (n=2), Reciprocating Gait Orthoses [RGO] (n=5). **Intervention:** Lower extremity Functional Electrical Stimulation (FES) implant which delivered a balanced	1. Two subjects did not complete training and were not included for analysis 2. 12/72 originally implanted electrodes required revision primarily due to inadequate force production 3. Subjects completed four activities more quickly when using FES as compared to LLB: donning (p=0.0026), stand and reach (p=0.0012), high transfer (p=0.0009), bathroom (p=0.0164) 4. Subjects completed five activities with less assistance when using FES as compared to LLB: donning (p=0.0001), stand and reach (p=0.0036),

		asymmetrical biphasic waveform with pulse duration up to 200 msec, 20 Hz frequency, and 20 mA current. Bilateral ankle foot orthoses (AFO) set in zero degrees of dorsiflexion were worn when ambulating with the FES system. After implantation and immobilization participants did 2-4 wk of FES strengthening followed by standing and walking exercise, and upright mobility training. **Outcomes:** Completion of eight upright mobility activities, scored based on completion time and level of independence: donning, stand and reach, high transfer, bathroom, floor to stand, 6-meter walk test(6MWT), stair ascent, stair descent.	high transfer (p=0.0191), bathroom (p=0.0006), and floor to stand (p=0243) 5. No activity required more time or more assistance to complete with FES as compared to LLB 6. Subjects reported preferring FES for 87.5% of the activities, LLB for 3.6% of the activities, and showed no preference for 8.9% of the activities
FES	(Johnston et al. 2005) USA Post Test N=3	**Population:** Age: 17-21; Gender: males=3; Level and Severity of Injury: Motor complete T3-T8; Time since injury: 1.0-1.5 yr; **Intervention:** Functional electrical stimulation (FES) consisting of 22-channel implant stimulator, extension leads and epineural electrodes. Leads emanating from the stimulator include two tresses of nine leads each for stimulation of lower extremity muscles and one tress of four leads for stimulation for bladder and bowel function (parameters: 0.2–8 mA amplitude, 25–600 ms pulse	1. Three of the 52 electrodes placed for lower extremity stimulation experienced changes in the responses of the muscles 2. Two subjects used a walker with wheels to perform the mobility activities and one subject used forearm crutches. 3. None of the subjects required physical assistance to complete the activities but two required supervision 4. One individual could not ascend/descend stairs as it was felt to be unsafe for him; several activities could not be performed by another subject secondary to complaints of shoulder pain related to poor scapular muscle control 5. All subjects reported preferring a swing through pattern for walking as they felt

		duration, 2–500 Hz pulse frequency per channel). After implantation and immobilization participants completed exercise phase (FES strengthening) followed by lower extremity conditioning, standing and upright mobility training (13 wk). **Outcome Measures:** Completion of eight upright mobility activities, scored based on completion time and level of independence: donning, stand and reach, high transfer, bathroom, floor to stand, 6-meter walk test (6MWT), stair ascent, stair descent.	it was faster; two subjects could ambulate up to 20 feet and the third subject up to 75 feet 6. Just one subject demonstrated positive neuromodulation effects of the bladder; stimulation suppressed reflex bladder contractions acutely thereby reducing vesical pressure 7. For one subject, low frequency stimulation significantly increased rectal and anal sphincter pressure which reduced time to defecate; compared to bowel management without stimulation, the patient reported greater satisfaction with stimulation.
FES	(Moynahan, Mullin, et al. 1996) USA Observational N=5	**Population:** Age: 18.4±1.1 yr; Gender: males=2, females=3; Level of Injury: T4 (n=2), T5 (n=1), T8 (n=1), T11 (n=1); Severity of Injury: AIS A; Orthotics Use: Molded Shoe Insert=4, Ankle Foot Orthosis [AFO]=1. **Intervention:** Hybrid system of implanted Functional Electrical Stimulation [FES] (pulse duration 0-150μsec, frequency 0-50 Hz) with wearable AFO. After implantation, participants completed training for standing and mobility. **Outcome Measures:** Patterns of home and community FES use; barriers and facilitators of use. Assessed every 1-4 wk for 1 yr.	1. The frequency of donning the system ranged 23%-34% of the days surveyed; this is equivalent to donning the system once every 3 to 4 days. 2. The two most common standing activities were "one-handed activities (e.g., painting furniture, changing a car's air filter, pushing a sibling on a swing-set) or reaching" and "standing for exercise or to stretch," accounting for 62% of all reported standing activities across subjects. 3. Maneuvering" was typically performed in areas of the house that were easily accessed by wheelchair. 4. The FES system was used to perform swing-to gait with their walkers around the house, sometimes transferring to other seats. 5. "Standing with others" included showing friends or family standing ability, to take pictures or for hugging.

			6. "Transfers" (e.g., for weighing or to transfer into a car) were not widely performed. 7. "Motivators" for FES use included: being able to do things that would be difficult/impossible otherwise, perceiving a healthful benefit from exercise/standing, having a sense of well-being, and feeling an obligation to stand as a member of the research study. 8. "Barriers" included: not having time to stand or exercise, having difficulty seeing opportunities and reluctant to wear it all day.
FES	(Bonaroti et al. 1999a) USA Case Report N=1	**Population:** 11 yr, T10 AIS A SCI **Intervention:** Functional electrical stimulation, Knee Ankle Foot Orthoses **Outcome Measures:** Functional Independence Measure (FIM) and time to completion during upright mobility activities: donning, high transfer, toilet transfer, floor-to-standing transfer, ascend/descend stairs.	1. FIM measurements of bathroom transfer and descending stairs completed significantly faster with KAFO (p<0.001 and p=0.04 respectively) 2. For the remaining activities there was a trend towards faster completion times with FES, but this was not statistically significant (donning: p=0.28; high transfer: p=0.36; floor transfer: p=0.67; ascending stairs: p=0.32) 3. While performing the 10 subset activities of the FST, the subject displayed no significant differences in completion times between the 2 modes 4. Subject was significantly more stable in the static position using KAFO (p=0.03) whereas in dynamic testing subject was slightly more stable using FES, but was not statistically significant (p=0.7) 5. Ambulation velocity was significantly faster using FES during the 100 feet ambulation (p<0.001) and maximum ambulation (p<0.001) test but not during

			energy expenditure testing (p=0.13)
FES	(Bonaroti et al. 1999b) USA Pre-Post N=5	**Population:** Age: 9 yr (n=2), 10 (n=1), 18 yr (n=2); Gender: males=4, females=1; Etiology: Traumatic SCI=4, Non-Traumatic SCI=1; Level of Injury: cervical=2, thoracic=3; Severity of Injury: Paraplegia=5. Bracing for Standing & Therapy: Knee Ankle Foot Orthoses [KAFO]=5. **Intervention:** Hybrid system of implanted Functional Electrical Stimulation [FES] (pulse duration 0-150μsec, frequency 0-50 Hz) with wearable Ankle Foot Orthoses (AFO). After implantation, participants completed FES strengthening followed by sit/stand exercise, and then upright mobility training for 4 weeks. **Outcome Measures:** Completion of eight upright mobility activities, scored based on completion time and level of independence with FES versus Long Leg Braces (LLB): donning, stand and reach, high transfer, floor to stand, 6-meter walk test (6MWT), toilet transfer.	1. When comparing the upright mobility activities between using FES versus LLB, subjects required equal (70%) or less (24%) assistance when using FES compared with using LLB 2. One subject had greater independence using LLB for the *floor to stand* transfer 3. One subject had greater independence using LLB for the 6MWT 4. For each activity in which FES provided greater independence, subjects improved from requiring contact assistance (3 or 4) while using LLB to not needing contact assistance (5 or 6) while using FES 5. There were two subjects who required minimal contact assist (4) with LLB but were independent with FES (6), both for the *stand and reach* activity, and six instances in which minimal (4) or moderate (3) contact assistance was required with LLB and no contact assistance (5) was required using FES 6. Two activities, *stand and reach* and *high transfer,* were performed significantly faster with FES 7. When subjects were asked which mode of standing they preferred, FES was preferred in 62% of the cases, LLB were preferred 27% of the time, and there was no preference 11% of the time.
FES	(Betz et al. 2002) USA Case Report N=1	**Population:** 13 yr, male, T8 SCI. **Intervention:** Lower extremity implanted Functional Electrical Stimulation (FES) with a Knee Ankle Foot Orthoses (KAFO).	1. Across all time periods, the subject required less time to don the FES system (P<0.0001) and to complete the high reach (P<0.0001), high transfer (P<0.0001), and 6MWT (P=.006) compared with KAFO

		Outcome Measures: Completion of eight upright mobility activities, scored based on completion time and level of independence: donning, stand and reach, high transfer, bathroom, floor to stand, 6-meter walk test (6MWT), stair ascent, stair descent.	2. More time was needed to complete the floor-to-stand activity for FES compared to KAFO (P=0.0001) 3. No time differences were seen between FES and KAFO for the inaccessible bathroom transfer (P=0.507) and ascending (P=0.753) and descending stairs (P=0.164) 4. Subject was able to more quickly complete the sit-to-stand transition (P<0.0001), reach for a videotape on a high shelf (P<0.0001), and return to sitting in the wheelchair (P<0.0001) when using FES 5. Subject preferred FES to KAFO for all activities but floor-to-stand at 2-yr. follow-up
Dynamic gait trainer	(Altizer et al. 2017) USA Case Report N=1	**Population:** 23 mo, female, T10 AIS A SCI. **Intervention:** Overground supported stepping intervention using a dynamic gait trainer. **Outcome Measures:** Paediatric Evaluation of Disability Inventory (PEDI), Spinal Cord Independence Measure (SCIM), Gross Motor Function Measure (GMFM-66), Developmental Profile (DP-3), Support Walker Assessment Ambulation Performance Scale (SWAPS), 6-Minunte Walk Test (6MWT).	1. PEDI score improved by 6 points (60%) from age 36-54mo. and by 18 points (75%) from age 54-72mo 2. SCIM score improved over the 3 yr of intervention (36mo. – 19; 54mo. – 31; 72mo. – 43) but remained well below the median adult score for those with injury at T10 of 63 3. GDFM-66 score improved minimally over 3 yr of intervention 4. DP-3 score demonstrated a continued motor deficit in comparison to age, but also shows progress in physical skills 5. 6MWT change from 54-72mo. was double what was expected from documentation in literature for her age and level of SCI.
Dynamic Gait Trainer	(Choksi et al. 2010) Observational USA N=32	**Population:** Mean age 10.6±6.2 (1-19) yr; Injury Etiology: Traumatic=24, Non-traumatic=8; Level of Injury: Cervical=18, Thoracolumbar=14.	1. PEDI mobility (functional skills): ↑24.0±14.7 2. PEDI mobility (caregiver assistance): ↑26.1+21.5 3. All children improved or showed no change on walking-related PEDI items:

		Intervention: Inpatient rehabilitation physiotherapy and occupational therapy (3 hr/day). **Outcome Measures:** Pediatric Evaluation of Disability Inventory (*mobility* and *self-care*) via Functional Skills and Caregiver Assistance scales).	• Indoor locomotion methods: 8/21 ↑ • Indoor locomotion distance/speed: 11/21 ↑ • Indoor locomotion pulls/carries: 13/21 ↑ • Outdoor locomotion methods: 1/21 ↑ • Outdoor locomotion distance/speed: 12/21↑ • Outdoor locomotion surfaces: 12/21↑
	GAIT		
Orthoses	(Vogel & Lubicky, 1995) USA Observational N=39 N(Parapodium)=26 N(RGO)=13 RGO – Reciprocating Gait Orthoses	**Population:** (Parapodium) Age at injury=3.2yr. (range birth-9yr.); Gender: males=15, females=11; Level and severity of injury: T1-T4 paraplegia=7, Tetraplegia=6, Not reported=13; Time since injury: Not reported. (RGO) Age at injury= 8.1yr. (range birth-15yr.); Gender: males=5, females=8; Level and severity of injury: T4 paraplegia=1, Tetraplegia=0, Not reported=12; Time since injury: Not reported. **Intervention:** Chart review of parapodium and RGO users. **Outcome Measures:** Post-orthotic use outcomes.	1. No patients in either group were community ambulators 2. Among the 20 children that began using parapodia at less than 6yr., 12 were household ambulators 3. All 6 children who began using parapodia after 6yr. old were therapeutic ambulators 4. Among children that initially used RGOs, 2 were household ambulators and the remaining 11 were all therapeutic ambulators 5. Of the 26 children in the parapodium group, four were lost to follow-up or died after a mean of 3.7 yr. of orthotic use, 12 continued to use their parapodia with a mean follow-up of 3.4 yr., and 10 stopped using their parapodia after 2.2 vr on average 6. 12 children who continued to use their parapodium. the mean age at injury was 2 1/2 yr., mean age at initiation of parapodium use was 3.7 yr., and their mean age at current follow-up was 7.1 yr. 7. For the 10 children who had discontinued use of their parapodium, the mean age at injury was 5 yr., mean age at initiation of orthotic use was 5.7 yr., and mean age at discontinuation of parapodium use was 7.9 yr.

			8. Among the 13 children who initiated their orthotic use with RGOS, three were lost to follow-up after using their RGOs for an average of 2 1/2 yr., two are still using RGOs and 8 have stopped using them 9. The two children still using them were approximately 2 1/2 yr. old when injured and began orthotic use at three and 3 1/2 yr. of age, each has been followed for 1 1/2 yr. 10. The eight individuals who discontinued RGO use were on average 10.8 yr. old at the time of their injury, began using the RGO at a mean age of 12 1/2 yr. and stopped using their RGOs at a mean age of 16.7 yr. 11. Of the eight individuals who discontinued RGO use seven did not progress to another orthotic device and one teenager with T10 paraplegia progressed to a knee ankle foot orthosis (KAFO) which she used sporadically for 1 1/2 yr.
FES	(Johnston et al. 2003) USA Pre-Post N=9	**Population:** Age: 12.7±5.2 yr (range 7-20 yr); Level and Severity of Injury: C7 tetraplegia (n=1), T1-11 paraplegia (n=8); Long Leg Bracing [LLB] Used: Knee Ankle Foot Orthoses [KAFO] (n=2), Hip Knee Ankle Foot Orthoses [HKAFO] (n=2), Reciprocating Gait Orthoses [RGO] (n=5). **Intervention:** Lower extremity Functional Electrical Stimulation (FES) implant which delivered a balanced asymmetrical biphasic waveform with pulse duration up to 200 msec, 20 Hz frequency, and 20	1. Two subjects did not complete training and were not included for analysis 2. 12/72 originally implanted electrodes required revision primarily due to inadequate force production 3. Subjects completed four activities more quickly when using FES as compared to LLB: donning (p=0.0026), stand and reach (p=0.0012), high transfer (p=0.0009), bathroom (p=0.0164) 4. Subjects completed five activities with less assistance when using FES as compared to LLB: donning (p=0.0001), stand and reach (p=0.0036), high transfer (p=0.0191), bathroom (p=0.0006), and floor to stand (p=0243)

		mA current. Bilateral ankle foot orthoses (AFO) set in zero degrees of dorsiflexion were worn when ambulating with the FES system. After implantation and immobilization participants did 2-4 wk of FES strengthening followed by standing and walking exercise, and upright mobility training. **Outcomes:** Completion of eight upright mobility activities, scored based on completion time and level of independence: donning, stand and reach, high transfer, bathroom, floor to stand, 6-meter walk test(6MWT), stair ascent, stair descent.	5. No activity required more time or more assistance to complete with FES as compared to LLB 6. Subjects reported preferring FES for 87.5% of the activities, LLB for 3.6% of the activities, and showed no preference for 8.9% of the activities
FES	(Johnston et al. 2005) USA Post Test N=3	**Population:** Age: 17-21; Gender: males=3; Level and Severity of Injury: Motor complete T3-T8; Time since injury: 1.0-1.5 yr; **Intervention:** Functional electrical stimulation (FES) consisting of 22-channel implant stimulator, extension leads and epineural electrodes. Leads emanating from the stimulator include two tresses of nine leads each for stimulation of lower extremity muscles and one tress of four leads for stimulation for bladder and bowel function (parameters: 0.2–8 mA amplitude, 25–600 ms pulse duration, 2–500 Hz pulse frequency per channel). After implantation and immobilization participants completed	1. Three of the 52 electrodes placed for lower extremity stimulation experienced changes in the responses of the muscles 2. Two subjects used a walker with wheels to perform the mobility activities and one subject used forearm crutches 3. None of the subjects required physical assistance to complete the activities but two required supervision 4. One individual could not ascend/descend stairs as it was felt to be unsafe for him; several activities could not be performed by another subject secondary to complaints of shoulder pain related to poor scapular muscle control 5. All subjects reported preferring a swing through pattern for walking as they felt it was faster; two subjects could ambulate up to 20 feet and the third subject up to 75 feet

		exercise phase (FES strengthening) followed by lower extremity conditioning, standing and upright mobility training (13 wk). **Outcome Measures:** Completion of eight upright mobility activities, scored based on completion time and level of independence: donning, stand and reach, high transfer, bathroom, floor to stand, 6-meter walk test(6MWT), stair ascent, stair descent;	6. Just one subject demonstrated positive neuromodulation effects of the bladder; stimulation suppressed reflex bladder contractions acutely thereby reducing vesical pressure 7. For one subject, low frequency stimulation significantly increased rectal and anal sphincter pressure which reduced time to defecate; compared to bowel management without stimulation, the patient reported greater satisfaction with stimulation

Table 3. Studies assessing Measurement of Recovery-Based strategies for lower limb for pediatric-onset SCI

Main Outcomes	Author, Year Country Study Design Sample Size	Study Characteristics	Results
	TRUNK		
SATCo	(Singh et al. 2020) USA Not Reported N=36 (SCI=26) N(TD)=10	**Population:** *SCI:* Mean age=5.0±2.0yr; Gender: males=17, females=9; Level of injury: C2-L2; Level of severity: AIS A=4, B=3, C=2, D=1, N/A=16 (younger than 6yr.); Time since injury=2.7±2.0yr. *Typically Developing (TD):* Mean age=6.0±2.0 yr; Gender: males=5, females=5. **Intervention:** Trunk Control Assessment SCI vs TD groups. **Outcome Measures:** Trunk Control Assessment (SATCo), Surface Electromyography (EMG), EMG Normalization	1. SCI group scored significantly lower on the SATCo compared to the TD group (p<0.001) 2. Every participant in the TD group completed all levels of the SATCo test, where 21 of the 26 individuals in the SCI group did not complete all levels 3. SCI group had significantly higher thoracic paraspinal (PST) muscle activation than the TD group over lower ribs (p=0.01), below ribs (p=0.001) and pelvis (p=0.03) 4. SCI group produced significantly lower PST muscle activation at inferior scapula (p=0.03), and significantly higher EMG magnitude at no support (p=0.004) level compared to the TD group
SATCo	Argetsinger et al. (2020) USA Case Study N=1	**Population:** Age=35mo; Gender: males=0, females=1; Level of injury: C5-C7; Level of severity: tetraplegia; Time since	5. Neuromuscular capacity improved significantly, especially for head and trunk control – allowed for major improvements in respiratory health, novel engagement with her

		injury=32mo. **Intervention:** Activity-based therapy (ABT) for 8 months **Outcome Measures:** Neuromuscular capacity (Segmental Assessment of Trunk Control (SATCo))	environment, and improved physical abilities
SATCo	(Argetsinger et al. 2019) USA Prospective Study N=21	**Population:** Mean age=63.3±27.2mo.; Gender: males=10, females=11; Level of injury: cervical=9, thoracic=12; Level of severity: Not reported; Time since injury=18.3±18mo. **Intervention:** Activity-based locomotor training (AB-LT) with outcomes reported with regards to chronicity, initial score, ad injury level **Outcome Measures:** Segmental Assessment of Trunk Control (SATCo); Pediatric Balance Scale; Modified Functional Reach (MRF-Forward-Right-Left); Timed Short Sit; Timed Long Sit; Timed Stand.	1. SATCo scores increased significantly ($p<0.05$) regardless of chronicity, injury level, or initial score 2. Significant difference from first to last evaluations for MRF-Forward-Right-Left, Timed Short Sit, Timed Long Sit and Timed stand scores 3. No significant change in Pediatric Balance Scale from first to last evaluation
ABT	(Goode-Roberts et al. 2021) Switzerland Case Report N=1	**Population:** Age:2.7yr; Gender: males=1; Level of injury: C1-Sacrum; Severity of injury: Not reported; Time since injury=2.7 yr. **Intervention:** The patient received 144 sessions of Activity-Based Locomotor Training (AB-LT) and 90 sessions of Activity-Based Neuromuscular Electrical Stimulation (AB-NMES) over a seven-month period. AB-LT was provided for 1.5h/day, 5 days per week, followed by 1h/day, 5 days per week of AB-NMES. **Outcome Measures:** Resting respiratory rate, Segmental Assessment of Trunk	1. The patient's resting respiratory rate steadily declined over a 4-month period from 60 to 30 BPM 2. The number of times the patient required to be suctioned during therapy sessions declined overall, with the exception of periods of viral respiratory illness 3. The patient's SATCo score increased from 0/20 to 5/20 4. Bayley-III assessment at discharge revealed dramatic developmental changes; non-verbal cognitive abilities improved from that of a 16-day old to a 9-month developmental level and social/emotional skills from 0-3 month to 15-18 developmental level

		Control (SATCo), Bayley-III Assessment.	
SATCo	(A. L. Behrman et al. 2019) USA Pre-Post N=26	**Population:** Age: 5.0±3.0 yr; Gender: 15 males, 11 females; Etiology: 12 traumatic, 14 non-traumatic; Time since injury: 1.4±1.3 yr; Level of Injury: cervical=9, thoracic=15, lumbar=2; AIS: A (n=6), B 9 (n=4), C (n=3), D (n=1); Chronicity: 13 acute, 13 chronic. **Intervention:** Activity-based locomotor training (AB-LT), 5 times per week for 60 sessions, 1.5 hr per session. Body weight support (1 hr) followed by overground walking with supports, as necessary. Integration of training principles encouraged in daily activities. Neuromuscular electrical stimulation (40-100 Hz) provided 1-1.5 hr per week, 5 days per week, for 4 participants only. **Outcome Measures:** Segmental Assessment of Trunk Control (SATCo), Pediatric Neuromuscular Recovery Scale (Pediatric NRS) at baseline, sessions 20, 40, and 60 and/or discharge.	1. Pediatric NRS scores improved significantly from baseline to session 20 (p<0.05), from session 20 to 40 (p<0.05); while scores improved from session 40 to 60 they were not significant 2. On average, the inter-evaluation change in Pediatric NRS score was 3.7 (p<0.05) 3. SATCo scores improved significantly from baseline to session 20 (p<0.05), from session 20 to 40 (p<0.05); while scores improved from session 40 to 60 they were not significant 4. On average, the inter-evaluation change in SATCo score was 1.7 (p<0.05) 5. There was no significant difference in Pediatric NRS or SATCo scores by chronicity of SCI.
Supine Functional Neurophysiological Assessment	Atkinson et al. (2019) USA Observational N=43 N=43 (SCI=24)	**Population:** *SCI:* Mean age=7.5±3.4yr.; Gender: males=12, females=12; Level of injury: C1-T12; Level of severity: AIS N/A=10 (younger than 6 yr.), A=4, B=1, C=8, D=0, Not reported=1; Time since injury=4.6±3.6 yr. *Typically Developing (TD):* Mean age=6.9±2.8yr.; Gender: males=12, females=12; Level of injury: N/A; Level of	1. SCI participants in both the IMA and NMA groups had significantly lower magnitudes and SI values in comparison with TD children (p < 0.01) 2. Magnitude significantly different between the NMA and IMA groups for all tasks (p < 0.05), with little variability in magnitude or SI values in the NMA group due to lack of EMG activity in these participants 3. In TD children, SI values were close to one for each task, and were not significantly correlated with age. In contrast, significantly greater

		severity: N/A; Time since injury: N/A. **Intervention:** None – observational, SCI were split into 2 groups – Voluntary Movements (IMA) and Non-voluntary Movements (NMA). **Outcome Measures:** Left Ankle Dorsiflexion (LADF), Right Ankle Dorsiflexion (RADF); Left Knee Flexion (LKF); Right Knee Flexion (RKF), Bilateral Hip and Knee Flexion (BHKF), Bilateral Hip and Knee Extension (BHKE); Bilateral Hip Adduction (BHA); Neck Flexion (NF); Sit-up.	variability in SI values was observed for IMA participants ($p < 0.0001$) 4. Across all tasks, SI values were significantly larger in TD group as compared with either the NMA or the IMA groups ($p < 0.01$), however no significant differences were observed between SCI groups 5. With regard to magnitude, significant differences were found for all events and all groups, with the exception of NF (IMA vs. TD) ($p < 0.05$), wherein NMA magnitude values were significantly lower than all other groups 6. IMA magnitudes were significantly larger than the NMA group, and significantly smaller than the TD group. A positive correlation was found between SI and qualitative scores across all tasks (CC = 0.67, $p <0.0001$)
	STAND		
NMRS	Ardolino et al. 2016 USA Observational N=12	**Population:** Children with SCI=5: Age Range: 48mo-143mo; Gender: males=3, females=2; Level of severity: Not reported; Time since injury: Not reported Children without SCI=7: Age Range: 22mo-126mo; Gender: males=4, females=3 **Intervention:** None - observational **Outcome Measures:** draft Pediatric NRS, revised draft Pediatric NRS, clarity of wording and scoring	1. After the Delphi process and field testing, the final Pediatric NRS consists of 13 items scored on a 12-point scale. 2. All items, except 1, achieved 80% agreement by experts, in terms of clarity of wording and scoring.
NMRS	(Andrea L Behrman et al. 2019) USA Observational $N_{(HCP)}$=14 $N_{(SCI-P)}$=32 HCP – Healthcare Professional	**Population:** (SCI-P) Mean age=6.0±3.0yr.; Gender: males=17, females=15; Level of injury: C1-L5; Level of severity: AIS A=6, B=5, C=2, D=5, N/A=14 (younger than 6yr.); Time since injury: Not reported. **Intervention:** None – observational. **Outcome Measures:** Interrater reliability.	1. Interrater reliability coefficient was determined to be near 1 overall for Pediatric NRS score (ICC=0.966; 95% CI, 0.89-0.98) 2. 12 of 16 individual items exhibited high concordance coefficients (Kendall's W ≥0.8) 3. 4 items were found to have concordance coefficients <0.8 and >0.69. 4. Interrater reliability was equal among groups defined by

	SCI-P – Spinal Cord Injury - Pediatric		neurological level and age, but lower among non-ambulatory individuals.
	GAIT		
LEMS, Home Activities	(Behrman et al. 2008) USA Case Report N=1	**Population:** 4.5 yr, male, C8 AIS C traumatic SCI, 16 mo post-injury. **Intervention:** Body weight support, overground walking. **Outcome Measures:** Functional Independence Measure for Children II (WeeFIMII), preferred speed, fast speed, community steps	1. AIS score remained the same after session 74 2. LEMS score remained at 4/50 at session 74 3. From session 51 to 76 gait speed increased from 0.19m/s to 0.29m/s 4. From session 51 to 76 fastest walking speed increased from 0.3m/s to 0.48m/s 5. WISCI score increased from 0/20 to 13/20 6. At session 33 the child showed multiple non-cued steps 7. From session 49 to 74 the child increased from 926 steps per day to 2488 steps per day
LEMS, Berg Balance	(Behrman et al. 2012) USA Case Reports N=3	**Population:** *Case 1:* 15 yr, male, T5 SCI, AIS D. *Case 2:* 14 yr, male, T5 AIS C ruptured arteriovenous malformation; *Case 3:* 14 yr, male, C2 AIS D SCI. **Intervention:** Locomotor Training (Body weight support treadmill training, overground walking), community integration. **Outcome Measures:** 10-meter walk test (10MWT),6-minute walk test 6MWT, Berg Balance Scale (BBS),	*Case 1* 1. 10MWT with initial rolling walker (RW) device improved from 0.16m/s at initial evaluation to 1.12m/s at discharge and declined to 1.06m/s at 12mo. follow-up 2. 10MWT with current bilateral single point canes (BSPCs) devices improved from 0.77m/s at session 20 (started use of BSPCs) to 1.22m/s at discharge and declined to 1.01m/s at 12mo. follow-up (use of BSPCs stopped after session 40) 3. 6MWT with initial rolling walker (RW) device improved from 53.07m at initial evaluation to 291.69m at discharge and improved further to 298.4m at 12mo. follow-up 4. 6MWT with current bilateral single point canes (BSPCs) devices improved from 242.32m at session 20 (started use of BSPCs) to 308.15m at discharge and improved further to 316.11m at 12mo. follow-up (use of BSPCs stopped after session 40) 5. BBS score improved from 8/56 at initial evaluation to 48/56 at discharge and declined to 47/56 at 12mo. follow-up *Case 2* 1. 10MWT with initial rolling walker (RW) device improved from 0.12m/s

			at initial evaluation to 0.22m/s at session 80 and improved further to 0.38m/s at session 200 2. 10MWT with current bilateral loftstand crutches (BLCs) devices remained at 0.1m/s from session 40 (started use of BLCs) session 80 and improved to 0.45m/s at session 200 (use of bilateral single point canes (BSPCs) at session 200) 3. 6MWT with initial rolling walker (RW) device improved from 25.6m at initial evaluation to 44.8m at session 80 and improved further to 117.3m at session 200 4. 6MWT with current bilateral loftstand crutches (BLCs) devices declined from 13.6m at session 40 (started use of BLCs) to 7.6m at session 80 but improved to 123.8m at session 200 (use of bilateral single point canes (BSPCs) at session 200) 5. BBS score increased from 7/56 at initial evaluation to 23/56 at session 80 and improved further to 31/56 at session 200 *Case 3* 1. 10MWT increased from 1.3m/s at initial evaluation to 1.5m/s at session 20 and increased further to 1.72m/s at discharge 2. 6MWT increased from 435m at initial evaluation to 467m at session 20 and increased further to 500m at discharge 3. BBS score increased from 55/56 at initial evaluation to 56/56 at session 20 and sustained a score of 56/56 at discharge LEMS • LEMSs for the three reported cases were 29, 22, and 46, respectively • Only the adolescent in Case 1 demonstrated significant change (17 points) in his LEMS post-LT that could also account for improvement in function • For the other two instances, the LEMS change was relatively minor

BERG Balance, NRS	(Behrman et al. 2017) USA Not reported N=Not reported	**Population:** Not reported **Intervention:** Basic scientific findings that legs to locomotor training (LT) and activity-based therapies (ABT). **Outcome Measures:** Neuromuscular recovery scale (NRS), Berg Balance Scale (BBS).	1. BBS over time revealed scores that spanned the entire breadth of the scale and his variation did not reduce when this sample was divided into groups by AIS classification • To be able to make comparisons across groups in research studies, or make clinical predictions, a tool that can classify persons according to activity domain, in addition to impairment, is needed 2. NRS has been found to have strong test-retest reliability (Spearman correlation coefficients of 0.92–0.99) as well as high inter-rater reliability (Kendall coefficient of concordance ≥0.90) 3. The construct validity of the original NRS was established using Rasch analysis, which revealed that the NRS stratifies individuals with all AIS classifications into 5 distinct strata 4. No floor or ceiling effects were found for the NRS, and the scale also demonstrated a logical order of item difficulty 5. NRS was found to be a stronger predictor of recovery than AIS classification when measuring the change in performance of persons with motor-incomplete SCI on the BBS, 6MWT and 10MWT 6. Pediatric Neuromuscular Recovery Scale (Peds NRS) was developed by clinicians and researchers with pediatric expertise and consists of 13 items graded on a 12-point scale 7. The use of the adult NRS and Peds NRS in other neurological populations is also being investigated
LEMS	(O'Donnell & Harvey, 2013) Australia Case Report N=1	**Population:** 17 yr, male, T6 AIS C traumatic SCI, 16 mo post injury. **Intervention:** Body weight support treadmill training, overground walking **Outcome Measures:** Lower extremity motor score (LEMS), Walking index for	1. LEMS score improved from 16 to 17 from pre- to post-training and from 17 to 18 from post-training to follow-up 2. WISCI score improved from 6 to 9 from pre- to post-training and remained at 9 at follow-up 3. 6MWT score improved from 67m (1 rest) at pre-training to 76m (no rests) at post-training and further

		spinal cord injury (WISCI II), 6-min walk test (6MWT), 10-m walk test (10MWT), Timed up and go (TUG), Pediatric Quality of Life Inventory (PedsQL).	improved to 80m (no rests) at follow-up 4. 10MWT score improved from 32.2s at pre-training to 30.3s at post-training but declined to 33.6s at follow-up 5. TUG score improved from 44.6s at pre-training to 40.1s at post-training but declined to 42.0s at follow-up, remaining improved compared to pre-training 6. Overall PedsQL score improved from 38/92 at pre-training to 23/92 at post-training and remained at 23/92 at follow-up
Home activities	(Prosser, 2007) USA Case Report N=1	**Population:** 5 yr.10 mo, female, C4 AIS A SCI and mild traumatic brain injury. **Intervention:** Locomotor training including body weight support treadmill training, overground walking, inpatient rehabilitation with aquatic therapy. **Outcome Measures:** Functional Independence Measure for Children II (WeeFIMII), Walking Index for Spinal Cord Injury II (WISCI II), home activities.	1. WeeFIM score improved from 5/35 to 21/35 over 5 months of locomotor training 2. WISCI score improved from 0 to 12 over 5 months of locomotor training 3. At home, she walked most of the time and walked up the stairs to her bedroom with a handrail and minimal assistance
Home Activities, Observational Gait Analysis	(Fox et al. 2010) USA Case Report N=1	**Population:** 3.5 yr, male, C8 AIS C SCI. **Intervention:** Description of child's walking function and musculoskeletal growth and development during the 2 yr after locomotor training **Outcome Measures:** Walking Index for Spinal Cord Injury II (WISCI II), gait speed, cadence, step length, stride length, daily steps activity at home and in the community, musculoskeletal growth and development, gross motor function measure (GMFM-66).	1. Walking independence remained unchanged with WISCI score staying at 13/20 as he still used a reverse rolling walker to ambulate 2. Fastest gait speed increased from 0.45m/s at baseline (1 month post LT) to 0.67m/s at 2 yr follow-up • After 2 yr., gait pattern was improved • Able to generate reciprocal stepping with noticeable absence of shoulder and trunk compensations, particularly on his left side • Despite being able to step reciprocally, he could not walk backwards, side step, or maintain balance without upper-extremity support 3. Cadence increased from 63.35 steps/min at baseline to 70.75 steps/min at 2 yr follow-up

			4. Step length increased in both legs: • Left leg: increased from 42.25cm at baseline to 51.31cm at 2 yr follow-up • Right leg: increased from 44.07cm at baseline to 63.55cm at 2 yr follow-up 5. Stride length increased in both legs: • Left leg: increased from 85.95cm at baseline to 114.79cm at 2 yr follow-up • Right leg: increased from 87.19cm at baseline to 114.47cm at 2 yr follow-up 6. Daily steps increased from about 1600 steps/day at baseline to 3000 steps/day at 2 yr follow-up 7. Over the 2-yr. period the child was not diagnosed with scoliosis, but mild coxa valga was noted at both hip joints and radiology reports indicated all findings stable 8. GMFM-66 scores remained stable over the 2-yr. period
Observational Gait Analysis	Fox et al. (2013) USA Pre-Post N=5	**Population:** Mean age:8.6±2.7yr; Gender: males=4, females=1; Level of injury: C1-C7=2, T1-T12=3; Time since injury>1yr. **Intervention:** Modular control of patients with incomplete spinal cord injury (ISCI) was examined via locomotor tasks including treadmill training, overground walking, pedaling, stair climbing, supine lower extremity flexion/extension, and crawling. **Outcome Measures:** Lower extremity motor score (LEMS), variance accounted for (VAF), electromyogram (EMG) recordings.	1. Fewer modules were needed to account for muscle activation in the lower extremities of children with ISCIs compared with controls ($p<0.05$) 2. An average of 2.11±0.71 modules was required to account for the EMG data recorded in lower extremities of children with ISCI 3. With the use of the muscle weightings from treadmill walking and task-specific timing profiles, the VAF exceeded 86% for all locomotor tasks 4. The VAF exceeded 90% for all tasks performed by the children with ISCIs 5. Modularity is constrained in children with ISCI
Observational Gait Analysis	(Heathcock et al. 2014) USA Case Report N=1	**Population:** 15 mo, male, T11-L4 in-utero spinal cord tumour resulting in SCI with subsequent removal at 5.5 wk of age.	1. An increase in the percentage of alternating steps and a matching decrease in the percentage of single steps over the 20-month intervention period were observed

		Intervention: Treadmill Step Training Program **Outcome Measures:** Number and pattern of walking steps, gait speed, observational gait analysis, standing.	2. At 30 months of age, a pattern of alternating stepping on the treadmill occurred more than 80% of the time, in sharp contrast to the initial 6 months of training when alternating steps comprised fewer than 10% of the total steps 3. Number of steps increased from 1 step at 16mo to 10 steps at 22mo. 4. At 22mo. of age, steps were measured in distance and increased from 3m at 22mo. to about 6m at 31mo. 5. Gait speed varied over the 20 mo period (0.48m/s at 31mo. and 0.40m/s at 35mo.) 6. Only the right leg accounted for most of the stepping rate from 15 through 20 months of age because there were few or no independent steps on the left 7. Over the 20-month intervention period, stepping with the right and left legs increased, with a greater rate of improvement being observed for the left leg, suggesting improvements in symmetry and bilateral function 8. Static standing improved from standing with an arm support on the walker for 30s with contact guard assistance (CGA) at 15mo. to static standing for 20s with standby assistance
NRS	Ardolino et al. 2016 USA Observational N=12	**Population:** Children with SCI=5: Age Range: 48mo-143mo; Gender: males=3, females=2; Level of severity: Not reported; Time since injury: Not reported Children without SCI=7: Age Range: 22mo-126mo; Gender: males=4, females=3 **Intervention:** None - observational **Outcome Measures:** draft Pediatric NRS, revised draft Pediatric NRS, clarity of wording and scoring	1. After the Delphi process and field testing, the final Pediatric NRS consists of 13 items scored on a 12-point scale. 2. All items, except 1, achieved 80% agreement by experts, in terms of clarity of wording and scoring.

NRS	(Andrea L Behrman et al. 2019) USA Observational $N_{(HCP)}=14$ $N_{(SCI-P)}=32$ HCP – Healthcare Professional SCI-P – Spinal Cord Injury - Pediatric	**Population:** (SCI-P) Mean age=6.0±3.0yr.; Gender: males=17, females=15; Level of injury: C1-L5; Level of severity: AIS A=6, B=5, C=2, D=5, N/A=14 (younger than 6yr.); Time since injury: Not reported. **Intervention:** None – observational. **Outcome Measures:** Interrater reliability.	1. Interrater reliability coefficient was determined to be near 1 overall for Pediatric NRS score (ICC=0.966; 95% CI, 0.89-0.98) 2. 12 of 16 individual items exhibited high concordance coefficients (Kendall's W ≥0.8) 3. 4 items were found to have concordance coefficients <0.8 and >0.69. 4. Interrater reliability was equal among groups defined by neurological level and age, but lower among non-ambulatory individuals.

Table 4. Studies assessing Interventions for Recovery Strategies for Lower Limb for Pediatric-Onset SCI

Main Outcomes	Author, Year Country Study Design Sample Size	Study Characteristics	Results
	TRUNK		
ABT	Argetsinger et al. (2020) USA Case Study N=1	**Population:** Age=35mo; Gender: males=0, females=1; Level of injury: C5-C7; Level of severity: tetraplegia; Time since injury=32mo. **Intervention:** Activity-based therapy (ABT) for 8 months **Outcome Measures:** Neuromuscular capacity (Segmental Assessment of Trunk Control (SATCo))	1. Neuromuscular capacity improved significantly, especially for head and trunk control – allowed for major improvements in respiratory health, novel engagement with her environment, and improved physical abilities
ABT	(A. L. Behrman et al. 2019) USA Pre-Post N=26	**Population:** Age: 5.0±3.0 yr; Gender: 15 males, 11 females; Etiology: 12 traumatic, 14 non-traumatic; Time since injury: 1.4±1.3 yr; Level of Injury: cervical=9, thoracic=15, lumbar=2; AIS: A (n=6), B 9 (n=4), C (n=3), D (n=1); Chronicity: 13 acute, 13 chronic. **Intervention:** Activity-based locomotor training (AB-LT), 5 times per week for 60 sessions, 1.5 hr per	1. Pediatric NRS scores improved significantly from baseline to session 20 (p<0.05), from session 20 to 40 (p<0.05); while scores improved from session 40 to 60, they were not significant 2. On average, the inter-evaluation change in Pediatric NRS score was 3.7 (p<0.05) 3. SATCo scores improved significantly from baseline to session 20 (p<0.05), from session 20 to 40 (p<0.05); while scores improved from session 40 to 60 they were not significant

		session. Body weight support (1 hr) followed by overground walking with supports, as necessary. Integration of training principles encouraged in daily activities. Neuromuscular electrical stimulation (40-100 Hz) provided 1-1.5 hr per week, 5 days per week, for 4 participants only. **Outcome Measures:** Segmental Assessment of Trunk Control (SATCo), Pediatric Neuromuscular Recovery Scale (Pediatric NRS) at baseline, sessions 20, 40, and 60 and/or discharge.	4. On average, the inter-evaluation change in SATCo score was 1.7 ($p<0.05$) 5. There was no significant difference in Pediatric NRS or SATCo scores by chronicity of SCI
ABT	(Argetsinger et al. 2019) USA Prospective Study N=21	**Population:** Mean age=63.3±27.2mo.; Gender: males=10, females=11; Level of injury: cervical=9, thoracic=12; Level of severity: Not reported; Time since injury=18.3±18mo. **Intervention:** Activity-based locomotor training (AB-LT) with outcomes reported with regards to chronicity, initial score, ad injury level **Outcome Measures:** Segmental Assessment of Trunk Control (SATCo); Pediatric Balance Scale; Modified Functional Reach (MRF-Forward-Right-Left); Timed Short Sit; Timed Long Sit; Timed Stand.	1. SATCo scores increased significantly ($p<0.05$) regardless of chronicity, injury level, or initial score 2. Significant difference from first to last evaluations for MRF-Forward-Right-Left, Timed Short Sit, Timed Long Sit and Timed stand scores 3. No significant change in Pediatric Balance Scale from first to last evaluation.
ABT	(Goode-Roberts et al. 2021) Switzerland Case Report N=1	**Population:** Age:2.7yr; Gender: males=1; Level of injury: C1-Sacrum; Severity of injury: Not reported; Time since injury=2.7 yr. **Intervention:** The patient received 144 sessions of Activity-Based Locomotor Training (AB-LT) and 90	1. The patient's resting respiratory rate steadily declined over a 4-month period from 60 to 30 BPM 2. The number of times the patient required to be suctioned during therapy sessions declined overall, with the exception of periods of viral respiratory illness 3. The patient's SATCo score increased from 0/20 to 5/20

		sessions of Activity-Based Neuromuscular Electrical Stimulation (AB-NMES) over a seven-month period. AB-LT was provided for 1.5h/day, 5 days per week, followed by 1h/day, 5 days per week of AB-NMES. **Outcome Measures:** Resting respiratory rate, Segmental Assessment of Trunk Control (SATCo), Bayley-III Assessment.	4. Bayley-III assessment at discharge revealed dramatic developmental changes; non-verbal cognitive abilities improved from that of a 16-day old to a 9-month developmental level and social/emotional skills from 0-3 month to 15-18 developmental level
ABT	(Fox et al. 2010) USA Case Report N=1	**Population:** 3.5 yr, male, C8 AIS C SCI. **Intervention:** Description of child's walking function and musculoskeletal growth and development during the 2 yr after locomotor training **Outcome Measures:** Walking Index for Spinal Cord Injury II (WISCI II), gait speed, cadence, step length, stride length, daily steps activity at home and in the community, musculoskeletal growth and development, gross motor function measure (GMFM-66).	1. Walking independence remained unchanged with WISCI score staying at 13/20 as he still used a reverse rolling walker to ambulate 2. Fastest gait speed increased from 0.45m/s at baseline (1 month post LT) to 0.67m/s at 2 yr follow-up • After 2 yr., gait pattern was improved • Able to generate reciprocal stepping with noticeable absence of shoulder and trunk compensations, particularly on his left side • Despite being able to step reciprocally, he could not walk backwards, side step, or maintain balance without upper-extremity support 3. Cadence increased from 63.35 steps/min at baseline to 70.75 steps/min at 2 yr follow-up 4. Step length increased in both legs: • Left leg: increased from 42.25cm at baseline to 51.31cm at 2 yr follow-up • Right leg: increased from 44.07cm at baseline to 63.55cm at 2 yr follow-up 5. Stride length increased in both legs: • Left leg: increased from 85.95cm at baseline to 114.79cm at 2 yr follow-up • Right leg: increased from 87.19cm at baseline to 114.47cm at 2 yr follow-up

			6. Daily steps increased from about 1600 steps/day at baseline to 3000 steps/day at 2 yr follow-up 7. Over the 2-yr. period the child was not diagnosed with scoliosis, but mild coxa valga was noted at both hip joints and radiology reports indicated all findings stable 8. GMFM-66 scores remained stable over the 2-yr. period
ABT	Felter et al. (2018) USA Case Report N=1	**Population:** Age: 3yr; Gender: female; Level of injury: tetraplegia; Severity of injury: Not reported; Time since injury=3yr. **Intervention:** The effectiveness of activity-based therapies (ABT) in a tetraplegic 3-yr.-old girl born with intrauterine spinal cord infarcts (IUSCI). **Outcome Measures:** Gross Motor Function Measure-88 (GMFM-88) and Physical Abilities and Mobility Scale (PAMS).	1. Developmental milestones in functional mobility included rolling supine to side-lying, sitting for five mins wearing a trunk orthosis, social interactions, and upper extremity function 2. Body weight supported treadmill training combined with transcutaneous spinal cord stimulation improved ambulation and stepping 3. ABT did not restore function, rather, the neurological and musculoskeletal system were trained to function as intended
	STAND		
ABT	(A. L. Behrman et al. 2019) USA Pre-Post N=26	**Population:** Age: 5.0±3.0 yr; Gender: 15 males, 11 females; Etiology: 12 traumatic, 14 non-traumatic; Time since injury: 1.4±1.3 yr; Level of Injury: cervical=9, thoracic=15, lumbar=2; AIS: A (n=6), B 9 (n=4), C (n=3), D (n=1); Chronicity: 13 acute, 13 chronic. **Intervention:** Activity-based locomotor training (AB-LT), 5 times per week for 60 sessions, 1.5 hr per session. Body weight support (1 hr) followed by overground walking with supports, as necessary. Integration of training principles encouraged in daily activities. Neuromuscular electrical stimulation (40-100 Hz) provided 1-1.5 hr per week,	1. Pediatric NRS scores improved significantly from baseline to session 20 ($p<0.05$), from session 20 to 40 ($p<0.05$); while scores improved from session 40 to 60 they were not significant 2. On average, the inter-evaluation change in Pediatric NRS score was 3.7 ($p<0.05$) 3. SATCo scores improved significantly from baseline to session 20 ($p<0.05$), from session 20 to 40 ($p<0.05$); while scores improved from session 40 to 60 they were not significant 4. On average, the inter-evaluation change in SATCo score was 1.7 ($p<0.05$) 5. There was no significant difference in Pediatric NRS or SATCo scores by chronicity of SCI.

		5 days per week, for 4 participants only. **Outcome Measures:** Segmental Assessment of Trunk Control (SATCo), Pediatric Neuromuscular Recovery Scale (Pediatric NRS) at baseline, sessions 20, 40, and 60 and/or discharge.	
ABT	(McCain, Farrar, & Smith, 2015) USA Case Report N=1	**Population:** 11 yr, female, T4 AIS C non-traumatic ischemic spinal cord stroke, 6 mo post-injury. **Intervention:** Strengthening, Standing Activities, Body weight support treadmill training, overground walking, functional electrical stimulation, walking 2 Conditions: Condition 1: FES on left quads, bilateral ankle foot orthoses (AFOs), back brace, reverse walker, level surfaces and walking independently Condition 2: Reverse walker, left AFO, back brace, level surfaces and walking independently **Outcome Measures:** Walking index for spinal cord injury (WISCI II), Lower extremity motor score (LEMS), myotomes for light touch (LT) and pinprick (PP) scores, 6-minute walk test (6MWT), cadence, step length.	1. Subjects WISCI score was calculated at her highest possible level at discharge 2. Total LEMS score increased from 16 at baseline to 22 at 18mo. 3. LT scores remained at 55 from baseline to 18mo. 4. PP scores increased from 16 at baseline to 33 at 18mo. 5. 6MWT at 16mo. was 166ft. with 6 brief standing rests in condition 1 and improved to 368ft. with 2 brief standing rests at 18mo. in condition 2 6. Cadence at 16mo. was 32.4steps/min in condition 1 and improved to 42.3steps/min in condition 2 at 18mo. 7. Step length was measures in both legs • Right leg at 16mo. was 31.1cm in condition 1 and improved to 46.8cm at 18mo. in condition 2 • Left leg at 16mo. was 39.9cm in condition 1 and improved to 53.9cm at 18mo. in condition 2
ABT	(Murillo et al. 2012) Spain Case Report N=1	**Population:** 15 yr, female, T6 AIS B, traumatic SCI, 24 mo post-injury. **Intervention:** Functional Electrical Stimulation-assisted Lokomat, Overground walking with Dynamico walker, with and without Functional Electrical Stimulation.	10MWT at the end of 3 months of training yielded the following results 1. Cadence was 29.1 steps/min 2. Stride length was 0.63m 3. Walking speed was 0.15m/s 4. Stance times were 2.94 s (right) and 2.84 s (left). 5. Energy expenditure not measured, but patient was nearly exhausted after completing a distance of 200m

		Outcome Measures: 10-Meter Walk Test (10MWT), cadence, stride length, distance.	
	GAIT		
ABT	(Prosser, 2007) USA Case Report N=1	**Population:** 5 yr. 10 mo., female, C4 AIS A SCI and mild traumatic brain injury. **Intervention:** Activity Based Restorative Therapy including body weight support treadmill training, overground walking, inpatient rehabilitation with aquatic therapy. **Outcome Measures:** Functional Independence Measure for Children II (WeeFIMII), Walking Index for Spinal Cord Injury II (WISCI II), home activities.	1. WeeFIM score improved from 5/35 to 21/35 over 5 months of locomotor training 2. WISCI score improved from 0 to 12 over 5 months of locomotor training 3. At home, she walked most of the time and walked up the stairs to her bedroom with a handrail and minimal assistance
ABT	(Behrman et al. 2017) USA Not reported N=Not reported	**Population:** Not reported **Intervention:** Basic scientific findings that legs to locomotor training (LT) and activity-based therapies (ABT). **Outcome Measures:** Neuromuscular recovery scale (NRS), Berg Balance Scale (BBS).	1. BBS over time revealed scores that spanned the entire breadth of the scale and his variation did not reduce when this sample was divided into groups by AIS classification 2. NRS has been found to have strong test-retest reliability (Spearman correlation coefficients of 0.92–0.99) as well as high inter-rater reliability (Kendall coefficient of concordance ≥0.90) 3. The construct validity of the original NRS was established using Rasch analysis, which revealed that the NRS stratifies individuals with all AIS classifications into 5 distinct strata 4. No floor or ceiling effects were found for the NRS, and the scale also demonstrated a logical order of item difficulty 5. NRS was found to be a stronger predictor of recovery than AIS classification when measuring the change in performance of persons with motor-incomplete SCI on the BBS, 6MWT and 10MWT 6. Pediatric Neuromuscular Recovery Scale (Peds NRS) was developed by clinicians and researchers with

			pediatric expertise and consists of 13 items graded on a 12-point scale 7. The use of the adult NRS and Peds NRS in other neurological populations is also being investigated
ABT	(Andrea L Behrman et al. 2019) USA Observational $N_{(HCP)}$=14 $N_{(SCI-P)}$=32 HCP – Healthcare Professional SCI-P – Spinal Cord Injury - Pediatric	**Population:** (SCI-P) Mean age=6.0±3.0yr.; Gender: males=17, females=15; Level of injury: C1-L5; Level of severity: AIS A=6, B=5, C=2, D=5, N/A=14 (younger than 6yr.); Time since injury: Not reported. **Intervention:** None – observational. **Outcome Measures:** Interrater reliability.	1. Interrater reliability coefficient was determined to be near 1 overall for Pediatric NRS score (ICC=0.966; 95% CI, 0.89-0.98) 2. 12 of 16 individual items exhibited high concordance coefficients (Kendall's W ≥0.8) 3. 4 items were found to have concordance coefficients <0.8 and >0.69. 4. Interrater reliability was equal among groups defined by neurological level and age, but lower among non-ambulatory individuals.
ABT	Melicosta et al. (2019) USA Case Series N=31	**Population:** Children with acute flaccid myelitis; Age range: 17mo-16yr; Gender: males=17, females=14; Level of injury: Not reported; Severity of injury: Not reported; Time since injury: 0.5-77mo. **Intervention:** Participants underwent an intensive Activity Based Restorative Therapy (ABRT) program between March 2005 and January 2017. Participants completed weight bearing daily through lower and upper limbs as appropriate for their presentation. Locomotor training was completed 3-5x/wk when applicable, including treadmill and over-ground retraining using a body weight supported system. Task-specific practice and massed practice were completed daily with the goal of completing as many repetitions as possible for neurological and daily function	1. SCIM scores improved significantly from baseline to post-intervention among participants who had admission and discharge scores (p=0.007). 2. PAMS improved significantly from baseline to post-intervention (p<0.001) 3. Significant improvements were observed in the self-care (p<0.001), mobility (p=0.001), cognition domains of WeeFIM (p=0.039), as well as total WeeFIMR developmental quotient (DQ) scores (p<0.001)

		restoration. Seventeen of the participants received inpatient treatment, and fourteen received solely outpatient interventions. **Outcome Measures:** Spinal Cord Independence Measure (SCIM), Physical Ability and Mobility Scale (PAMS), Functional Independence Measure for Children (WeeFIM), assessment of mobility and transfers, balance, ambulation, activities of daily living (ADLs), hand function (strength and skills), durable medical equipment, and orthotic use.	
ABT	Hagen et al. (2020) USA Case Series N=29	**Population:** Age:6.47±4.14yr ; Gender: males=22, females=7; Level of injury: C1-Sacrum; Severity of injury: Not reported; Mean time since injury= 253.59 days. **Intervention:** Activity-based restorative therapy (ABRT) was administered to children with acute flaccid myelitis (AFM). The therapy consisted of 1-2h of occupational therapy and 2-3h of physical therapy, which were structured to include interventions of ABRT: functional electrical stimulation (FES), locomotor gait training (LT), massed and task specific practice, and weight loading. **Outcome Measures:** Functional Independence Measure for Children (WeeFIM), Manual Muscle Testing (MMT), the Spinal Cord Independence Measure (SCIM), the Physical Abilities and	1. On the WeeFIM, significant change was seen from admission to discharge across all subdomains, including self-care ($p<0.001$), mobility ($p<0.001$), and cognition ($p<0.05$) 2. Significant change from admission to discharge was seen across all muscle groups on the MMT, with effect sizes ranging from $p<0.05$ (ankle dorsiflexion, knee extension) to $p<0.001$ (elbow flexion/extension) 3. Most muscle groups tested showed a moderate effect size 4. More than a third (39%) of the group improved in mRS rating over the course of admission, with eight individuals improving by 1 point and three individuals improving by 2 points 5. Overall, children showed significant improvements across all outcome measures, with effect sizes ranging from moderate to large

		Mobility Scale (PAMS), Modified Rankin Scale for Neurologic Disability (mRS).	
ABT	(Behrman et al. 2008) USA Case Report N=1	**Population:** 4.5 yr, male, C8 AIS C traumatic SCI, 16 mo post-injury. **Intervention:** Body weight support overground walking. **Outcome Measures:** American Spinal Injury Association Impairment Scale (AIS), Lower extremity motor score (LEMS), gait speed, walking independence, walking index for spinal cord injury II (WISCI-II), number of steps.	1. AIS score remained the same after session 74 2. LEMS score remained at 4/50 at session 74 3. From session 51 to 76 gait speed increased from 0.19m/s to 0.29m/s 4. From session 51 to 76 fastest walking speed increased from 0.3m/s to 0.48m/s 5. WISCI score increased from 0/20 to 13/20 6. At session 33 the child showed multiple non-cued steps 7. From session 49 to 74 the child increased from 926 steps per day to 2488 steps per day
ABT	(Fox et al. 2010) USA Case Report N=1	**Population:** 3.5 yr, male, C8 AIS C SCI. **Intervention:** Description of child's walking function and musculoskeletal growth and development during the 2 yr after locomotor training **Outcome Measures:** Walking Index for Spinal Cord Injury II (WISCI II), gait speed, cadence, step length, stride length, daily steps activity at home and in the community, musculoskeletal growth and development, gross motor function measure (GMFM-66).	1. Walking independence remained unchanged with WISCI score staying at 13/20 as he still used a reverse rolling walker to ambulate 2. Fastest gait speed increased from 0.45m/s at baseline (1 month post LT) to 0.67m/s at 2 yr follow-up • After 2 yr., gait pattern was improved • Able to generate reciprocal stepping with noticeable absence of shoulder and trunk compensations, particularly on his left side • Despite being able to step reciprocally, he could not walk backwards, side step, or maintain balance without upper-extremity support 3. Cadence increased from 63.35 steps/min at baseline to 70.75 steps/min at 2 yr follow-up 4. Step length increased in both legs: • Left leg: increased from 42.25cm at baseline to 51.31cm at 2 yr follow-up • Right leg: increased from 44.07cm at baseline to 63.55cm at 2 yr follow-up 5. Stride length increased in both legs: • Left leg: increased from 85.95cm at baseline to 114.79cm at 2 yr follow-up • Right leg: increased from 87.19cm at baseline to 114.47cm at 2 yr follow-up

			6. Daily steps increased from about 1600 steps/day at baseline to 3000 steps/day at 2 yr follow-up 7. Over the 2-yr. period the child was not diagnosed with scoliosis, but mild coxa valga was noted at both hip joints and radiology reports indicated all findings stable 8. GMFM-66 scores remained stable over the 2-yr. period
ABT	(Behrman et al. 2012) USA Case Reports N=3	**Population:** *Case 1:* 15 yr, male, T5 SCI, AIS D. *Case 2:* 14 yr, male, T5 AIS C ruptured arteriovenous malformation; *Case 3:* 14 yr, male, C2 AIS D SCI. **Intervention:** Locomotor Training (Body weight support treadmill training, overground walking), community integration. **Outcome Measures:** 10-meter walk test (10MWT),6-minute walk test (6MWT), Berg Balance Scale (BBS),	*Case 1* 1. 10MWT with initial rolling walker (RW) device improved from 0.16m/s at initial evaluation to 1.12m/s at discharge and declined to 1.06m/s at 12mo. follow-up 2. 10MWT with current bilateral single point canes (BSPCs) devices improved from 0.77m/s at session 20 (started use of BSPCs) to 1.22m/s at discharge and declined to 1.01m/s at 12mo. follow-up (use of BSPCs stopped after session 40) 3. 6MWT with initial rolling walker (RW) device improved from 53.07m at initial evaluation to 291.69m at discharge and improved further to 298.4m at 12mo. follow-up 4. 6MWT with current bilateral single point canes (BSPCs) devices improved from 242.32m at session 20 (started use of BSPCs) to 308.15m at discharge and improved further to 316.11m at 12mo. follow-up (use of BSPCs stopped after session 40) 5. BBS score improved from 8/56 at initial evaluation to 48/56 at discharge and declined to 47/56 at 12mo. follow-up *Case 2* 1. 10MWT with initial rolling walker (RW) device improved from 0.12m/s at initial evaluation to 0.22m/s at session 80 and improved further to 0.38m/s at session 200 2. 10MWT with current bilateral loftstand crutches (BLCs) devices remained at 0.1m/s from session 40 (started use of BLCs) session 80 and improved to 0.45m/s at session 200 (use of bilateral single point canes (BSPCs) at session 200)

			3. 6MWT with initial rolling walker (RW) device improved from 25.6m at initial evaluation to 44.8m at session 80 and improved further to 117.3m at session 200 4. 6MWT with current bilateral loftstand crutches (BLCs) devices declined from 13.6m at session 40 (started use of BLCs) to 7.6m at session 80 but improved to 123.8m at session 200 (use of bilateral single point canes (BSPCs) at session 200) 5. BBS score increased from 7/56 at initial evaluation to 23/56 at session 80 and improved further to 31/56 at session 200 *Case 3* 1. 10MWT increased from 1.3m/s at initial evaluation to 1.5m/s at session 20 and increased further to 1.72m/s at discharge 2. 6MWT increased from 435m at initial evaluation to 467m at session 20 and increased further to 500m at discharge 3. BBS score increased from 55/56 at initial evaluation to 56/56 at session 20 and sustained a score of 56/56 at discharge LEMS • LEMSs for the three reported cases were 29, 22, and 46, respectively • Only the adolescent in Case 1 demonstrated significant change (17 points) in his LEMS post-LT that could also account for improvement in function • For the other two instances, the LEMS change was relatively minor
ABT	(Heathcock et al. 2014) USA Case Report N=1	Population: 15 mo, male, T11-L4 in-utero spinal cord tumour resulting in SCI with subsequent removal at 5.5 wk of age. Intervention: Treadmill Step Training Program Outcome Measures: Number and pattern of walking steps, gait speed, observational gait analysis, standing.	1. An increase in the percentage of alternating steps and a matching decrease in the percentage of single steps over the 20-month intervention period were observed 2. At 30 months of age, a pattern of alternating stepping on the treadmill occurred more than 80% of the time, in sharp contrast to the initial 6 months of training when alternating steps comprised fewer than 10% of the total steps

			3. Number of steps increased from 1 step at 16mo to 10 steps at 22mo. 4. At 22mo. of age, steps were measured in distance and increased from 3m at 22mo. to about 6m at 31mo. 5. Gait speed varied over the 20mo. period (0.48m/s at 31mo. and 0.40m/s at 35mo.) 6. Only the right leg accounted for most of the stepping rate from 15 through 20 months of age because there were few or no independent steps on the left 7. Over the 20-month intervention period, stepping with the right and left legs increased, with a greater rate of improvement being observed for the left leg, suggesting improvements in symmetry and bilateral function 8. Static standing improved from standing with an arm support on the walker for 30s with contact guard assistance (CGA) at 15mo. to static standing for 20s with standby assistance
TM and OG walking	(O'Donnell & Harvey, 2013) Australia Case Report N=1	Population: 17 yr, male, T6 AIS C traumatic SCI, 16 mo post injury. Intervention: Body weight support treadmill training, overground walking Outcome Measures: Lower extremity motor score (LEMS), Walking index for spinal cord injury (WISCI II), 6-min walk test (6MWT), 10-m walk test (10MWT), Timed up and go (TUG), Pediatric Quality of Life Inventory (PedsQL).	1. LEMS score improved from 16 to 17 from pre- to post-training and from 17 to 18 from post-training to follow-up 2. WISCI score improved from 6 to 9 from pre- to post-training and remained at 9 at follow-up 3. 6MWT score improved from 67m (1 rest) at pre-training to 76m (no rests) at post-training and further improved to 80m (no rests) at follow-up 4. 10MWT score improved from 32.2s at pre-training to 30.3s at post-training but declined to 33.6s at follow-up 5. TUG score improved from 44.6s at pre-training to 40.1s at post-training but declined to 42.0s at follow-up, remaining improved compared to pre-training 6. Overall PedsQL score improved from 38/92 at pre-training to 23/92 at post-training and remained at 23/92 at follow-up

Compared SCI to non-SCI	Fox et al. (2013) USA Pre-Post N=5	**Population:** Mean age:8.6±2.7yr; Gender: males=4, females=1; Level of injury: C1-C7=2, T1-T12=3; Time since injury>1yr. **Intervention:** Modular control of patients with incomplete spinal cord injury (ISCI) was examined via locomotor tasks including treadmill training, overground walking, pedaling, stair climbing, supine lower extremity flexion/extension, and crawling. **Outcome Measures:** Lower extremity motor score (LEMS), variance accounted for (VAF), electromyogram (EMG) recordings.	1. Fewer modules were needed to account for muscle activation in the lower extremities of children with ISCIs compared with controls ($p<0.05$) 2. An average of 2.11±0.71 modules was required to account for the EMG data recorded in lower extremities of children with ISCI 3. With the use of the muscle weightings from treadmill walking and task-specific timing profiles, the VAF exceeded 86% for all locomotor tasks 4. The VAF exceeded 90% for all tasks performed by the children with ISCI 5. Modularity is constrained in children with ISCIs.
BWSTT	(Nymark, 1998) Canada Case Report N=1	**Population:** Mean age=33.2±17.6yr.; Gender: males=3, females=2; Level of injury: C2-T10; Severity of injury: AIS A=0, B=1, C=3, D=1; Time since injury=36.8±7.0d. **Intervention:** Body Weight Support Treadmill Training (BWSTT) **Outcome Measures:** Clinical Outcome Variables Scale (COVS), treadmill speed, cadence, stride length, Range of Motion (ROM) hip and knee sum, Electromyography (EMG) summed indices.	1. Mean COVS scores significantly increased from pre- to post-training ($p=0.03$) 2. Mean treadmill speed significantly increased from pre- to post-training ($p=0.001$) 3. Mean cadence significantly increased from pre- to post-training ($p=0.001$) 4. Mean stride length (m) increased from pre- to post-training but not significantly ($p=0.16$) 5. Mean ROM (degrees) increased from pre- to post-training but not significantly ($p=0.07$) Mean summed indices of ROM increased from pre- to post-training but not significantly ($p=0.09$)
TMNOG Walking	(Hornby et al. 2005) USA Case Reports N=3	**Population:** Case1: 13 yr., female, C6 AIS B traumatic SCI, 6 mo. post-injury. Case 2: 40 yr., male, T2 AIS B spinal vascular accident, 5wk. post-injury. Case 3: 43 yr., male, C6 AIS C, 18 mo. post-injury. **Intervention:** Robotic- or therapist-assisted body	Case 1 1. AIS score improved from class C at initial evaluation to class D at final evaluation 2. LEMS score increased from 6 at initial evaluation to 48 at final evaluation 3. FIML subscale increased from 0 at initial evaluation to 6 at final evaluation

		weight support treadmill training. Outcome Measures: American Spinal Cord Injury (AIS) classification, Lower Extremity Motor Score (LEMS), Functional Independence Measure Locomotor (FIML) subscale, Walking Index for Spinal Cord Injury II (WISCI II), gait speed, gait endurance, Timed Up and Go (TUG) tests, Standing Functional Reach Test (FRT), Sitting Functional Reach Test (FRT).	4. WISCI score increased from 0 at initial evaluation to 16 at final evaluation 5. Gait speed increased from 0.29m/s at transition evaluation to 0.55m/s at final evaluation 6. Gait endurance increased from 243ft at transition evaluation to 480ft at final evaluation 7. TUG score not evaluation in case 1 8. Sitting FRT remained >10in at both transition and final evaluation 9. Standing FRT increased from 4in at transition evaluation to 7in at final evaluation Case 2 1. AIS score improved from class C at initial evaluation to class D at final evaluation 2. LEMS score increased from 19 at initial evaluation to 50 at final evaluation 3. FIML subscale increased from 0 at initial evaluation to 6 at final evaluation 4. WISCI score increased from 0 at initial evaluation to 13 at final evaluation 5. Gait speed increased from 0.36m/s at transition evaluation to 0.58m/s at final evaluation 6. Gait endurance increased from 460ft at transition evaluation to 632ft at final evaluation 7. TUG score improved (decreased) from 30.6s at transition evaluation to 18.5s at final evaluation 8. Sitting FRT remained >10in at both transition and final evaluation 9. Standing FRT increased from 6in at transition evaluation to >10in at final evaluation Case 3: 1. AIS score remained at class C from initial to final evaluation 2. LEMS score decreased from 31 at initial evaluation to 30 at transition evaluation, but increase back to 31 at final evaluation 3. FIML subscale increased from 5 at initial evaluation to 6 at final evaluation

			4. WISCI score remained at 13 from initial to final evaluation 5. Gait speed increased from 0.11m/s at transition evaluation to 0.21m/s at final evaluation 6. Gait endurance increased from 100ft at transition evaluation to 204ft at final evaluation 7. TUG score not evaluation in case 3 8. Sitting FRT remained at >10in from initial to final evaluation 9. Standing FRT decreased from 10in at initial evaluation to 6in at final evaluation

Table 5. Systematic Reviews and Scoping Reviews

Author, Year Country Study Design Number of Studies Included for Review	Method Databases Search Level of Evidence Research Question	Results
Donenberg et al. (2019) USA Systematic review of published articles N=11	Method: Comprehensive literature search of articles discussing the effectiveness of locomotor training (LT) in children following spinal cord injury (SCI). Forms of LT included boy-weight supported treadmill or over ground training, functional electrical stimulation, robotics, and virtual reality. Articles were restricted to children between the ages of 15 mo to children 18 yr. Databases: PubMed, PEDro, CINAHL, Cochrane, PsycINFO, Web of Knowledge. Level of evidence: Evidence was categorized according to the American Academy for Cerebral Palsy in Developmental Medicine (AACPDM) levels of evidence. *Level 4*: 2 papers, *Level 5*: 9 papers. Questions/measure/hypothesis:	1. Outcomes assessed: Gait Speed, TUG, WISCI II, FES, Robotics, LEMS, NRS, ABT 2. Age, completeness, and level of injury remain the most important prognostic factors to consider with the LT intervention. 3. There was a greater likelihood for recovery of locomotion for adults with incomplete SCI when training begins closer to the time of injury. 4. All forms of LT used in studies within this review had positive changes in locomotion. No one form of LT has been determined to be superior. 5. Children might benefit from LT to develop or restore ambulation following SCI.

	Examine the effectiveness of LT in children with SCI through measuring improvements in ambulation.	
(Gandhi et al. 2017) Canada Systematic Review N=13 (N=13 pediatric SCI)	"A systematic review to summarize the who, what, when and how of walking interventions in children with SCI" OMs: Gait Speed, Robotics, TM and OG walking, WeeFIT, TUG, WISCI II, ABT, Observational gait analysis	1. Outcome Assessed: Training parameters and walking outcomes, total training duration (duration × frequency × number of weeks) 2. The training durations, frequencies, and modes used with the children varied; however, overground walking practice was included in 10/13 pediatric studies. 3. Improvements in walking capacity, speed, and distance were comparable between children and adults. 4. There was a trend for greater gains with greater total training durations. 5. There is a paucity of high-quality research examining interventions targeting walking after pediatric SCI; however, intensive training, including practice overground, results in notable improvements.
(Funderburg et al. 2017) USA Scoping Review N=26 (N=10 pediatric SCI)	"This is a scoping review of the literature on interventions for gait in individuals with pediatric spinal cord impairments." OMs: Gait Speed, WeeFIM, TUG, WISCI II, orthoses, FES, ABT	1. Four categories of interventions were identified: • Orthoses/assistive devices • Electrical stimulation • Treadmill training • Infant treadmill stepping 2. Studies on orthotic intervention, electrical stimulation, and treadmill training reported benefits for various components of gait. 3. The majority of studies (77%) were classified as levels of evidence III and IV.
(Damiano & DeJong, 2009) USA Systematic Review N=29 (N=6 pediatric SCI)	"A systematic review was undertaken to explore the strength, quality and conclusiveness of the scientific evidence supporting the use of treadmill training and body weight support in those with pediatric motor disabilities." OMs: ABT, Home activities	1. A total of 29 studies were identified, 6 of which concern individuals with pediatric SCI. 2. The studies identified for those with SCI were either individual case reports or individual subject data from a multiple case series. 3. All six studies included other types of intervention including stretching, overground training or other non-specific physical and/or occupational therapy rehabilitation exercises. 4. Most outcome results were positive, with some showing large and clearly clinically significant changes such as progression from no ability to step, to walking independently with an assistive device by the end of training.

Discussion

Compensation Focused Interventions for Standing and Gait/Walking

The evidence for compensation-based approaches to standing and walking in pediatric SCI spans from 1994-2017. The use of functional electrical stimulation (FES) to stand has been tested in small-scale studies and includes examination of the criteria for eligibility for surface lower extremity stimulation (Triolo et al. 1994), study of FES home use for standing/mobility (Moynahan, Mullin, et al. 1996), comparison of percutaneous intramuscular electrodes to leg braces for those with thoracic complete SCI (Bonaroti et al. 1999a; Bonaroti et al. 1999b), a 3-year follow-up study in one subject with percutaneous intramuscular electrodes (Betz et al. 2002), and FES compared to long-leg braces (knee-ankle-foot orthoses, KAFOs)(Betz et al. 2002), and FES for upright mobility (Johnston et al. 2003) and for walking via swing-to gait pattern (Johnston et al. 2005). While able to achieve standing with surface FES, researchers noted significant barriers to use of surface FES, such as the impracticality of application of electrodes for function, and reluctance of the participant to use the system for the entire day (Moynahan, Mullin, et al. 1996). Implanted FES systems showed comparable functional impact when compared to KAFOs and even better performance in accomplishing certain tasks (Betz et al. 2002; Johnston et al. 2005; Johnston et al. 2003). While promising, the most relevant information is that the FES surface and implantable systems did not advance from experimental study to clinical translation for use by children and adolescents with SCI in the home and community.

Standing frames, braces and assistive devices to achieve upright standing and “walking” (i.e., brace-walking) have also been investigated as compensatory strategies for lower limb paralysis. Lower limb braces provide external support and joint alignment to achieve the standing position and possibly swing-through gait with a walker or forearm crutches. Vogel and colleagues (1995) provide a thorough description of the pediatric population using braces and devices to achieve standing and walking describing “who” (e.g., age, injury level, time since injury), progress to a different device (e.g., parapodium to reciprocating gait orthosis, RGO), and duration of use (including age at point of change to another device, abandonment or ceasing to ambulate, i.e., approximately age 10 years). Choksi et al. (2010) reported outcomes of 32 child and adolescent patients with subacute SCI who received inpatient rehabilitation (occupational therapy and physical therapy) using the Pediatric Evaluation of Disability Inventory. While significant gains in distance and speed were achieved for basic indoor, outdoor locomotion and more complex locomotion (i.e., being able to carry objects and walk independently without devices) did not significantly change. Several case studies addressed the type of assistive device being used during gait training and its potential impact on outcomes (Altizer et al. 2017), thus demonstrating the merits of certain types of equipment. Research concerning the use of braces and assistive devices to achieve “brace-walking” beyond the reports of by Vogel et al. 1995 and 2010 is negligible. This may mean that the use of these strategies remains the standard of care. While robotic devices for ambulation have been introduced to the market for pediatric use, scientifically reported outcomes and follow-up via research is lacking.

Recovery-Focused Interventions for Standing and Gait/Walking

The plethora of research providing foundational rationale and arguments for recovery-based approaches to achieve walking via repair of the neuromuscular system through activity-dependent plasticity (Edgerton et al. 2004) is beyond the scope of this review. This critical new knowledge of the neurobiological control of posture and locomotion, however, provides a physiological and neural basis for training strategies to focus on accessing the "smart" spinal cord below the lesion for practical use. Published research in adults with SCI using activity-based locomotor training or activity-based restorative therapy have preceded research and clinical use of these strategies for children with SCI. Most literature regarding activity-based locomotor training and activity-based restorative therapy in pediatric SCI are case studies or studies with small sample sizes. Nevertheless, they introduce the potential for a new direction in rehabilitation.

Prosser et al. (2007) and Heathcock et al. (2014) reported the benefits of "locomotor training" in case studies of children during the acute phase post-injury (< 1 year) with the potential for interaction with "natural recovery". In addition, the case study by Heathcock and colleagues (2014) was the first to report use of activity-based locomotor training in a child who had not yet mastered ambulation as a developmental milestone prior to their injury. In comparison, Behrman et al. (2008) and Fox et al. (2010) (follow-up) reported achievement of a reciprocal pattern of walking in a child with chronic, cervical SCI and non-ambulatory (American Spinal Injury Association Impairment Scale C, lower extremity motor score < 10) via locomotor training. Similarly, Behrman et al. (2012), O'Donnell and Harvey (2013), and Hornby et al. (2005) reported positive outcomes in standing and walking using treadmill training for adolescents with incomplete SCI. Both manually-facilitated stepping and robotic-assisted stepping were reported, though not compared. Similar to the literature in adult SCI, achievement or improvement in ambulation using activity-based locomotor training/activity-based restorative therapy appears most effective in those with incomplete SCI. The findings for 26 consecutively-enrolled children in a clinical activity-based locomotor training program demonstrate the high percentage of improvements in walking for children with incomplete SCI and the very low percentage of children with complete injuries who achieve even therapeutic or household ambulation (Andrea L Behrman et al. 2019). Clinicians may thus speculate that activity-based locomotor training should be abandoned for those children with complete injuries. Evidence from research with adults with complete SCI, however, may once again point the direction for children with severe SCI and motor paralysis. Recent literature on epidural stimulation combined with activity-based locomotor training to achieve reciprocal walking in adults with SCI (Angeli et al. 2018) and the use of transcutaneous spinal stimulation to enable stepping behavior in adults and a 17 year old with acute SCI (Baindurashvili et al. 2020) may suggest important future directions (Baindurashvili et al. 2020) may for the rehabilitation of children with severe SCI and motor paralysis. Reporting the findings for adults with SCI is beyond the scope of this chapter. Pilot work studying the use of transcutaneous spinal stimulation combined with activity-based locomotor training to enable stepping in non-ambulatory children with chronic SCI is ongoing and findings have yet to be published (Clinicaltrials.gov # NCT04077346).

Three reviews are also considered among the body of evidence for achievement of ambulation post pediatric SCI (Damiano & DeJong, 2009; Funderburg et al. 2017; Gandhi et al. 2017), and are each discussed below.

Damiano and DeJong's (2009) systematic review explored the strength, quality and conclusiveness evidence on the use of treadmill training and body weight support in those with pediatric motor disabilities. Of the 29 studies identified from the literature search, six involved individuals with pediatric SCI. The outcome results of using treadmill training and/or body-weight support in the pediatric SCI population were positive, with some showing large and clinically significant changes, such as progression from no ability to step, to walking independently with an assistive device by the end of training. However, the authors pointed out that since the studies identified were either individual case reports or individual subject data from a case series, conclusions regarding the efficacy of the use of treadmill training and body-weight support in children with SCI should be drawn with caution, and more controlled studies, especially those utilizing randomized designs, are needed (Damiano & DeJong, 2009).

Funderberg et al. (2017) reported evidence for three approaches: use of orthotics and assistive devices, electrical stimulation (surface and implanted), and “treadmill-training”. It was noted that orthotic studies typically compare one type of orthosis to another for utility, but that the evidence for any orthotic device is not sufficient to warrant development of a clinical guideline. Electrical stimulation, while showing benefit, requires equipment, intensive training, potentially invasive procedures, and lacks long-term assessments for physiological effects and meaningful use. As noted, FES and implantable stimulation has not advanced to a level of clinical application for ambulation goals. Lastly, “treadmill training” leads to use of less restrictive devices and improvements in speed, distance, capacity for walking (number of steps per hour), and community-based activity (number of steps per day) for children with varying impairment levels. Funderberg et al. (2017) recommended this mode of training for functional gains. Infant treadmill training has been reported in the context of spina bifida as potentially beneficial, yet long-term follow-up studies are needed. While not reported in the pediatric SCI literature, Funderberg et al also postulated that early implementation (i.e., at the typical age of cruising, standing and step initiation) of therapies promoting the sensorimotor experience of walking and activity-dependent plasticity may be advantageous to children injured in utero or under one year of age.

Gandhi et al. (2017) further explored the parameters of training, reporting the many differences across cases and studies with the treadmill being a common thread across studies. In this review, understanding the intent and therapeutic goal in selecting and using specific equipment (e.g., treadmill, partial body weight support), how to perform and deliver the training and make clinical decisions, and progress a child through therapy were highlighted as critical to the success of any training program. It should also be noted that the use of the term “treadmill training” to describe an intervention is felt to be insufficient and likely results in grouping of evidence and outcomes in a way that may lead to misinterpretation and misunderstanding of the therapy and its effect (Behrman et al. 2008). Gandhi et al. (2017) summarized key findings from a review of 13 pediatric studies for walking. First, there was a trend towards greater improvement in studies of greater dosage/duration of training. Second, 10/13 studies included overground training as a transfer of skill from treadmill to the real-world environment, and this strategy appeared to be beneficial. Third, an argument was made that children with complete SCI should be included in research for walking recovery despite earlier concerns about their potential for recovery. This is based on the likelihood that children have greater potential for recovery relative to those with adult-onset SCI.

Lastly, while advocating for more rigorous studies (e.g., inclusion of blinded assessors) Gandhi et al. (2017) cautioned that the traditional randomized clinical trial may not be feasible with this "low-prevalence population". Thus, the design of studies for pediatric SCI may require alternative methodological design strategies. With the very low incidence of recovery of walking in the chronic stages of SCI, non-ambulatory pediatric subjects serving as their own control should provide optimal "controls", decrease heterogeneity of the sample, and allow for a smaller "n". Understanding "who" benefits beyond the simplistic view of SCI as "complete" or "incomplete" will necessitate more sensitive exploration of predictors and biomarkers for response (Mesbah et al. 2021; Rejc et al. 2020), as well as study of mechanisms for response to interventions.

Measurements: Compensation Focus and Recovery Focus

Outcome measurements for standing/walking are distinct in whether they do or do not take into account the mechanism through which the outcome is achieved (i.e., via compensatory strategies or recovery of function). Measures that allow the use of compensation strategies emphasize achievement of a "functional" goal regardless of the behavioral strategy or equipment used to accomplish the goal. For instance, a patient may successfully move from sitting to standing using a walker to assist with balance, and strength of the arms to compensate for leg weakness. Achieving standing is the only goal and employed compensation strategies are not "counted against" achievement of the goal. The many outcome measures employed to assess standing/walking in SCI that *do* allow patients to use compensatory strategies without penalty include:

- Pediatric Evaluation of Disability Inventory
- Spinal Cord Independence Measure
- Time to complete a task
- Functional Independence Measure
- Gait speed
- Years using a device
- Functional Independence Measure for Children
- Timed Up and Go
- Walking Index of SCI I and II - in some instances (e.g., Walking Index of SCI II), the use of equipment is accounted for in the scoring, but equipment and compensation are allowed.

A recovery-focused measure, in comparison, provides a means, even stepwise, to assess the neuromuscular capacity to perform a task without behavioral or device/equipment compensation. Thus, a sit-to-stand is performed and the incremental capacity to perform with a typical, kinematic pattern of trunk and limbs is assessed. The Neuromuscular Recovery Scale and Pediatric Neuromuscular Recovery Scale (Behrman et al. 2017; Andrea L Behrman et al. 2019; Behrman et al. 2012); observational gait analysis, and the Segmental Assessment of Trunk Control (Argetsinger et al. 2019; Goode-Roberts et al. 2021) are examples of recovery- or restorative-focused measures. Compensations are not "allowed" or are noted with scoring relevant to their presence or absence during task performance.

Interventions and Measurements for Trunk Control:

Trunk control is instrumental to the achievement of a variety of tasks from breathing and coughing to sitting/standing upright to reaching overhead to walking. The knowledge that SCI induced trunk paralysis is irreversible guides the current clinical decision-making by therapists and the medical field (Schottler et al. 2012). Historically, therapy does not expect to restore function, but to adapt the task or environment to achieve a novel solution to the problem (Chafetz et al. 2007; Mehta et al. 2004; Mulcahey et al. 2013; Sison-Williamson et al. 2007).

Clinically, the Trunk Impairment Scale, the Gross Motor Function Classification System, and the Pediatric Berg Balance Scale have been used to measure trunk control in children with SCI. However, independent sitting and standing by participants is a prerequisite for these tests. Therefore, testing trunk control in children who have not achieved independent sitting and in children with a low functional level is limited. In addition, these tests measure trunk performance as a single unit allowing for a compensatory posture (e.g., kyphotic posture). To determine the motor impairment of trunk function, the International Standards for Neurological Classification of SCI is used by clinicians (Mulcahey et al. 2011). Unfortunately, because function of trunk muscles cannot be tested individually, the scale relies on truncal sensory perception (tested with the patient in supine) as a stand in for trunk motor function (assuming that motor function is preserved at the truncal levels where sensation is preserved). In addition, the scale is only valid for children 6 years and above (Mulcahey et al. 2011).

A new pediatric measurement instrument, the Segmental Assessment of Trunk Control, was recently introduced and validated to assess and track improvements in trunk control in children with SCI who lack independent sitting or in whom sitting control is impaired (Argetsinger et al. 2019; A. L. Behrman et al. 2019). This evidence demonstrated improved trunk control in children with SCI post activity-based locomotor training, and has set forth a paradigm shift in our expectation of recovery of trunk function after SCI. In recent studies, surface electromyography collected during Segmental Assessment of Trunk Control and active trunk tasks revealed an apparent preservation of postural extensor muscle activation after pediatric-onset SCI. This preservation reflects residual supraspinal influence on spinal motor circuits and has important implications for the potential to tap into preserved trunk activation below the lesion level in pediatric-onset SCI (Atkinson et al. 2019; Singh et al. 2020). The implications of this finding (beyond a measurable improvement in a performance score (i.e., improved Segmental Assessment of Trunk Control score) without compensation) are unclear. Further investigation is needed to determine any meaningful impact of preserved and trainable trunk control in the home, school, and community for children with SCI, as well as potential reduction of risk for scoliosis (Argetsinger et al. 2020; Goode-Roberts et al. 2021).

Conclusion

In reviewing the evidence for lower extremity and trunk control rehabilitation across time (i.e., 1994-2021), a paradigm shift in the intended therapeutic end-goal is observed. The original intent was to achieve upright trunk posture, standing and walking as a functional goal with the implementation of external support (i.e., leg braces and assistive devices). Now, the intent is to achieve upright trunk posture, standing and walking via the intrinsic neurobiology for the control of posture, standing and walking. For instance, leg braces (e.g., knee ankle foot orthoses or reciprocating gait orthosis) are meant precisely as an end goal to train the patient to walk with braces. Thus, the braces serve to compensate for paralysis of the lower extremities. The braces are not a therapeutic step towards standing or walking without braces. The goal is to achieve the "functional" ability to stand or walk dependent upon braces (and assistive devices) to provide an external support for an extended position of the knees, stable position of the ankles, and in some cases, advance a step with brace-promoted hip flexion during gait. This functional goal for standing and walking is based on the premise that these goals are achieved only in the context of external support, that the voluntary motor control of the lower extremities is insufficient for standing or stepping, and that the functional goal of standing and stepping is meritorious for a child whether practical, developmentally-appropriate, or simply desirable. Achieving standing and walking via this strategy is reported as changing with musculoskeletal growth and aging into adolescence and ultimately adulthood when for practical circumstances (e.g., speed of mobility) brace walking is abandoned for wheeled mobility.

Restorative Treatment

After a pediatric SCI, it has been assumed that paralysis is permanent, especially in the chronic period post-SCI (typically considered >1-year post SCI), and the individual will never stand or walk independently again. Upright posture and mobility provide interactions with the child at the same height as their peers, opportunity for participation in school and community. Therefore, children have been encouraged to use wheeled standers or devices such as orthoses, robotics, and FES (Betz et al. 2002; Bonaroti et al. 1999a; Bonaroti et al. 1999b; Johnston et al. 2005; Johnston et al. 2003; Vogel & Lubicky, 1995). Measurements to evaluate the uses of equipment for upright posture and mobility includes gait speed and the speed to perform a task (Betz et al. 2002; O'Donnell & Harvey, 2013). However, these measures ignore the mechanics of how the task was performed and places increased demands on the upper extremities. Furthermore, the devices that passively produce an upright posture and upright mobility are cumbersome and lead to a high rate of user abandonment, especially as the child develops into adolescence.

Edgerton et al. (1991) identified that a restoration approach may have potential for humans after SCI. His findings were based on a decade of animal research, showing the potential of motor recovery and walking after SCI. Since then, there has been a divergence between compensatory interventions (with braces and wheeled standers) and restorative interventions (including locomotor training). Over a decade of research has supported restoration interventions for children with spinal cord injuries to improve motor function below the level of the lesion (Baindurashvili et al. 2020; Behrman et al. 2008; Andrea L Behrman et al. 2019; Behrman et al. 2012; Fox et al. 2010; Heathcock et al. 2014; Hornby et al. 2005; O'Donnell & Harvey, 2013; Prosser, 2007). No intervention, compensatory or restorative- based, however, has consistently resulted in children with motor complete SCI standing or walking reciprocally independently without bracing or assistive devices. Alternatively, children and adolescents with incomplete SCI demonstrate benefit.

Restoration interventions continue to be a "new frontier" of research, with early research based on case studies (Behrman et al. 2008; Behrman et al. 2012; Fox et al. 2010; Heathcock et al. 2014; Prosser, 2007). Outcomes have measured how the movement occurs, including step length, stride length, and stepping patterns (Fox et al. 2010) and modular contributions to movement patterns across motor tasks (Fox et al. 2013). Restoration interventions require maximizing weight bearing on the legs, promoting normal kinematics, optimizing sensory cues, minimizing compensation strategies, and knowledge of the intrinsic biology for motor control: posture and locomotion, particularly contributions of the spinal circuitry and sensory input. The requirements for restoration interventions significantly contrast the approach to compensatory interventions (Behrman et al. 2008; Roy et al. 2012). The future of compensatory intervention models is focused on robotics, or potentially "smart orthotics" but with no evidence to date in the scientific literature to support application in the clinic for children. Research for restorative interventions is focused on altering the state of excitability of the spinal cord via various interventions from those emphasizing the sensorimotor experience/training of posture and walking to spinal stimulation and combining interventions (Angeli et al. 2018; Gerasimenko et al. 2015; Harkema et al. 2011).

Key Points

Functional electrical stimulation and implantable, percutaneous electrical stimulation, while shown to have a functional impact on standing and swing-thru gait and even with greater satisfaction than knee-ankle foot orthoses, other barriers persist and neither approach has been effectively translated to clinical practice and home use.

The use of orthotics and assistive devices has been described according to who, what, when and sustained use or abandonment by adolescence due to convenience of mobility, e.g., wheelchair. Parapodiums appear favored in early childhood, with progression to knee ankle foot orthoses and reciprocating gait orthoses with advancing age and abandonment in adolescence for wheeled mobility. No distinct orthotic is recommended but instead individualized care. The use of braces does not lead to walking without braces.

The use of a treadmill in the context of restorative activity-based locomotor training has demonstrated benefit in those with incomplete SCI, though a variety of training approaches and delivery of training has been reported.

The term "treadmill training" is insufficient to use for classifying and intervention comparison. The principles guiding clinical decision-making using this tool, the overall goal and intent, and the "how" behind progression are key to understanding each intervention regardless of commonality in the selected equipment used for delivery.

There has been limited achievement of walking in pediatrics with complete SCI, thus research should advance this agenda.

Most of the pediatric literature for rehabilitation of standing/walking has been case studies and small "n" studies.

Trunk control after pediatric SCI can be improved via activity-based locomotor training in children with acute (< 1-year post-SCI) and chronic SCI (> 1-year post-SCI).

While greater rigor in pediatric research is recommended, e.g., inclusion of blinded assessors, the limited population numbers and particularly limited availability in one geographic location and its heterogeneity of etiology, presentation, and impairment level provide challenges to the use of the randomized clinical trial design. Other designs, including within subjects (subjects as own control), wait-list design, or adaptive designs should be considered alternatively and as informative, especially when examining interventions in children with chronic SCI. Small "n" studies in children with chronic SCI often provide the needed pilot work to direct a larger study of mechanisms and efficacy. This is especially true when the intended goal, e.g., recovery of walking, is clearly absent in those with chronic SCI and complete SCI.

Walking outcome measures mirror the use of compensation-focused interventions targeting function and independence with use of braces and equipment due to paralysis providing external support.

Measures that disallow compensation focus on "how" a movement or task, such as sitting upright, standing, or walking is performed to denote progress and align with the use of recovery-focused therapies.

3.2 Upper Extremity

The spinal cord is an integral aspect of the central nervous system because it is involved in the exchange of information between the body and brain; it carries motor information from the brain to the body and transports sensory information from the body back to the brain. Any injury to the spinal cord can disrupt and prevent the body's ability to perceive sensation and create a motor response below the level of injury. As the spinal cord provides segmental innervation of the body, disruption or loss of motor function is determined by the level of injury. Because the upper extremities are controlled by nerve fibers that originate in the neck (C5-T1) damage to the cervical spine results in the loss of motor and/or sensory function to the upper extremities, trunk, and lower extremities, resulting in tetraplegia. The overall SCI incidence for children (aged 0-18 years) in the United States is 1.99 cases per 100,000 children (Vitale et al. 2006). US hospitals admit and provide SCI treatment to approximately 1455 children annually (Vitale et al. 2006). Children with SCIs experience paraplegia and complete injuries at higher rates than the adolescent and adult populations (DeVivo & Vogel, 2004; Massagli, 2000). However, it is essential to consider the prevalence of pediatrics with SCIs that experience tetraplegia. Although incidences of pediatric SCI, where upper extremity function is impaired, is not widely published, one study looking at traumatic injury (n=490) found that 6.1% of individuals 0-15 and 8.5% of individuals 16-21 experienced complete tetraplegia, while 33.8% of individuals 0-15 and 25.2% of individuals 16-21 experienced incomplete tetraplegia (Saunders et al. 2015). Therefore, roughly 40% of children with SCI will have some upper extremity dysfunction.

It is not surprising that individuals with tetraplegia find challenges in many aspects of life due to impairments in the function of their upper extremities. Two categories that negatively affect the quality of life of tetraplegics, more so than paraplegics, are physical function, specifically lack of hand function, and independence (Manns & Chad, 2001). The occupation of children is play. Play is a developmental activity that fosters necessary skills including sensory, motor, cognitive, communication and social domains (O'Brien J, 2019). Through use of their hands, children learn about cause and effect by interacting with their environment, and they gain a sense of control. Physical impairments, such as SCI, affect play behavior by limiting movement and access (O'Brien J, 2019). SCI significantly impacts children's growth and development because an inability to engage in play could lead to decreased mastery over the environment and decreased social participation (Vogel et al. 1997). Through mobility, children explore and act on the environment, which leads to positive effects on emotional, social, and intellectual states (O'Brien J, 2019). The upper extremity function of a tetraplegic child facilitates mobility such as pushing their wheelchair, utilizing a joystick, opening a door, and performing transfers. Therefore, the use of upper extremities is required for increased independence. Engagement in social participation is also influenced by upper extremity function (Kim, 2016). Not only is social participation paramount to a child's development of social skills, it is also related to emotional well-being and life satisfaction, which puts those with SCIs at risk for negative psychological outcomes (Law et al. 2007). Upper extremity function is positively correlated with increased independence. For example, performance of Activities of Daily Living is closely related to upper extremity function (Kim, 2016). A primary milestone of childhood is increased participation and independence in self-care activities, such as dressing, bathing, and feeding. Even if a child is able to help with Activities of Daily Living, tetraplegics often require increased time, effort, and adaptive equipment, as compared to their typically developing or less involved peers (Manns & Chad, 2001). The inability to gain independence as a child due to decreased upper extremity function could have a detrimental impact on a child's self-concept and familial relationships. Upper extremity function is crucial to engagement and participation in daily living. This chapter will review the available literature on children with SCI with affected upper extremity function, discuss trends in interventions, and identify the gaps in the research, as compared to adult interventional studies.

Table 6. Studies Assessing Hand and Upper Limb Function Among Children With SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Mulcahey et al. 1997) USA Pre-Post N=5	**Population:** Age: 16.8±0.8 yr; Gender: males=4, females=1; Time since injury: 25.8±16.1 mo; Level of injury: C5=4, C6=1. **Intervention:** Implantable Functional Electrical Stimulation (FES) and tendon transfers, lengthenings, and releases of the upper extremity unique to each patient. **Outcome Measures:** Pinch and grasp, Grasp and Release Test (GRT), six activities of daily living (ADL): eating with a fork, drinking from a cup, placing a telephone call, writing with an ink pen, storing data on a diskette, and brushing teeth.	Muscle Strength 1. Three of the four adolescents who underwent the deltoid to triceps transfer gained 4/5 muscle strength in elbow extension which, in all cases, was sufficient to stabilize the elbow and expand the horizontal and vertical work areas. 2. One subject achieved 215 elbow extension strength. 3. Three subjects who had brachioradialis transfer gained at least 4+/5 in wrist extension strength; however, they did not have sufficient strength to stabilize the wrist during stimulated finger and thumb flexion so this movement had to be limited to preserve each of the subject's ability to control their wrists; FPL split tendon transfer provided good positioning of the thumb during lateral pinch without compromising stimulated force of FPL. 4. In three of the four subjects, intrinsic tenodesis transfer prevented MCP joint hyperextension during stimulated finger extension. 5. The intrinsic transfer of subject 1 had minimal effect on the intrinsic minus posturing of her hand. 6. One subject, who underwent a capsulodesis procedure, had poor stimulated finger extension because of MCP flexion deformities. Grasp and Release Test 7. FES forces were significantly greater than tenodesis forces for lateral and palmer grasps (p=0.043). 8. The primary difference in performance was with the heavier objects; of the four heavier objects (can, weight, tape, fork) no subject could manipulate them with tenodesis, but with FES all subjects could manipulate the weight and fork, 3 subjects could manipulate the can, and 1 could move the tape. Activities of Daily Living 9. Using the FES hand system, independence scores increased in 25 out of 30 cases as compared to baseline testing (six activities, five subjects). 10. All baseline activities performed with PA before surgery could be achieved using the FES hand system without attendant assistance. 11. In 11 out of 12 cases, the FES hand system eliminated the need to don and use AE.

		12. After system training, FES was preferred in 21 out of 30 cases; every subject preferred FES for eating, and except for one, preferred FES for writing. 13. The one subject who preferred writing with a splint was unable to maintain his wrist in extension against the stimulated force of the lateral pinch. 14. Satisfaction with the FES hand system came from no longer needing adaptive equipment, citing "I can press harder" (writing, brushing teeth), "it's easier" (writing, phoning, eating) and "it makes me look more normal" (writing, eating, phoning, storing data). 15. For the times FES was not preferred, the most frequently cited reason was "it's too hard" (phoning, storing data). 16. Although they were more independent as defined by the ADL test scoring, it was easier for several of the adolescents to place a phone call and manipulate a diskette with multiple pieces of adaptive equipment or physical assist. 17. For the drinking activity, three subjects had difficulty stabilizing their wrists against stimulated flexion while holding the cup and felt more confident that they would not spill the water when using alternative strategies.
(Smith et al. 1996) USA Pre-Post N=5* *Same study sample from (Mulcahey et al. 1994)	Population: Age: 15.8±2.6 yr; Gender: males=3, females=2; Time since injury: 29.8±33.8 mo (<1 yr=3, >4 yr=2); Level of injury: C5=2, C6=3. Intervention: Functional neuromuscular stimulation (FNS) neuroprosthesis for the upper limb; site of stimulation included fingers extensors, thumb abductors, thumb extenders, finger flexors, and thumb flexors. Outcome Measures: Grasp and Release Test (GRT).	FNS versus Tenodesis 1. With FNS, subjects were able to manipulate each test object in at least 1 test session with the exception of subject 4 who could never complete the tape task. 2. With a tenodesis, all subjects were able to complete the peg task, 1 subject could not manipulate the block, 2 subjects could never complete the can task and no subject was able to pass the pretest with the weight, fork or tape. 3. For 23 of the 30 (77%) task comparisons, performance was significantly improved with FNS. 4. In 14 of the 15 cases involving the heaviest test objects (weight, fork, tape), tasks could only be completed with FNS. 5. For the lighter test objects (peg, block, can), FNS was more effective in 9 of 15 cases (60%): • In 3 cases (2 can, 1 block) FNS was needed to complete the task; 2 of these situations involved subject 1, the only individual who lacked wrist extension. • In 4 cases (2 can, 1 block, 1 peg) there was no difference in completions but significantly more trials where there were fewer failures using FNS. • In 2 cases (1 block, 1 peg) there were more completions with FNS in a greater number of trials. • Of the 6 remaining cases with the lighter objects, there was 1 case (can) in which there were no differences in completions or failures and 5 situations

		(3 peg, 2 block) in which more completions, but also more failures, occurred with a tenodesis. 6. Lateral pinch forces ranged from 8.9 N to 22.5 N and palmar grasp forces from 2.1 N to 11. 1 N; tenodesis grasp force was not measurable. 7. Of 29 testable cases with FNS, completions were consistent across sessions in 8 instances (28 %); 6 of which involved the peg or block. 8. The number of failures was consistent in 10 instances (34%). 9. Tenodesis performance was consistent in 3 of the 12 (25%) testable cases for completions and 7 of 12 (58%) instances for failures. 10. With FNS, 5 of the 21 (24%) inconsistent cases were due to increases in completions in early sessions; in 4 of those cases, the median number of completions plateaued by the second or third session whereas for the last subject, they were only able to complete the tape task in the eighth session, after surgery to facilitate stimulated finger extension. 11. With tenodesis, 7 of the 9 (78%) inconsistent cases were related to improved performance, all on peg or block tasks; plateaus in performance occurred between the second and fourth session. 12. With FNS and tenodesis, each case of improved performance in later sessions was significantly better as compared to the initial session ($p<0.05$).
(Mulcahey et al. 1994) USA Pre-Post N=5 *Same study sample from (Smith et al. 1996)	Population: Age: 15.8±2.6 yr; Gender: males=3, females=2; Time since injury: 29.8±33.8 mo (<1 yr=3, >4 yr=2); Level of injury: C5=2, C6=3. Intervention: Functional neuromuscular stimulation (FNS) neuroprosthesis for the upper limb; site of stimulation included fingers extensors, thumb abductors, thumb extenders, finger flexors, and thumb flexors. Outcome Measures: Common Object Test (COT) involving performance and satisfaction of five	Acquire Phase 1. Without FNS, two hands (*self-assist*) were required in almost all activities to acquire the objects. 2. Two subjects scored *physical assist* for eating and writing since they required wrist splints specifically for those two activities and were unable to don them without help. 3. With FNS, independence increased for at least one subject in each activity. 4. Three subjects were able to use stimulation to acquire toothpaste with one hand (*independent*) which freed the non-FNS extremity to hold or stabilize the toothbrush; all three could *independently* acquire the toothbrush. 5. The remaining two subjects acquired a pen and fork with two hands (*self-assist*), eliminating the need for attendant care (*physical assist*). 6. For the drinking activity, one subject was able to acquire the cup *independently*. 7. One subject was unable to grasp the cup with his fingers because of insufficient finger extension (*physical assist*). Performance Phase (repetitive activity or performing for extended period of time)

	activities: eating with a fork, drinking from a cup, writing, applying toothpaste and brushing teeth; device usage survey (activity patterns in home, work, and school setting) with open-ended questions.	8. During the hold phase in the majority of the activities without FNS, *adaptive equipment* or two hands (*self-assist*) were required to maintain the objects in the hand; for example, to hold a toothbrush and a pen, most subjects used a universal cuff, and two subjects relied on Wanchik splints to hold their pens. 9. Four subjects used a universal cuff to hold a fork (thereby not requiring stimulation) and one was able to weave his utensil through his tight fingers *independently*. 10. Without FNS four subjects required modifications to the handle of the fork (*adaptive equipment*) to stab food; with FNS, no subject required any modifications to the fork to stab food (*independent*). 11. Each subject was able to write and grasp a cup *independently* and, for each activity, lift and lower the arm without assistance (*independent*). 12. Without FES, all subject typically required two hands (*self-assist)* for squeezing and applying toothpaste, brushing teeth and drinking the first and last sip; with FES two subjects used lateral pinch (*independent*) to squeeze the toothpaste and four subjects were able to use one hand (*independent*) to brush both sides of their mouths; one subject used two hands (*self-assist*) to brush the contra-lateral side. Release Phase 13. Without FNS, release of objects in each activity usually required two hands (*self-assist*) during tenodesis flexion, or the mouth (*self-assist*) to doff adaptive equipment. 14. One subject required a *physical assistance* to remove the wrist splint used specifically in the eating and writing tasks. 15. With FNS, all subjects scored higher on the independence; for most, stimulated lateral and palmar extension was sufficient to release the objects (*independent).* 16. One subject no longer needed to insert a fork in the cuff and was able to release the toothbrush and fork with one hand (*independent*). 17. For most subjects their quality of performing activities improved and they preferred using the FES system. 18. Reasons for not using the system included mood (4/5), no time (3/5), no attendant (3/5), skin irritation (1/5), system complications (1/5) and illness (1/5).

Table 7. Case reports assessing hand and upper limb function among children with SCI.

Author, Year Country Study Design	Objective/Purpose
(Smith et al. 2001) USA Case Report N=1	**Population:** 10 yr, female, C5 SCI, 10 mo post injury. **Intervention:** Freehand System (functional electrical stimulation neuroprosthesis). **Outcome Measures:** Manual Muscle Test, stimulated pinch force, Grasp and Release Test, Functional Independence Measure, bone growth, lead unwinding.
(Mulcahey et al. 1999b) USA Case Report N=3	**Population:** *Case I:* 9 yr, C7 SCI; *Case II*: 6 yr, C7 SCI; *Case III* 9 yr, C6 SCI. **Intervention:** Surgical transfers of the brachioradialis to the flexor pollicis longus and extensor carpi radialis longus to flexor digitorum profundus for thumb and finger flexion, respectively. **Outcome Measures:** Pinch and finger flexion force, Grasp and Release Test, Functional Independence Measure.
(Davis et al. 1997) USA Case Report N=1	**Population:** 17 yr, male, C5 complete SCI. **Intervention:** Bilateral tendon transfers and unilateral implementation of the Freehand System (functional electrical stimulation neuroprosthesis). **Outcome Measures:** Range of motion, Manual Muscle Test, Pinch force.
(Mulcahey et al. 1995) USA Case Report N=1	**Population:** 11 yr, male, C7 complete SCI. **Intervention:** Surgical transfers of the brachioradialis to the flexor pollicis longus and the extensor carpi radialis longus to the flexor digitorum profundus. **Outcome Measures:** Pinch force, Jebsen Test of Hand Function for Children, Grasp and Release, Functional Independence Measure, Common Object Test.
(Smith et al. 1992) USA Case Report N=1	**Population:** 8 yr, male, C7-8 Frankel C SCI. **Intervention:** Functional neuromuscular stimulation neuroprosthetic hand system. **Outcome Measures:** Manual muscle test, muscle strength, Grasp and Release Test.

Discussion

Pediatric patients with cervical SCI face challenges when performing daily tasks and resuming developmentally appropriate roles due to their lack of upper extremity function (Mulcahey et al. 1994). Although research indicates that family members may find it easier to complete tasks for their children (Mulcahey et al. 1994), encouraging children's independence is crucial to their growth and development. There is a paucity of research on upper extremity interventions and outcomes for children with tetraplegia. Nearly all articles are low level research, including observational cohorts, limited case reports, and expert reviews and focus primarily on surgical reconstruction and functional electrical stimulation (FES).

Surgical reconstruction of the upper extremity aims to improve positioning of the upper extremity and augment overall hand function (Mulcahey et al. 1997). Surgical reconstruction occurs through various methods such as transferring tendons or nerves, synchronizing, releasing or lengthening tendons, and fusing adjacent bones to immobilize a joint (Mulcahey MJ, 1997).

Different surgical approaches are described in the literature, most notably tendon transfers (Davis et al. 1997; Mulcahey et al. 1999a; Mulcahey et al. 1995; Vova & Davidson, 2020) and more recently nerve transfers (Vova & Davidson, 2020). Tendon transfers involve unipolar transfer of a strong redundant muscle to replace a function lost to SCI (Davis et al. 1997; Mulcahey et al. 1995). Nerve transfers involve unipolar transfer of a nerve, branch, or fascicle to reinnervate a target muscle (Vova & Davidson, 2020). In theory, nerve transfers could innervate more than one muscle and restore multiple functions, depending on the location of coaptation (Tung & Mackinnon, 2010). Nerve transfers have gained recent favor in peripheral nerve conditions, like brachial plexus injury, but the SCI community has been slower to adopt these practices. The most common upper extremity transfers aim to restore elbow extension, wrist extension, finger flexion, and thumb flexion and opposition (Bryden et al. 2012; Mulcahey et al. 1999a; Vova & Davidson, 2020).

Articles that review surgical reconstruction as a method to increase upper extremity function report various approaches and functional outcomes related to stability, strength, and cosmesis. Tendon transfers from the posterior deltoid to the triceps are found to be successful in stabilizing the elbow (Davis et al. 1997; Mulcahey et al. 1999a), and brachioradialis transfers to wrist extensors successfully stabilize the wrist (Mulcahey et al. 1999a). Surgical reconstruction in the form of tendon transfers also positively influences upper extremity positioning. Split tendon transfers of the Flexor Pollicis Longus muscle are used to promote thumb flexion and opposition, which is required for grasping, and intrinsic transfers are used to reduce intrinsic minus positioning to improve the hand's usability (Mulcahey et al. 1999a). Following tendon transfers, parents report that their children look more normal (Mulcahey et al. 1999a) which most likely contributes to the child's self-esteem and acceptance. Tendon transfers positively influence individuals' range of motion, allowing them greater environmental access by expanding the horizontal and vertical workspace (Davis et al. 1997; Mulcahey et al. 1999a). Tendon transfers also result in improvements in upper extremity strength, even for nonexistent movement before surgery (Davis et al. 1997; Mulcahey et al. 1999a). Tendon transfers were also reported to improve grasp and pinch function, functional independence and mobility, bilateral coordination and unilateral control, and eliminate the need for orthoses (Davis et al. 1997; Mulcahey et al. 1999a; Mulcahey et al. 1995).

Although surgical reconstruction has various benefits, it does have drawbacks. An individual must have voluntary control and sufficient strength of at least 4/5 in two or more muscles that perform a similar function in order to be a candidate for tendon transfer surgery (Davis et al. 1997; Mulcahey et al. 1999a). Following surgery, the upper extremity needs to be immobilized, and surgical management such as the prevention of contractures and edema control need to be employed (Mulcahey et al. 1995). The child also needs to receive tendon transfer education (Mulcahey et al. 1995). Clinicians should keep in mind how contractures or severe spasticity would affect surgical reconstruction outcomes (Mulcahey et al. 1999a). Furthermore, there is not a specific universal measure that is used to evaluate upper extremity function following surgical reconstruction in pediatrics (Mulcahey et al. 1999a).

The other significant area of intervention discussed in the literature is FES. Many articles describe the use of implanted percutaneous electrodes, as part of the now defunct Freehand System. The specific technology notwithstanding, there are lessons to be gleaned on the use of both implanted and surface stimulation. FES is demonstrated to improve both physical and social aspects of upper extremity function for pediatrics with SCI. When utilizing grasp and release abilities to manipulate objects, FES is found to be significantly more effective than tenodesis, owing to the improvements in palmar and lateral power (Davis et al. 1997; Smith et al. 1996). FES improves grip efficiency and consistency, particularly as the weight of objects increases (Mulcahey et al. 1997; Smith et al. 1996). FES is useful in increasing children's ability to engage with the environment, be independent with Activities of Daily Living, reduce reliance on adaptive equipment, and improve overall self-concept and autonomy (Mulcahey et al. 1997; Mulcahey et al. 1994; Smith et al. 1996). Overall independence scores for Activities of Daily Living performance increased in 83% of cases when using the FES hand system compared to tenodesis (Mulcahey et al. 1997). Worth noting, compared to children's and adolescents' baseline performance that required physical assistance to complete daily tasks, the need for physical assistance was eliminated with the use of FES (Mulcahey et al. 1997; Mulcahey et al. 1994)

Although there are many advantages, the limitations of FES must be considered. Due to the increased pinch force created by FES, it may be harder for children to maintain wrist extension while pinching (Mulcahey et al. 1997), which reduces the natural tenodesis effects. Because it requires learning and practice, children may feel as though utilizing FES is too hard, and may prefer tenodesis (Mulcahey et al. 1997). Furthermore, children who have had their injuries for over one year felt more comfortable using FES in public places such as school, stores, and restaurants than those with recent SCI (Mulcahey et al. 1994). FES may be most beneficial to pediatrics with C5 level injuries, as they typically experience less independence than those with C6 injuries who are able to use tenodesis to their advantage (Mulcahey et al. 1997). It is also worth noting that, despite all this evidence, FES use in general clinics is still limited and the evidence for children has not progressed since the mid-1990's. While adult literature is available, it should be applied with caution, as parameter selection, torque production, and growth considerations would be different in children.

Both surgical reconstruction and FES identify increased independence as a positive outcome; this reduces the burden on parents and family members and promotes a feeling of accomplishment not only for the child but also for the entire family unit (Mulcahey et al. 1999a; Mulcahey et al. 1994). Increased upper extremity function is positively correlated with emotional well-being and life satisfaction, and interventions such as surgical reconstruction and FES should be considered to promote these positive outcomes that give children with cervical SCI the best opportunity to lead a happy and productive life (Law et al. 2007).

Notably missing from the current body of literature is any interventional studies for children post SCI and predictive studies regarding the likelihood of recovering function based on injury level, type, and early indicators. While these outcomes have been reported in the context of case studies and anecdotal evidence, there has been no systematic examination of interventions improving upper extremity function. And so, we are left to extrapolate from adult studies of robotic devices, gravity compensation training, massed practice of component skills, telerehabilitation, virtual reality, and transcranial direct current stimulation/neuromodulatory inputs. Interventional studies in children are challenging for multiple reasons. First, there is an issue of development on top of recovery and, in some cases, cultivating skills which the child never had, if the injury was sustained in infancy or early childhood. Secondly, there are issues related to measurement. Many adult studies use biomechanic or kinematic evaluation to measure range of motion and tissue extensibility, or actigraph data for information on frequency of use. These metrics are more limited in children and are largely dependent on normal value comparisons not available for children. Finally, there is the challenge of recruitment to sufficiently power an interventional study, as the population of children with SCI is relatively small. For these reasons, the literature on upper extremity function in children with tetraplegia lacks the breadth of interventions and careful measurement of function present in the adult literature.

Key Points

Evidence on upper extremity function for children with tetraplegia is limited to low level studies on finite topics. The body of literature lacks the breadth of interventions and careful measurement of function present in the adult literature.

Functional electrical stimulation (FES) is effective at improving upper extremity movement efficiency, consistency, and strength. Performance of skilled tasks is better with FES as compared to tenodesis alone. FES may be used in combination with tendon transfers to build more options for movement, where there previously was none. Children who participated in FES therapies reported greater confidence in movement and resulting enhancements in quality of life (Davis et al. 1997; Mulcahey et al. 1997; Mulcahey MJ, 1997; Mulcahey et al. 1994; Smith et al. 1994; Smith et al. 1996, 2001; Smith et al. 1992; Triolo et al. 1994).

Tendon transfers are useful in restoring both proximal functions, like elbow extension, and distal skill, like lateral pinch. Good surgical candidates have strong redundant functions. There is little consensus on priorities, approaches, and post-operative care (Davis et al. 1997; Mulcahey et al. 1999a; Mulcahey et al. 1995; Vova & Davidson, 2020).

Nerve transfers are useful for multi-step reanimation of the upper extremity following SCI. These require intervention earlier post injury. There is little consensus on priorities, approaches, and post-operative care (Vova & Davidson, 2020).

3.3 Wheeled Mobility

For persons with SCI who require a wheelchair as their primary means of mobility, an estimated 90% of them will use a manual wheelchair (Kaye et al. 2000). In order to self-propel, manual wheelchair users must exert significant forces through their shoulders and other upper extremity (UE) joints (Boninger et al. 2002; Crane, 2007; Langenhoff, 1998). Thus, the demand on the upper extremity in children with SCI who rely on wheeled mobility is significant (Hasara Krey & Calhoun, 2004; Schnorenberg, Slavens, Graf, et al. 2014; Slavens et al. 2015). This puts them at risk of developing pain and upper extremity pathology which may interfere with their independence (Hasara Krey & Calhoun, 2004; Schnorenberg, Slavens, Graf, et al. 2014;

Schnorenberg, Slavens, Wang, et al. 2014). Although data pertaining to the impact of manual wheelchair use in children is limited, their risk of developing upper extremity injury, pain, and dysfunction that might impact manual wheelchair use, transfers, independence, and quality of life is substantial, particularly since children with SCI who are manual wheelchair users have long life expectancies and will rely on upper extremity function for mobility, including transfers and wheeled mobility, over the lifespan (Crane, 2007). In this section, studies examining manual wheelchair users' biomechanics are reviewed; these studies are summarized in Table 8. These studies focus mainly on understanding biomechanics which may theoretically affect the risk of upper extremity injury, but provide little insight for clinical implications.

Table 8. Studies assessing wheeled mobility among children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Schottler, Graf et al. 2019) USA Pre-Post (N=23)	**Population:** Age: 11.9 (7-19) yr; Gender: males=13, females=10; Level of injury: C6-L2; duration of manual wheelchair use 43.6 (3-132) mo; 26% had shoulder pain. **Intervention:** SmartWheel wheelchair training program. **Outcome Measures:** Peak force; peak backwards force; speed; push length; push frequency; peak/average force ratio; average push force; push mechanical effectiveness before and after training; Wheelchair User's Shoulder Pain Index.	1. After completion of the wheelchair training program, participants showed statistically significant improvements in mean peak backwards forces (reduction of 0.71 N) and pushing effectiveness (increase of 5.6%). 2. These changes suggest training improved participants' ability to translate energy into forward propulsion, but the clinical significance is unclear. 3. The effect sizes were small for these improvements. Other parameters neared statistical significance; as this was a pilot study, additional research is required as this may have been underpowered.
(Slavens et al. 2015) USA Observational N=12	**Population:** Age: 13.2±5.0 yr; Gender: males=10, females=2; Height: 137.4±29.9 cm; Weight: 41.8±13.4 kg. **Intervention**: A SmartWheel with an air tire, replaced the wheel on the dominant side of the subject's wheelchair for kinetic data collection; the SmartWheel companion wheel replaced the subject's wheel on the nondominant side. A 10-camera Vicon MX system captured the 3D marker trajectories at 120 Hz, while simultaneously the SmartWheel collected the 3D forces and	1. The average propulsion speed was 1.23±0.26 (0.79-1.6) m/s with an average cadence of 1.1±0.2 strokes/sec. 2. The average contact phase occurred from 0-35.8% stroke cycle with a range of 25-45% stroke cycle. Within the contact phase, the initial contact period occurred on average from 0-3.6% stroke cycle, the propulsion period on average occurred from 3.6-34.1% stroke cycle, and the release period occurred on average from 34.1-35.8% stroke cycle. 3. One subject used the single-looping overpropulsion (SLOP) pattern, 3 subjects used the double-looping overpropulsion (DLOP) pattern, and 3 subjects used the recommended semicircular (SC) pattern.

	moments occurring at the hand-handrim interface at 240 Hz. Vicon Nexus was used to process the marker trajectories. Outcome Measures: Upper Extremity Biomedical model – 3D joint angles, forces, and moments; Segment coordinate systems (SCS); wheelchair stroke cycle phases and periods; peak joint forces, angles, and moments.	The remaining five subjects used a mixture of patterns making the primary pattern unidentifiable. 4. The average contact phase angle was 85.6 ± 15.7° and the average propulsion period angle was 72.6 ± 11.9°. 5. The average peak resultant handrim force was 10.1% BW ± 3.7% BW. 6. The elbow joint range of motion was statistically significantly higher than the acromioclavicular (AC; p<0.001) and thorax (p<0.001) joint ranges of motion in the sagittal plane. The elbow joint range of motion was significantly higher than the wrist (p<0.001), AC (p<0.001), sternoclavicular (SC; p<0.001) and thorax (p<0.001) joint ranges of motion in the transverse plane. 7. The glenohumeral (GH) joint range of motion was significantly higher than the elbow (p<0.001), AC (p<0.001), SC (p<0.001) and thorax (p<0.001) joint ranges of motion in the sagittal plane. The GH joint range of motion was significantly higher than the wrist (p<0.001), AC (p<0.001), and thorax (p<0.001) joint ranges of motion in the transverse plane. The GH joint range of motion was significantly higher than the AC (p<0.001), SC (p<0.001), and thorax (p<0.001) joint ranges of motion in the coronal plane. 8. The wrist joint range of motion was significantly higher than the AC (p<0.001), and thorax (p<0.001) joint ranges of motion in the sagittal plane. The wrist joint range of motion was significantly higher than the thorax joint range of motion in the transverse plane (p<0.001) and the AC (p<0.001) SC (p<0.001), and thorax (p<0.001) joint ranges of motion in the coronal plane. 9. The AC joint range of motion was significantly higher than the thorax joint range of motion in the transverse plane (p=0.015) and the coronal plane (p=0.002), while the SC joint range of motion was significantly higher than the thorax joint range of motion in the transverse plane (p=0.002). 10. The GH joint forces were statistically significantly higher than the wrist joint forces directed superiorly (p<0.001), laterally (p=0.019), and posteriorly (p<0.001). The wrist joint forces in the anterior (p=0.033) and inferior (p=0.046) directions were

		significantly greater than those at the GH joint. 11. The GH joint experienced significantly higher joint forces directed superiorly (p<0.001) and posteriorly (p<0.001) than the elbow joint. 12. The elbow joint experienced significantly higher forces than the wrist in the superior (p<0.001) and posterior (p<0.001) directions. 13. The GH joint experienced significantly greater moments in flexion (p=0.009) and extension (p<0.001) than the wrist joint. 14. The elbow was significantly greater than the wrist in the extension moment (p<0.001). 15. The GH joint experienced significantly higher moments than the elbow joint in internal rotation (p=0.043) and extension (p=0.002). The elbow experienced significantly higher flexion moment than the GH joint (p=0.001).
(Schnorenberg, Slavens, Graf, et al. 2014) USA Observational N=12	**Population**: Age: 13.2±5.0 yr; Gender: males=10, females=2; Height: 137±30 cm; Weight: 42±13 kg. **Intervention**: A SmartWheel (Out-Front, Mesa, AZ) replaced the wheel on the dominant side of the subject's wheelchair for kinetic data collection. A 14-camera Vicon MX System captured the 3D marker trajectories at 120 Hz, while the SmartWheel simultaneously collected 3D forces and moments occurring at the hand-hand-rim interface at 240 Hz. **Outcome Measures**: UE model – 3D joint angles, forces and moments; stroke cycles; peak forces and moments.	1. The average propulsion speed was 1.23±0.26 m/s. The average contact and recovery phases occurred from 0-35.8% stroke cycle and 35.8-100% stroke cycle, respectively. The relative transition time between phases occurred on average at 35.8% stroke cycle, with a range of 25-45% stroke cycle. 2. Within the contact phase, the initial contact period occurred on average from 0-3.6% stroke cycle, and the release period occurred on average from 34.1-35.8% stroke cycle. 3. One subject used the single looping over-propulsion (SLOP) pattern, 3 subjects used the double looping over-propulsion (DLOP) pattern, and 3 subjects used the semicircular (SC) pattern, which is recommended in the literature. The remaining 5 subjects used a variety of patterns. 4. The GH joint demonstrated the highest average peak forces, with 6.5% BW in the posterior direction and 6.1% BW in the superior direction, which were significantly higher (p<0.001) than the posteriorly and superiorly directed forces at the elbow and wrist joints. 5. The highest average joint moment was 1.36% BWxH of elbow flexion, with the GH joint flexion moment significantly less than both the elbow and wrist joint flexion moments (p<0.01).

		1. The highest average peak GH joint moment was 1.2% BWxH of extension, which was significantly higher than the average peak extension moment of the elbow and wrist joints (p<0.01).
(Schnorenberg, Slavens, Wang, et al. 2014) USA Case Report N=1	**Population:** 17 yr, male, C7 SCI. **Intervention:** None. Measurements taken during wheelchair propulsion using a SmartWheel manual wheelchair system and passive reflective markers applied to the bilateral upper extremity joints. **Outcome Measures:** Bilateral upper extremity joint dynamics (for motion and loading patterns).	1. Asymmetry in joint forces and range of motion is common across the UE joints during manual wheelchair propulsion, but the clinical significance of this is unclear.

Discussion

The available data on manual wheelchair use in children with SCI is limited; most data come from three observational trials using the same SmartWheel technology to evaluate biomechanics of manual wheelchair users in real-time. In these studies, joint biomechanics vary between subjects; the implications of specific forces acting at various joints has yet to be determined in children who use manual wheelchairs post SCI. There is evidence from one pre-post study that wheelchair training programs may improve the effectiveness of wheelchair propulsion, albeit modestly (5.6% improvement in efficiency) (Schottler et al. 2019). There are no studies on the effectiveness or efficiency of various wheelchair propulsion stroke patterns. Observational studies by the same group of authors both describe the stroke patterns of 12 patients with the same findings: one subject used the single-looping overpropulsion pattern, 3 subjects used the double-looping overpropulsion pattern, 3 subjects used the recommended semicircular (SC) pattern; and, 5 subjects used a mixture of patterns making the primary pattern unidentifiable (Schnorenberg, Slavens, Graf, et al. 2014; Slavens et al. 2015).

Key Points

There is level 5 evidence that the typical manual wheelchair propulsion stroke patterns used by children with SCI varies across subjects.

There is level 4 evidence that a wheelchair training program may improve measured manual wheelchair propulsion efficiency.

4 Neuromusculoskeletal Complications of SCI

It is important to distinguish between the direct consequences of a SCI/SCD and the secondary health conditions and complications of SCI/SCD. Direct consequences of the condition cannot be avoided, and must instead by addressed through supportive care and rehabilitation approaches. In contrast, secondary health conditions/complications are, by definition, potentially preventable or at least partially treatable. There are a number of potential complications of SCI that can impact upon the neuromusculoskeletal system,

4.1 Nervous System Function

4.1.1 Late Neurological Decline

Temporary alterations in certain neurological functions of people with SCI may be related to disturbances outside of the central nervous system (i.e., apparent decline in bladder function or increased extremity tone in the setting of a urinary tract infection (UTI)). However, progressive neurological decline in the chronic phase of SCI is unexpected, and signs or symptoms of decline should result in a comprehensive assessment to determine the cause of the change.

Progressive myelomalacia of the spinal cord is a potential long-term complication of SCI. Traction on the spinal cord from arachnoid scars acting as “tethers” on the surrounding dura is one potential cause of neurologic decline – a so called “tethered cord syndrome,” also called “progressive post-traumatic non-cystic myelomalacia” (Falci et al. 2010). The clinical harbingers of a significant tethered cord syndrome may include but are not limited to neuropathic pain, sensory or motor functional decline, change in tone or reflexes, and altered bowel/bladder or sexual function.

Another potential cause of neurologic decline arises from the expansion of fluid filled cysts (syrinx) within the grey mater of the cord itself. Though these cysts may exist in the cord from soon after the injury (following the resorption of necrotic tissue, edema and hematoma), it can be decades before they expand to the point of causing neurologic decline, if in fact they ever do. This results in a clinical syndrome referred to as “progressive post-traumatic cystic myelomalacia”, or simply “syringomyelia” (Svircev & Little, 2010). Because the syrinx is typically located at or near the centre of the spinal cord, it may result in a dissociated sensory loss, with pain and temperature (transmitted by the centrally located spinothalamic tract) more affected than proprioception and vibration (transmitted through the dorsal columns). Other clinical features of syringomyelia may be very similar to the features of progressive post-traumatic non-cystic myelomalacia/tethered cord syndrome described above.

Both conditions are typically diagnosed based on clinical symptoms coupled with magnetic resonance imaging. Treatment may be conservative or may involve a neurosurgical approach (involving the release of tethered tissue or the drainage of a spinal syrinx), particularly if the symptoms are more significant or progressive. Very little is known about the impact of progressive myelomalacia in the pediatric SCI population.

Table 9. Studies assessing progressive neurological deterioration among children with SCI.

Author, Year Country Study Design Sample Size	Study Characteristics	Results
(Vogel et al. 2002c) *Part II* USA Observational N=216	**Population:** Age at injury: 14.1±4.0 yr; Age at interview: 28.6±3.4 yr; Gender: males=150, females=66; Time since injury: 14.2±4.6 yr; Level of injury: tetraplegia=123, paraplegia=93. Severity of injury: C1-4 ABC=41, C5-8 ABC=67, T1-S5 ABC=82, tetra/para D=26. **Intervention:** None. Survey. **Outcome Measures:** Prevalence of syringomyelia and neurological deterioration.	1. Neurological deterioration occurred in 12 subjects 2. Syringomyelia necessitating surgery occurred in 6 subjects 3. Neurological deterioration was significantly associated with older age at follow-up (p=0.022), longer duration of SCI (p<0.001), higher ASIA Motor scores (p=0.019); there were no significant associations between neurological deterioration and neurological level or FIM scores.

Discussion

Progressive neurologic decline in the chronic phase of SCI may conceivably have significant implications for the mental and physical well-being of individuals already living with functional limitations. That said, relatively little is known about the causes and treatment of the various causes of post traumatic progressive spinal cord dysfunction (SCD), and this is particularly true in the pediatric SCI literature. Only one observational study of pediatric SCI (Vogel et al. 2002c) provides any insight into this phenomenon. The numbers of individuals identified with neurological deterioration (6% of the study sample), and more specifically with syringomyelia requiring surgical intervention (3% of the study sample) are not insignificant. Contributors to these conditions are difficult to identify given the small numbers, but neurological decline did seem to be clearly associated with longer duration of SCI. This speaks to the importance of monitoring for neurologic changes over time in individuals with chronic SCI.

Unfortunately, there is no published literature in pediatric SCI detailing the clinical presentation of syringomyelia or other forms of late neurologic decline post SCI, nor is there any literature available describing or comparing various treatment approaches.

Key Points

There is very little data regarding frequency, management and outcomes of late neurologic decline in pediatric SCI. Given the potential implications of these conditions, neurologic function in individuals with chronic SCI should be monitored.

4.1.2 Neuropathic and Nociceptive Pain

Pain after SCI can appear in many forms, and is commonly divided into nociceptive or neuropathic pain. The International Association for the Study of Pain defines nociceptive pain as "pain that arises from actual or threatened damage to non-neural tissue and is due to the activation of nociceptors" (International Association for the Study of Pain, 2021). In contrast, the International Association for the Study of Pain defines neuropathic pain as "caused by a lesion or disease of the somatosensory nervous system" that can be related to either the central or peripheral nervous system (International Association for the Study of Pain, 2021). In SCI, neuropathic pain may arise from the territory below the level of neurologic injury, or from the border zone (the region of transition between normal and abnormal sensation). There is no question that pain of all types is a frequent occurrence for adults with SCI, and the institution of effective management strategies remains a challenge.

There has been little formal research regarding pain in pediatric SCI. The literature does provide some insights into the high prevalence of pain for this population, which serves to clearly highlight a need for more information about effective pain management in children with SCI.

Table 10. Studies assessing nociceptive pain among children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Jan & Wilson, 2004) USA Observational N=31	Population: Age at interview: 13.9 (3-46) yr; Age at Injury: 5 mo-18 yr (n=20 <8 yr); Gender: males=15, females=16; Level of Injury: cervical=12 (n=4 ventilator dependent), thoracic=16, lumbar=3. Severity of injury: complete=18, incomplete=13. Intervention: None. Outcome Measures: Type (i.e., nocioceptive [musculoskeletal or visceral] versus neuropathic), quantity and severity of pain, Lansky Play Performance Scale, Adolescent Pediatric Pain Tool.	1. In the entire group, 35% reported no pain and 65% reported pain. 2. Nocioceptive pain was identified in 48% (15/31) and neuropathic pain was identified in 19% (6/31). 3. The nocioceptive cohort was subclassified as having 10 with musculoskeletal and 8 with visceral pain. 4. For group injured at a very early age (<3 yr old) 72% reported pain and 28% were pain free. 5. The nocioceptive-musculoskeletal group had 60% complete and 40% incomplete injuries. 6. All the nocioceptive-visceral group had complete injuries. 7. The neuropathic group had 50% complete and 50% incomplete injuries. 8. Lansky Play Scale scores ranged 50-100 with a mean of 92 and mode of 90. For word-graphic ratings, the range of scores was 0.5-8.0 with a mean of 4.9.

(Defresne et al. 2003) France Observational N=24	**Population:** Age: 2-14 yr; Gender: males=11, females=13. **Intervention**: None. **Outcome Measures**: Motor outcomes; urinary sequelae; Paine's scale; cerebrospinal fluid obtained by lumbar puncture; spinal MRI.	Initial phase 1. 88% (21/24) of the patients had severe pain, which was usually symmetric (18/21) and located in one or more spinal segments (11/21), although 6 patients had leg pain and 5 had headaches. 2. Fever was a presenting symptom in 14 of 24 patients and was not more common in the patients with a prior infection. 3. Neurologic symptoms were present initially in only 50% of the patients and consisted of motor loss (10/12) or sphincter dysfunction (4/12). 4. Sudden onset of a severe motor deficit was noted in 8 patients, of whom 7 became unable to walk within 12 hours and one had respiratory insufficiency. 5. The motor symptoms antedated the sphincter dysfunction in two thirds of the patients (16/24) and were asymmetric in 71%. Plateau 6. Back pain was noted in 75% (18/24) of patients, more commonly in the neck (56%, 10/18); all but 1 patient had flaccid paralysis. 7. The motor deficit became symmetric in 67% (16/24) of the patients. 8. The lower limb weakness was severe in 18 (75%) patients, and one or more deep tendon reflexes in the lower limbs were abolished in 20 (83%) patients. 9. Weakness in the upper limbs was present in 10 (42%) patients and was consistently moderate. 10. A single patient had tetraplegia. 11. Abnormalities in sensation were found in 19 (83%) patients, being asymmetric in 20 (82%) patients and consistent with a thoracic lesion in 21 (88%) patients and with a cervical lesion in 3 (12%) patients. 12. Sphincter dysfunction was present in 20 patients: in 12 patients, whereas in 8 patients, the dysfunction was moderate; 11 patients had anal sphincter dysfunction. 13. Optic neuritis was present in 4 patients. Recovery phase (n=16) 14. 2 (13%) children had severe motor sequelae. 15. 8 (50%) patients recovered normal motor function. 4 (25%) patients had moderate motor sequelae and 2 (13%) had mild motor sequelae. 16. Sensory abnormalities resolved completely in 7 children (54%).

		17. Of the 15 patients with sphincter dysfunction, 5 (33%) recovered normal sphincter function within a mean of 7 months (15 days-2 yr), 5 (33%) had mild sequelae, and 5 (33%) had severe sequelae. 18. According to Paine's scale, 5 (31%) children achieved a full recovery, 4 (25%) had minimal sequelae, and 7 (44%) had mild or severe sequelae. 19. Supraspinal symptoms recovered fully in all 16 patients. Prognostic factors 20. An unfavorable outcome was more common among patients with complete paraplegia (p=0.03) and/or a time to maximal deficit shorter than 24 hours (p=0.005). 21. A favorable outcome was associated with a plateau shorter than 8 days (p=0.03), the presence of supraspinal symptoms (p=0.01), and a time to independent walking shorter than 1 month (p=0.01). Cerebrospinal fluid 22. Abnormalities were found in 15 (62%) patients. The white blood cell count ranged from 0 to 1800/µL (mean 210/µL), and lymphocytes were the main cell type in 12 of 15 patients. 23. The protein level was slightly elevated (up to 120 mg/dL) in 3 (20%) patients. 24. Cerebrospinal fluid protein electrophoresis was normal in 9 of 13 patients and showed a pattern consistent with a transudate (no oligoclonal bands) in the remaining 4 patients. 25. 5 of 24 patients had serologic evidence of a recent viral infection (herpes simplex virus, n1=; Epstein-Barr virus, n=1, varicella-zoster virus, n=1; and measles, n=2). MRI data 26. 2 of 6 children who underwent spinal MRI had normal findings; among the 4 other children, 1 had multiple lesions in the cervical region and conus medullaris and 3 each had a single lesion in the thoracic spinal cord. 27. Edema of the spinal cord was visible on T1-weighted sequences in 2 children. 28. On T2-weighted sequences, all lesions exhibited high signal intensity and extended along two or more vertebral segments. 29. In 3 children, the high-signal lesions on the T2-weighted sequences of the initial MRI showed

		postgadolinium enhancement in a nodular (n=1), diffuse (n=1), or peripheral (n=1) pattern. 30. Among the 4 patients who underwent cerebral MRI, only 1 had abnormal findings, which consisted of multiple areas of high signal in the cortex and basal ganglia on T2-weighted sequences. 31. Follow-up MRI was performed in 3 patients and showed a return to normal in 2; the remaining patient had cervical and conus lesions on the initial MRI and persistent high signal in the conus on T2-weighted sequences after 4 months.
(Vogel et al. 2002b) Part II USA Observational N=216	**Population:** Age at injury: 14.1±4.0 yr; Age at interview: 28.6±3.4 yr; Gender: males=150, females=66; Time since injury: 14.2±4.6 yr; Level of injury: tetraplegia=123, paraplegia=93. Severity of injury: C1-4 ABC=41, C5-8 ABC=67, T1-S5 ABC=82, tetra/para D=26. **Intervention:** None. Survey. **Outcome Measures:** Prevalence of pain.	Ankle Pain and Contractures 1. Ankle pain or contractures affected 53 subjects, with 29 individuals having contractures alone, 18 reported pain only, and 6 had complaints of both contractures and pain. 2. Ankle pain was significantly associated with older age at injury (p=0.018) and tetraplegia (p=0.005). 3. Ankle contractures were not significantly associated with any of the study variables. Elbow Pain and Contractures 4. Elbow pain or contractures affected 43 subjects with 27 experiencing elbow pain alone, 10 had elbow contractures alone, and 6 had both. 5. Those with elbow pain were significantly older at follow-up (p=p=0.026) and had a longer duration of their SCI (p=0.041). 6. As expected, elbow contractures were significantly more common in those with tetraplegia (p=0.040) and were significantly associated with lower ASIA motor scores (p=0.016) and lower total FIM (p=0.010) and motor FIM scores (p=0.009). Shoulder, Back, and General Pain 7. Shoulder pain was reported by 48% of subjects and limited activities in 21% of those affected. 8. Shoulder pain was significantly associated with older age at interview (p=p=0.045), and longer duration of injury (p=0.034). 9. Shoulder pain was not significantly associated with degree of neurological impairment or FIM scores. 10. Of the 216 participants, 22% complained of back pain, which was not associated with any of the demographic, impairment or functional limitation variables. 11. Overall, 69% complained of pain. 12. In addition to shoulder, back, elbow, and ankle, pain involved other areas including leg (19), neck

		(14), hip (12), wrist (1 0), knee (9), feet (8), hands (8), and miscellaneous sites (12). 13. Race/ethnicity was the only study variable that was significantly associated with pain, with pain more common in whites (p=0.016). 14. There was no significant difference in the prevalence of pain among those with violent injuries (71%) in comparison to those with nonviolent injuries (69%); however, pain was significantly more common in subjects with spasticity compared to those without spasticity (p=0.001).

Table 11. Case reports assessing nociceptive pain among children with SCI.

Author, Year Country Study Design Sample Size	Objective Statement
(Shiwlochan et al. 2020) USA Case Report N=1	**Population:** 12 yr, male, T1-2 AIS A SCI. **Intervention:** Ketamine infusion. **Outcome Measures:** Pain intensity.
(Armstrong et al. 1992) Canada Case Report N=2	**Population:** *Case I*: 13 yr, male, complete tetraplegia SCI, severe spasticity; *Case II:* 5 yr, female, C1 complete tetraplegia SCI, severe spasticity. **Intervention:** Intrathecal baclofen. **Outcome Measures:** Spasticity, pain, transfers, dressing, catheterizations, sleep, potential adverse effects.

Discussion

As is the case with SCI in adults, the prevalence of chronic pain appears to be high in those with SCI incurred in childhood. Among the three studies described above, prevalence of pain in various cohorts of youths with SCI ranged from 65 to 88%. In the observational study by Jan and Wilson (2004), the majority of participants with childhood-onset SCI reported nociceptive rather than neuropathic pain, though this was not specifically delineated in other studies. Therefore, it's unclear if that observation would apply broadly to the pediatric SCI population.

Factors influencing pain prevalence are difficult to conclusively identify. Jan and Wilson (2004) reported that pain prevalence did not vary significantly with age at time of injury, level of injury, or completeness of injury, though patient numbers were small. The one notable exception to this was for visceral pain, which was reported exclusively by individuals with complete injuries. Vogel et al. (2002c) noted that pain in some body regions (shoulder and elbow in particular) was reported more frequently in those with longer duration of injury, while others (ankle and back pain) were not. They also noted that pain overall was more common in Caucasians and those with concomitant spasticity.

Reports of pain interference are somewhat conflicting. Defresne et al. (2003) found that 70% of participants with transverse myelitis who reported pain also described pain interfering with their daily activities. Jan and Wilson (2004), on the other hand, noted that very few patients with pain identified limitations in daily activities or play. Notably, the data presented is limited by small sample sizes and incomplete information regarding SCI characteristics.

There has been no published systematic research regarding specific rehabilitative, pharmacologic, or interventional approaches to pain management for pediatric patients with SCI, representing a significant opportunity for future directions. There is a single case report (Shiwlochan et al. 2020) demonstrating improvement in acute allodynic pain in the immediate post-injury and post-operative stages with ketamine infusion, but the applicability of this information to the overall pediatric SCI population is minimal without further study.

Key Points

Both nociceptive and neuropathic pain are common consequences of pediatric SCI.

There is inadequate evidence to guide pain management for patients with pediatric SCI, resulting in providers relying on available data regarding pain management in children without SCI.

4.2 Musculoskeletal Function

4.2.1 Spasticity

Spasticity is one of the most common secondary health conditions associated with SCI, especially when the level of injury is above the region of the conus medullaris/cauda equina. Spasticity can be a disabling condition, but with appropriate treatment and rehabilitation, its negative impact on patients' quality of life can be significantly mitigated. There are several different definitions of spasticity, which can shed light on clinical diagnosis and evaluation. The most widely used definition in recent years is that spasticity is "disordered sensorimotor control, resulting from an upper motor neuron lesion, presenting as intermittent or sustained involuntary activation of muscles" (Pandyan et al. 2005). Literature on epidemiology, impact, measurement and treatment of spasticity in the pediatric-onset SCI population will be reviewed.

Table 12. Studies assessing spasticity among children with SCI

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Johnston, Smith, et al. 2008b) USA Case Series* N=4 *Subjects were a subset from a larger RCT by (Johnston, Smith, et al. 2009)	Population: *Case 1:* 7 yr, female, T4-T6, ASIA A SCI at 2 yr of age; *Case 2:* 9 yr, female, C7, ASIA A SCI at 4 yr of age; *Case 3:* 7 yr, male, T3, ASIA A SCI at 3 yr of age; *Case 4:* 11 yr, male, C7, ASIA A SCI at 3 yr of age. Intervention: *Intervention Group:* Functional Electrical Stimulation while cycling at 50 rpm while seated in wheelchair (pulse duration (150 ls) and frequency (33 Hz) were fixed; current amplitude (max 140 mA) increased automatically to generate sufficient force to maintain the cadence). *Control Group:* Passive cycling at 50 rpm. Sessions were conducted for 1 hr, 3 times/week for 6 mo. Outcome Measures: Bone mineral density (BMD) of the left femoral neck, distal femur, and proximal tibia; left quadriceps muscle volume, electrically stimulated strength of the left quadriceps, quadriceps and hamstrings muscles Ashworth scale scores; fasting lipid, profile via high density lipoprotein (HDL) and low-density lipoprotein (LDL); heart rate (HR); and oxygen consumption (VO_2/kg).	*Case 1: FES Cycling* 1. Improvements in BMD at the femoral neck, distal femur, and proximal tibia; quadriceps muscle volume; stimulated strength of the quadriceps muscles; HDL cholesterol; resting HR; peak VO_2/kg; and peak HR; however, cholesterol, LDL, and triglyceride levels and the cholesterol/HDL ratio increased compared to baseline. 2. No changes in Ashworth scores, but parents reported decreased spasticity and looser muscles. *Case 2: FES Cycling* 3. Improvements in BMD at the femoral neck, distal femur, and proximal tibia; quadriceps muscle volume; stimulated quadriceps muscle strength; and hamstring muscle spasticity; however, cholesterol, LDL, HDL, and triglyceride levels and the cholesterol/HDL ratio worsened as compared to baseline. 4. The parents reported bigger, firmer muscles; decreased bowel program completion times; increased appetite; and increased spasticity that did not require medical intervention. *Case 3: Passive Cycling* 5. Improvements in femoral neck BMD, hamstring spasticity, and triglyceride levels. 6. Distal femur and proximal tibia BMD and stimulated quadriceps strength were lower as compared to baseline, and LDL levels and the cholesterol/HDL ratio were elevated. 7. Parents reported decreased bowel accidents and new sensation in his knees and stomach. *Case 4: Passive Cycling* 8. Improvements in BMD at the femoral neck, distal femur, and proximal tibia;

		quadriceps muscle volume; stimulated quadriceps strength; hamstring spasticity; cholesterol; LDL cholesterol; resting HR; and peak VO_2/kg. 9. HDL cholesterol decreased as compared to baseline but the cholesterol/HDL ratio was unchanged. 10. Parents reported decreased spasticity, looser muscles, increased energy, decreased lower extremity swelling, and increased appetite.
(Pierce et al. 2008b) USA Observational N=27 (N=18 SCI)	**Population:** *SCI:* Age: 9.3±2.7 (5-13) yr; Gender: males=11, females=7; Time since injury: 5.3 yr; Severity of injury: AIS A=15, AIS B=3. *Typical Development (TD; n=9):* Age: 10.0±1.6 (7-12) yr; Gender=males=7, females=3. **Intervention:** None. Measurements. **Outcome Measures:** Ashworth Scale (AS), Spasm Frequency Scale (SFS), knee flexion and knee extension velocity and peak passive torque.	1. There were no significant differences in peak passive torque in any muscle group at any movement velocity between children with SCI and TD. 2. For both the children with SCI and children of TD, velocity dependent increases in peak passive torque were found for the knee flexors ($p<0.001$) and knee extensors ($p<0.001$) at 15, 90, and 180 deg/s. 3. Children with TD demonstrated significantly more reflex activity of the medial hamstrings during the assessment of knee flexor spasticity at all movement velocities than did children with SCI ($p<0.05$). 4. There were no significant differences in vastus lateralis reflex activity between groups at any movement velocity during the assessment of knee flexor spasticity; however, children with TD demonstrated significantly more reflex activity of the medial hamstrings during the assessment of knee extensor spasticity with movements at 15 deg/s and 180 deg/s and significantly more reflex activity of the vastus lateralis during the assessment of knee extensor spasticity with movements at 180 deg/s ($p<0.05$). 5. For AS of the knee flexors, 8 children were scored as 0, 8 children were scored as 1, 1 child was scored as 2, and 1 child was scored as 3. 6. For AS of the knee extensors, 12 children were scored as 0, and 6 children were scored as 1. 7. For the SFS, 4 children were scored as 1, 10 children were scored as 2, and 4 children were scored as 3. 8. No significant relationships were found between the quantitative measurements of spasticity (peak passive torque at 15, 90,

		and 180 deg/s) and the clinical measurements (AS and SFS) for either muscle group with the exception of a significant relationship found between the SFS and peak passive torque of both the knee flexors and knee extensors with movements at 90 deg/s (p<0.05). 9. During the assessment of knee flexor spasticity, positive correlations were found between comparisons of peak passive torque at 15 to 90 deg/s and 90 to 180 deg/s (p<0.05). 10. During the assessment of knee extensor spasticity, positive correlations were found between measurements of peak passive torque at all movement velocities (p<0.05). 11. There were no significant correlations between AS and SFS during the assessment of knee flexor and knee extensor spasticity.
(Vogel et al. 2002b) Part II USA Observational N=216	**Population:** Age at injury: 14.1±4.0 yr; Age at interview: 28.6±3.4 yr; Gender: males=150, females=66; Time since injury: 14.2±4.6 yr; Level of injury: tetraplegia=123, paraplegia=93. Severity of injury: C1-4 ABC=41, C5-8 ABC=67, T1-S5 ABC=82, tetra/para D=26. **Intervention:** None. Survey. **Outcome Measures:** Prevalence of spasticity.	1. Among the 216 subjects, 123 reported having spasticity requiring treatment. 2. Spasticity was significantly associated with older age at injury (p=0.017), sports-related SCI (p=0.041), tetraplegia (p<0.001), lower ASIA Motor scores (p<0.001), and lower total FIM (p<0.001) and motor FIM scores (p<0.001).

Table 13. Case reports assessing spasticity among children with SCI.

Author, Year Country Study Design Sample Size	Objective Statement
(Reynolds et al. 2014) USA Case Report N=3	**Population:** *Case I*: 9 yr, female, T2 AIS A SCI; *Case II:* 11 yr, female, high lumbar SCI; *Case III:* 13 yr, male, C2 tetraplegia SCI. **Intervention:** Selective dorsal rhizotomy. **Outcome Measures:** Spasticity.
(Armstrong et al. 1992) Canada Case Report N=2	**Population:** *Case I*: 13 yr, male, complete tetraplegia SCI, severe spasticity; *Case II:* 5 yr, female, C1 complete tetraplegia SCI, severe spasticity. **Intervention:** Intrathecal baclofen. **Outcome Measures:** Spasticity, pain, transfers, dressing, catheterizations, sleep, potential adverse effects.

Discussion

Very few publications relating to pediatric SCI and spasticity were found.

In their study examining the prevalence of musculoskeletal and neurological complications of adults with pediatric-onset SCI, Vogel et al. (2002c) found that of the 216 patients who had been enrolled in the SCI programs of the Shriners Hospitals for Children, 57% had spasticity requiring medication; this rate is slightly lower than the prevalence of spasticity among adults who acquired SCI later in life (68%) (Levi et al. 1995). Vogel and colleagues (2002c) also observed that spasticity was associated with tetraplegia, lower American Spinal Injury Association motor scores, and lower total and motor Functional Independence Measure scores. It should be noted that based on these findings, conclusions cannot be drawn regarding whether spasticity has a direct impact on activities of daily living and/or participation.

In terms of the measurement and evaluation of spasticity in the pediatric SCI population, in most papers, only constructs of body structure/function were assessed (spasms, via the Spasm Score and Spasm Frequency Scale, and muscle tone via the Ashworth scale/Modified Ashworth scale) (Armstrong, 1992; Johnston, Smith, et al. 2008b; Reynolds et al. 2014; Vogel et al. 2002c). One study used Functional Independence Measure (Vogel et al. 2002c), but not specifically to evaluate the impact of spasticity. Pierce et al. (2008a) evaluated passive torque as a discriminator for spasticity with an isokinetic dynamometer using different speeds from 5 deg/s to 180 deg/s. They compared 18 children with chronic SCI with 10 healthy children (Typical Development) but could not find any significant difference between the groups or correlation between passive torque and the clinical scales of Ashworth scale and Spasm Frequency Scale.

The literature search did not yield any controlled studies on spasticity treatment for patients with pediatric-onset SCI. Nevertheless, three case studies on this topic were found. The first study by Armstrong et al (1992) reported the use of intrathecal baclofen in two children with severe spasms stemming from SCI who were ventilator-dependent, and suggested that baclofen significantly reduced spasms. In another study, Reynolds et al (2014) examined three children with SCI who underwent selective dorsal rhizotomy for their lower limb spasticity. Two of the children had good long-term relief in spasticity with decreased muscle tone and improved mobility. The third child had short-term reduction in spasticity but with full return of the problem after six months; he then received treatment with intrathecal baclofen with full resolution of the problematic spasticity. Lastly, Johnston and colleagues' (2008a) work compared the effects of stationary cycling in home environment, either as FES or passive cycling, in four children with SCI. The participants cycled for 1 hour, 3 times per week, for 6 months. The findings revealed several positive health outcomes following the intervention, including improved bone mineral density (BMD), muscle volume, stimulated quadriceps strength, and lower resting heart rate; but no consistent change in spasticity was found.

To date, no studies have examined the development of spasticity in different age-groups and over time and how it could interfere with musculoskeletal development. This represents a major gap in the literature and should be addressed in future research. In addition, no studies were found on the impact of spasticity on health-related quality of life. Spasticity has been shown to decrease health-related quality of life in adults with SCI (Adriaansen et al. 2016; Westerkam et al. 2011), but further research should validate whether this finding can be generalized to the pediatric SCI population. Systematic, controlled studies need to be conducted to inform clinical practice, guideline development, and the most optimal method for treating spasticity in this population. Until then, clinicians must rely on clinical experience as well as scientific evidence from spasticity treatment of other aetiologies in children and the adult SCI population to drive assessment and treatment.

Key Points

Spasticity may be associated with tetraplegia, lower American Spinal Injury Association motor scores, and lower total and motor Functional Independence Measure scores in individuals with pediatric-onset SCI.

Measures of spasms (Spasm Score and Spasm Frequency Scale) and muscle tone (Ashworth scale/Modified Ashworth scale) are commonly used to evaluate spasticity in the pediatric SCI population.

Intrathecal baclofen and selective dorsal rhizotomy may be effective in managing spasticity in children with SCI.

Systematic, controlled studies are needed to drive clinical practice, guideline development, and the most optimal method for treating spasticity in the pediatric SCI population.

4.2.2 Bone Composition and Complications (Osteoporosis, Heterotopic Ossification, Hypercalcemia)

The skeleton develops during the first two decades of life. During this period, there is objective accrual of both bone mineral content (BMC) and BMD, with a fairly steady pace through childhood, pace that is markedly accelerated during adolescence, with close to 40% of total body bone mineral accrual occurring within 2 years of the adolescent growth spurt (Baxter-Jones et al. 2011). Bone health is insured by bone remodeling, which consists of the continuous, balanced removal/deposition of small portions of bone performed by osteoclasts and osteoblasts; this process is under endocrine, paracrine, neural and mechanical factors regulation (Siddiqui & Partridge, 2016). In the case of pediatric SCD related paralysis, in addition to abnormal bone development, all 4 regulatory mechanisms are affected through immobility/lack of weight loading, autonomic nervous system dysfunction (especially in mid thoracic and higher injuries), endocrine dysfunction triggered by exodus of calcium from the bones and paracrine abnormalities related to disrupted cytokines and growth factors secretion. Bone mineral loss has been documented as early as 6 weeks post SCI onset (Warden et al. 2002), with the greatest loss occurring within the first 2 years (Mohr et al. 1997). Few interventions have been shown to stave off or improve bone loss post SCI, with FES ergometry being one of the researched ones in pediatric SCI.

Table 14. Studies assessing bone composition and complications among children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
Bone Composition and Osteoporosis		
(Zebracki et al. 2013b) USA Observational N=279	**Population:** Age: 14.9±4.9 yr; Gender: males=46, females=36; Time since injury: 4.3±3.3 yr; Level of injury: paraplegia=50, tetraplegia=32; Severity of injury: AIS A=34. **Intervention:** None. Chart review. **Outcome Measures:** Serum 25(OH) D level.	1. Serum 25(OH) D levels ranged from 4.1 to 89.4 ng/ml with a mean of 24.7ng/ml (SD=13.1). 2. Most of the youth demonstrated vitamin D deficiency (39%) or insufficiency (40%), whereas only 21% had sufficient levels of vitamin D. 3. There was no difference in vitamin D status as a function of gender or injury level. 4. Vitamin D status differed by age groups ($p<0.05$); although the percent sufficient was similar for the two age groups, the percent deficient relative to the percent insufficient was greater in the "13-21 yr" age group.
(Biggin et al. 2013) Australia Observational N=19	**Population:** Age: 6.6±4.1 yr; Gender: males=10, females=9; Injury etiology: traumatic=10, non-traumatic=9; Time since injury: 5.6±3.6 yr; Level of injury: C3-4=5, C5-7=5, T1-6=6, T7-12=3; Severity of injury: complete tetraplegia=5, incomplete tetraplegia=5, complete paraplegia=6, incomplete paraplegia=3. **Intervention:** None. Chart review. **Outcome Measures:** Using Peripheral Quantitative Computer Tomography (pQCT) the following measurements were made: volumetric Bone Mineral Density (vBMD, mg/cm^3), total and Cortical Cross-sectional Area (CSA, mm^2), Muscle CSA (mm^2), total and cortical Bone Mineral Content (BMC, mg/mm) and polar SSI (pSSI, mm^3)	1. There was no statistical difference in the radial data from those with paraplegia compared to able-body control data. 2. In the radius of subjects with tetraplegia, there was a significant reduction in BMC at both the metaphysis and diaphysis ($p<0.05$ for both), trabecular vBMD was significantly reduced, and cortical vBMD was indistinguishable from able-bodied controls; total CSA at the radial metaphyseal site and diaphyseal sites was reduced ($p<0.05$ for both). 3. In the tibia, there was no statistical difference between those with paraplegia versus tetraplegia so data were pooled. 4. vBMD of the metaphysis showed significant reduction ($p<0.05$). 5. In the tibial diaphysis, the bone cortex was thinner with decreased bone mineral as reflected by a reduction in CSA and cortical thickness. 6. Despite the thinner cortex, vBMD of the tibial diaphysis was preserved. 7. The PSSI (surrogate measure of bone strength) was significantly reduced. 8. There was a significant loss of muscle CSA in the calves of all patients; however, when examining the cortical BMC for muscle CSA,

		there was a significant increase compared to able-bodied controls. 9. Patients who were able to load bear (even if only in a standing frame) had significantly greater tibial trabecular vBMD, cortical CSA and improved muscle CSA than those who could not ($p<0.05$). 10. There was no association between pQCT parameters and the occurrence of fractures. 11. Fractures were femoral or tibial in six out of seven patients (86%); lower limb fractures did not occur if tibial trabecular vBMD was greater than 100 mg/cm3. 12. There was no correlation between the occurrence of fractures and load-bearing status. 13. There was a reduction in trabecular vBMD between 7.6 yr and 10.7 yr post SCI ($p<0.01$), while cortical vBMD did not change. 14. There was no statistically significant change in BMC, cortical thickness or pSSI Z-scores. 15. Following SCI, there was a statistically significant reduction in circularity Z-score ($p<0.001$) which resulted in a change from the typically teardrop appearance of the tibia to a more circular shape. 16. Circularity Z-scores did not change over time in those individuals with serial pQCT scans and was not associated with fracture risk; those who were not mobile had significantly lower circularity Z-scores compared to those who were mobile but there was no difference between those who could load bear (i.e., stand in a standing frame) compared to those who could not.
(Castello et al. 2012) USA Pre-Post N=6	Population: Age: 16.6±4.4 yr; Gender: males=3, females=3; Time since injury: 3.9±3.1 yr; Level of injury: Cervical=4, Thoracic=2; Severity of injury: AIS A=3, AIS B=1, AIS C=1, AIS D=1. Intervention: Functional Electrical Stimulation (FES) cycling. Stimulators were placed on hamstrings, quadriceps and gluteal muscles (45-50 rpm, 250 µs, 33.3 Hz, 70-120 mA). Sessions were 30 min, 3 times/wk over 9 mo.	1. A positive, non-significant, relationship was found between change in BMD and the total number of FES biking sessions from their first to last DXA scan ($r_s=0.77$). 2. A positive, non-significant, relationship was found between the change in BMD and the number of months using the FES cycle from their first to last DXA scan ($r_s= 0.77$). 3. A weakly positive, non-significant, relationship was found between the change in BMD and the average number of biking sessions per month ($r_s=0.60$), as well as between the change in BMD and the time from injury at the initial evaluation ($r_s=0.49$).

	Outcome Measures: Bone mineral density (BMD) measured using Dual X-ray Absorptiometry (DXA) scans.	
(Lauer et al. 2011) USA RCT N=28 PEDro=6	**Population:** Age: 9.6±2.4 (5-12) yr; Gender: males=17, females=11; Time since injury: 5.1±2.9 yr; Level of injury: cervical=9, thoracic=19; Severity of injury: AIS A=20, AIS B=5, AIS C=3. **Intervention:** Subjects were randomized to one of three groups: 1) *Functional Electrical Stimulation while Cycling* (FESC): 50 rpm while seated in wheelchair (pulse duration (150 ls) and frequency (33 Hz) were fixed; current amplitude (max 140 mA) increased automatically to generate sufficient force to maintain the cadence); 2) *Passive Cycling (PC)*: Passive cycling at 50 rpm; or 3) *Electrical Stimulation (ES):* contraction of bilateral hamstrings, quadriceps, and gluteal muscles, 20 min each, 33 Hz, 300us, and 100mA. Sessions were conducted for 1 hour, 3 times/wk for 6 mo. **Outcome Measures:** Hip, distal femur, and proximal tibia Bone Mineral Density (BMD).	1. Following the interventions, there were no significant increases in BMD between or within any of the groups. 2. The FESC group exhibited non-significant increases in hip, distal femur and proximal tibia BMD. 3. The PC group exhibited a non-significant increase in hip BMD but not distal femur or proximal tibia. 4. The ES group exhibited no change in hip and distal femur BMD, but a non-significant loss at the proximal tibia. 5. There were no hip BMD differences between groups with respect to time post SCI.
(Liu et al. 2008) Australia Observational N=18	**Population:** Median age: 5.3 (0.5-15.6) yr; Gender: males=9, females=9; Time since injury: 5.0±3.6 yr; Level of injury: Cervical=6, Thoracic=12; Severity of injury: complete paraplegia=13, incomplete paraplegia=1, complete tetraplegia=2, incomplete tetraplegia=2. **Intervention:** Functional Electrical Stimulation (FES) cycling. Stimulators were placed on hamstrings, quadriceps and gluteal muscles (45-50 rpm, 250 μs, 33.3 Hz, 70-120 mA). Sessions were 30 min, 3 times/wk over 9 mo.	*Total Group Data Combined, Cross-Sectionally* 1. The 10 children with a complete motor lesion had significantly lower Legs BMC, FN and Legs BMD Z-scores at baseline; with the exception of the Arms and FN, Z-scores decreased during the 1st year, and in the 2nd year Z-scores remained low but did not decrease further. 2. Children with incomplete motor lesions showed age-appropriate scans. 3. BMD Z-scores were significantly less than zero in the Legs (p<0.001), total body (p=0.02), L2-L4 (p=0.04), and the FN (p<0.001), but not in the Arms. 4. BMC Z-scores of the total body (p=0.002) and Legs (p<0.001) were also less than zero.

	Outcome Measures: Bone mineral density (BMD) and Bone Mineral Content (BMC) of the total body, lumbar vertebrae, and femoral neck (FN), Lean Tissue Mass (LTM).	5. With increasing time post-injury, there was a decrease in total body BMD (p=0.02) and BMC Z-scores (p=0.04). 6. The three ambulant children had normal Legs BMD and BMC; when they were excluded the time-related decrease in either Legs BMD or BMC became non-significant (p=0.08) and LTM Z-score was reduced in the Legs (p<0.001) and remained stable with time. 7. Ambulant children had higher Legs LTM Z-scores; in contrast, Arms BMD and LTM Z-scores were normal and increased with time (p=0.003 and p=0.01, respectively). 8. L2–L4 BMD Z-scores were stable with time (p>0.05). 9. There were no changes seen in body fat (% and Z-scores). *Immediate group (scans <2 yr post SCI; n=13)* 10. Only Legs BMD, Legs BMC and FN Z-scores were significantly less than zero at baseline. 11. In the first year post-SCI, BMD and BMC Z-scores of the total body fell significantly and trended towards lower values in the Legs - (p=0.07; bone mass did not increase at the expected rate); there was no reduction in BMD Z-scores in the arms. 12. In the second year, there were no significant changes in BMD or BMC Z-scores for any region, suggesting an age-appropriate accrual of bone mass. 13. Legs LTM Z-score and total body BMC/LTM Z-score decreased significantly in the first year post-SCI but not during the 2nd year of follow-up; in contrast, Arms LTM Z-score increased over the 2-yr period. *Long-term group (scans >2 yr post SCI; n=5)* 14. At the first scan they had similar BMD and BMC Z-scores to the 2-yr results of the *Immediate* group (p>0.05); there was no significant change in Z-scores over the following 2 yr (age-appropriate accrual of bone mass). 15. All children had age-appropriate increases LTM in all regions.
	Population: *Case 1:* 7 yr, female, T4-T6, ASIA A SCI at 2 yr of age; *Case 2:* 9 yr, female, C7, ASIA A	*Case 1: FES Cycling*

(Johnston, Smith, et al. 2008b) USA Case Series* N=4 *Subjects were a subset from a larger RCT by (Johnston, Smith, et al. 2009)	SCI at 4 yr of age; *Case 3:* 7 yr, male, T3, ASIA A SCI at 3 yr of age; *Case 4:* 11 yr, male, C7, ASIA A SCI at 3 yr of age. Intervention: *Intervention Group:* Functional Electrical Stimulation while cycling at 50 rpm while seated in wheelchair (pulse duration (150 ls) and frequency (33 Hz) were fixed; current amplitude (max 140 mA) increased automatically to generate sufficient force to maintain the cadence). *Control Group:* Passive cycling at 50 rpm. Sessions were conducted for 1 hr, 3 times/wk for 6 mo. Outcome Measures: Bone mineral density (BMD) of the left femoral neck, distal femur, and proximal tibia; left quadriceps muscle volume; electrically stimulated strength of the left quadriceps; quadriceps and hamstrings muscles Ashworth scale scores; fasting lipid profile via high density lipoprotein (HDL) and low-density lipoprotein (LDL); heart rate (HR); and oxygen consumption (VO_2/kg).	1. Improvements in BMD at the femoral neck, distal femur, and proximal tibia; quadriceps muscle volume; stimulated strength of the quadriceps muscles; HDL cholesterol; resting HR; peak VO_2/kg; and peak HR; however, cholesterol, LDL, and triglyceride levels and the cholesterol/HDL ratio increased compared to baseline. 2. No changes in Ashworth scores, but parents reported decreased spasticity and looser muscles. *Case 2: FES Cycling* 3. Improvements in BMD at the femoral neck, distal femur, and proximal tibia; quadriceps muscle volume; stimulated quadriceps muscle strength; and hamstring muscle spasticity; however, cholesterol, LDL, HDL, and triglyceride levels and the cholesterol/HDL ratio worsened as compared to baseline. 4. The parents reported bigger, firmer muscles; decreased bowel program completion times; increased appetite; and increased spasticity that did not require medical intervention. *Case 3: Passive Cycling* 5. Improvements in femoral neck BMD, hamstring spasticity, and triglyceride levels. 6. Distal femur and proximal tibia BMD and stimulated quadriceps strength were lower as compared to baseline, and LDL levels and the cholesterol/HDL ratio were elevated. 11. Parents reported decreased bowel accidents and new sensation in his knees and stomach. *Case 4: Passive Cycling* 12. Improvements in BMD at the femoral neck, distal femur, and proximal tibia; quadriceps muscle volume; stimulated quadriceps strength; hamstring spasticity; cholesterol; LDL cholesterol; resting HR; and peak VO_2/kg. 13. HDL cholesterol decreased as compared to baseline but the cholesterol/HDL ratio was unchanged.

		14. Parents reported decreased spasticity, looser muscles, increased energy, decreased lower extremity swelling, and increased appetite.
(Lauer et al. 2007) USA Observational N=28	Population: Age: 9.6±2.5 yr; Gender: males=17, females=11; Time since injury: 4.5±2.9 yr; Level of injury: Cervical=8, Thoracic=20; Severity of injury: AIS A=25, AIS B=3. Intervention: None. Outcome Measures: Bone mineral density (BMD) of the left hip, distal femur, and proximal tibia.	1. For the group as a whole, BMD values at the hip were 0.48±0.17 g/cm^2, 0.41±0.17 g/cm^2, and 0.47±0.17 g/cm^2 for femoral neck, greater trochanter, and Ward's triangle, respectively. 2. Total hip BMD was 0.48±0.17 g/cm^2. 3. At the knee, BMD values were 0.38±0.10 and 0.37±0.07 g/cm^2 for the distal femur and proximal tibia, respectively. 4. In the regions where the Z-scores could be calculated, overall BMDs were 64.4%, 64.2%, and 57.8% of age- and sex-matched normative values for the femoral neck, greater trochanter, and Ward's triangle, respectively. **Given the large variations and small sample size, no statistical tests were performed.
(Kannisto et al. 1998) Finland Observational N=35	Population: *Pediatric-onset SCI:* Median age at interview: 31 (18-63) yr; Median age at injury: 12.9 (0-17.1) yr; Gender: males=25, females=10; Median time since injury: 19 (1.5-57) yr; Level of injury: complete paraplegia=24, incomplete paraplegia=3, complete tetraplegia=3, incomplete tetraplegia=5. Intervention: None. Densitometry and laboratory assays. Outcome Measures: Bone Mineral Density (BMD) of lumbar spine, proximal femur and regional sites (femoral neck, trochanteric area, intertrochanteric area, Ward's triangle), presence of osteoporosis (decrease of more than 2.5 SD compared to peak bone density reference data), urinary calcium, phosphate and creatinine, Alkaline Phosphatase (AP), Bone isoenzyme (BAP), Osteocalcin (OC) assay, urinary Hydroxyproline (HYP) and deoxypyridinoline (DPD).	1. BMD levels were within the normal range in the lumbar spine; mean BMD at the lumbar spine was 1.08±0.17 g/cm^2 which represents 99.5% of the age and sex adjusted mean (Z-score) and 70.04 SD of peak bone mass measured in 30-yr old persons of the same gender as the patients (T- score). 2. At the hips, accurate subtraction between bone and soft tissues with the densitometer failed in seven out of the 34 patients. 3. BMD at the proximal femur was on an average 0.72±0.23 g/cm^2 which is 72.05 SD of the age and gender adjusted mean value (Z-score); mean T-score was 72.61 which represents established osteoporosis. 4. BMD in the femoral neck was 0.69±0.19 g/cm^2. 5. BMD in Ward's triangle was 0.60±0.24 g/cm^2. 6. Lowest measurements were at the intertrochanteric level where mean BMD was 0.52 g/cm^2. 7. At the lumbar spine 10/29 of the patients had a T-score which was under 71 SD and 3/29 of the patients had T-scores less than 72 SD; none of the patients had a T-score less than 72.5 SD at the lumbar spine. 8. At the femoral neck 21/27 of the patients had T-scores under 71 SD, 19/27 had T-

		scores less than 72 SD and 16/27 had a T-score less than 72.5 SD. 9. The dissociation between axial and peripheral BMD (lumbar spine versus total femoral area) was significant (p<0.001). 10. Though statistically significant (p=0.04), there was no clinical difference in BMD between those with tetraplegia or paraplegia at the lumbar level. 11. There was no statistically significant difference in hip BMD between those with paraplegia versus tetraplegia. 12. In comparing individuals with lesions at C1±T6 to those with lesions ≤T7, there were significant differences in BMD at lumbar (p=0.004) and hip (p<0.01) with those sustaining higher injuries having lower BMD. 13. Regression showed BMD of the proximal femur (b=0.49, p<0.01) and the femoral neck (b=0.57, p<0.01) was correlated with bodyweight but not body height, age at the time of injury, age at the time of examination or to the time elapsed since injury. 14. Biochemical markers of bone metabolism showed no signs of still ongoing accelerated bone formation or resorption.
(Moynahan, Betz, et al. 1996) USA Observational N=51	Population: Age: 14.5±4.2 (3-20) yr; Gender: males=30, females=21; Level of injury: cervical=19, thoracic/lumbar=32. Intervention: None. Densitometry and laboratory assays. Outcome Measures: Bone Mineral Density (BMD) of femoral neck, Ward's triangle and intertrochanteric region of the hip, presence of spasticity, number of pathological fractures.	1. Baseline measurements at the femoral neck, Ward's Triangle and intertrochanteric region were normalized by sex and age and then averaged; there was a trend toward lower BMD at the hip in SCI subjects as compared with their non-disabled peers: femoral neck=64.2±17.6%, Ward's Triangle=64.4±17.6% and intertrochanteric region=55.9±16.0%. 2. In total, 10 subjects had one or more pathological fractures of the leg. 3. Normalized BMD were compared to non-fracture SCI subjects and there was a trend toward lower BMD in subjects with fractures (p<0.05); the upper limit of the fracture group (the value above which no subject showed a fracture) was 87 percent for the femoral neck, 90 percent for Ward's Triangle and 65 percent for the intertrochanteric region. 4. At only the intertrochanteric region, those with tetraplegia had lower BMD than those with paraplegia (p<0.05). 5. In total, 46 subjects had spastic legs and 5 subjects had flaccid legs.

		6. Subjects with spasticity generally showed higher bone densities than those without spasticity at the femoral neck and Ward's triangle (p<0.05 for both) but not the intertrochanteric region (analysis lacked statistical power).
Heterotopic Ossification		
(Vogel et al. 2002b) *Part II* USA Observational N=216	**Population:** Age at injury: 14.1±4.0 yr; Age at interview: 28.6±3.4 yr; Gender: males=150, females=66; Time since injury: 14.2±4.6 yr; Level of injury: tetraplegia=123, paraplegia=93. Severity of injury: C1-4 ABC=41, C5-8 ABC=67, T1-S5 ABC=82, tetra/para D=26. **Intervention:** None. Survey. **Outcome Measures:** Prevalence of heterotopic ossification.	1. Heterotopic ossification was reported by only 24 subjects. Heterotopic ossification was more common in those with more severe injuries (C1-4 A-B-C) (23%), compared to the other injury severity groups (9%) (p=0.013).
(Garland et al. 1989) USA Observational N=152	**Population:** Heterotopic Ossification Group: Age: 8.5 yr (3 mo-15 yr); Gender: males=12, females=3; Injury etiology: trauma=11, vascular compromise=2, infection=1, progressive kyphosis=1. Level and severity of injury: thoracic complete=13, cervical incomplete=2. **Intervention:** None. Chart Review. **Outcome Measures:** Heterotopic Ossification (HO) incidence location, signs and symptoms, incidence of pressure ulcers, hip dislocations, alkaline phosphatase levels, surgical treatment.	1. Among 152 individuals, 15 developed HO (9.9%). 2. There were 19 different HO locations, most commonly the hip. 3. Three ossification patterns of the hip were identified: anterior, abductor muscle region, and inferomedial. 4. The femur was the only area of non-joint HO formation. 5. Two patients had HO at two joints and one patient had HO at three joints. 6. Average time from spinal insult to diagnosis of HO was 6 yr 5mo (2 mo-19 yr); considering only neurogenic HO, the average time was 14 mo (3-36 mo). 7. Most common sign of HO was a reduction in joint motion. 8. At the hip, 11 patients had pressure ulcers. 9. At the hip, 3 patients had dislocations, two of which had pressure ulcers as well. 10. When HO was detected, eight patients had alkaline phosphatase levels obtained of which they were elevated in five (3 primary, 2 secondary). 11. Three patients had resorption of HO of at least one grade. 7. Five patients were treated with surgery at the hip (mean 3.2 surgeries) for wound debridement, resection of HO, etc.
Hypercalcemia		
(Massagli & Cardenas, 1999)	**Population:** Age: 0-18 yr=3, 19-25 yr=4, 26-41 yr=2; Gender: males=7, females=2; Level of injury: C1-4=1,	1. Hypercalcemia onset occurred 3-16 weeks post injury with typical symptoms including nausea.

USA Case Series N=9	C5-7=6, T1-12=1; Severity of injury: AIS A=6, AIS B=1, AIS C=1, AIS D=1. **Intervention:** 60 mg pamidronate. **Outcome Measures:** Calcium levels.	2. Ionized calcium levels at the time of treatment ranged from 1.29 to 1.53 mmol/L and the corrected serum calcium was 12.7 mg/dL. 3. Original 60 mg pamidronate dose sufficiently treated seven of nine patients; the remaining two required additional doses. 4. One patient experienced transient drug-related fever. 5. For four patients, the serum or ionized calcium level decreased to the hypocalcemic range after treatment, but they were asymptomatic.

Table 15. Case reports on bone composition in children with SCI.

Author, Year Country Study Design	
(Ooi et al. 2012) Australia Case Report N=1	**Population:** 12 yr, male, transverse myelitis (at 8 yr), C3 tetraplegia. **Intervention:** Zoledronic acid (0.05 mg/kg/dose) for 6 mo. **Outcome Measures:** Calcium, phosphate, alkaline phosphatase, parathyroid hormone, 25-hydroxyvitamin D, osteocalcin, calcium/creatinine ratio, deoxypyridinoline/creatinine ratio, bone mineral content, bone mineral density

Discussion

Our search identified 9 papers that assessed BMC and BMD in the pediatric post SCI population and looked at the effect of FES on bone health in the context of SCD related paralysis. Moynahan et al. (1996) compared the BMD at 3 areas in the hip in children with SCI and age and sex matched able body controls and noted that there was a trend toward lower BMD at the hip in SCI subjects as compared with their non-disabled peers. 10/51 participants experienced fractures and there was a trend toward lower BMD in subjects with fractures. There was no significant hip BMD difference between individuals with tetraplegia and paraplegia (except at the intertrochanteric area) and children with lower limbs spasticity generally had higher bone densities than those without (femoral neck and Ward's triangle).

Biggin (2013) used Peripheral Quantitative Computer Tomography to evaluate the BMD and morphology of tibia and radius in 19 subjects (10 males and 9 females) with SCI (mean age at injury was 6.6, mean time to first Peripheral Quantitative Computer Tomography 5.6 years post-SCI). The analysis showed that, in children with tetraplegia, but not in those with paraplegia, trabecular bone density in the radius was decreased while the cortical one was similar with able body controls. In the tibia, the bone cortex was thinner with decreased bone mineral in both children with paraplegia and tetraplegia. Despite the thinner cortex, the BMD of the tibial diaphysis was preserved, but the polar stress–strain index, a surrogate measure of bone strength, was significantly reduced. In addition, individuals with SCI that were able to weight load (even if only in a standing frame) had significant better BMD and muscle mass than those who did not.

The mean tibial trabecular BMD in children who sustained fractures (7/19, 6 of them occurring in the lower limbs) was 57 +/- 34 mg/cm^3 compared with 120 +/- 72 mg/cm^3 in the group who did not sustain fractures and lower limb fractures did not occur if tibial trabecular BMD was greater than 100 mg/cm^3. 7/19children had serial Peripheral Quantitative Computer Tomography's that revealed a further reduction in trabecular BMD between 7.6 years -10.7 years post-SCI, while cortical BMD did not change.

Liu (2008) described BMD, BMC and lean tissue mass within 0.2-3.3 years median time post injury in 18 children (9 males), median age 5.3 with traumatic and non-traumatic SCI, C3 to T12 level (six cervical and 12 thoracic lesions),13 of them non-weight bearing paraplegia American Spinal Injury Association Impairment Scale (AIS) A, B, C and two non-weight bearing tetraplegia AIS A-C + one weight bearing individual with paraplegia and functional walking. They had multiple Dual X-ray Absorptiometry's over the ensuing <9.6 years post SCI which allowed for descriptive follow up of both clinical and Dual X-ray Absorptiometry measures. Three children (17%) sustained a minimal trauma fracture; all fractures were femoral and occurred within 18 months post SCI in non-ambulatory children. BMD, BMC and lean tissue mass fell significantly in the first year post SCI, more in non ambulatory children, as expected. In the second year, there were no significant changes in BMD, BMC for any region, suggesting an age-appropriate accrual of bone mass. Like in Kannisto's paper (Kannisto et al. 1998), no reduction in arm BMD was seen and, actually, an increase in arm BMD and lean tissue mass was noted over time.

Kannisto et al. (1998) looked at BMD assessed by Dual X-ray Absorptiometry (spine and proximal femur) of 35 adults with pediatric onset SCI (median age at injury was 12.9 years old and the median time period from the injury was 19 years). The researchers combined the Dual X-ray Absorptiometry data with measurement of blood and 24 urine testing of bone metabolic markers like urinary calcium, phosphate, alkaline phosphatase bone isoenzyme, osteocalcin, carboxyterminal propeptide of human type I procollagen and carboxyterminal telopeptide of type I collagen, urinary hydroxyproline and deoxypyridinoline. He found that lumbar spine BMD was similar to age and sex adjusted values from able body individuals, supporting the concept that bone deposition proceeds fairly normal in adolescents post SCI; the hip BMD values were around 2 standard deviations below compared with age and sex matched able body normal, which the authors attributed to lack of weight loading. Individuals with C1-T6 lesions had lower lumbar spine and hip BMD than those with levels T7 and below. BMD at the proximal femur and in the femoral neck (but not at the spine) correlated with body weight but not with body height, age at time of injury, age at examination nor with the time elapsed since injury. Measurement of bone metabolic markers did not show ongoing loss at the time of the evaluation.

Three papers examined the effects of FES/electrical stimulation (e-stim) on BMD/BMC in the lower limbs. In an observational study observational study conducted as part of a larger FES intervention study, Lauer (2007) assessed BMD of the hip, distal femur, and proximal tibiain in 28 children with chronic SCI. Higher BMD values were observed for individuals with lower injury levels (thoracic versus cervical) and injury duration less than 2 years; boys had higher BMD compared with girls. BMD at the hip in children with SCI were approximately 60% of the able body values. he Philadelphia Shriner's group conducted a prospective, randomized study on 28 children aged 5-13 with chronic SCI, to determine the effect of cycling and/or electrical stimulation on hip and knee BMD and muscle mass. Johnston (2008b) described the musculoskeletal effects of long term (6 months, 1 hr x 3 times/week) FES and passive cycling in 4 of the enrolled children (2 FES +2 passive): 3 of the 4 (2 undergoing FES and 1 passive cycling) were found to have improvements in BMD at the femoral neck, distal femur, and proximal tibia; quadriceps muscle volume was also found to be increased (as measured by magnetic resonance imaging); the 4th child (passive cycling) only had improvements in femoral neck BMD. In a more recent study, Lauer (2011) published the findings on all 28 children that completed the protocol (which also included an electrical stimulation non cycling arm) and concluded that there were no significant increases in BMD between or within the 3 groups; the FES group exhibited non-significant increases in hip, distal femur and proximal tibia BMD and the passive cycling group exhibited a non-significant increase in hip BMD, but no change at the distal femur or the proximal tibia; the non cycling e-stim group exhibited no change in hip and distal femur BMD, and a non-significant loss at the proximal tibia.

Castello (2012) reported on 6 children and adolescents (9.6-20.4 years old) with chronic traumatic and non traumatic SCI undergoing 15-69 FES sessions lasting 30 minutes over a 2-9-month period. Dual X-ray Absorptiometry scans assessing the BMD at R1 region of the right distal femur were obtained at baseline, after 3 and 6 months of intervention, and for the 2 participants who biked for the full duration of the study, at the completion of 9 months of intervention. Positive, but non-significant, relations were found between the change in BMD and the total number of FES biking sessions, the number of months using the FES cycle, the average number of biking sessions per month and the time from injury at the initial evaluation.

As a part of a larger chart review of the medical record of 279 children with SCI, Zebracki (2013b) looked at 82 children with SCI who had recorded levels of 25 heterotopic ossification (HO) vitamin D and found that majority of youth demonstrated vitamin D deficiency (39%) or insufficiency (40%), with only 21% having sufficient levels of vitamin D. Finally, Ooi et al (2012) reported metaphyseal and diaphyseal BMC and volumetric BMD increase (assessed by Dual X-ray Absorptiometry and Peripheral Quantitative Computer Tomography) in a 9- year-old child treated with 18 months of intravenous zolendronic acid following femoral fracture occurring a little more than 1 year after transverse myelitis related paralysis onset. Because the case report involves a growing child and administration of oral prednisolone to minimize the acute phase reaction associated with zolendronic acid administration, it is unclear if a conclusion on the effects of the drug itself can be drawn.

Heterotopic ossification

Heterotopic ossification (HO) is a pathologic process that is characterized by deposition of extra-skeletal bone in soft tissues. The pathophysiology of bone deposition varies according to the trigger (trauma, burns, neurologic injury) and can involve an intramembranous or endochondral pathways (Meyers et al. 2019).

Pediatric and adult SCI related HO present notable differences. Garland et al. (1989) retrospectively evaluated the charts of 152 children with SCI admitted to one center between June 1976 and July 1984. The researchers divided the HO occurrences into neurogenic-only HO (occurring early after SCI, without associated complicating factors) and secondary HO, occurring in neurologically affected individuals but having an extra compromising factor (e.g., local pressure ulcers, hip dislocation, additional local trauma including surgery). Of the 152 individuals (aged 14.9 +/- 4.9 years old, average of 8.5 years post SCI) whose charts were reviewed, only 15 developed HO (9.9%), with 5/15 having neurogenic only HO (3.3 %); most of the times, the trigger for diagnosis was therapist detected limitation in range of motion, specifically flexion and extension of hip, although some of the HO was detected incidentally on IV pyelograms. The HO was detected in 19 different locations, with hip being the most common. Average time from SCI to HO onset was 6.5 years (2 months-19 years), with neurogenic-only HO having a shorter onset time (average 14 months; range 3-16 month). Alkaline phosphatase was measured in 8/15 patients at the time of HO diagnosis and was find high in 5 of the cases. Follow up x-rays at > 6 months post HO diagnosis were done 11/15 cases and showed some degree of resorption (decrease in exoskeletal bone mass size) in 3/11. Surgical interventions (in 5 cases) at the site of HO (described as debridement for pressure injuries and osteomyelitis and femoral head and neck resection) were followed by HO recurrence and need for more surgeries.

Vogel et al. (2002b) presented results from a survey administered to 216 adults with pediatric onset SCI aiming to quantify the prevalence of medical complications and found that HO was reported by only 24 subjects (11%), more common in those with more severe injuries (24% in those with C1-4, AIS A, B or C).

The last topic related to bone metabolism in pediatric SCI that needs to be noted is hypercalcemia of immobility, a condition more commonly occurring in the first 6 months post neurologic deficit onset in children, adolescents and young adults. Typically, immobilization triggers bone resorption and a dump of calcium into the blood stream; if calcium filtration by the kidneys if overwhelmed by the amount of calcium extracted from bones (a process accentuated in the case of ongoing skeletal growth), clinically relevant hypercalcemia occurs. Massagli and Cardenas (1999) retrospectively reported on 9 individuals (mean age =22 years, 7 males, 2 women) treated with Pamidronate for immobilization hypercalcemia in two centers between 1994-1998. Immobilization hypercalcemia was more common in higher and more severe injuries, nausea was the most common complaint, pamidronate (with or without associated hydration) was the initial treatment in 6/9 cases and a 60 mg dose was sufficient to alleviate the clinical symptoms and calcium level 6-15 days post administration in 7/9 patients. Because of the retrospective nature of the convenience case series, systematic conclusions about incidence and natural course of immobilization hypercalcemia cannot be drawn.

Key Points

Only a few studies have prospectively assessed the BMD and BMC changes following onset of SCD related neurologic deficit. Findings from those studies seem to confirm significant bone loss occurring shortly (first year or so) following injury at the sub-lesional level (as opposed to adults with SCI, where bone loss has been documented for ≥ 5 years post injury).

The bone loss in the pediatric population is ameliorated by weight bearing and possibly spasticity and FES usage. Age related bone accrual appears to resume after the first year post injury, but BMD and BMC post SCI does not achieve age and sex matched able body values. Bone and muscle mass appear to be closely correlated.

As for HO in pediatric onset SCI, it is rarer than in adults, is mainly diagnosed by clinical onset of range of motion limitation and should probably not undergo resection surgery. Like in the adult individuals with SCD related paralysis, it is more common in higher (cervical, upper thoracic) injuries. Presence of a focal trigger factor (pressure injuries, trauma, including iatrogenic) increases the risk of occurrence.

Hypercalcemia of immobility occurs early (up to 6 months) post injury mostly in children, adolescents and young adults and is clinically manifested with mainly GI abnormalities (nausea, vomiting, abdominal pain, etc.); intravenous pamidronate (with or without hydration) is effective in restoring calcium levels.

Bone metabolic changes post SCD related pediatric paralysis onset could benefit from prospective, multi-centered studies to better inform the field.

4.2.3 Orthopedic Complications

Orthopedic complications are common in children with neuromuscular dysfunction of any etiology, and pediatric SCI is no exception. Orthopedic complications of SCI may include scoliosis, hip dysplasia, contractures, and fractures.

Scoliosis refers to an abnormal spinal curvature involving both vertebral rotation about the long axis of the spine as well as curvature in the coronal plane. Scoliosis is diagnosed once the coronal curvature is at least ten degrees (Murphy et al. 2015). The implications of scoliosis vary dramatically based on the degree of abnormality, with some patients being completely asymptomatic, and others being significantly affected by abnormal positioning, unequal weight bearing in seated and even restrictive lung disease related to rotation of the thoracic cage.

Hip dysplasia refers to a condition in which the components of the hip joint (one or both of the proximal femur and/or acetabulum) become abnormally shaped such that the joint can more easily slide apart. The degree of joint displacement, as measured by the amount of the femoral head not covered by the acetabulum (migration percentage), determines whether the joint is described as subluxed (partially displaced) or dislocated (completely displaced) (Miller et al. 2017). Neuromuscular hip dysplasia is distinct from congenital hip dysplasia (also called developmental dysplasia of the hip) in that the hips of those with neuromuscular hip dysplasia were normal at birth but become dysplastic over time. The pathophysiology underlying this is not well understood, though abnormal muscle tone and strength and a lack of typical weightbearing through the joint likely all contribute to the development of hip dysplasia across pediatric neuromuscular disorders, including SCI.

Muscle and joint contractures (causing fixed limitations in range of motion) can occur for a number of different reasons. In pediatric SCI, contractures are most likely related to immobility and increased muscle tone (spasticity), causing shortening of muscles, tendons and peri-articular connective tissue. Fractures may be more likely to occur in this population due to reduced BMD below the level of the injury (discussed elsewhere in this review).

Table 16. Studies assessing orthopedic complications among children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Kulshrestha et al. 2020) United Kingdom Observational N=62	**Population:** Age at injury: 17 (13-17) yr; Gender: males=44, females=18; Injury etiology: traumatic=51, non-traumatic=11; Time since injury: 28 (22-33) yr. **Intervention:** None. Chart review. **Outcome Measures:** Incidence of scoliosis.	Scoliosis 1. At the time of discharge, 4/62 patients (6%) had developed scoliosis, increasing to 19/62 (30%) 10 yr post injury and 21/62 (34%) at the latest clinical assessment. 2. The Cobb angle could be determined for seven patients, giving a median value of 70° (21–72). 3. The overall incidence of scoliosis was smaller in the traumatic group (13/52; 25%) than in the neurological group (8/11; 72%). 4. Patients older at injury were less likely to have developed scoliosis at 10 yr (p<0.001). 5. Younger age did (p=0.001) but being non-traumatic did not (p=0.29) predict development of scoliosis.
(Mulcahey, Gaughan et al. 2013) USA Observational N=217	**Population:** Age at interview: 13.2 yr; Age at injury: 9.0 yr; Gender: males=127, females=90; Time since injury: 4.2 yr; Level of injury: tetraplegia=112, paraplegia=95; Severity of injury: complete=105, incomplete=96. **Intervention:** None. Chart review. **Outcome Measures:** International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI), Cobb angles as a measure of the prevalence of scoliosis, prevalence of spinal fusion.	Scoliosis 1. 78% (145/186) of subjects had >10° scoliosis, 47% (87/186) had >20° scoliosis, and 20% (37/186) had >45° scoliosis. 2. When grouped as an entire sample, age at injury (p=0.0001) and AIS classification (p=0.0095) were the only significant predictors of worse curve. 3. With the exclusion of subjects with AIS D, age at injury (p=0.0140) was the only significant predictor of worse curve. 4. Age at injury (p=0.007) was the only significant predictor of spinal fusion in the entire sample and remained as such with the exclusion of subjects with AIS D (p=0.009). 5. The risk of spinal fusion increased 11% for each year decrease in age at injury; this finding is consistent with or without inclusion of subjects with AIS D. 6. Sex, motor score, and neurological level were not predictors of worse curve or spinal fusion. 7. Of the subjects >14 yr old at the time of their evaluation and injured at <12 yr old (16/43), 13%

		required a spine fusion compared to 4% injured at >12 yr old (27/43). 8. Subjects injured at <12 yr old were 3.7 times more likely to require a spinal fusion than those injured at >12 yr old.
(Johnston, Betz, et al. 2009) USA RCT N=30 PEDro=2	**Population:** Age: 9.7±2.5 yr; Gender: females=13, males=17; Level of injury: C=11, T=19; Severity of injury: ASIA A=22, AIS B=5, AIS C=3. **Intervention:** Subjects were randomized to one of three groups: 1) Functional Electrical Stimulation (FES) cycling (50 rpm while seated in wheelchair, pulse duration=150 ls, frequency=33 Hz, amplitude max 140 mA, increased automatically to generate sufficient force to maintain the cadence); 2) passive leg cycling (50 rpm), or 3) non-cycling with 20 min daily surface stimulation to lower extremity muscles. Sessions were conducted for 1 hr/day, 3 days/wk for 6 mo. **Outcome Measures:** Hip subluxation as measured by migration index of the femoral head.	Hip Subluxation 1. No differences in migration indices were found between baseline and 6 months (p=0.667), indicating that the intervention had no effect on these values. 2. No differences were found between groups over time (p=0.891); however, differences were found between groups (p<0.001), with the passive cycling group having greater migration indices than the FES cycling group at any time (p<0.001).
(Sison-Williamson et al. 2007) USA Observational N=20	**Population:** Age: 10.9±3.0 yr; Gender: males=10, females=10; Level of injury: cervical=1, thoracic=17, lumbar=2; Severity of injury: AIS A=18, AIS C=2. **Intervention:** Subjects were positioned on a standard chair to decrease sitting and posture differences, introduced by variations in wheelchair designs. Subjects' hips, knees, and ankles were positioned at 90°. Reflective markers were placed on the C7, sternal notch, acromion joints, olecranon, ulnar and radial	Scoliosis 1. Without the TLSO, the average reaching volume was 112,836 cm^3. 2. With the TLSO, the average reaching volume was 80,711 cm^3, which represents a 28% decrease in volume of reach (p=0.0002). 3. The largest increase in volume of reach without the TLSO was 77.3%, while the smallest increase in volume was 4.9%. 4. 10 of 39 cases had less than a 10% change between the TLSO and non-TLSO conditions, while 6 cases had increases in volume greater than 50%. 5. There were 6 cases in which volumes were larger in the TLSO condition compared with the non-TLSO condition; the percent differences ranged from 5-28%.

	styloid, and hands. Three-dimensional upper extremity motion analysis using an 8-camera Motion Analysis System was used to capture the subjects' reaches. Outcome Measures: Workspace volume and reach with and without a thoracic lumbar sacral orthosis (TLSO).	6. The non-TLSO average ranges of reach in the anterior-posterior (AP), medial-lateral (ML), and vertical (V) directions were 80±26 cm, 118±24 cm, and 97±21 cm, respectively. 7. The TLSO average ranges of reach in AP, ML, and V directions were 72±19 cm, 113±24 cm, and 94±21 cm, respectively. 8. The AP and ML average ranges of reach were statistically greater in the non-TLSO condition than the TLSO condition (p=0.002, p=0.01), whereas the V reach showed no significant difference. 9. When comparing non-TLSO condition to TLSO condition, the nondominant ML reach was significantly greater in the non-TLSO condition than the TLSO condition (p=0.003), while AP and V reaches showed no significant difference. 10. For the non-TLSO condition, AP reach was significantly greater than the TLSO condition (p=0.009), while ML and V reaches showed no significant difference. 11. There were no significant differences between AP, ML, and V ranges of reach when comparing nondominant and dominant arms in the non-TLSO condition. 12. In the TLSO condition, ML reach was significantly greater for the dominant arm than the nondominant arm (p<0.05).
(Chafetz et al. 2007) USA Pre-Post N=14	Population: Age: 10.8±2.4 yr; Gender: males=7, females=7; Level of injury: cervical=1, thoracic 1-5=3, T6-11=10. Intervention: Subjects completed the activities of the functional activities scale (FAS) and the timed motor test (TMT) which included 6 activities involving dressing, transfers, and wheelchair propulsion, with a thoracic lumbar sacral orthosis (TLSO) and without a TLSO. Subjects were asked their preference for wearing or not wearing the TLSO during each of the activities. Outcome Measures: Functional Independence Measure (FIM), 6 wheelchair/transfer skills,	Scoliosis 1. For donning a shirt, there was a 26% increase in time with a TLSO compared to without a TLSO (p<0.001). 2. For donning pants, there was a 21% increase in time with a TLSO compared to without (p<0.001). 3. The time to complete increased by 42% for even transfers and 28% for uneven transfers with TLSO compared to without (p<0.001). 4. For wheelchair propulsion down a hallway, there was a 6% increase in time with a TLSO than without (p<0.001). 5. Wheelchair propulsion ascending a ramp was not significantly impacted by wearing a TLSO (p=0.11). 6. Wearing a TLSO did not impact the activities of eating, grooming, wheelchair propulsion, curb management, "popping wheelies," or transitioning from sitting at the edge of a bed to a supine position. 7. A reduction of scores was evident for dressing (upper and lower body), bladder management,

	Timed Motor Test (TMT), preference.	bed transfers, reaching for the floor, and transitioning from a supine position to sitting at the edge of the bed, but only upper-body dressing was statistically significantly different (p<0.01). 8. For eating, grooming, wheelchair propulsion, and popping a wheelie, subjects did not have a preference to wear or not wear a TLSO. 9. Preference for not wearing a TLSO was significantly different (p<0.05) for lower-body dressing, reaching for the floor, and transitioning from a supine position to sitting at the edge of the bed.
(Mehta et al. 2004) USA Observational N=123	**Population:** Age at interview: 7.4 yr; Age at injury: 5.3 yr; Gender: males=69, females=54; Injury etiology: traumatic=115, non-traumatic=8; Level of injury: cervical=69, thoracic=54; Severity of injury: AIS A=71, AIS B=49, AIS C=1, AIS D=2. **Intervention:** None. Chart review. **Outcome Measures:** Radiographic curve severity of the spine, prevalence of bracing, surgery and cessation of growth	Scoliosis At follow-up (range 2-13 yr), 95% of patients had developed scoliosis; surgical stabilization was required in 65% of the total sample. Group I (initial curve <10°; n=42) 1. 29 of the patients in this group were braced, and 13 who were not. 2. Of the braced group, 13 (45%) went on to surgery, whereas 10 (77%) of the non-braced group had surgical correction (p=0.03). 3. Of the patients who were initially braced, the average time to surgery was 8.5 yr, whereas that for the non-braced group was 4.2 yr (p=0.002). 4. There was no significant difference between time to surgery for the braced and non-braced patient groups at higher (>20°) initial curve presentations. Group II (Initial curve 11 ° to 20°; n=25) 1. Eighteen (72%) patients in this group were braced and 72 8%) were not braced. 2. Nine of the 18 children in the braced group (50%) required surgery at 6.8 years after initial presentation, whereas 6 of 7 of the nonbraced group (86%) required surgery at 3.7 years after presentation. 3. The difference between the rate of surgery (p=0.04) and the length of time to surgery (p=0.008) in the braced vs nonbraced group was statistically significant, whereas the curve at the time of surgery was not (p=0.52). Group III (Initial curve 21 ° to 40°; n=28)

		1. Of the 20 (61%) children initially braced in this group, 1 2 (60%) went on to have surgery at 4.2 years after presentation, whereas 8 (40'7'o) did not require surgery. 2. Of the 8 children (3 9%) who were not braced, 6 (7 5%) went on to surgical correction at 3.2 years after presentation. 3. While there was no statistical difference for time to surgery between the braced and nonbraced patients in group III (p=0.3 6), there was a trend toward less surgical intervention in the braced patients (p=0.08). **Group IV (Initial curve > 41 ° but < 50°; n=16) & Group V (curves > 51 ° at presentation; n=12)** 1. In Group IV, one patient (6%) was not braced and proceeded to surgery, whereas 15 (94%) were braced, of which 12 (80%) went on to have surgical correction of their deformity. 2. In Group V, ten patients (83%) were braced and 2 (17%) were not braced; surgical correction of the spine was performed on 8 children (80%) in the braced group and both children (100%) in the nonbraced group. 3. In group IV and V, There was no significant difference between time to surgery for the braced and non-braced patient groups.
(Vogel et al. 2002c) *Part II* USA Observational N=216	**Population:** Age at injury: 14.1±4.0 yr; Age at interview: 28.6±3.4 yr; Gender: males=150, females=66; Time since injury: 14.2±4.6 yr; Level of injury: tetraplegia=123, paraplegia=93. Severity of injury: C1-4 ABC=41, C5-8 ABC=67, T1-S5 ABC=82, tetra/para D=26. **Intervention:** None. Survey. **Outcome Measures:** Prevalence of scoliosis.	**Scoliosis** 1. Scoliosis affected 40% of participants and was significantly associated with younger age at injury (p<0.001); prevalence of scoliosis was 86% in children injured at ≤12 yr, and 31% in those injured at older ages. 2. Subjects with scoliosis had a longer duration of injury (p<0.001) and were more likely to have had a violent etiology (p=0.003) compared to those without scoliosis. 3. Scoliosis was not associated with gender or level of injury. 4. Scoliosis more commonly affected individuals with hip subluxation or contractures compared to those without these hip complications (p=0.003). 5. Scoliosis was not statistically associated with back pain, pressure ulcers, or respiratory complications. **Hip Subluxation** 1. Hip subluxation or contractures affected 68 participants, with 18 experiencing hip

		subluxation alone, 33 contractures alone, and 17 with both hip contractures and subluxation. 2. Hip subluxation was significantly associated with younger age at injury and longer duration of injury (p<0.001); rates of hip subluxation were 43% (6/14) for those injured at ≤5 yr, 52% (11/21) injured at ≤8 yr, and 41% (11/27) of those injured at ≤10 yr. 3. Hip subluxation was not significantly associated with gender, neurological level, ASIA motor score, or FIM scores. 4. Hip contractures were not associated with age at injury or duration of injury or spasticity. 5. Hip contractures were significantly more prevalent in those with injuries due to violence than non-violent injuries (59% versus 20%; p<0.001) and those with paraplegia compared to those with tetraplegia (p<0.001). 6. Those with hip contractures demonstrated significantly higher total FIM (p=0.001) and motor FIM scores (p=0.002). Fractures 1. A total of 45 pathological fractures were experienced by 32 subjects. 2. Individuals who developed pathological fractures were significantly older at the time of interview, (p=0.038) had a longer duration of their SCI (p=0.011), and more likely to have lower cervical level injuries (C5-C8 A-B-C) (p=0.010). 3. There were no other significant associations between pathological fractures and the remaining study variables. Ankle Pain and Contractures 1. Ankle pain or contractures affected 53 subjects, with 29 individuals having contractures alone, 18 reported pain only, and 6 had complaints of both contractures and pain. 2. Ankle pain was significantly associated with older age at injury (p=0.018) and tetraplegia (p=0.005). 3. Ankle contractures were not significantly associated with any of the study variables. Elbow Pain and Contractures 1. Elbow pain or contractures affected 43 subjects with 27 experiencing elbow pain alone, 10 had elbow contractures alone, and 6 had both.

		2. Those with elbow pain were significantly older at follow-up (p=p=0.026) and had a longer duration of their SCI (p=0.041). 6. As expected, elbow contractures were significantly more common in those with tetraplegia (p=0.040) and were significantly associated with lower ASIA motor scores (p=0.016) and lower total FIM (p=0.010) and motor FIM scores (p=0.009).
(Moynahan, Betz, et al. 1996) USA Observational N=51	**Population:** Age: 14.5±4.2 (3-20) yr; Gender: males=30, females=21; Level of injury: cervical=19, thoracic/lumbar=32. **Intervention:** Patients underwent bone density measurements using dual photon absorptiometry. **Outcome Measures:** Bone Mineral Density of femoral neck, Ward's triangle and intertrochanteric region of the hip, presence of spasticity, number of pathological fractures.	**Fractures** 1. Subjects with SCI had lower bone densities compared to their non-disabled peers, ranging from 56-65 % of normal across the three anatomic regions. 2. On average, subjects who had a previous history of fractures had significantly lower bone density measurements than those without fractures (p<0.05). 3. At the intertrochanteric region, a 10.6% difference was noted between subjects with tetraplegia versus those with paraplegia. 4. At the femoral neck and Ward's Triangle, an 8.5% difference was noted between subjects with and without spasticity.
(Dearolf et al. 1990) USA Observational N=155	**Population:** *Preadolescent Group (N=61):* Age at injury: 8.5 yr (males, N=43), 7.5 yr (females, N=18); Injury etiology: traumatic=57, non-traumatic=4; Level of injury: cervical=13, thoracic=45, lumbar=3; Severity of injury: complete=50, incomplete=11. *Post-adolescent Group (N=94):* Age at injury: 17.0 yr (males, N=68), 16.0 yr (females, N=26); Injury etiology: traumatic=94, non-traumatic=0; Level of injury: cervical=67, thoracic=23, lumbar=4. **Intervention:** None. Chart review. **Outcome Measures:** Prevalence of scoliosis.	**Scoliosis** *Preadolescent Group* 1. 55 (96.5%) of the patients that did not receive treatment developed a paralytic scoliosis. 2. Curve progression was rapid in this group; 8 (14%) of patients who were <1 year postinjury had developed curves of >20 deg; 17(31%) of patients who were <2 years post injury had developed curves of >20 deg. 3. Curve progression was 10.6 deg/year on average 4. The degree of curve that developed was not related to the level or completeness of the spinal cord injury. 5. Of the 12 patients braced and followed for an average of 48 mo, 5 progressed and either have had surgery already or planned, while 7 have progressed <5°. 2 of the braced patients developed pressure sores. 6. 19 (33%) patients required surgical intervention for a progressive paralytic scoliosis.4 of them initially underwent Luque rodding with wires without fusion; their curves progressed without gains in spinal height, without gains in spinal height necessitating further spinal stabilization with fusion.

		7. The average prefusion curve was 52° with post-fusion correction to 25°, for an average correction of 50%. 8. Pseudarthrosis developed in 5 (26%) of the patients and 11 (58%) of the patients required reoperation. 9. Loss of correction after surgery >5° occurred in 10 patients. *Post-adolescent Group* 10. 41 (48%) of the patients that did not receive treatment developed a progressive paralytic scoliosis. 11. Curves slowly progressed to a significant degree in 15 (36%) of the patients in whom curves >20° developed >2 yr post injury. 12. Curve progression was 5.4 degrees/year, on average. 13. 13. 5 patients (5.3%) eventually required a surgery for a progressive paralytic scoliosis; the average prefusion curve was 50 degrees and the average postfusion curve was 12 degrees.

Discussion

Scoliosis is a major potential complication of pediatric SCI. Estimates of the incidence of progressive scoliosis related to paralysis range from 46 to 98% (Mehta et al. 2004). A review of the studies presented here suggests that more precise estimates of the frequency of scoliosis in pediatric SCI can be made if one considers the age of the individual at the time of injury. This is perhaps best demonstrated in the observational study by Dearolf et al. (1990), where children were divided into two groups based on their age when they were injured: the preadolescent group and the skeletally mature group. In the preadolescent group, without treatment, 96.5% developed scoliosis. Spinal curves progressed rapidly (at a rate of 10.6 degrees per year on average), and degree of curvature was not related to the level or completeness of injury. Of the patients who underwent bracing, about half stabilized, and half still went on to needing surgery (and it was noted that 2 of the 12 braced patients developed significant pressure sores with bracing). Overall, 33% of this group required spinal surgery to manage the degree of scoliosis, with the authors carefully noting that if individuals in this group who were within one year of reaching skeletal maturity at the time of injury were excluded from analysis, that number rose to approximately 60% requiring surgical management. In contrast, only 48% of individuals who were skeletally mature at the time of injury had scoliosis without treatment. Curve progression was much slower (5.4 degrees per year) and only 18% went on to require surgery. In any instance of very rapid progression (>15 degrees in 6 months), it is suggested that evaluation for syringomyelia be considered (Dearolf et al. 1990). Kulshrestha et al. (2020), Mulcahey et al. (2013) and Vogel et al. (2002c) also reported that age at time of injury appeared to be the most important predictor of progressive paralytic scoliosis amongst children with SCI.

Bracing for scoliosis in the setting of SCI was discussed in a number of studies. In their chart review of 123 patients, Mehta et al. (2004) found that those braced when curves were smaller (less than 20 degrees) were less likely to go on to require surgery, or at least were able to prolong the time to surgery. This raises an interesting question around early bracing, in contrast to conventional treatment protocols, which dictate that bracing should be considered for scoliotic curves between 20-40 degrees (Mehta et al. 2004). Dearolf et al. (1990) found bracing to be effective for a small number of preadolescent individuals with scoliosis, though the rationale for who was and who was not braced was not well described. In younger patients, delaying the need for surgery may be desirable, so as to avoid spinal instrumentation before skeletal maturity is reached. There is a limited role for bracing larger curves (>40 degrees) (Dearolf et al. 1990; Mehta et al. 2004) and older (skeletally mature) patients (Dearolf et al. 1990), as successful management of scoliosis is less likely in these cases. Two studies examined the impact of bracing with a thoracolumbosacral orthosis on function amongst children with SCI. Sison-Williamson et al. (2007) demonstrated that use of a thoracolumbosacral orthosis resulted in reduced anterior/posterior and medial/lateral reach. Chafetz et al. (2007) demonstrated that, while some functions were not significantly impacted by thoracolumbosacral orthosis use, there was a significant impact on dressing and transfer time, and that patients preferred not to have the thoracolumbosacral orthosis on for certain tasks (such as reaching to the floor, dressing the lower body, and certain transfers). These functional implications, coupled with the risk of pressure ulceration with thoracolumbosacral orthosis use (Dearolf et al. 1990) serve as a reminder that bracing should be considered as any other intervention, with considerations given to potential risks and benefits of treatment.

In comparison to scoliosis, information about other orthopedic complications of pediatric SCI is relatively limited. In one observational study, hip subluxation was documented in 40-50% of individuals who were injured before the age of 10 (Vogel et al. 2002c), with younger age at time of injury and longer duration of SCI found to significantly impact hip position. No information about rate of subluxation in older age categories was provided. A single interventional study assessed the impact of FES cycling, passive leg cycling, and surface stimulation without cycling on hip position (as measured by migration percentage) (Johnston, Betz, et al. 2009). None of the interventions were found to have an impact on hip subluxation at six months, though it could certainly be argued that the follow up interval would be too short to observe a significant effect. Information regarding contracture and fractures in SCI was similarly limited. Vogel et al. (2002c) observed ankle contractures in 16% of their sample of 216 individuals with chronic pediatric SCI, while elbow contractures were documented in 7.5% of the sample. There were no associations between ankle fractures and any of the study variables, though elbow fractures were significantly associated with tetraplegia and lower American Spinal Injury Association motor scores, and Functional Independence Measure total and motor scores. Vogel et al. (2002c) also documented 45 pathologic fractures in 35 individuals with pediatric SCI (representing fracture(s) in 16% of the overall sample). Fractures were significantly associated with older age at the time of the study, longer duration of SCI and cervical level injury. BMD amongst individuals with pediatric SCI was found by Moynahan et al. (1996) to be reduced by 56-65% as compared to peer controls, with greater reductions noted in those with a documented history of fracture.

Conclusion

Orthopedic complications of pediatric SCI are common. The risk of scoliosis requiring intervention is particularly high amongst those who experienced their injury at least one year prior to reaching skeletal maturity. While bracing with thoracolumbosacral orthosis does have some negative implications for function and skin health, bracing may delay or eliminate the need for invasive spine surgery, particularly if it is used before curves are overly large (certainly before 40 degrees, with some literature suggesting it could be instituted at less than 20 degrees) and while individuals are still skeletally immature. Hip subluxation is also relatively frequent, again with rates appearing to be higher amongst those who are injured at a younger age. Very little is known about effective rehabilitation-based intervention to slow the progression of hip subluxation. Contractures and fractures also occur at significant rates in this population, but there is no available literature regarding interventional strategies to reduce their incidence.

Key Points

All individuals with pediatric onset SCI are at significantly increased risk of scoliosis, especially if the injury occurs at a younger age. In particular, those with injuries occurring prior to skeletal maturity are at much greater risk of developing scoliosis, of rapid curve progression and of requiring surgical intervention.

Bracing for scoliosis in this population may be beneficial, particularly in younger, skeletally immature patients with smaller curves (either to prevent surgery or to delay it until skeletal maturity). The role of bracing for older patients with larger curves (>40 degrees) is limited.

Hip displacement is more common in individuals injured at a younger age and with a longer duration of SCI. The implications and management of hip displacement in pediatric SCI are unclear.

Contractures and fractures are both common complications of pediatric SCI but little is known about targeted intervention in this specific population.

5 Medical Complications

5.1 Gastrointestinal Function

5.1.1 Nutrition

In children with significant neurologic deficit, neurogenic bowel changes are part of, and contribute to, the development of secondary co-morbidities. Generally, this population is at risk of developing long-term nutritional consequences (i.e., obesity, malnutrition) and are confronted with the need to develop behavioral modifications related to performing a physiologic function in a modified way (e.g., neurogenic bowel regimen).

These youths can face numerous individual, social, and environmental barriers to a healthy lifestyle (Bandini L, 2015) which has been postulated to be related to three different mechanisms: 1) biological, medical, and developmental factors, such as metabolic abnormalities and medication disrupting appetite regulation or altering the metabolism and restricting physical activity; 2) parent, family, and caregiver related factors, such as lack of knowledge about the interplay between nutrition and the actual physical activity level (which is decreased in many instances). Over- or underfeeding may also occur because of a lack of awareness of child's satiety, use of food as a reward or because other health issues faced by a child with disabilities may make weight seem less important. Parents and caregivers may also exhibit overprotective instincts and there is also the possibility of lacking anticipatory guidance from health care professionals, as other comorbidities are taking priority in the care of a child with complex medical status; and 3) school and community related factors, exemplified by the lack of tailored services for children with disabilities and lack of guidance and support during transitions to a more independent living state.

Table 17. Studies assessing nutrition among children with SCI

Author, Year Country Study Design Sample Size	Study Characteristics	Results
(Wang et al. 2017) China Observational N=45	**Population:** Time since injury: <1 yr=22, 1-5 yr=23; Level of injury: paraplegia=40, tetraplegia=5; Severity of injury: AIS A=29, AIS B/C=7, AIS D=9; *Gender by Age Groups:* 1) Males 0-5 yr=7, 2) Males 6-12 yr=5, 3) Females 0-5 yr=24, Females 6-12 yr=4) 9.	1. Mean WAZ, HAZ and BAZ values and STAMP scores were not significantly different among the different gender and age groups. 2. Using STAMP, 22 (48.9%) children were classified as low risk (STAMP: 0–1), 18 (40.0%) were classified as medium risk (STAMP: 2–3) and 5 (11.1%) were classified as high risk (STAMP: 4–5); there were no motor score differences among these three groups of children. 3. The mean WAZ, HAZ and BAZ values and appetite levels were significantly different between the low, moderate and high-risk STAMP

	Intervention: None. Measurements and survey. **Outcome Measures:** Height, height-for-age (HAZ), weight, weight-for-age (WAZ), body mass index (BAZ), appetite level (% of meals eaten), Screening Tool for the Assessment of Malnutrition in Pediatrics (STAMP).	groups; values decreased with increasing degree of malnutrition risk (p<0.001 for all). 4. STAMP scores also showed a significant negative correlation with WAZ, HAZ and BAZ levels in regression analysis (p<0.001 for all). 5. There were no significant differences in gender, age, cause of injury, time since SCI, level of injury, completeness of injury, AIS category and walking ability between those with risk or no risk of malnutrition. 6. A total of 20 patients (44.4%) were found to have a normal status, 12 (26.7%) were found to have mild undernutrition, 3 (6.7%) showed moderate undernutrition, 6 (13.3%) were overweight and 4 (8.9%) were obese. 7. The agreement between the nutrition status and malnutrition risk was moderate (k=0.603).
(Wong et al. 2011) United Kingdom Observational N=62	**Population:** Median age: 13 (1-18) yr; Gender: males=37, females=25; Mean time since injury=4 yr; Level of injury: tetraplegia=27 (13 complete, AIS A), paraplegia=31 (18 complete AIS A). **Intervention:** None. Measurements and survey. **Outcome Measures:** Height, weight, body mass index, biochemistry, Screening Tool for the Assessment of Malnutrition in Pediatrics (STAMP).	1. There were no significant differences between genders on anthropometric, biochemical or nutritional indices, apart from a higher concentration of serum creatinine in the boys (p<0.05). 2. In total, 47.1% (24/51) of children screened with STAMP were found to be nutritionally at risk and 23.5% (12/51) were at 'high risk'. 3. Comparing well-nourished and undernourished patients via STAMP, those at risk of under-nutrition were found to receive more medications p=0.048); no other relationships were uncovered. 4. Undernourished patients with paraplegia were found had lower height centile than well-nourished patients with paraplegia (p<0.05) 5. Of the 51 screened patients, 15 (29.4%) were deemed to be at risk of under-nutrition after assessment by dietitian. 6. When comparing the well-nourished and undernourished patients, as identified by the dietitian's assessments, undernourished patients were found to have statistically significant lower BMIs and BMI centiles (p=0.041), less appetite (p=0.01), higher C-reactive protein (p=0.029) and received more prescribed medications (p=0.017). 7. Undernourished patients determined by *STAMP* were more likely to have had a past need for artificial nutritional support (p=0.01). 8. Undernourished patients determined by a *dietician* experienced more previous intensive care (p<0.05), mechanical ventilation (p<0.01), and to have had a past need for artificial nutritional support (p<0.01). 9. Malnutrition risk was common in new admissions than in those with chronic SCI (readmissions) (p=0.034).

Discussion

Two papers were identified that assessed nutritional status in children with SCI. Both used height, weight, body mass index (BMI) and the Screening Tool for the Assessment of Malnutrition in Pediatrics (STAMP) as outcome measures and were observational in nature. Wang et al. (Wang et al. 2017) looked at 45 children with SCI, stratified according to time since injury and level and severity of injury and concluded that mean weight, height and BMI values and STAMP scores were not significantly different among the different gender and age groups. 48.9% children were classified as low risk for malnutrition, (STAMP: 0–1), 40.0% were classified as having a medium risk (STAMP: 2–3) and 11.1% were classified as high risk (STAMP: 4–5) for developing malnutrition, but there were no motor score differences among these three groups. STAMP scores showed a significant negative correlation with weight, height and BMI levels in regression analysis ($p<0.001$ for all) and the mean weight, height and BMI values and appetite levels were significantly different between the 3 different STAMP groups. There were no significant differences in gender, age, cause of injury, time since SCI, level of injury, completeness of injury, AIS category and walking ability between those with different risks of malnutrition. Of the 45 children, 44.4% were found to have a normal status, 26.7% were found to have mild undernutrition, 3 6.7% showed moderate undernutrition, 13.3% were overweight and 8.9% were obese.

Wong et al.(Wong et al. 2011) also conducted an observational study examining 62 participants with SCI using height, weight, BMI, STAMP and biochemistry as outcomes; in addition, 51 of 62 children were assessed by a dietician regarding their nutritional status. This cohort was characterized by a median age of 13 (1-18) years, with 59.6 % males (n=37), mean time since injury of 4 years; 43.5 % with tetraplegia (n=27; 13 complete, AIS A) and 56.5 % with paraplegia (n=31: 18 complete AIS A). Again, there were no significant differences between genders on anthropometric, biochemical or nutritional indices, apart from a higher concentration of serum creatinine in the boys ($p<0.05$). Nearly half (47.1%, 24/51) of children screened with STAMP were found to be nutritionally at risk and nearly a quarter (23.5%, 12/51) were at “high risk”. Those undernourished were more likely to receive more medications, to have had a past need for artificial nutritional or ventilator support, have less appetite and have a higher C-reactive protein level. Malnutrition risk was less common in children with chronic injuries.

In conclusion, pediatric population with SCI exhibit abnormalities in their nutritional intake (and caloric consumption), placing them at risk for the gamut of disturbances ranging from undernourished (most common in the acute period following the injury) to obesity, in the long term. The nutritional and metabolic disturbances do not seem to correlate with gender, age or level and grade of neurologic injury, although prior need of nutritional and ventilator support and higher numbers of medication intake appeared to correlate with an undernourished status.

5.1.2 Bowel Management

The pediatric spinal cord related dysfunction literature does not abound in manuscripts documenting prospective studies of neurogenic bowel management. In fact, a systematic review of the recent literature showed just 5 papers relevant to the subject. Briefly, the clinical management of the neurogenic bowel dysfunction associated with SCI involves utilization of mechanical, pharmacologic and interventional methods. Mechanical methods include rectal stimulation and rectal evacuation (digital or enema); the pharmacologic agents utilized are either administered orally or rectally and can be classified as softeners or laxatives. The most common procedures helping with bowel evacuation in pediatric SCI include anterograde continent enema and colostomy.

Table 18. Studies assessing bowel function in children with SCI.

Author, Year Country Study Design Sample Size	Study Characteristics	Results
(Hwang et al. 2017) South Korea Observational N=131	**Population**: Mean age: 33.4 ±6.1 yr; Gender: males=84, females=47; Mean time since injury: 19.5 ±7.0 yr; Level of injury: paraplegia=54, tetraplegia=77; Severity of injury: incomplete=31, complete=100.. **No Invervention**: Longitudinal cohort survey. Follow-up occurred annually for a total of 466 interviews, with most participants (75%) contributing to at least 3 consecutive interviews. **Outcome Measures**: Type and evacuation time of bowel management programs, Satisfaction with Life Scale (SWLS), Patient Health Questionnaire-9 (PHQ-9), SF-12v2™ Health Survey (SF-12v2), Craig Handicap Assessment and Recording Technique (CHART)	1. At first interview, rectal suppository/enema use was most common (51%). 2. Over time, the likelihood of using manual evacuation (OR, 1.077; 95% C.I., 1.023-1.134; p=.005), oral laxatives (OR, 1.052; 95% C.I., 1.001-1.107; p=.047), and colostomy (OR, 1.071; 95% C.I., 20 1.001-1.147; p=.047) increased, whereas the odds of rectal suppository use decreased (OR, .933; 21 95% C.I., .896-.973; p=.001). 3. Bowel evacuation times were likely to decrease over time in participants using manual evacuation (OR, .499; 95% C.I., .256-.974; p=.042) and digital rectal stimulation (OR, .490; 95% C.I., .274-.881; p=.017), but increase for rectal suppository/enema use (OR, 1.871; 95% C.I., 1.264-2.771; p=.002). 4. Controlling for level of injury, participants using manual evacuation and digital rectal stimulation were more likely to have increases in community participation scores (p<.05).
(Midrio et al. 2016) Italy Observational N=78, N=37 SCI	**Population:** *Patients with anorectal malformation (ARM; N=41) or spinal cord lesion (SCL; N=37):* Age: *Group 1 (N=46):* 6-11 yr, *Group 2 (N=32):* 12-17 yr. **Intervention:** Patients were trained to use the Peristeen transanal irrigation (PTAI) for 3 mo. The volume of water used was 10/20 ml/kg every day for the first week and then three times a week, increasing the amount of water as needed to a maximum of 1L. **Outcome Measures:** Bristol Stool Scale, questionnaire assessing	1. Stool consistency was improved after 3 mo treatment with PTAI in both ARM and SCL patients. 2. Before treatment, 47.5% of patients with ARM and 77.5% with SCL presented with hard lumpy stools (types 1 and 2), whereas only 30% with ARM and 2.5% with SCL presented with type 4 and 5 stools. 3. After treatment, hard stools were recorded in 0% in ARM and 2.5% in SCL (types 1 and 2), and soft stools increased to 87% in ARM and 82% in SCL (types 4 and 5). 4. The most common form of bowel dysfunction before treatment was constipation in 69% and 92.7% in ARM and

Author, Year Country Study Design Sample Size	Study Characteristics	Results
	bowel function, Child Health Questionnaire, Short Form Survey.	SCL respectively and faecal incontinence in 50% and 39%. 5. After treatment, constipation was reduced in ARM from 69% to 25.6% and in SCL from 92.7% to 41.5%, faecal incontinence in ARM from 50% to 18.6% and in SCL from 39% to 9.8%, and flatus incontinence in ARM from 20.9% to 9.8% and in SCL from 31.7% to 10%.
(Johnston et al. 2005) USA Post Test N=3	**Population:** Age: 17-21 yr; Gender: males=3; Time since injury: 1.0-1.5 yr; Level and Severity of Injury: Motor complete T3-T8. **Intervention:** Praxis system consists of a 22-channel implant stimulator, extension leads and epineural electrodes. Leads emanating from the stimulator are configured in three tresses: two tresses of nine leads each for stimulation of lower extremity muscles and one tress of four leads for stimulation for bladder and bowel function (parameters: 0.2–8 mA amplitude, 25–600 ms pulse duration, 2–500 Hz pulse frequency per channel). After implantation and immobilization participants completed exercise phase (FES strengthening) followed by lower extremity conditioning, standing and upright mobility training (13 wk). **Outcome Measures:** Completion of eight upright mobility activities, scored based on completion time and level of independence: donning, stand and reach, high transfer, bathroom, floor to stand, 6m walk, stair ascent, stair descent.	1. Acute testing demonstrated that low-frequency electrical stimulation (20 Hz, 350 ms, 8 mA) of S3 bilaterally in subject 2 caused a significant increase in both rectal pressure and anal sphincter pressure. 2. High-frequency stimulation alone (500 Hz, 350 ms, 8 mA) appeared to have no effect on rectal pressure and produced a reduced pressure in the anal sphincter as compared to low-frequency stimulation alone. 3. A combination of low- and high-frequency (500 Hz, 350 ms, 8 mA) stimulation appeared to increase rectal and anal sphincter pressures, but to a level less than that caused by low-frequency stimulation alone. 4. The daily use of electrical stimulation appeared to cause a reduction in the time to complete defecation by 40% with the first stimulation strategy and by 60% with the second strategy. 5. As compared to bowel management without stimulation, with stimulation there was also a reduction in the proportion of days the subject failed to defecate and greater satisfaction with bowel management overall.
(Vogel et al. 2002b) USA	**Population:** Age at injury: 14.1±4.0 yr; Age at interview: 28.6±3.4 yr; Gender: males=150,	1. Bowel accidents were experienced by 135 subjects, with 19 having incontinence more frequently than once a month.

Author, Year Country Study Design Sample Size	Study Characteristics	Results
Observational N=216	females=66; Time since injury: 14.2±4.6 yr; Level of injury: tetraplegia=123, paraplegia=93. Severity of injury: C1-4 ABC=41, C5-8 ABC=67, T1-S5 ABC=82, tetra/para D=26. **Intervention:** None. Survey. **Outcome Measures:** Prevalence of urinary tract infections (UTI), hospitalizations, urinary stones, orchitis or epididymitis, bladder incontinence, dysreflexia.	2. The subjects who experienced bowel incontinence were older at interview (p=0.038) and exhibited significantly lower ASIA Motor (p<0.001), FIM total (p=0.002) and motor scores (p=0.003). 3. 55 individuals complained of constipation, 37 experienced diarrhea and 73 complained of hemorrhoids or rectal bleeding. 4. Individuals with bowel programs >60 min were significantly older at follow-up (p=0.001) and had a longer duration of injury (p=0.005). 5. Prolonged bowel programs were experienced by 42% of those with tetraplegia compared with 18% of those with paraplegia (p=0.002). 6. Those with prolonged bowel programs also had a lower mean ASIA Motor score (p=0.009). 7. Prolonged bowel programs were associated with significantly lower motor (p=0.002) and total FIM scores (p=0.002).
(Goetz et al. 1998) USA Observational N=31	**Population**: Mean age: Gender: males=15, females=16; Mean time since injury: 3.9yr; Level of injury: paraplegia=14, tetraplegia=17; Severity of injury: ASIA A=24, ASIA D=7 **No Intervention**: Surveys were sent to all persons under age 19 with a diagnosis of SCI who had received care at a medical center since 1985. **Outcome Measures**: Individual patterns of bowel management and use of medications, levels of satisfaction with bowel management, incidence of incontinence, subject/caregiver perceptions regarding the impact of the bowel program on social functioning	1. A bowel management program, including medications or manual manipulation, was required for 81% of the subjects; only two were independent in their bowel mgmt. 2. There was an association between being able to walk, even for short distances, and having normal bowel function (p<0.01). 3. Over half of the subjects performed evening bowel care and over half performed their care daily. 4. Digital stimulation tended to be used more commonly by younger children. 5. Medications, either oral, rectal, or both, were used by 88% of of the subjects. 6. Sixty percent of the subjects reported they were completely or very satisfied with their bowel management. 7. About half the subjects had limited freedom because of their bowel programs, which caused some dissatisfaction. 8. Sixty-eight percent reported occasional or frequent interference with school activities because of their bowel programs. 9. almost 84% of the children reported at least rare accidents. 10. No correlation was found between bowel accidents and satisfaction with bowel mgmt.

Discussion

Only one paper described methods of bowel management in children with SCI (Goetz et al. 1998). Goetz et al. (1998) surveyed 33 individuals under age 19 with a diagnosis of SCI who received care in one medical center between 1985-1998. The average age at injury was 8.1 years and the average follow-up period was 3.9 years; 55% had tetraplegia and 77% had a complete injury (American Spinal Injury Association Class A). 81 % of them required performance of a bowel management program consisting of medications or manual manipulation, and only two were independent in their bowel management. Over half of the subjects performed their bowel care in the evening and over half performed it daily. Pharmacologic agents, either oral, rectal, or both, were used by 88% and mechanical methods (i.e., digital stimulation) tended to be used more commonly by younger children. A total of 60% of subjects reported they were completely or very satisfied with their bowel management. Among dissatisfying factors, limited freedom was reported in about 50% of participants and 68% reported occasional or frequent interference with school activities. 84% reported some accidents, but no correlation was found between bowel accidents and satisfaction with bowel management.

Vogel et al. (2002b) and Hwang et al.(2017) reported on long-term outcomes and longitudinal changes of neurogenic bowel management in adults with pediatric-onset SCI. Both studies examined the medical and psychosocial consequences of neurogenic bowel in individuals that suffered their SCI while they were children. Vogel et al. (2002b) surveyed 216 adult individuals who suffered their injury before 18 years treated at Shriners hospital. Bowel accidents were experienced by 135 subjects, with 19 having incontinence more frequently than once a month; the subjects who experienced bowel incontinence were older at interview and exhibited significantly lower American Spinal Injury Association Motor, Functional Independence Measure total, and motor scores. In total, 55 individuals complained of constipation, 37 experienced diarrhea and 73 complained of hemorrhoids or rectal bleeding. Individuals with bowel programs >60 min were significantly older at follow-up and had a longer duration of injury. Prolonged bowel programs were experienced by 42% of those with tetraplegia compared with 18% of those with paraplegia; those with prolonged bowel programs also had a lower mean American Spinal Injury Association Motor score and prolonged bowel programs were associated with significantly lower motor and total Functional Independence Measure scores. Hwang et al. (2017) performed a longitudinal cohort survey with an annual follow-up of 131 individuals who had sustained an SCI before the age of 19 years. They collected 466 interviews, with 75% of the participants contributing to at least 3 consecutive interviews. At first interview, rectal suppository/enema use was most common (51%). Over time, the likelihood of using manual evacuation, oral laxatives, and colostomy increased, whereas the odds of rectal suppository use decreased. Bowel evacuation times were likely to decrease over time in participants using manual evacuation and digital rectal stimulation, but increase for rectal suppository/enema use. When the level of injury was controlled for, participants using manual evacuation and digital rectal stimulation were more likely to have increases in community participation scores.

The literature search identified two interventional studies, one describing the effectiveness of an implanted FES system on bladder and bowel function(Johnston et al. 2005) and the other looking at the use of the Peristeen transanal irrigation for 3 months (Midrio et al. 2016).

Johnston et al. (2005) studied three adolescents/young adult males with thoracic level complete (AIS A) paraplegia who underwent implantation of a 22 channel Praxis stimulator with 18 leads destined to stimulate muscles in the lower limbs and 4 leads meant to stimulate the bilateral S2-4 roots in order to modulate the bladder and bowel function. Electrical current parameters were: 0.2-8 mA amplitude, 25-600 µs pulse duration and 2-500 Hz pulse frequency. Acute testing demonstrated that low-frequency electrical stimulation (20 Hz, 350 ms, 8 mA) of S3 bilaterally in one subject caused a significant increase in both rectal pressure and anal sphincter pressure. High-frequency stimulation alone (500 Hz, 350 ms, 8 mA) appeared to have no effect on rectal pressure and produced a reduced pressure in the anal sphincter as compared to low-frequency stimulation alone. A combination of low- and high-frequency (500 Hz, 350 ms, 8 mA) stimulation appeared to increase rectal and anal sphincter pressures, but to a level less than that caused by low-frequency stimulation alone. The investigators tested the daily use of electrical stimulation (about 18 hr/day) which appeared to cause a reduction in the time to complete defecation by 40% when only using low frequency stimulation 30 seconds on and 30 seconds off for 5-10 min cycles and by 60% when 5-10 min of low frequency stimulation was followed by 5 minutes of low/high frequency stimulation. When compared to usual, routine bowel management without stimulation, there was a reduction in the proportion of days the subject failed to defecate and greater satisfaction with bowel management overall when using the electrical stimulation.

Midrio et al. (2016) studied 37 children with SCI age 6-11 (n=15) and 12-17 (n=22) who were trained to use the Peristeen transanal irrigation for 3 mo. The volume of water used was 10/20 ml/kg every day for the first week and then three times a week, increasing the amount of water as needed to a maximum of 1L. Outcome Measures were the Bristol Stool Scale, a questionnaire assessing bowel function and 2 questionnaires assessing quality of life (one for each age group). Stool consistency was improved after 3 months of treatment with Peristeen transanal irrigation: before treatment, 77.5% of individuals with SCI presented with hard lumpy stools (types 1 and 2) and 2.5% presented with soft stools (type 4 and 5). After treatment, hard stools were recorded in 2.5% of individuals and soft stools in 82 %. The most common form of bowel dysfunction before treatment was constipation in 92.7% and fecal incontinence in 39% of individuals. After treatment, constipation was reduced to 41.5%, fecal incontinence to 9.8%, and flatus to 10 % (from 31.7%).

Key Points

The neurogenic bowel management in pediatric population with SCI is important for long term medical management and quality of life.

In view of the fact that neurogenic bowel is a significant contributor to quality of life in individuals with SCI and its' manner of performance changes along neurodevelopmental and disease chronicity lines, it is imperative that we summarize the current knowledge and develop research strategies that can optimize gastro-intestinal function lifelong when neurogenic dysfunction ensues.

5.2 Genitourinary Function

The bladder performs two functions: storage and elimination of urine. Performance of those functions depends on anatomic and physiologic integrity and neurologic conditions affect the latter. Congenital neural tube defects, such as myelomeningocele, spinal dysraphism, and tethered cord lesions, are the most common causes of neurogenic bladder in children. However, SCI and diseases (stroke, myelopathies, tumors, etc.) also can cause acquired dysfunction, with significant long term consequences (Lucas, 2019).

Pediatric SCI related neurogenic dysfunction of the urinary tract differs from the adult type in the fact that it affects a developing organ. Normal voiding in newborns is largely reflexive with some input from the cerebral cortex. Detrusor and sphincter function remain uncoordinated through the first several years of life (Yeung et al. 1995). As children grow, the brainstem takes more control with the pontine micturition center (Blaivas, 1982). In SCI/D (spinal cord injury/dysfunction) related paralysis, the lower urinary tract dysfunction characteristics depend on the type of neurologic injury, specifically, upper and lower motor neuron type, with a small percentage having a mixed pattern (i.e., conus medularis). The upper motor neuron pattern SCI/D related urinary tract dysfunction, a consequence of injury to the spinal cord itself, is characterized by over-active detrusor/detrusor hyperreflexia, detrusor-sphincter dyssynergia, decreased bladder compliance and increased detrusor pressures, leading to the risk of developing vesicoureteral reflux. In this instance, the bladder acts under reflex control; as the bladder fills, the sacral micturition reflex triggers an involuntary contraction leading to bladder evacuation, clinically expressed as incontinence. Because the lesion is below the pontine micturition center (thus eliminating its' control), there is loss of coordinated detrusor/sphincter relaxation; instead, there are intermittent contractions of the external sphincter during a detrusor contraction which can result in high intra-vesical voiding pressures, ultimately leading to upper urinary tract dysfunction and renal deterioration if not addressed. The lower motor neuron type urinary tract dysfunction, characteristic to injuries to cauda equina/nerve roots leads to a flaccid bladder which prevents emptying; external sphincter may be flaccid and incontinence can occur with any increase in intra-abdominal pressure (such as when coughing or straining). The internal sphincter tone may be intact because the sympathetic innervation originates above the conus medullaris, and this may contribute to incomplete emptying.

Most common complications of lower motor neuron type urinary tract dysfunction are recurrent UTI's related to bladder stasis and injury to the bladder wall because of distension. The small number of mixed injury bladder patterns are type A, where the detrusor is rendered flaccid, there is hypertonic external urinary sphincter and incontinence is uncommon; and type B pattern characterized by spastic bladder due to a disinhibited detrusor nucleus, a flaccid external urinary sphincter with resulting incontinence. Development of pyelonephritis and nephrolithiasis can occur in both upper motor neuron and lower motor neuron type of urinary tract dysfunction.

Goals of treatment change in the pediatric SCI as they advance through life. While preservation of kidney and bladder function remain the most important goals throughout life, social continence becomes essential as the child grows beyond the potty-training period, followed by achieving independence from caregivers. Achieving low-pressure urinary storage associated with bladder continence and efficient and complete emptying with normal pressures and minimizing the number of infections become mainstay of day-to-day bladder management.

Table 19. Studies assessing genitourinary function in children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Patki et al. 2006) United Kingdom Observational N=10	**Population**: *Pediatric-onset SCI*: Mean age: 28 (18-37) yr; Age at injury: 13.6 (6-16) yr; Time since injury: 13.1 (6-31) yr; Severity of injury: complete=6, incomplete=4. *Group 1*: neurogenic detrusor overactivity (NDO) with or without detrusor sphincter dyssynergia (DSD) (*n*=6), *Group 2*: acontractile detrusor with or without low bladder compliance (*n*=4). **Intervention**: None. Review. **Outcome Measures**: Urodynamics and ultrasound studies (USS), video-urodynamic (VCMG).	*Group 1: NDO* 1. 2 patients, each on urge/reflex voiding (T2 complete and T5 incomplete) with sheath drainage reported 2-3 urinary tract infections (symptomatic bacteriuria) per month. The patient with T5 incomplete injury underwent sphincterotomy and memokaths stent insertion. The stent had to be removed due to malposition within a year. Subsequently CSIC and oxybutynin was instituted in both patients leading to control of recurrent infections. 2. Upper tract changes with bilateral renal scarring and reduced glomerular filtration rate (GFR) were reported in 2 patients. In the patient (C3 complete) managed with supra pubic catheter (SPC) and oxybutynin, the changes were secondary to recurrent bilateral reflux with small, contracted, poorly controlled neuropathic bladder. The upper tract deterioration was stabilised with ileal conduit diversion. In the patient (T5 complete), kidney stone and recurrent pyelonephritis were responsible for upper tract changes. Sacral anterior root stimulator implant (SARSI) with posterior rhizotomy resolved the NDO and emptying, and the kidney stone was treated with lithotripsy with no further complications. Incidental bladder stone was picked up on routine ultrasound in the remaining patient with DSD. The stone was treated with cystolitholapaxy with no change in management. 3. During the follow-up, complications involving upper and lower urinary tracts were reported in 5/6 patients with NDO all of whom also had DSD. The single patient (C3 incomplete) with NDO without DSD has remained complication free on urge/reflex voiding for 13 yr. 4. Overall, at the last follow-up, 4 patients were continent with normal renal functions and 2 patients have stable renal function with ileal conduit and SARSI.

		Group 2: acontractile detrusor 5. 2 patients had low compliance on initial VCMG. A kidney stone was detected incidentally in one of them (T12 incomplete) and was treated with extracorporeal shockwave lithotripsy (ESWL). The other patient (T12 complete) changed management from CSIC to indwelling urethral catheter (IDUC). After 10 months of long-term catheter drainage he developed urethral fistula, which was subsequently excised. He is currently managed on CSIC and oxybutynin without further complications. 6. A small noncompliant bladder was seen in a patient (T12 complete) who on initial VCMG had no loss of compliance. The loss of compliance seen subsequently was secondary to long-term suprapubic catheterisation (3 yr) and noncompliance with SPC clamping routine. The patient required ileocystoplasty and Mitrofanoff procedure for good capacity and low-pressure storage. 7. During the follow-up, a total of 16 urological interventions were performed. 12/16 (75%) were carried out in NDO + DSD group. 7/12 interventions (58%) in this group were for change of management. In acontractile detrusor group, 2 interventions changed management and 2 were for treatment of complications. Apart from occasional "firing off", continence and renal function was well maintained in all.
(Tanaka et al. 2006) USA Observational N=22	Population: *Pediatric patients with transverse myelitis*: Age at injury: 8.8 yr (3 mo-18yr); Gender: males=15, females=7; Time since injury: 7.1 yr (6 mo-22 yr); Level of injury: cervical=7, thoracic=9, lumbar=6; Severity of injury: complete=9, incomplete=13. Intervention: None. Review. Outcome Measures: American Spinal Injury Association Impairment Scale (AIS), urinary and bowel continence, urodynamic studies, augmentation cystoplasty, upper tract imaging studies, CIC and anticholinergics.	1. At last follow-up, 19 patients (86%) had persistent bladder dysfunction. Of these patients, 16 (73%) used CIC and 14 (64%) took anticholinergic medications. 3 patients continued to have urinary incontinence despite CIC and anticholinergics. 1 patient with urinary incontinence refractory to medical therapy was successfully treated with detrusor botulinum toxin injection. 2. All patients with complete injury remained on CIC. When evaluated continence status, they did not significantly correlate with neurological level of lesion (p=0.58). 3. 17 patients (77%) had persistent bowel dysfunction. Of these patients, 15 (68%) followed a daily bowel program, including stool softeners, digital stimulation, suppositories and/or enemas. Of the 7

		patients not on a bowel program, only 5 had complete bowel control. Fecal incontinence refractory to medical management resolved with the Malone antegrade continence enema procedure in 1 case. 4. Urodynamics were performed in 17 patients. Detrusor overactivity was present in 10 of these patients (59%), DSD in 7 (41%), low compliance in 8 (47%) and detrusor leak point DLPP >40 cm water in 2 (12%). Detrusor overactivity, DSD, low compliance and increased DLPP did not significantly correlate with lower extremity tone (p=0.48, p=0.16, p=0.37 and p=0.40, respectively) or ambulatory status (p=0.58, p=0.58, p=0.60 and p=0.26, respectively). 5. No patient with complete injury had increased DLPP. When patients with complete injury were evaluated the presence of detrusor overactivity, DSD and low compliance did not significantly correlate with the neurological level of the lesion (p=0.58, p=0.58 and p=0.58, respectively). 6. Augmentation cystoplasty was performed in 4 patients for worsening compliance, incontinence and upper tract changes. 1 male patient had placement of an artificial urinary sphincter during augmentation for a Valsalva leak point pressure of <40 cm water, 1 patient underwent an antegrade continence enema for stool incontinence refractory to medical therapy, and 1 patient with incontinence and detrusor overactivity refractory to anticholinergics underwent endoscopic detrusor botulinum toxin injection. 7. Of the 19 patients with upper tract imaging studies, 5 (26%) had upper tract changes, consisting of hydronephrosis in 3, reflux in 1, and hydronephrosis and reflux in 1. Chronic renal insufficiency developed in 1 patient during the study period. The patient presented for rehabilitation 2.7 yr after disease onset with a complete thoracic level lesion and no increased lower extremity tone. Initial imaging studies showed hydronephrosis and vesicoureteral reflux; initial urodynamics revealed low compliance. Although CIC and anticholinergics were started, detrusor compliance continued to decrease. The

		patient ultimately underwent augmentation cystoplasty and bilateral ureteral reimplantation. 8. 5/6 patients in the early CIC group and all of those in the delayed group underwent urodynamic testing. Low compliance was found in 7 of 10 patients in the delayed CIC group and no patient in the early group. Bladder compliance was significantly worse in the delayed CIC group (p=0.02). 9. None of the 6 patients in the early CIC group had development of upper tract changes. Conversely, 4/10 patients in the delayed group had development of upper tract changes. Renal deterioration correlates with time elapsed between disease onset and institution of CIC (p=0.1, 90% confidence limit). However, standard statistical significance (p≤0.05, 95% confidence limit) was not reached by Fisher's exact test.
(Johnston et al. 2005) USA Post Test N=3	Population: Age: 17-21 yr; Gender: males=3; Time since injury: 1.0-1.5 yr; Level and Severity of injury: Motor complete T3-T8. Intervention: Praxis system consists of a 22-channel implant stimulator, extension leads and epineural electrodes. Leads emanating from the stimulator are configured in three tresses: two tresses of nine leads each for stimulation of lower extremity muscles and one tress of four leads for stimulation for bladder and bowel function (parameters: 0.2–8 mA amplitude, 25–600 ms pulse duration, 2–500 Hz pulse frequency per channel). After implantation and immobilization participants completed exercise phase (FES strengthening) followed by lower extremity conditioning, standing and upright mobility training (13 wk).	1. Just one subject demonstrated positive neuromodulation effects of the bladder; stimulation suppressed reflex bladder contractions acutely thereby reducing vesical pressure.

	Outcome Measures: Completion of eight upright mobility activities, scored based on completion time and level of independence: donning, stand and reach, high transfer, bathroom, floor to stand, 6m walk, stair ascent, stair descent.	
(Generao et al. 2004) USA Observational N=42	**Population:** Age at injury: 5.3 yr (1 day-14 yr), Age at follow-up: 5.5 (1-15.5) yr; Gender: males=19, females=23; Level of injury: cervical=10, thoracic=26, lumbar=6. **Intervention:** None. Retrospective review. **Outcome Measures:** Bladder management, infection history, anticholinergic and antibiotic usage, continence, renal ultrasounds, video-urodynamics.	1. Bladder management included clean intermittent catheterization (CIC) in 40 of 42 patients and antispasmodics in 37. 2. No patient had reflux, hydronephrosis or renal scarring. 3. In patients with cervical injuries, safe bladder capacity was less than the expected capacity in 80% but all patients undergoing multiple urodynamics had increasing capacity with time. 4. In patients with thoracic injuries, 58% had a safe bladder capacity less than expected and 76% of those undergoing multiple urodynamics had increasing capacity. 5. In patients with lumbar injuries, 50% had a safe bladder capacity less than expected and 67% of those undergoing multiple urodynamics had increasing capacity.
(Vogel et al. 2002b) USA Observational N=216	**Population:** Age at interview: 28.6±3.4 yr; Age at injury: 14.1±4.0 yr; Gender: males=150, females=66; Time since injury: 14.2±4.6 yr; Level of injury: tetraplegia=123, paraplegia=93. Severity of injury: C1-4 ABC=41, C5-8 ABC=67, T1-S5 ABC=82, tetra/para D=26. **Intervention:** None. Survey. **Outcome Measures:** Prevalence of urinary tract infections (UTI), hospitalizations, urinary stones, orchitis or epididymitis, bladder incontinence, dysreflexia.	1. Most (160/216) of the study subjects experienced at least 1 UTI in the year before their interview. 2. Among those who had a UTI, the mean number of infections per year was 3.9, and 41 (26%) of these individuals experienced UTIs that required intravenous antibiotics or hospitalization (severe UTI). 3. Compared with those who did not have UTI, individuals who experienced UTI had significantly lower ASIA motor scores ($p<0.001$) and were less likely to have AIS scores of D ($p<0.001$). 4. Both the ASIA Motor score ($p=0.003$), ASIA Impairment Scale scores of D ($p=0.009$), and both the total ($P = .013$) and motor ($P = .017$) FIM scores were significantly lower among individuals who experienced severe UTI. 5. Urinary stones affected 25% of the subjects. 6. Compared with those without stones, those with stones had significantly more severe neurologic deficits, with a lower mean ASIA Motor score ($p=0.007$), and lower total ($p=0.001$) and motor ($p<0.001$) FIM scores.

		7. Frequency of urinary incontinence greater than monthly was reported by 25% of the subjects; there were no significant associations between bladder incontinence and the demographic, impairment, or functional limitation variables. 8. Urinary incontinence was not more common in those who experienced UTI (or severe UTI) compared with those who did not have UTI (or severe UTI). 9. Of the male subjects, 15 (10%) reported having orchitis or epididymitis; those who had experienced either orchitis or epididymitis were older at follow-up (p=0.018), had been injured longer (p=0.04), and more likely to have had severe UTI (p=0.049). 10. Compared with those with normal bladder function, UTI (but not severe UTI) was more commonly experienced by subjects who performed intermittent catheterization, had indwelling catheters, or who used external collection devices (p<0.001). 11. Urinary stones were more common in individuals with indwelling catheters compared with those with normal bladder function, and those who were performing intermittent catheterization or using external collection devices (p=0.004). 12. Bladder incontinence was statistically associated with bladder management, with incontinence most common in those with external collection devices and least common among those with normal bladder control (p=0.050). 13. There was no significant association between the type of bladder management program and the development of orchitis or epididymitis.
(Anderson et al. 1997) USA Observational N=37	Population: *Females with Pediatric-onset SCI:* Injured Before Menarche (n=22): Age at injury: 5.8 (0-13 yr); Age at interview: 16.4 (12-25) yr; Level of injury: tetraplegia=3, paraplegia=10; Injured After Menarche (n=15): Age at injury: 14.6 (12-16) yr; Age at interview: 17.6 (16-22) yr; Level of injury: tetraplegia=9, paraplegia=6. Intervention: None. Survey.	*Injury Before Menarche Group* 1. Mean age of menarche was 12.3 (10-15) yr which was not significantly different from their mother's age of menarche or the age of menarche of females in this study who were injured after menarche. 2. The average age of menarche for those injured prior to menarche is comparable to the standard for North American females (12.5 yr). 3. There was no significant association between age of menarche and age at injury or level of injury.

	Outcome Measures: Menstrual onset, regularity, frequency, duration, dysmenorrhea, dysreflexia, menstrual flow management and age of menarche of the patients' mothers.	4. Characteristics of menstruation included regular cycles, within a normal range of 20-36 days, for 14 of the 22; remaining eight showed a variety of irregularities in their cycles. 5. Six subjects occasionally miss a month of their cycle or their periods come one to two weeks early or late; for example, one has a sixty-day cycle and another started menstruating immediately after her injury (age 11 yr) but then stopped until she turned 14 yr. 6. Seven reported having minor dysmenorrhea. 7. None experienced dysreflexia during their menstrual cycles. *Injury After Menarche* 8. Of the 15 females who were injured after menarche, seven reported no interruption in menses while eight had an interruption ranging from one to seven months. 9. There was no association between length of time until resumption of menstruation and level of injury. 10. Comparing the characteristics of menstruation pre- and post-injury, 12 females reported no changes in regularity or flow and three reported minor changes including one who became more regular and two less regular after injury. 11. Six reported changes in dysmenorrhea, including two who had less discomfort and four who had more discomfort; in all cases, dysmenorrhea was mild and none reported dysreflexia or any other complications. *Menstrual Flow Management* 12. Of the 36 with SCI who were menstruating at the time of interview, 16 used pads, 11 used tampons, 7 used both; 2 used diapers for menstrual flow management. 13. Most women reported no medical problems with either pads or tampons, although one person who had initially used pads switched to tampons because she felt she experienced more urinary tract infections with pads. 14. Another individual switched from tampons to pads because she felt that reduced urinary tract infections.

		15. Five females who had used tampons prior to injury stopped using them after injury because they found them inconvenient; four of those five were tetraplegic. 16. Five other females with tetraplegia use tampons by choice.
(Fanciullacci et al. 1988) Italy Observational N=18	**Population**: Age at injury: 5.7 yr (*n=18*), Age at follow-up: 7.7 yr (*n=14*); Gender: males=16, females=2; Level of injury: cervical=2, thoracic=8, lumbar=8; Severity of injury: complete=13, incomplete=5. **Intervention**: None. Review. **Outcome Measures**: Urodynamic studies (UDS), intermittent catheterisation (IC), upper urinary tract (UUT) condition, urinary tract infection (UTI) rate, detrusor/sphincter balance.	1. Generally, the bladder recovered its emptying quite easily. 2. Spinal shock was shorter in those with upper motor neuron lesions compared to the 4-6 wk period seen in adults. 3. Urological data at the initial evaluation following spinal shock (2 mo-1.5 yr after trauma) showed that UUT was normal in 13 patients, slight dilation in 2, vesico-ureteral reflux in 2 (ureteral stone in 1), and renal stone in 1 patient. UTI was present in 15/18 (83%) patients. 4. UDS showed that 12 had hyperreflexia. Of the 12 patients, 6 had bladder/sphincter dyssynergia. 3 had areflexia with denervation of the perineal floor. 3 were not evaluated. 5. 2 children with stones were operated on. One of the 2 patients with reflux later developed a urethrocele and vesical stones (had an indwelling catheter for 1 year). Incontinence was not diagnosed until the child was 5 yr old. Continence was partial in all cases. Only 2 children were given oxybutynin + IC, in 1 case for initial ureteroidronephrosis and in the other to try to obtain good continence. 6. Follow-up of the conservative management of the neuropathic bladder was carried out in 14 children. UUT was normal in 8/11 patients. Slight dilation in 1, and vesico-urethral reflux in 2 with normal IVP. UTI was present in 7/14 patients (50%). 12 patients had a residue of <200 0 of the bladder capacity (balanced bladder). 7. 2 children who had reflux, have a UUT in good conditions, as shown by IVP. Of the 3 children where the condition of their UUT was not checked, 2 are free of UTI, 1 has asymptomatic bacteriuria and 2 have no residue. 8. The UUT of the boy managed by IC + oxybutynin, because of initial ureteroidronephrosis, improved. 9. For all the children, the control of urinary continence is a problem.

		10. UTI was generally asymptomatic except for 2 children.
(Burke, 1974) US Observational N=29	**Population:** *Injury at birth (N=5):* Gender: males=2, females=3; Level of injury: cervical=4, thoracic=1; Severity of injury: complete=3, incomplete=2. *Injury post birth (N=24):* Gender: males=11, females=13; Level of injury: cervical=9, thoracic=14, lumbar=1; Severity of injury: complete=22, incomplete=2. **Intervention:** None. Chart review. **Outcome Measures:** Prevalence of scoliosis, urodynamic management.	1. No patients have died of renal complications, and none had a raised serum creatinine, but 6 patients had serious urological problems which could reduce their life expectancy. 2. In the group with a survival period of 0-5 yr (N=14), 1 patient died after a few months, another had bilateral vesico-ureteric reflux, but a normal pyelogram after 4.5 yr; one patient had a Leadbetters operation for left-sided vesico-ureteric reflux. 3. In the group with a survival period of 5-10 yr (N=6), 1 patient had multiple renal and bladder stones, but a normal pyelogram and normal blood chemistry 9 yr after injury; 1 had an early left nephrectomy for hydro-nephrosis, was drained by a suprapubic catheter for some yr, and had a right nephrostomy 9 yr after injury. 4. In the group with a survival period of 10-15 yr (N=3), all patients had renal damage, infected urine, 1 patient had a suprapubic catheter and 1 had bilateral cutaneous ureterostomies. 5. In the group with a survival period of more than 15 yr (N=3), 2 had poor function of one kidney, 1 had a U tube draining both suprapubically and through a peno-scrotal fistula. 6. None of the 6 longest survivors had any elevation of blood urea nitrogen or serum creatinine.

Table 20. Case reports assessing genitourinary function in children with SCI.

(Abbo et al. 2013) France Case Report N=2	**Population:** *Case I:* 23 mo, male, C7-T1 SCI; *Case II*: 18 mo, female, T6 SCI. **Intervention:** Clean Intermittent Catheterization. **Outcome Measures:** Detrusor hyperactivity, detrusor-sphincter dyssynergia, urinary retention.
(Tuite et al. 2013) USA Case Report N=1	**Population:** 10 yr, male, T10-11 SCI. **Intervention:** Xiao procedure. **Outcome Measures:** Bladder and bowel function, electrophysiological and histological evaluation.

Discussion

Given the low incidence of pediatric SCI/D (Blaivas, 1982), it is quite expected that we only found seven observational studies, one post-test, and two case reports looking at in individuals with pediatric-onset SCI. Due to the heterogeneity of the presentation of the findings and the small sample size of most studies identified from the literature, conclusions regarding the prevalence of bladder dysfunctions in children with SCI/D cannot be drawn. In a larger scale study involving 216 adults with pediatric-onset SCI, the majority (74%) of participants reported experiencing at least one UTI in the past year (Vogel et al. 2002b). Etiology wise, most study participants suffered motor vehicle accidents, either being in the vehicle during accident or as pedestrians struck by cars; some studies included participants with birth injuries (Burke, 1974; Chao & Mayo, 1994; Fanciullacci et al. 1988; Generao et al. 2004), domestic accidents (Fanciullacci et al. 1988), gunshot wounds (Chao & Mayo, 1994; Generao et al. 2004), iatrogenic causes (Fanciullacci et al. 1988; Generao et al. 2004), transverse myelitis (Chao & Mayo, 1994; Tanaka et al. 2006).

Population wise, the papers looked at individuals who sustained SCI between the ages of 0 and 18 years (Generao et al. 2004). The mean time post injury was 46 months (Chao & Mayo, 1994) to 28 years (Patki et al. 2006). Topics of examination consisted of bladder management method (Burke, 1974; Chao & Mayo, 1994; Fanciullacci et al. 1988; Generao et al. 2004; Patki et al. 2006; Tanaka et al. 2006), and continence (Fanciullacci et al. 1988; Patki et al. 2006; Tanaka et al. 2006; Vogel et al. 2002b), urodynamic studies (UDS; with or without video and cystography) (Chao & Mayo, 1994; Fanciullacci et al. 1988; Generao et al. 2004; Patki et al. 2006; Tanaka et al. 2006), upper tract health, as established by renal ultrasound (Chao & Mayo, 1994; Generao et al. 2004; Patki et al. 2006; Tanaka et al. 2006) and/or intravenous pyelogram (Burke, 1974; Chao & Mayo, 1994; Fanciullacci et al. 1988), medical complications like infections (Burke, 1974; Fanciullacci et al. 1988; Patki et al. 2006; Vogel et al. 2002b), renal insufficiency (Burke, 1974; Patki et al. 2006; Tanaka et al. 2006), lithiasis (Burke, 1974; Vogel et al. 2002b), and need for subsequent surgical interventions, like sphincterotomies/stent placement, urinary diversions and bladder augmentation, nephrectomies, etc.

Surprisingly, the severity and level of neurologic injury was not necessarily predictive of urodynamic findings. Detrusor pressures and activity did explain changes in bladder capacity, compliance and cystometric appearance at times of follow up (Patki et al. 2006)

Burke et al. (1974) looked at 29 children who sustained C1 to below T12 SCI under the age of 13 years; 26 of them had urologic follow up. Among the 20 children who were less than 10 years after injury, 17 had normal upper tracts, 15 were using reflex voiding, 10 were having infected urine, and 1 already had a nephrostomy in the single residual kidney he had. In the 6 individuals that suffered the neurologic injury more than 10 year prior to data collection, only 1 had intravenous pyelogram (which was normal), 1 emptied his bladder by reflexive void, 4 had indwelling catheters (urethral or suprapubic) and 1 had bilateral cutaneous ureterostomy.

Fanciullaci et al. (1988) reported on 18 children with SCI seen 1972-1985 in 1 unit in Italy. Participants were first assessed 2-18 months post injury, and follow-up assessment was done in 14 children 7.7 years post injury on average, to evaluate results of the conservative management of the neurogenic bladder. Authors noted that the initial indwelling catheter was removed within 4 months in 14 of the participants. In the initial urologic follow up, the upper urinary tract was normal in 13 patients; slight dilatation and vesicoureteral reflux was noted in 2 each and renal stone in 1 patient; UTI was deemed present in 15/18 patients, but 13 of the 15 were noted to be asymptomatic bacteriuria. 15/18 underwent UDS which showed over-active detrusor in 12 children. In the 14 children that were evaluated 2-16 years post injury, the upper urinary tract was deemed normal in 8/11 patients; 1 child was found to have a slight dilatation of the upper tract; vesicoureteral reflux was found in 2 children (with normal intravenous pyelogram) and UTI was present in 7/14 patients, with 5/7 noted to be asymptomatic bacteriuria.

Chao et al. (1994) looked at 40 children with SCI receiving urological care; Initial bladder management was done by reflex voiding (with acceptable voiding pressures <40 cm H2O) in 11 of the participants; the rest of 29 emptied their bladder by intermittent catheterization, utilizing anticholinergic drugs to address higher than 40 cm H2O voiding pressures, presence of detrusor-sphincter dyssynergia and/or having moderate to severe bladder trabeculations. First UDS showed that all 22 patients with cervical injury had over-active detrusor; 8 were reflexively voiding and 14 emptied their bladder by intermittent catheterization; in the thoracic injured category, 11 patients had over-active detrusor and two were areflexic; among them, 2 were reflexively voiding and 11 were using intermittent catheterization; in the 5 individuals with lumbar spine injury, bladder management was by reflexive void in 2 and intermittent catheterization in 3 and UDS showed that all of them had areflexic bladders. 28/40 participants were followed for more than 1 year undergoing bladder management assessment and video UDS; 11/19 patients with cervical injury, 5/6 with thoracic injury and 1/3 with lumbar injury were emptying the bladder using intermittent catheterization/anti-cholinergic drugs at this follow up; video fluoroscopy during UDS showed the bladder wall to be smooth in 43%, mildly trabeculated in 50% of participants, and markedly trabeculated in 7%. Five patients had a change from a smooth bladder wall to mild trabeculation (four cervical injuries and one thoracic injury). Four patients had a change from a trabeculated bladder wall to a smooth wall (three cervical injuries and one thoracic injury) at six month follow up after institution of intracranial pressure and anticholinergic therapy. One patient had a grade 2/5 vesicoureteral reflux, which resolved on intermittent catheterization/anticholinergics. The authors noted that neurogenic management treatment failure was related to non-compliance with catheterization or pharmacologic regimen.

Unlike the studies discussed previously, Vogel and colleagues' (2002b) work assessed the consequences of pediatric SCI/D related neurogenic bladder by interviewing 216 adults with pediatric-onset SCI using a structured questionnaire. Mean number of UTI's/year was reported to be 3.9 and occurred in 74% of individuals; those experiencing more UTI's had lower International Standards for Neurological Classification of Spinal Cord Injury motor scores and were less likely to have AIS D grade injury. In addition, History of severe UTI's and urinary stones were associated with lower motor scores, higher injury level, and Functional Independence Measure scores. Those who reported having orchitis and epididymitis tended to be older, injured for a longer period of time and reported having had severe UTI's. Bladder incontinence was reported by 25% of participants, more common in those using external catheters; UTI's were more common in individuals managing bladder with all types of catheters. Severe UTI's, orchitis and epididymitis were not associated with any specific type of bladder program, but stones were more common in individuals using indwelling catheters.

Generao et al. (2004) performed a retrospective review of 42 pediatric patients who had been living with SCD related paralysis for a minimum of 1 year. Assessed outcomes were bladder management, continence, medication, UTI occurrence, upper urinary tract health (US) and video-UDS in the context of safe bladder capacity (defined as pressure specific volume of 40 cm water or less. 40/42 children were managing the bladder using intermittent catheterization and 37 were taking anti-cholinergic medications. Upper tract exploration showed no vesicoureteral reflux, hydronephrosis or renal parenchymal scarring. Bladder capacity was less than expected in 80% of cervical injuries (but increasing with time); it was less than expected in 58% of thoracic injuries (and only 76% were found to progress as expected with time); and was less than expected in 50% of lumbar injuries. Early bladder management with intermittent catheterization and anticholinergic drugs usage was considered to prevent hydronephrosis, scarring, reflux and bladder trabeculation, improve continence and decrease rates of infection. In addition, thoracic injuries were found to have the most variable bladder pattern.

Patki et al.(2006) conducted a retrospective review of urological follow-up in 10 adults with paediatric onset SC The group was divided in Neurogenic Detrusor Overactivity with or without Detrusor Sphincter Dyssynergia and a-contractile detrusor with or without low bladder compliance, based on initial UDS studies. It was found that patients with Neurogenic Detrusor Overactivity and Detrusor Sphincter Dyssynergia were at higher risk of developing complications. In addition, those who opt for reflex voiding and SPC were more likely to experience multiple problems requiring hospitalisations and interventions. The authors also noted that over time, most participants required changes to optimise urological management.

Finally, Tanaka et al. (2006) retrospectively examined the long-term urological outcomes in 22 children affected by transverse myelitis, as well as the correlation between bladder dysfunction and lower limbs spasticity and ambulatory status in addition to neurologic level of injury. Lower limbs spasticity was documented in 14/22 (61%) and, while none of the children were ambulatory immediately post onset of neurologic deficit, 9/22 (41%) became ambulatory during the follow up period. At follow up, 86% of children reported persistent bladder dysfunction. Bladder management was done by intermittent catheterization in 73% and 64% was using anticholinergic medications. Three were still incontinent despite adequate bladder management and 1 had the incontinence resolved by undergoing intra-detrusor onabotulinumtoxin type A injections. 6/22 were able to void volitionally, 2 of them having incomplete cervical injuries and maintaining continence (one using anticholinergic medication) and 4 of them having incomplete lumbar injuries, with only 2/4 maintaining continence. All patients with complete injury remained on intermittent catheterization. UDS were completed in 17 at follow up, an average of 2.2 years after disease onset; detrusor over-activity was present in 10 patients (59%), Detrusor Sphincter Dyssynergia in 7 (41%), low compliance in 8 (47%) and detrusor leak point pressure greater than 40 cm water in 2 (12%). Upper tract was evaluated in 19/22 individuals using renal ultrasound and cystography for vesicoureteral reflux; 26% had upper tract changes (hydronephrosis in 3, reflux in 1, and hydronephrosis and reflux in 1). Chronic renal insufficiency developed in only 1 individual that did not have adequate urologic care for the initial 2.7 years post injury, developed hydronephrosis and vesicoureteral reflux despite having a complete thoracic injury with no lower limb spasticity; the bladder was found to have low compliance and, despite treatment with intermittent catheterization and anticholinergics, patient needed to undergo augmentation cystoplasty and bilateral ureteral reimplantation to address the complications. 6 individuals that subsequently underwent upper tract and UDS evaluation started intermittent catheterization in the first 9 months post injury, and another 10 in the first 2.3 years post injury and were considered early intermittent catheterization users; none of the early catheterization users developed low bladder compliance of upper pathologic tract changes, as opposed to 7 of 10 patients in the delayed catheterization group exhibiting low bladder compliance and 4 of 10 having upper tract changes at follow up.

Conclusion

Major shortcomings of the literature pertaining to management and consequences of neurogenic upper and lower urinary tract dysfunction in children with SCI/D related paralysis is the retrospective, observational case studies reporting type. That is because high quality evidence regarding management and follow up does not exist in the literature (Averbeck & Madersbacher, 2015). There is no standardization of intervention or even follow up. The approach is not scientifically rigorous but clinically driven and there are no controls. Sometimes, even the definition of terms is variable (e.g., bladder compliance).

With that said, given the fact that pediatric SCI/D is extremely rare, learning from robust case series is the first step towards building knowledge. The reviewed papers consistently point to the lack of predictive value of neurological injury category on bladder function and management. To that point, it does appear that thoracic injuries are less likely to be predictable when it comes to the type and subsequent management of neurologic bladder dysfunction. The ideal urological treatment needs to be individualized and tailored to suit a specific patient's medical and social needs and both needs are changing as the child grows. Changes in bladder management required at later stage in injury and variation of renal deterioration with different bladder managements make a strong case for regular and long-term follow-up of the pediatric SCI population. Ongoing long-term comprehensive assessment utilizing imaging (renal ultrasound and scan, computed tomography scan, cystometogram, cystoscopy) and functional (video-urodynamics, creatinine clearance, glomerular filtration rate, cystatin C, radio-isotope studies etc.) tools to assess both upper and lower tracts is strongly recommended for management guidance in the ever growing and evolving genitourinary system. Preservation of renal function is the most important objective of any long-term treatment plan in children with SCI/D related neurogenic bladder dysfunction. Early assessment of the bladder function in this population and ongoing treatment compliance monitoring appears to play a major role in preventing long term medical complications. Asymptomatic bacteriuria and recurrent infections are frequent, especially in the instrumented bladder and prophylactic antibiotic usage is not well supported. There is a great need for developing prospective, controlled studies looking at effect of specific interventions on renal function preservation and prevention of bladder pathologic changes.

Key Points

Preservation of renal function is the most important objective of any long-term treatment plan in children with SCI/D

Continence and bladder management status does not significantly correlate with neurological level of lesion

Personalized, long-term neuro-urologic care is necessary in individuals with pediatric onset neurologic upper and lower urinary tract dysfunction.

5.3 Thromboembolic Function

Pediatric venous thromboembolism (VTE), which includes deep vein thrombosis and pulmonary embolism has a relatively low incidence compared with adults, estimated at 0.07 to 0.14 per 10 000 children (Andrew et al. 1994; Stein et al. 2004). The incidence is considerably higher in hospitalized children, reaching values of ≥58 per 10 000 admissions (Andrew et al. 1994; Gibson B, 2003; Sabapathy et al. 2016; van Ommen CH, 2001). Preventing episodes of VTE is essential for minimizing the significant morbidity and mortality associated with its occurrence, namely post thrombotic syndrome, recurrence of thrombo-embolism and death (Goldenberg et al. 2012; Monagle et al. 2000; Rajpurkar M, 2015; Revel-Vilk et al. 2012).

While the literature is extensive when it comes to risk factors, diagnosis and prevention of VTE in adults (Heit, 2015; Phillippe, 2017), there is substantially less knowledge about pediatric VTE (Branchford et al. 2018; Monagle et al. 2018). Identified risk factors for VTE include presence of central vein catheters, trauma and associated injury severity score, spinal fractures and associated SCI, ventilator dependency, chest injuries, BMI/obesity, family/personal history of clots, age (bimodal distribution, more frequent in neonates and teenagers, with the latest possibly influenced by hormones (intrinsic or exogenous - contraceptive pills) (Monagle et al. 2018; Witmer & Takemoto, 2017). The easiest construct when assessing VTE risk in pediatric population appears to be the Virchow's triad activation: stasis of blood flow, injury to the endothelial lining, and hypercoagulability of blood components. The most common precipitating factor is the presence of a central venous catheter, which is related to almost 90% of VTE in neonates and >60% in older children (Tran et al. 2018). More than 90% of cases of pediatric VTE have >1 risk factor, with venous access devices being the most common single risk factor and accounting for >90% of neonatal VTE and >50% of pediatric VTE (Carrillo et al. 2019). VTE has been found to be the most likely cause of preventable death in hospitalized population (Paiement, 1995). And VTE, pediatric or adult, has the potential for significant morbidity and mortality (Witmer C, 2016).

The natural history of VTE in children remains unclear in many circumstances. The reported VTE mortality from registry data is ~3%, in the context of ~16% of children dying from their underlying illness (Witmer & Takemoto, 2017). Finally, as there are no anticoagulant drugs approved for use in children, with very little specific research in children, the European Society for Vascular Surgery issued clinical guidelines about venous thrombosis treatment in February 2021 advising that management of pediatric deep vein thrombosis should be guided by clinicians with specific expertise in pediatric thrombosis and hemostasis (Kakkos et al. 2021). In this context, an increased VTE likelihood in children with traumatic spinal cord injuries and the interest in its prevention and management can easily be explained. And while there is substantially more information about pediatric trauma related VTE (Thompson et al. 2013), this section attempts to summarize the data pertinent to the traumatic SCI diagnosis.

Table 21. Studies assessing deep vein thrombosis and pulmonary embolism among children with SCI.

Author, Year Country Study Design Sample Size	Study Characteristics	Results
(Blevins & Raffini, 2015) USA Case Report N=2	*Case Report 1:* **Population:** Age: 17 yr; Gender: male; Injury etiology: SCI; Mechanism: MVC; Severity of injury: triplegia. **Intervention:** Prophylactic, non-retrievable IVC filter and 40 mg enoxaparin daily for 12 mo. **Outcome Measures:** VTE incidence and outcome. *Case Report 2:* **Population:** Age: 15 yr; Gender: male; Injury etiology: SCI; Mechanism: gunshot; Severity of injury: paraplegia. **Intervention:** Prophylactic, removeable IVC filter with removal scheduled. **Outcome Measures:** VTE incidence and treatment.	*Case Report 1:* 1. Presentation: Occlusive thrombi extending from the IVC filter bilaterally down to the popliteal veins within two months of stopping enoxaparin. 2. Treatment: Catheter- directed thrombolysis with recombinant tissue plasminogen activator and balloon venoplasty were performed to restore vascular patency. 3. Follow-up: Warfarin as an outpatient for long-term anticoagulation. *Case Report 2:* 4. Presentation: IVC filter was never removed due to loss of follow-up. Occlusive thrombi extending from the IVC filter bilaterally down to the popliteal veins within 7 months of injury. 5. Treatment: Catheter- directed thrombolysis with recombinant tissue plasminogen activator and balloon venoplasty were performed to restore vascular patency. 6. Follow-up: Warfarin as an outpatient for long-term anticoagulation.
(Jones et al. 2005) USA Observational	**Population:** Age: 44.5±21.0 yr; Gender: males=11,777, females=4,463; Level and	1. In total, 70 of 1,585 (4.4% pediatric patients (aged 8-19 yr) with SCI

N=16,240 (N=1,585 <20 yr)	severity of injury: complete paraplegia=1017, complete tetraplegia=1218 **Intervention:** None **Outcome Measures:** Incidence of venous thromboembolism (VTE).	developed a VTE within one year of hospitalization.
(Vogel et al. 2002b) USA Observational N=216	**Population:** Age at injury: 14.1±4.0 yr; Age at interview: 28.6±3.4 yr; Gender: males=150, females=66; Time since injury: 14.2±4.6 yr; Level of injury: tetraplegia=123, paraplegia=93. Severity of injury: C1-4 ABC=41, C5-8 ABC=67, T1-S5 ABC=82, tetra/para D=26. **Intervention:** None. Survey. **Outcome Measures:** Prevalence of thromboembolism.	1. Forty-one subjects experienced thromboembolism after the immediate postinjury period. 2. Among all the study variables, thromboembolism was only significantly associated with older age at interview (p=0.044) and longer duration of injury (p=0.004).

Table 22. Pediatric Trauma Centers/Datasets (where SCI is included)

Author, Year Country Study Design Sample Size	Study Characteristics	Results
(Bigelow et al. 2018) USA Observational N=692	**Population:** Median Age (IQR): 4.0 (0.8-11.0) yr; Gender: 358 male, 180 female; Setting: Pediatric Intensive Care Units; Etiologies: intracranial head injury, thoracic injury, abdominal/pelvic injury, burn injury, blood vessel injury, lower extremity fracture, upper extremity fracture, crush injury, SCI, coagulation disorder, hemorrhagic condition. **Intervention:** Mechanical (pneumatic compression device), Pharmacologic (heparin, LMW heparin, direct thrombin inhibitor, oral Xa inhibitor, warfarin) or dual (mechanic and pharmacologic) DVT prophylaxis. **Outcome Measures:** Factors associated with prophylaxis.	1. There was no significant association between injury diagnoses, without the corresponding procedure (aside from head injury), which was inversely associated with any prophylaxis.
(Leeper et al. 2017) USA Observational N=753 (N=57 SCI)	**Population:** Median Age (IQR): 4 (1-13) yr for DVT group, 9 (3-14) yr for no DVT group; Gender: 503 males, 250 females. Setting: Pediatric Intensive Care Unit. **Intervention:** None.	1. Just 5 of 57 individuals with SCI developed a DVT and none developed PE.

	Outcomes: Incidence of DVT and PE.	
(Faustino et al. 2014) USA Observational N=2,484	**Population:** Age <1 yr: 1,025; Age 1-13 yr: 1,191; Age >13 yr: 268; Gender: 1,389 males, 1,095 females; Setting: 59 Pediatric Intensive Care Units in Australia, Canada, New Zealand, Portugal, Singapore, Spain, and the United States. **Intervention:** None. **Outcome Measures:** Predictors of pharmacological and mechanical thromboprophylaxis.	1. The presence of cyanotic congenital heart disease (OR, 7.35; p<0.001) and SCI (OR, 8.85; p=0.008) strongly predicted the use of pharmacologic and mechanical thromboprophylaxis, respectively. 2. The presence of SCI had the highest likelihood of mechanical thromboprophylaxis (OR, 8.85; 95% CI, 1.79–43.82; p=0.008).
(O'Brien & Candrilli, 2011) USA Observational N=135,032 (N=3,172 SCI)	**Population:** Mean Age (SE): 13.6 (0.1) yr; Gender: 94,204 males, 40,828 females; Setting: Pediatric Critical Care Unit. **Intervention:** None. **Outcomes:** Incidence and risk factors of VTE.	1. Among 3,172 patients SCI, 68 (8.2%) developed a VTE. 2. SCI was a significant risk factor for developing a VTE in this pediatric trauma population (OR 1.77, p<0.0001).
(Hanson et al. 2010) USA Observational N=144	**Population:** Age: 8.6 (2.3-17.9) yr for VTE group, 11.5 (0.4-17.8) yr for non-VTE group; Setting: Pediatric Intensive Care Unit. **Intervention**: None. **Outcomes:** Risk factors for developing VTE.	1. SCI was not a significant risk factor for VTE.
(Cyr et al. 2006) Canada Observational N=3,291	**Population:** Age: <18 yr; Setting: Pediatric Intensive Care Unit. **Intervention:** None. **Outcomes:** Incidence of VTE.	1. SCI was a significant risk factor VTE (OR 23.4; 95% CI 3.2-170.8).
(Azu et al. 2005) USA Observational N=13,894	**Population:** Age: <13 yr, 13-17 yr, >17 yr; Setting: Trauma Registry. **Intervention:** None. **Outcomes:** Incidence of VTE.	1. SCI was not a significant risk factor VTE.
(Cook et al. 2005) USA Observational N=116,357	**Population:** Age 0-13 yr: 72,279; Age 14-17 yr: 44,078; Gender: 75,743 males, 40,511 females; Database: National Trauma Databank (Pediatric): head injury, severe SCI, vertebral fracture, severe pelvic fracture, severe femur fracture, and tibia fracture. **Intervention:** None. **Outcome Measures:** Risk factors associated with vena cava filtration placement.	1. SCI was a significant risk factor associated with vena cava filtration (p<0.001).
(Vavilala et al. 2002) USA Observational N=58,716	**Population:** Age: >16 yr; Setting: Trauma Registry. **Intervention:** None. **Outcomes:** Incidence of VTE.	1. Individuals with SCI had a VTE rate of 6.0 per 1,000 patients. 2. SCI was significantly associated with VTE (RR 7.9, CI 1.9-32.7).

(McBride et al. 1994) USA Observational N=28,692 (N=290 SCI)	**Population:** Mean Age: 9 yr; Setting: National Pediatric Trauma Registry. SCI Severity: 108/290 with paraplegia or tetraplegia. **Intervention:** None. **Outcomes:** Incidence of DVT and PE.	1. Just 6 of 28,692 patients had a DVT. 2. Just 2 of 28,692 patients had a PE (no DVT); both patients had sustained a SCI resulting in paraplegia. 3. Among those with a PE, one patient had a vena cava filter placed prior to the PE and died; the other patient had a vena cava filter placed after the PE and survived.
(Radecki & Gaebler-Spira, 1994) USA Observational N=532 (N=87 SCI, N=4 transverse myelitis)	**Population:** Mean Age: <18 yr; Setting: Pediatric Rehabilitation Unit. **Intervention:** None. **Outcomes:** Incidence of DVT and PE.	1. Just 1 of 87 patients with SCI and 1 of 4 patients with transverse myelitis each had a PE. 2. DVT was confirmed in 8 of 87 patients with SCI; just 1 patient with confirmed DVT in SCI was under age 13 yr.

Table 23. Systematic review assessing deep vein thrombosis and pulmonary embolism among children with SCI.

Author, Year Country Study Design Number of Studies Included for Review	Method Databases Search Level of Evidence Research Question	Results
(Thompson et al. 2013) USA Systematic Review N=18 articles	**Databases:** English-language articles identified through Pubmed published from 1995 until November 2012, and from bibliographies of relevant articles. **Research Questions:** In the pediatric traumatic injury population: (1) What is the overall incidence of VTE? (2) Is age (adolescence versus pre-adolescence) associated with higher VTE incidence? (3) Which risk factors are associated with higher VTE incidence? (4) Does mechanical and/or pharmacological prophylaxis impact outcomes?	1. N=18; In the spinal cord injury population, patients aged 14–19 yr had significantly more VTE (4.4% compared to 1.1% of younger patients; p = .035). 2. In multivariate logistic modeling, the younger age group (b 14 yr) had a decreased risk of VTE (odds ratio 0.2, 95% confidence interval 0.1 to 0.9). Most episodes (90%) of VTE occurred within 91 days of injury. 3. Patients with a SCI represent a subset of the trauma population with a higher risk for VTE, although data in children younger than 15 yr are sparse.

Discussion

Among the studies idented in the literature search, three focused exclusively on the pediatric SCI population (Blevins & Raffini, 2015; Jones et al. 2005; Vogel et al. 2002b). Most of the papers were retrospective in nature, and the data were heterogeneously presented, with variations amongst assessed outcomes, analysis of co-existing or pre-existing VTE risk factors and diagnosis, usually based on clinical symptoms. Nevertheless, the studies generally revealed a low prevalence of VTE (deep vein thrombosis and pulmonary embolism) in hospitalized children and adolescents with SCI, ranging from 0.6% to 10% (Faustino et al. 2014; Hanson et al. 2010; Jones et al. 2005; Leeper et al. 2017; McBride et al. 1994; O'Brien & Candrilli, 2011). In addition, in a study investigating the prevalence of various medical complications, such as UTI, pressure ulcers, thromboembolism, and AD, in 216 adults with pediatric-onset SCI, VTE was amongst the least reported medical complications in that sample (Vogel et al. 2002b).

Of those with pediatric onset SCI, older age was found to be associated with higher likelihood of developing VTE (Jones et al. 2005; Radecki & Gaebler-Spira, 1994; Thompson et al. 2013). In a sample of 1,585 hospitalized children and adolescents with SCI from Jones and colleagues' (2005) study, the incidence of VTE was considerably higher in adolescents between ages 14-19 (4.4%) compared to that in children between ages 8-13 (1.1%). Similar results were revealed in several other studies examining the prevalence of VTE across different age groups in the pediatric SCI population (Cyr et al. 2006; McBride et al. 1994; Thompson et al. 2013). According to Cyr et al. (2006), those with higher level of injury severity may also be more likely to develop VTE than those with less severe injuries. However, this relationship was not established in

Concerning the relation between gender and occurrence of VTE, the research findings are mixed. Furthermore, there is conflicting evidence regarding whether SCI is associated with heightened risk of developing VTE in the pediatric population. While the majority of the studies suggested that having SCI was a significant risk factor for VTE (Cyr et al. 2006; O'Brien & Candrilli, 2011; Thompson et al. 2013; Vavilala et al. 2002), some did not demonstrate such link (Azu et al. 2005; Hanson et al. 2010; Leeper et al. 2017).

Jones et al. (2005) found that boys age 8-13 years were just slightly more likely than girls to experience VTE; in the 14-19 age group, adolescent boys were 3.5 more likely than females to be diagnosed with thromboembolic events. There were just 181 VTE cases age 13 or under, and only 8 of those were coded as having complete paraplegia or quadriplegia, thus a relationship between injury severity and likelihood of VTE was not established in the pediatric population.

In terms of VTE prophylaxis, both mechanical (applied in children 8 years or older) and pharmacological prophylaxis were common in the younger children and becomes more common in adolescents, especially those admitted to adult trauma centers (Azu et al. 2005; Bigelow et al. 2018; Faustino et al. 2014). Because of the low incidence of VTE in pediatric patients with SCI, some have suggested VTE prophylaxis may not be necessary for this population (Azu et al. 2005). Among pediatric patients with various trauma etiology who received VTE prophylaxis, both Bigelow et al.(2018) and Faustino et al.(2014) found that pediatric SCI was predominantly associated with initiation of mechanical prophylaxis.

Key Points

SCI related paralysis is a risk factor for VTE occurrence, especially in adolescents and young adults

Preventions and treatment of VTE in this population is highly individualized and, in most cases, left to the treating clinicians' decision and there is no pediatric specific mechanical or pharmacologically proven intervention

VTE diagnosis is clinically based not on active screening and the role of active screening is not known in this population; older kids are found to have more VTE but that could also be related to them being more actively screened in adult trauma hospital protocols

Children with traumatic SCI may have associated risk factors for VTE, like central vein catheters, long bone fractures, vascular injuries, higher injury severity scores, etc.).

5.4 Cardiovascular and Autonomic Function

5.4.1 Cardiovascular Health and Fitness

Accumulating evidence supports the important role of pediatric cardiovascular (CVS) health in CVS health throughout life (Umer et al. 2017; Urbina et al. 2019; Wright et al. 2001). The accumulation of behavioral and clinical risk factors that will later influence adult CVS health could be substantially accentuated in children with SCI/D related paralysis, because, as shown in previous studies, different measures of physical performance, like strength, walking speed, balance, can act as markers of current and future health in adults (Cooper et al. 2011). Growing and living with paralysis can influence numerous factors that, in turn, could impact lifelong CVS and metabolic health: 1) biological factors: inflammation, gut microbiome, levels of total cholesterol, blood pressure, and fasting glucose; 2) behavioral factors: activity/exercise level, diet and healthy weight/BMI, smoking (including marijuana), sleep, social isolation/bullying, participation, electronic media usage; and 3) economic factors: socioeconomic status, access to care, transition to adult care.

It is suspected that individuals with childhood onset SCI/D paralysis may fair worse as it pertains to CVS health lifelong. As CVS disease is number one cause of morbidity and mortality in adults living with chronic paralysis (Whiteneck et al. 1992) and the prevalence rate of symptomatic CVS disease is higher in individuals with paralysis than in able body individuals (Myers et al. 2007). While there is no concrete evidence that individuals with childhood onset paralysis have higher CVS morbidity and mortality than those with adult onset of paralysis, they do have a 31% increase in the annual odds of dying compared with persons injured at older ages (Shavelle et al. 2007). Thus, assessing and improving CVS fitness in children with paralysis appears quite essential amidst the confluence of multiple inter-relating biological, interpersonal, and behavioral features of this life stage.

Evidence to guide optimal care is quite limited in pediatric medicine and even more so in the relatively small field of SCI/D related paralysis.

This section reviews evidence examining the following CVS factors:

1. body composition (as assessed by Dual X-ray Absorptiometry), specifically total lean mass, fat mass, percentage body fat and BMC/BMD
2. anthropmetric measures, like weight, height and BMI
3. measures of metabolic efficiency meant to assess metabolic syndrome likelihood, like fasting lipids, fasting glucose, insulin resistence, resting metabolic rate
4. measures of cardio-respiratory function: resting heart rate, VO_2
5. measures of functional performance, like muscle strength, power output, forced vital capacity

Table 24. Studies assessing cardiovascular risk factors in children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Johnston, Smith, et al. 2009) USA RCT N=30 PEDro=5	**Population:** *Original RCT (n=30):* Age: 9.7±2.5; Gender: males=17, females=13; Injury etiology: Traumatic SCI=26, Transverse Myelitis=2, Chemotherapy=1, Ischemia=1; Level of Injury: cervical=11, thoracic=19; Severity of Injury: AIS A=22, B=6, C=2. **Intervention:** Subjects were randomized to one of three groups: 1) Functional Electrical Stimulation Cycling [FESC; n=10] (50 rpm while seated in wheelchair, pulse duration=150 ls, frequency=33 Hz, amplitude max 140 mA, increased automatically to generate sufficient force to maintain the cadence); 2) passive cycling [PC; n=10] (50 rpm), or 3) non-cycling with 20 min daily surface electrical stimulation [ES; n=10] to lower extremity muscles. Sessions were conducted for 1 hr/day, 3 days/wk for 6 mo. **Outcome Measures:** Heart rate (HR), oxygen consumption (VO_2/kg) under four conditions	1. There were no significant differences between groups in VO_2/kg, HR, FVC or any of the lipids between baseline and the 6 mo follow-up.

	(pre-exercise, warm-up, activity to fatigue, recovery), Forced Vital Capacity (FVC), Lipid Profile (i.e., high density lipoprotein [HDL], low density lipoprotein [LDL], cholesterol, triglycerides).	
(Johnston, Smith, et al. 2008b) USA RCT* N=4 *Subjects were a subset from the larger RCT by (Johnston, Smith, et al. 2009)	Population: *Case 1:* 7 yr, female, T4-T6, ASIA A SCI at 2 yr of age; *Case 2:* 9 yr, female, C7, ASIA A SCI at 4 yr of age; *Case 3:* 7 yr, male, T3, ASIA A SCI at 3 yr of age; *Case 4:* 11 yr, male, C7, ASIA A SCI at 3 yr of age. Intervention: Subset of patients randomized to one of two groups: 1) Functional Electrical Stimulation Cycling [FESC] at 50 rpm while seated in wheelchair (pulse duration (150 ls) and frequency (33 Hz) were fixed; current amplitude (max 140 mA) increased automatically to generate sufficient force to maintain the cadence), or 2) Passive cycling at 50 rpm. Sessions were conducted for 1 hr, 3 times/wk for 6 mo. Outcome Measures: Bone mineral density (BMD) using Dual Energy X-ray Absorptiometry (DEXA) of the left femoral neck, distal femur, and proximal tibia; left quadriceps muscle volume using magnetic resonance imaging (MRI); electrically stimulated strength of the left quadriceps using a dynamometer; spasticity of the quadriceps and hamstrings muscles using Ashworth scale scores; fasting lipid profile via high density lipoprotein (HDL) and low-density lipoprotein (LDL); heart rate (HR); and oxygen consumption (VO_2/kg).	*Case 1: FESC* 1. Improvements in BMD at the femoral neck, distal femur, and proximal tibia; quadriceps muscle volume; stimulated strength of the quadriceps muscles; HDL cholesterol; resting HR; peak VO_2/kg; and peak HR; however, cholesterol, LDL, and triglyceride levels and the cholesterol/HDL ratio increased compared to baseline. 2. No changes in Ashworth scores, but parents reported decreased spasticity and looser muscles. *Case 2: FESC* 3. Improvements in BMD at the femoral neck, distal femur, and proximal tibia; quadriceps muscle volume; stimulated quadriceps muscle strength; and hamstring muscle spasticity; however, cholesterol, LDL, HDL, and triglyceride levels and the cholesterol/HDL ratio worsened as compared to baseline. 4. The parents reported bigger, firmer muscles; decreased bowel program completion times; increased appetite; and increased spasticity that did not require medical intervention. *Case 3: PC* 5. Improvements in femoral neck BMD, hamstring spasticity, and triglyceride levels. 6. Distal femur and proximal tibia BMD and stimulated quadriceps strength were lower as compared to baseline, and LDL levels and the cholesterol/HDL ratio were elevated. 7. Parents reported decreased bowel accidents and new sensation in his knees and stomach. *Case 4: PC* 8. Improvements in BMD at the femoral neck, distal femur, and proximal tibia; quadriceps muscle volume; stimulated quadriceps strength; hamstring spasticity; cholesterol; LDL cholesterol; resting HR; and peak VO_2/kg.

		9. HDL cholesterol decreased as compared to baseline but the cholesterol/HDL ratio was unchanged. 10. Parents reported decreased spasticity, looser muscles, increased energy, decreased lower extremity swelling, and increased appetite.
(Johnston, Smith, Betz, et al. 2008) USA Observational N=29 *Subjects were a subset from the larger RCT by (Johnston, Smith, et al. 2009)	**Population:** Age: 9.7±2.5 yr; Gender: males=17, females=12; Injury etiology: Traumatic SCI=24, Transverse Myelitis=1, Other=4; Level of Injury: C8/C9=9, T1-4=9, T5-11=11. **Intervention:** Upper extremity, tabletop ergonomic testing. **Outcome Measures:** Heart rate (HR), and oxygen consumption (VO_2/kg) under four conditions (pre-exercise, warm-up, activity to fatigue, recovery), peak power output (PO) (W_{peak}/kg).	1. For all subjects, the following peak values were obtained: - HR=149.9±31.6 beats per minute - VO_2=14.0±7.9 mL/kg - PO=1.1±0.7 W/kg 2. Differences were seen between the three injury groupings (C8-9, T1-4, T5-11): - HR peak (p=0.013) - VO_2peak/kg (p=0.041) - PO (p=0.001) 3. Differences were noted between the C8-9 group and the T5-11 group for HR peak (p=0.010), VO_2 peak (p=0.038), and PO peak (p=0.001).
(Nelson et al. 2007) USA Observational N=114 (N=20 SCI)	**Population:** *SCI Group (n=20):* Age: 16.9±3.0 yr; Gender: males=11, females=9; Time since injury: 4.8±4.0. *Spina Bifida (SB) Group (n=34):* Age: 16.3±2.5 yr; Gender: males=18, females=16; Time since injury: 16.3±2.5. *Control (CTRL) Group (n=60):* Age: 16.2±2.5 yr; Gender: males=27, females=33. **Intervention:** None. Anthropometric testing. **Outcome Measures:** Height, weight, waist circumference, percentage of trunk fat by Dual X-ray Absorptiometry, blood pressure, body mass index, fasting serum samples (glucose, insulin, triglycerides, total cholesterol, high density lipoprotein (HDL), low density lipoprotein (LDL); metabolic syndrome.	1. There was a significant difference in body weight between SB and CTRL, with SB weighing 14.6% less than CTRL (p<0.001) but no significant difference between SCI and CTRL or between SB and SCI. 2. Percent total body fat and trunk fat was significantly different between each group, with SB averaging 6.3% more trunk fat than SCI and 11.5% more trunk fat than CTRL (among all 3 groups, p<0.001; SB versus SCI and SB versus CTRL, p=0.004). 3. Obese SCI had been injured almost twice as long as nonobese SCI subjects (p<0.001). 4. BMI z-scores were 0.7 higher in SB than CTRL and 1.36 higher in SB than SCI (p<0.001 for both). 5. There were no significant differences in systolic BP z-scores; serum LDL, triglyceride, or cholesterol concentrations, or glucose between groups. 6. Serum HDL concentrations lower in SCI. 7. There was no significant difference in glucose between SCI and CTRL groups. 8. A total of 5.9% of SB and 5.0% of SCI subjects had no components of metabolic syndrome. 9. A total of 32.4% of SB and 35.0% of SCI subjects had 1 risk factor. 10. A total of 61.8% of SB and 60.0% of SCI subjects had 2 risk factors of metabolic syndrome.

		11. In total, 32% of SB subjects and 55 .0% of SCI subjects met the criteria for metabolic syndrome (3+ criteria). 12. There was a strong association between diagnostic group (SCI, SB, and CTRL) and presence of metabolic syndrome.
(Widman et al. 2007) USA Observational N=115 (N=19 SCI)	Population: *SCI Group (n=19):* Age: 16.0±3.2 yr; Gender: males=10, females=9; Level of injury: T4-6=10, T7-11=6, L1-5=3. Severity of injury: AIS A=13, AIS B=3, AIS C=1, AIS D=2. Height: males=158.0±15.4 cm, females=162.4±11.9 cm; Weight: males=65.8±23.6 kg, females=66.3±22.8 kg. Injury etiology: SCI (n=19), Spina Bifida (SB, n=37), Normal Weight Controls (CTRL, n=34), Overweight Controls (OW, n=25). Intervention: Upper extremity, tabletop ergonomic testing. Outcome Measures: Body Mass Index (BMI), shoulder and elbow strength, heart rate (HR), and oxygen consumption (VO_2/kg), power output (PO).	1. For both males and females, the CTRL group was significantly lighter than the OW, SB, and SCI groups. 2. The male and female SB and OW groups had significantly higher BMI than CTRL. 3. Percent body fat of OW, SB, and SCI groups was significantly higher CTRL group. 4. There was no significant difference in any of the peak strength values between the SB and SCI groups for either gender. 5. Both the male and female CTRL groups had significantly greater shoulder extension strength values than the OW, SB, and SCI groups of the same gender. 6. Within each gender, the SB and SCI groups had significantly lower VO_2 peak values at rest than the CTRL and OW groups did. 7. Accounting for body mass, the SB, SCI, and OW groups had significantly lower VO_2 peak/kg than the CTRL group. 8. For the males, the CTRL and OW groups reached similar max PO (86±4.4 W and 93±8.5 W, respectively), while both the SB and SCI groups reached exhaustion at significantly lower levels (62±4.9 W and 60±6.6 W, respectively) than either the CTRL or OW subjects; females showed similar relationships. 9. All of the groups reached similar peak HR but the male and female SB groups had significantly higher resting HR than the CTRL group of the same gender. 10. Mean resting HR for female SCI groups was also higher than the CTRL and OW groups.
(Liusuwan et al. 2004) USA Observational N=54 (N=27 SCI)	Population: *SCI Group (n=27):* Age: 10-21 yr, Gender: males=18, females, 9. Time since injury: 1-3 yr; Severity of injury: complete=3, incomplete=24, paraplegia=23, tetraplegia=4, AIS A=18, AIS B=2, AIS C=4, AIS D=3. *Able-Bodied Controls (CTRL, n=27):* Age and sex matched to SCI group.	1. There was no difference in height between the SCI and control groups. 2. The weight of the SCI group was 14.5% lower than the weight of the able-bodied control group ($p<0.005$). 3. The BMI of the SCI group was 1 0.8% less than the control group (p<0 .007). 4. The SCI group had significantly lower mean LTM than CTRL group ($p<0.001$) and higher percent body fat ($p<0.02$) despite their reduced BMI (p<0.010.

	Intervention: None. Anthropometric Testing. **Outcome Measures: Height, weight,** Lean Tissue Mass (LTM), % Body Fat, Bone Mineral Content (BMC), Body Mass Index (BMI), body composition, Resting Metabolic Rate (RMR)	5. There was a significant reduction in the BMC in the SCI group compared with the controls (p<0 .007). 6. The SCI group had lower RMR than the CTRL group (p<0.001) but there was no difference in RMR when adjusted for LTM.

Discussion

Seven papers related to CVS health in children with SCI/D related paralysis were identified. Of the seven, four were observational studies, consisting of anthropometric measurements in cohorts of children that included those with traumatic and non-traumatic paralysis, specifically spina bifida (Liusuwan et al. 2007; Nelson et al. 2007; Widman et al. 2007); Liusuwan et al. (2007) and Widman et al. (2007) also included age and sex matched able-bodied controls and obese able-bodied cohorts. (Liusuwan et al. 2004) compared SCI with age and sex matched able-bodied controls.

Three of the papers described findings from the same randomized controlled study of 30 children with traumatic and non traumatic SCI undergoing either FES assisted lower extremity ergometry, passive lower extremity cycling or no cycling electrical stimulation (Johnston, Smith, Betz, et al. 2008; Johnston, Smith, et al. 2009; Johnston, Smith, et al. 2008b).

Children with SCI were found to have higher fat mass and fat %, lower total lean mass, lower BMI, higher rate of metabolic syndrome. Calculated BMI was found to underestimate body fat in children with SCI. Resting metabolic rate and energy consumtion was found to be similar with controls when adjusted for muscle mass. Obesity was not consistently defined, with cut off ranging 25-30% in males and 30-35% in females in different cohorts. Metabolic syndrome was more common in chidren with paralysis. Exercise was not found to significantly affect cardio-vascular or metabolic factors. FES assisted lower limbs ergometry induced a statistically significant change in measure VO2, especially in the children with less neurologic involvement (lower thoracic and lumbar paralysis), but no significant difference in objective pre-post intervention vaules was noted. Muscle mass, volume and strenght were found to increase with FES, but exercise's effect on lipid profice was, at the most, partial, limited and inconsistent. It does appear that response to exercise in pediatric SCI is influenced by injury level, same like in adults.

The only interventional randomized controlled trial was limited by lack of true controls, as all three arms received some sort of exercise intervention (Johnston, Smith, et al. 2009). In addition, normative data for cardio-metabolic parameters were obtained from able body children and adults with SCI. What the study did show was good adherence with the exercise protocol when the study is done in a home environment.

It is apparent from all controlled cohorts that, in children with SCI/D related paralysis, physical inactivity and muscle loss are driving factors in the onset of cardio-metabolic complications. In addition, paralysis onset appears to create enduring vulnerabilities that influence the trajectory of cardiovscular health in this population.

Similar to the adult population (Weil et al. 2002), obesity is more prevalent in children with SCI/D related paralysis and further studies are needed to assess if this is related to unhealthy diet, decreased physical activity patterns, and compunded by genetic, psychological, health behaviors (cigarette smoking, sleep>7hrs/night, etc.).

According to World Health Organization, children should exercise 60 min at moderate intensity per day with short bouts of anaerobic intensities and perform exercises to strengthen muscles and bones three times a week (World Health Organization, 2010). The American College of Sports Medicine launched Exercise in Medicine in 2007, a global initiative designed to make exercise part of standard clinical care for people of all abilities (Medicine., 2021).

We already know that CVS risk factors models underestimate the risk for CVS disease events in adults with SCI (Barton TJ, 2021). Assessing the role of inactivity related to pediatric onset paralysis should be performed in a systematic way. In addition, prospective randomized studies with controls and adequate power are essential. The systematic analysis of effect of exercise on functional and metabolic parameters that affect CVS health should be devised. Determining normative data for meaningful cardio-metabolic changes in children with paralysis should be undertaken. Looking at sensitive biomarkers of CVS health in the pediatric population, including those with paralysis is paramount. Instituting behavioral changes immediately after paralysis to offset the consequences of immobility should be a priority. Normalizing disability, eliminating inequality to access to resources and care will require a societal intervention. Using technology to improve adherence to exercise and access to resources should be leveled.

Key Points

Children with SCI/D paralysis consistently exhibit body composition and metabolic changes that predispose to poor CVS health

There is no exercise/therapeutic intervention that has been proven to consistently/predictably improve CVS profile in this population.

5.4.2 Autonomic Dysreflexia

Autonomic dysreflexia (AD) is a physiological phenomenon in spinal cord injuries with a neurological level of lesion above T6. Damage at or above T6 interrupts descending modulation of the thoracolumbar sympathetic preganglionic neurons that regulate vasomotor tone (arising from the T5-T12) in the splanchnic vascular bed (Eldahan & Rabchevsky, 2018). Aortic and carotid baroreceptors sense the hypertension and informs the brain, resulting in vagal stimulation and inhibition of the sympathetic nervous system above the neurological level of lesion (Hickey & Vogel, 2002).

Hypertensive episodes in AD occur as a response to noxious visceral or somatic stimulation below the neurological level of lesion, activating a sympathetic mass reflex leading to widespread vasoconstriction. This is especially common among patients with bladder and bowel problems.

AD is defined as an increase in blood pressure of 20-40 mm Hg in adults and 15-20 mm Hg in children (Eldahan & Rabchevsky, 2018). This often come with bradycardia as the parasympathetic innervation is non-affected, though tachycardia seems as frequent. The systolic blood pressure can reach as high as above 300 mm Hg with risk for brain injury related to the hypertensive crisis, though luckily rare (Kewalrami & Orth, 1980).

Other symptoms reported in AD are related to the sympathetic mass reflex and include pounding headache, pilomotor reflex with goosebump, paresthesia, shivering, flushing and hyperhidrosis above neurological level of lesion, nasal obstruction, ocular symptoms including Horner's syndrome, desire to void, anxiety, malaise, and nausea. There may be a feeling of dullness in the head and blurring of vision. More than 50% of patients experience severe headache, usually of occipital, bitemporal and bifrontal location and less frequent a sensation of precordial pressure (Karlsson, 1999; Kewalrami & Orth, 1980).

Education and prevention are essential in the management of AD (Hickey & Vogel, 2002). In addition, It is important to regularly measure blood pressure to find the baseline for comparison and individual monitoring (Zebracki et al. 2013a). Drug treatment must be considered when these measures are inadequate or in the case of an acute hypertensive episode where conservative management is inadequate. A comprehensive consensus-based recommendation involving all these steps are published from Shriners Hospitals for Children (McGinnis et al. 2004). A systematic review from 2009 on the management of AD as part of the Spinal Cord Injury Research Evidence project does not specifically include pediatric subjects, but gives an comprehensive report of the evidence for different treatments for adults post SCI (Krassioukov et al. 2009).

Table 25. Studies assessing autonomic dysreflexia among children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Canon et al. 2015) USA Observational N=13	**Population:** Mean age: 12.4 yr; Gender: males=5, females=8; Injury etiology: cervical SCI=6, thoracic SCI=3, transverse myelitis=2, encephalomyelitis=2. **Intervention:** None. Urodynamic study (UDS). **Outcome Measures:** Autonomic dysreflexia (systolic blood pressure 15-20 mmHg above baseline and/or presence of associated symptoms.	1. In total, 41 UDS were performed, with an average of 3.2 studies per patient. 2. Among 13 subjects, 1 adolescent (C1/2 level injury) and 1 prepubertal child (T2/3 level injury) experienced AD; both patients experienced AD initially and on subsequent UDS, with one having a total of seven episodes of AD. 3. Symptoms of AD for one subject included blood pressure elevation, facial flushing. 4. Symptoms of AD and hypertension were resolved in both subjects with bladder drainage alone, without any need for pharmacological intervention; no major complications were observed. 5. There did not appear to be noticeable correlations of AD with gender, actual-

		to-estimated bladder ratio, presence of uninhibited detrusor contractions, bladder compliance, presence of bacteria during UDS, or those with transverse myelitis or encephalomyelitis.
(Hwang et al. 2014a) USA Observational N=351	**Population:** *Pediatric-onset SCI*: Mean age at injury: 13.8 (0-18) yr; Mean age at interview: 26.7 yr; Gender: males=226, females=125; Time since injury: 12.9 yr; Level of injury: C1-4 AIS ABC=52, C5-8 AIS ABC=126, T1-S5 AIS ABC=136, AIS D=34, unknown=3. **Intervention:** None. Survey. **Outcome Measures:** Incidence and prevalence of medical complications (pressure ulcers [PU], autonomic dysreflexia [AD], spasticity).	1. In total, 1793 interviews were conducted. 2. The prevalence of PU, AD, and spasticity were higher in those with more rostral neurologic level of injury, whereas the prevalence of most complications were lower in the AIS D group compared to the other impairment groups. 3. At first interview, the prevalence of hypertension/cardiac disease was similar among the injury severity groups (2.0–2.9%), as was the prevalence of shoulder pain (38–50%). 4. Over a median interval of 5.1 yr between the first and last interviews in all our participants (n=351), the prevalence of bladder accidents, hypertension/cardiac disease, and activity limiting upper extremity joint pain showed a tendency to increase. 5. The prevalence of PUs, urolithiasis and bone fractures showed a pattern of decrease, while no patterns of change in prevalence was noted for UTI, AD, spasticity, pneumonia/respiratory failure, and bowel accidents between the two time points. 6. Odds of complication occurrence over time varied among severity groups, with increased ORs in the C1-4 ABC group of: • severe urinary tract infection (1.05, CI 1.02–1.09); • AD (1.09, CI 1.05–1.14); • spasticity (1.06, CI 1.01–1.11); • pneumonia/respiratory failure (1.09, CI 1.03–1.16); and • hypertension/cardiac disease (1.07, CI 1.01–1.15); • Odds of complication occurrence over time varied among severity groups, with increased ORs in the C5–8 ABC group: AD (1.08, CI 1.04–1.13); and pneumonia/respiratory failure (1.09, CI 1.02–1.16). • Odds of complication occurrence over time varied among severity groups, with increased ORs in the T1-S5 ABC group:

		hypertension/cardiac disease (1.08, CI 1.02–1.14). 7. Upper extremity joint pain had increased odds of occurrence in all injury severity groups.
(Hwang et al. 2014b) USA Observational N=283	Population: *Pediatric-onset SCI:* Age at interview: 27.3±3.7 (21-37) yr; Age at injury: 14.5±4.3 (0-18) yr; Gender: males=182, females=101; Time since injury: 12.7±5.0 (4-30) yr; Level of injury: tetraplegia=174; Severity of injury: complete=195; C1-4 AIS ABC=46, C5-8 AIS ABC=110, T1-S5 AIS ABC=99, AIS D=28. Intervention: None. Annual interviews. Outcome Measures: Satisfaction with Life Scale (SWLS), Short-Form 12 Health Survey (SF-12), Patient Health Questionnaire-9 (PHQ-9), and Craig Handicap Assessment and Recording Technique (CHART).	1. Those attaining a bachelor's degree or higher had increased from 33.2% at the first interview to 47.0% at the last interview. 2. There was no change in the proportion of employed versus unemployed from the first (56.8% versus 43.2%) to last interview (58.1% versus 41.9%) (less than general population estimates). 3. At the last interview, the proportion of employed participants was significantly higher in those with a baccalaureate and post-baccalaureate degrees, whereas the proportion of unemployed individuals was higher in those with a high school diploma. 4. Women and married participants also had higher rates of employment at the last interview than men and single participants, respectively. 5. There was no significant change in employment status over time (OR 1.01, confidence interval (CI) 0.98-1.04). 6. Odds of employment increased over time in participants who were women (1.04, CI 1.00-1.08), married (1.05, CI 1.02-1.08), attained a baccalaureate degree (1.03, CI 1.00-1.07), or post-baccalaureate degree (1.05, CI 1.02-1.08). 7. Odds of employment decreased over time in participants with occurrence of autonomic dysreflexia (0.80, CI 0.65-0.99), spasticity (0.80, CI 0.59-0.99) or chronic medical condition (0.83, CI 0.71-0.98). 8. Life satisfaction (SWLS) scores increased over time in those who remained employed (1.11, CI 1.01-1.22). 9. Odds of depression (PHQ-9) increased over time in those who remained unemployed (1.13, CI 1.04-1.23).

(Zebracki et al. 2013b) USA Observational *Part I (n=279)*	**Population:** Age: 0-5 yr=30, 6-12 yr=93, 13-15 yr=52, 16-18 yr=104; Gender: males=160, females=119; Time since injury: 38.7±44.0 mo; Level and severity of injury: C1-4 AIS ABC=29, C5-8 ABC=56, T1-S5 ABC=175, D=19; complete=174, tetraplegia=94. **Intervention:** None. Chart review. **Outcome Measures:** Systolic and diastolic blood pressure, heart rate.	1. There was a stepwise increase in baseline blood pressures and decrease in heart rates with increasing age (p<0.001). 2. Boys demonstrated higher systolic blood pressures (p<0.001) whereas girls had higher heart rates (p=0.02); this is similar to the difference observed in typically developing youths. 3. There was no difference in diastolic blood pressure between genders. 4. There was a significant diurnal difference in blood pressure and heart rate, with both elevated in the evening compared to morning values (p<0.001). 5. There was no significant difference in any measures between youth with tetraplegia and those with paraplegia. 6. A significant association was not found for duration of injury with any of the measures.
(Schottler et al. 2009) USA Observational N=215	**Population:** Age: 9.1 yr; Gender: males=127, females=88; Level of injury: tetraplegia=116, paraplegia=99; >T6=168, <T6=47; Severity of injury: complete=110, incomplete=105. **Intervention:** None. Survey. **Outcome Measures:** Patients and families were asked four yes/no questions: (1) Does the patient experience autonomic dysreflexia (AD)? (2) Does the patient/caregiver know what AD is? (3) Can the patient/caregiver name three signs/symptoms of an AD episode? (4) Does the patient/caregiver know how to treat AD?	*Does the patient experience AD?* 1. Overall, 40% of patients and 44% of caregivers said that the patient did experience or was symptomatic for AD. 2. Multiple logistic regression showed that children with injury levels ≥T6 (p<0.001) and those in the oldest age (14-21 yr; p<0.001) were more likely to say that they experienced AD. 3. Multiple logistic regression analysis showed that caregivers of people with injury levels ≥T6 (p=0.005) and those with a greater injury severity (AIS; p=0.014) were more likely to experience AD. *Does the patient/caregiver know what AD is?* 4. There was no association between patients' ability to define AD with gender, race or AIS classification. 5. Patients who were able to define AD were more likely to have traumatic etiologies (p<0.001), have ≥T6 injuries (p=0.007), have a shorter duration of injury (p<0.001) and be in the oldest age at injury group (14-21 yr; p<0.001). 6. Caregivers of who were able to define AD were more likely to have patients

		with traumatic etiologies (p=0.007), have ≥T6 injuries (p=0.001), and be in the oldest age at injury group (14-21 yr; p<0.010). *Can the patient/caregiver name three signs/symptoms of an AD episode?* 7. There was no association between a patient's ability to identify three signs/symptoms of AD with gender, race or AIS classification. 8. Patients with the ability to name three signs/symptoms of AD were more likely to have traumatic injuries (p=0.014), ≥T6 injuries (p=0.006), have a shorter duration of injury (p=0.030), and be in the oldest age at injury group (14-21 yr; p<0.001). 9. Caregivers with the ability to name three signs/symptoms of AD were more likely to have children with injuries ≥T6 (p=0.001) and who were older at interview (p=0.005). *Does the patient/caregiver know how to treat AD?* 10. There was no association between a patient's knowledge of how to treat AD with gender, race or AIS. 11. Patients who were able to express how to treat AD were more likely to have traumatic etiologies (p=0.001), have ≥T6 injuries (p=0.003), have a shorter duration of injury (p=0.003) and be in the oldest age at injury group (14-21 yr; p<0.001). 12. Caregivers who were able to express how to treat AD were more likely to have children with traumatic etiologies (p=0.020), level of injury (p<0.001), age at injury (p=0.032) and age of patient at time at interview (p=0.008). 13. Of the patients with a positive history of AD, 15% did not know the definition of AD, 20% could not identify three signs/symptoms of AD and 6% said they did not know how to treat an AD episode if it were to occur. 14. For the caregivers of patients who experienced AD, 9% did not know the

		definition of AD, 20% could not identify three signs/symptoms and 9% said they did not know how to treat an AD episode.
(Liusuwan et al. 2007) USA Observational N=215 (N=33 SCI)	**Population:** *SCI Group (n=33):* Age: 17.5±2.2 yr; Gender: males=21, females=12. *SB Group (n=66):* Age: 15.8±2.6 yr; Gender: males=36, females=30. *Able-Bodied Overweight (OW, n=31) Group:* Age: 15.6±2.6 yr; Gender: males=12, females=19. *Able-Bodied Control (CTRL, n=85) Group (n=60):* Age: 15.9±2.4 yr; Gender: males=44, females=16. **Intervention:** None. Anthropometric testing. **Outcome Measures:** Height, weight, Bone Mineral Content (BMC), Fat Tissue Mass (FTM), Total Lean Tissue Mass (TLM), Total Body Fat, Resting Energy Expenditure (REE).	1. There was no significant difference in height between the CTRL and OW groups, but the SB group was significantly shorter ($p<0.05$). 2. The OW group weighed significantly more than the SB, SCI, and CTRL groups($p<0.05$). 3. The OW group BMI was significantly higher than that of the SB group, which in turn was significantly higher than those of both the CTRL group and SCI group ($p<0.05$). 4. BMI was not significantly different between CTRL and SCI groups ($p<0.05$). 5. SB subjects had the lowest TLM compared to the CTRL and OW groups ($p<0.05$), but there was no significant difference in TLM between SB and SCI. 6. Although the OW group had significantly higher fat mass than all other groups, there was no significant difference between the percent fat of OW versus SB group. 7. When REE was adjusted for kg of TLM, there were no differences in REE/TLM ratio among the CTRL, OW, and SCI groups; SB had significantly higher REE/TLM ratios as compared to the REE/TLM ratios in the CTRL, OW, and SCI groups.
(Hickey et al. 2004) USA Observational N=121	**Population:** Age: 6 yr (0-13 yr), divided into three age groups: 0-5 yr, 6-13 yr, 14-21 yr. **Intervention:** None. Chart Review. **Outcome Measures:** Episodes of autonomic dysreflexia (AD).	1. Among 121 subjects, 62 (51%) experienced AD. 2. A total of 27 AD episodes were experienced while during hospitalization and 163 episodes during an outpatient visit for which there were no significant differences in causative factors or symptoms between settings. 3. The most common causes of AD were urologic complications (75%), primarily bladder distension (89%), and bowel impaction (18%). 4. For episodes of AD that occurred in all three age ranges, the most common symptoms were facial flushing (43%), headache (24%), sweating (15%), and piloerection (14%).

		5. In contrast to the two older age groups, the youngest age group experienced headaches (p=0.047) and piloerection (p=0.046) uncommonly and facial flushing more commonly (p=0.016). 6. Of the 62 affected participants, 27 AD episodes were observed in 18 individuals • 2 episodes occurred in children <5 yr, 19 occurred among those 6-13 yr and 6 in those 14-21 yr; • mean increases in systolic and diastolic blood pressure was 45 mm Hg and 30 mm Hg; • heart rate was evaluated in just 16 episodes for which it was within 10% of baseline values for 6 episodes, bradycardic for 2 episodes (>20% below baseline), and tachycardic for 8 episodes (>20% above baseline). • Pharmacological management was not required for any of the observed episodes, and there were no observed or reported complications of AD. 7. AD episodes were greater among those with: • complete tetraplegia compared to complete paraplegia (p=0.047); • traumatic SCI compared to medical or surgical causes (p=0.018; 6-13 yr age bracket only); • those injured at an older age (6-21 yr) compared to those injured younger (<5 yr; p=0.014); 8. Regression analysis showed that AD was significantly associated with completeness of injury (complete versus incomplete) and older age at injury (6-13 yr versus <5 yr).
(Vogel et al. 2002b) *Part I* USA Observational N=216	**Population:** Age at injury: 14.1±4.0 yr; Age at interview: 28.6±3.4 yr; Gender: males=150, females=66; Time since injury: 14.2±4.6 yr; Level of injury: tetraplegia=123, paraplegia=93. Severity of injury: C1-4 ABC=41, C5-8 ABC=67, T1-S5 ABC=82, tetra/para D=26. **Intervention:** None. Survey. **Outcome Measures:** Prevalence of urinary tract infections (UTI), pressure ulcers, hemorrhoids and rectal bleeding,	**Analyses of AD were limited to individuals with C1 to T61evels of injury: 1. Within this group, 54% experienced AD; of 85 individuals, 74 had tetraplegia, and 11 had paraplegia. 2. AD affected 62% of the subjects with tetraplegia and 30% of those with T1 to T6 paraplegia. 3. Of the individuals with T6 or higher SCI, who did not report AD, 24% had an ASIA Impairment Scale score of D; in contrast, none with T6 or higher lesions, who experienced AD, had ASIA Impairment scores of D (p<0.001).

	hospitalizations, urinary stones, orchitis or epididymitis, pneumonia, need for ventilatory assistance, thromboembolism, and latex allergy, bladder and bowel incontinence, length of bowel program, constipation or diarrhea, dysreflexia, hyperhidrosis frequency of smoking cigarettes or marijuana, drinking alcohol.	4. Those with AD had significantly lower ASIA Motor scores compared with those who did not experience AD ($p<0.001$). 5. A total of 31 subjects experienced hyperhidrosis (22 had tetraplegia and 9 had paraplegia). 6. Of the 9 subjects with paraplegia and hyperhidrosis, 5 had T1 -T6 lesions and 4 had lower thoracic lesions. 7. Individuals with hyperhidrosis had significantly lower ASIA Motor scores ($p=0.007$). 8. Subjects who reported having hyperhidrosis were significantly more likely to experience AD compared with those who did not have hyperhidrosis $p<0.001$). 9. Among those with C1 to T6 SCI, those who experienced hyperhidrosis were more likely to experience AD compared with those who did not experience hyperhidrosis ($p=0.002$).
(Vaidyanathan et al. 1998) United Kingdom Case Series N=24 (N=3 pediatric patients) (N=11 pediatric-onset SCI patients)	Population: *Children with SCI (n=3):* *Case CS:* 3 yr male, C1-2 tetraplegia; *Case SM:* 2 yr, male, ventilator-dependent tetraplegia; *Case NB:* 3 yr male, ventilator-dependent tetraplegia; *Adults with pediatric-onset SCI (n=11)* *Case WC:* 32 yr female with SCI at 14 yr, C4 tetraplegia. *Case MH:* 32 yr male with SCI at 21 yr, C5 tetraplegia. *Case KW:* 44 yr male with SCI at 15 yr, C4 tetraplegia. *Case DM:* 22 yr male with SCI at 17 yr, C6 tetraplegia. *Case GE:* 30 yr male with SCI at 17 yr, C5 tetraplegia. *Case SB:* 29 yr male with SCI at 17 yr, C5 tetraplegia. *Case AM:* 33 yr male with SCI at 14 yr, T4 paraplegia. *Case OL:* 29 yr male with SCI at 19 yr, C3 tetraplegia. *Case AG:* 30 yr male with SCI at 17 yr, C5 tetraplegia.	*Children (n=3):* 1. Case CS required a maximum dose of terazosin 2 mg + oxybutynin 5 mg + 2.5 mg + 5mg and had nil side affects. 2. Case SM required a maximum dose of terazosin 1 mg + oxybutynin 2.5 mg 2x/day and had nil side affects. 3. Case NB required a maximum dose of terazosin 1 mg + oxybutynin 2 mg 4x/day and had nil side affects. *Adults with pediatric-onset SCI (n=11)* 4. Case WC required a maximum dose of 3 mg + oxybutynin 5 mg and experienced nil side affects. 5. Case MH required a maximum dose of 5 mg and experienced nil side affects. 6. Case KW required a maximum dose of 6 mg and experienced nil side affects. 7. Case DM required a maximum dose of 5 mg and experienced nil side affects. 8. Case GE required a maximum dose of 2 mg and experienced nil side affects. 9. Case SC required a maximum dose of terazosin 5 mg and had nil side affects. 10. Case AM required a maximum dose of terazosin 3 mg and had nil side affects. 11. Case OL required a maximum dose of terazosin 1 mg and had nil side affects.

	Case DB: 16 yr male with SCI at 15 yr, C4 tetraplegia. *Case PD:* 27 yr male with SCI at 19 yr, C4 tetraplegia. **Intervention:** 1 mg (adults) or 0.5 mg (children) terazosin titrated up to a maximum dose, if appropriate (i.e., 10 mg in adults and 2 mg in children). **Outcome Measures:** Abatement of autonomic dysreflexia and side effects.	12. Case AG required a maximum dose of terazosin 4 mg and had nil side affects. 13. Case AG required a maximum dose of terazosin 2 mg and had nil side affects. 14. Case PD required a maximum dose of terazosin 2 mg and had nil side affects.

Table 26. Case reports assessing autonomic dysreflexia among children with SCI.

Author, Year Country Study Design	Objective/Purpose
(Lockwood et al. 2016) USA Case Report N=1	**Population:** 11 yr, male, T4 paraplegia SCI. **Intervention:** Oral oxybutynin, Botulinum toxin injections, Nifedipine, **Outcome Measures:** Autonomic dysreflexia
(Bjelakovic et al. 2014) Serbia Case Report N=1	**Population:** 12 yr, male, SCI (neck injury resulting in spastic paraplegia with CT scan showing spinal atrophy at C5-6 and T1-2). **Intervention:** Midazolam, Furosemide, Mannitol, and a urinary catheter in the emergency department, followed by Xatral, Enalapril, and Presolol post AD diagnosis. **Outcome Measures:** Autonomic dysreflexia.

Table 27. Studies assessing hyperhidrosis among children with SCI.

Author, Year Country Study Design Sample Size	Study Characteristics	Results
(McLean et al. 1999) USA Observational N=54	**Population:** *Temperature Instability (n=12):* Age: 11.9 (5.5-17.6) yr; Gender: males=11, females=1; Injury etiology: traumatic SCI; Time since injury: 7.3 months (10 days-11.5 mo); Level and severity of injury: paraplegia AIS A T5-6=2, tetraplegia AIS A=10. *Temperature Stability (n=42):* Age: 11.8 (2.4-20.3) yr; Gender: males=21, females=21; Etiology: traumatic SCI=37, tumour=4, meningitis=1, Coffin-Lowry Syndrome=1; Level and severity of injury: tetraplegia=38 (AIS A	1. Among 54 patients, 12 (22%) subjects endured 65 episodes of environmentally responsive hypothermia and 14 events of hyperthermia; one patient accounted for 34 episodes of hypothermia and 8 episodes of hyperthermia. 2. Average temperature of the hypothermic events was 35.28C, with a median temperature of 35.58C, and a range of 33.0±35.58 C. 3. The average temperature of the recorded hyperthermic events was 39.08 C, with a median temperature of 39.08 C, and a range of 38.0± 0.48 C.

	complete=36); Time since injury: 22.0 mo (13 days-160 mo). **Intervention:** None. Chart Review. **Outcome Measures:** Temperature.	4. The average duration of hypothermic events was 5.2 h, compared with an average duration of 8.5 h for the hyperthermic events. 5. Subjects in the temperature stability group had a greater duration of time since injury (p<0.001), and shorter rehabilitation length of stay (p<0.001).

Table 28. Case reports assessing hyperhidrosis among children with SCI.

Author, Year Country Study Design Sample Size	Study Characteristics
(Adams et al. 2002) USA Case Report N=1	**Population:** 12 yr, female, epidural hematoma secondary to non-traumatic ruptured cavernous venous malformation of the spinal cord, C7-T3, 5 mo post-injury. **Problem:** Hyperhydrosis. **Intervention:** Received 300 mg Gabapentin, twice daily (15 mg/kg), increased to 900 mg Gabapentin, three times per day (65 mg/kg), and then increased again to 1200 mg Gabapentin (88 mg/kg), three times per day, followed by propantheline bromide (7.5 mg three times and then reduced to twice per day).

Discussion

Several observational studies and case reports, as well as one case series examined the prevalence, etiology, and management of AD in the pediatric SCI population. Most of the studies originated from one center, Shriners Hospitals for Children (Hickey & Vogel, 2002; Hickey et al. 2004; Hwang et al. 2014a, 2014b; Schottler et al. 2009; Schottler et al. 2012; Vogel et al. 2002b; Zebracki et al. 2013a, 2013b).

As highlighted by Kewalramami and Orth (1980) and Krassioukov (2003), AD can occur at earliest 8 weeks postinjury in children with SCI, but most often presents its first signs 12 to 16 weeks post-injury. Kewalramami and Orth (1980) also found that the onset of AD correlated with the occurrence of a positive bulbocavernosus reflex in their sample of 68 patients. Urologic complications, bladder distension, and bowel impaction were identified as some of the most common causes of AD (Canon et al. 2015; Hickey et al. 2004). Regarding the prevalence of AD in the pediatric SCI population, the studies revealed a rate of around 50% among those with an neurological level of lesion at T6 and above, which is comparable to that in the adult population (Schottler et al. 2009; Schottler et al. 2012; Vogel et al. 2002b). Complete injuries, traumatic injuries, and older age seemed to be associated with higher risk of AD (Hickey et al. 2004; Hwang et al. 2014a; Kewalrami & Orth, 1980; Schottler et al. 2009; Schottler et al. 2012; Vogel et al. 2002b).

It is worth noting that the lower prevalence of AD in the younger age group may be confounded by factors such as young children's difficulties in articulating their symptoms as well as differences in the presentation of symptoms between younger and older children. (Hickey et al. 2004). Upon reviewing the medical record of 121 children with SCI who received care at Chicago

Shriners Hospital for Children, the researchers observed that headache and piloerection were reported less frequently in children with AD who were between ages 0-5 years compared to those between ages 6-13 and 14-21; on the other hand, facial flushing were more commonly reported in the youngest age group compared to that in the two older age groups.

As discussed previously, hyperhidrosis is a common symptom of AD. In one study, McLean et al. (1999) investigated the frequency and clinical implications of environmentally responsive temperature instability in 54 hospitalized pediatric patients with SCI. It was found that 12 (22%) patients experienced a total of 65 episodes of hypothermic events (i.e., oral temperatures less than 35.08 °C or rectal temperatures less than 35.68 °C) and 14 Hyperthermic events (i.e., oral temperatures greater than 38.08 °C or rectal temperatures greater than 38.48 °C). In addition, patients with environmentally responsive temperature instability more likely to have shorter time post-injury, longer lengths of stay, be ventilator dependent than those who did not have environmentally responsive temperature instability (McLean et al. 1999). Through examining a case of a 12-year-old girl with hyperhidrosis from a SCI, Adams et al. (2002) suggested that gabapentin may be an effective therapy for SCI-related hyperhidrosis. However, larger-scale studies are needed to confirm this finding.

Schottler et al. (2009) examined knowledge of AD from the perspectives of youth with SCI and their caregivers, as part of a multicenter study including 215 participants. Participants answered questions concerning the definition, signs and symptoms, and treatment of AD. Not surprisingly, the study found that patients with greater knowledge of AD were more likely to have traumatic etiology, have T6 or higher injuries and shorter duration of injury, and be in older age groups.

The occurrence of AD has not only been linked to various medical complications but also decreased likelihood of employment in adults with pediatric-onset SCI (Hwang et al. 2014a, 2014b). Therefore, the prevention and management of AD in this population is crucial. Zebracki (2013b) have suggested that one way of preventing and/or identifying early signs of AD in the pediatric SCI population is through the regular assessment and management of baseline blood pressure and heart rate.

The recommendations concerning the management of AD are mainly consensus-based (McGinnis et al. 2004) and/or drawn from anecdotal evidence from case reports (Bjelakovic et al. 2014; Lockwood et al. 2016; Tronnes & Berg, 2012), with the exception of a study by Vaidanathan et al. (1998). Vaidyanathan et al. (1998) examined the effectiveness of Terazosin, an alpha-1 blocking agent, in managing symptoms of AD in 24 patients with SCI who had recurrent episodes of AD. Three of the patients were children with SCI who were ventilator dependent, and 11 were adults with pediatric-onset SCI. The drug was individually titrated with a starting dose of 0.5 mg at bedtime for children and was thereafter titrated with 1.0/0.5 mg every 3-4 days until side effects or problem resolved. One patient discontinued the medication due to dizziness. For the others, the side effects were self-limiting and noticed only during the first week of treatment and included feelings of tiredness and drowsiness. Following the terazosin therapy, the dysreflexic symptoms subsided completely for all patients. However, the authors note that Terazosin is not the first line of treatment, and should only be considered for selected patients with recurrent episodes of dysreflexia, and in whom, it is not possible to identify the predisposing cause, or in whom it is not feasible to abolish the precipitating factor for the AD.

Key Points

The prevalence of AD in the pediatric SCI population is around 50%, which is comparable to that in the adult SCI population.

Complete injuries, traumatic injuries, and older may be linked to higher risk of AD in children with SCI.

5.5 Pulmonary Function

Both respiratory function and the ability to assess it in children with paralysis related to SCD are fraught by difficulties related to age and development and the neurologic deficit (Beydon et al. 2007; Frei et al. 2005; Singh et al. 2018). SCD related paralysis results in restrictive and sometimes obstructive respiratory dysfunction patterns, depending on injury level (Randelman et al. 2021). Because respiratory complications are an important source of morbidity and mortality in individuals with SCI (Randelman et al. 2021), being able to assess the residual respiratory function pattern becomes an important goal in long term management in this population.

The review of the literature pertaining to the subject reveals few and limited in scope papers. Most of them are retrospective case series/reports, with Vogel and colleagues' (2002b) study utilizing survey design being the exception. Their analysis reveals an eclectic collection of findings:

1. Methods of respiratory insufficiency management are varied (pressure/volume control ventilation)
2. Weaning off the ventilator is dependent on residual neurologic function and good pulmonary hygiene management
3. Respiratory complications in children with SCI related paralysis are frequent, just like in the adult population.

5.5.1 Lung Capacity

Table 29. Studies assessing lung capacity among children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Singh et al. 2018) USA	**Population:** *Typically Developing (TD; N=14):* Age: 7±2 yr; Gender: males=6,	*Pulmonary Function Test*

Observational N=26	females=8. *SCI (N=12):* Age 6±1 yr; Gender: males=7, females=5. Level of injury: C5=4, C8=1, T1-3=6, T12=1; Time since injury: 52±37 mo. **Intervention:** None. Measurements. **Outcome Measures:** Height, weight, Forced Vital Capacity (FVC), Forced Expiratory Volume (FEV_1), Maximum Inspiratory Pressure (PI_{max}), Maximum Expiratory Pressures (PE_{max}).	1. Compared to children with SCI, children in the TD group produced significantly greater FVC and FEV_1 ($p<0.01$). 2. TD children and those with SCI both showed a strong, positive correlation between age and FVC and FEV_1. 3. In TD children, a strong positive correlation was observed between FVC and height, and weight and between FEV_1 and height, and weight. 4. In the SCI group, height and weight did not significantly correlate to FVC or FEV_1 values. *Maximum Airway Pressure Measurements* 5. Children in the TD group generated significantly higher PE_{max} ($p<0.01$) than children in the SCI group. 6. No significant difference in PI_{max} was observed between the two groups. 7. For children in both groups, age was not significantly correlated to PE_{max} or PI_{max} values. 8. In TD children, height and weight were significantly correlated with PE_{max} and PI_{max} values ($p<0.05$); however, height and weight did not significantly correlate to PE_{max} or PI_{max} values in children with SCI. *Surface Electromyography (sEMG)* 9. During PE_{max} assessment, children with SCI produced significantly lower ($p<0.05$) muscle activation of rectus abdominous and external oblique and significantly higher ($p<0.05$) activation for upper trapezius compared to children in the TD group. 10. No significant differences in muscle activation of pectoralis major, external intercostal, thoracic paraspinal, and lumbar paraspinal were found. 11. During PI_{max} measurement, no significant differences were found between sEMG activation of respiratory muscles obtained from children in the TD and children in SCI groups.
(Bergström et al. 2003) United Kingdom Observational N=12	**Population:** Mean age at measurement: 13 (10-17) yr; Mean age at injury: 5 (0-11) yr; Gender: males=9, females=3; Mean time since injury: 8 (4-13) yr; Level of injury: C8=1, T1-L1=11; Severity of injury: Frankel A=7, B=2, C=2, D=1. **Intervention:** None. Anthropometry. **Outcome Measures:** Height, arm span, Forced	1. For all subjects, the arm span measurement was significantly greater than the height ($p<0.001$). 2. The predicted values for the lung function tests were calculated with height and arm span, respectively; they were significantly different ($p<0.001$). 3. Predicted lung function calculated by using height closely reflected the actual lung function; however, precited lung function calculated by using arm span overestimated the lung function by approximately 20%.

	Expiratory Volume (FEV$_1$), Peak Expiratory Flow Rate (PEFR), Forced Vital Capacity (FVC), Total Lung Capacity (TLC), and Residual Volume (RV).	4. For individuals with lesion level C8-T9 lung test results indicated underperformance relative to both predicted values, but more so when predicted values were calculated using arm span ($p<0.05$). 5. For individuals with lesion level T10-L1 actual lung test results were below normal predicted values when calculated using arm span but were over normal values when using the height in the prediction calculation ($p<0.01$).
(Padman et al. 2003) USA Observation N=47	**Population:** Mean age: 11.4±.5.9 yr; Gender: males=36, females=12; Injury etiology: SCI only=34, SCI and brain injury=13; Level of injury: C1-2=24, C3-5=23. **Intervention:** None. Chart Review. **Outcome Measures:** Inspiratory force, tidal volume, oxygen saturation, end tidal CO_2, respiratory rate, heart rate, accessory muscle use and retractions, ventilator weaning success.	1. There was no significant difference in age, sex, or weight between the two injury groups (C1-2 versus C3-4). 2. Sixty-three percent of patients were successfully weaned from mechanical ventilation. 3. Patients with injuries C3-4 or lower and tidal volumes of 18 to 20 cm^2/kg were more successfully weaned from mechanical ventilation. 4. There was a significant difference between the two lesion groups for height ($p=0.028$) in that those successfully weaned from the ventilator before discharge were taller. 5. Patients who had complications such as atelectasis were ventilator dependent at discharge ($p=0.001$). 6. There were fewer patients with complications in the group that was successfully weaned before discharge. 7. The rate of weaning depended on a patient's ability to maintain the work of breathing without signs of fatigue and tachypnea, his or her ability to maintain normal oxygen saturations and eucapnia, and his or her ability to remain free of infections. 8. Thirty-six percent of patients initially required synchronized intermittent mechanical ventilation, with 22% managed in assist control mode: the average tidal volume delivered was 15 cm^2/kg, with a maximum of 22 cm^2/kg. 9. A Shiley tracheostomy tube was used in 52% of patients, a Portex tube in 10%, and a Bivona tube in 5%. 10. To maintain adequate caloric intake and support successful weaning, 30% of patients required enteral feeding. 11. Twelve patients experienced complications during weaning, which included tracheitis, atelectasis, and pneumonia. 12. Flexible fiber-optic bronchoscopy was performed prior to decannulation; thirty-four percent of patients required the removal of

		suprastomal granulation tissue prior to decannulation. 13. There were no deaths, and none of the patients required readmission to the hospital for late-onset respiratory failure after weaning from mechanical ventilation. 14. All patients were discharged to their homes. 15. Successful school re-entry or home school programs were achieved in all patients by 6 to 12 months post-discharge.
(Gilgoff et al. 1988) USA Pre-Post N=8	**Population:** Mean age: 7 yr 5 mo (3 yr-16 yr 3 mo); Level and severity of injury: C2 tetraplegia=8. Respiratory function: spontaneous respiration completely absent among all. **Intervention:** Neck accessory muscle strengthening program with a physiotherapist with gradual removal of respiratory assistance. **Outcomes Measures:** End tidal CO_2, oxygen saturation, vital capacity	1. Seven of eight subjects learned the neck breathing technique, remaining disconnected between 20 min and 12 hr (mean=3.5 hr). 2. It took, on average, 18 to 454 days for the subject to achieve the confidence to be disconnected from the respirator for 20 min. 3. The patient who could not learn to neck breath had significantly decreased neck strength and required neck control while seated. 4. Follow-up information available for 3 subjects: • Subject 1: Patient 1 was studied seven hours after disconnection from respiratory equipment. End-tidal CO_2 values remained consistently 40 mmHg; vital capacity 410 mL, 12% of predicted normal for age and height; respiratory rate 26; patient refused bloodwork. • Subject 5: Arterial blood gas values were as follows: "on" the respirator-pH 7.48, PO_2 102 mmHg, PCO_2 26 mm Hg, HCO_3 19 mEqJL, oxygen saturation 99%; "off" the respirator with neck breathing for one hour 45 minutes - pH 7.45, P02 95 mm Hg, PCO_2 28 mm Hg, HCO_3 19 mEq/L, oxygen saturation 98%. • Subject 4: "On" his respirator, end-tidal CO_2 value was 28 mm Hg, oxygen saturations 98% to 99%, heart rate 90 beats per minute, and respiratory rate set on the respirator at 14 breaths per minute. After neck breathing for 20 minutes, his end-tidal CO_2 measurement was 32 mm Hg, oxygen saturations 95% to 97%, heart rate 112 beats per minute, and respiratory rate 42 breaths per minute. • All patients had a tracheostomy which helped to facilitate speaking. • All 8 patients were discharged home; the 7 patients who learned to neck breath continued using this technique post discharge. • Four patients relayed that there were episodes of accidental disconnection of their equipment for which neck breathing saved their lives.

		• Six patients were still alive at follow-up and two had died of causes not related to neck breathing.

Discussion

Singh et al. (2018) attempted to correlate anthropometric measurements (height and weight) to predict respiratory parameters in children with SCI and compare them with typically developing children and found, as expected, that children with SCI produced significantly lower forced vital capacity and forced expiratory volume at 1 second. A strong, positive correlation between age and forced vital capacity and forced expiratory volume was demonstrated in both the SCI group and typically developing group. However, while in typically developing children, a strong positive correlation was observed between forced vital capacity, forced expiratory volume and height, and weight, in the SCI group, height and weight did not significantly correlate to forced vital capacity or forced expiratory volume values. The typically developing children generated significantly higher expiratory pressures than children in the SCI group (related to significantly better recruitment of abdominal muscles as assessed by surface electromyography), but there was no significant difference in the inspiratory pressures between the two groups (again, confirmed by surface electromyography). Height and weight did not significantly correlate with inspiratory and expiratory pressures in children with SCI as opposed to the typically developing group. Age did not influence these pressures in either typically developing children or children with SCI.

In their observational study of 12 children with different levels and severity of SCI (C8-L11, Frankel A-D), Bergstrom et al (2003) assumed correlation of height and respiratory parameters (total lung capacity, forced vital capacity, forced expiratory volume, peak expiratory flow rate and residual volume) and found that using height is better at predicting these values than using arm span (which overestimate the pulmonary function tests predicted values). The predicted lung function calculated by using height closely reflected the actual measured lung function. The authors postulated that the over prediction of pulmonary function tests using arm span is related to the fact that the SCI triggers impaired growth (limbs and trunk) below injury level and might facilitate development of soft tissue contractures and scoliosis, which, in turn, affect the lung volumes and airway pressures.

5.5.2 Management and Complications

Table 30. Studies assessing pneumonia among children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Vogel et al. 2002b) USA Observational N=216	**Population:** Age at injury: 14.1±4.0 yr; Age at interview: 28.6±3.4 yr; Gender: males=150, females=66; Time since injury: 14.2±4.6 yr; Level of injury: tetraplegia=123, paraplegia=93. Severity of injury: C1-4 ABC=41, C5-8 ABC=67, T1-S5 ABC=82, tetra/para D=26. **Intervention:** None. Survey. **Outcome Measures:** Prevalence of respiratory complications.	1. In total, 68 subjects experienced pneumonia at least once, and 17 had required temporary or chronic ventilation since their injury. 2. Of the 68 subjects who had pneumonia, 39 experienced 1 episode, 10 had 2 episodes, and 19 had 3+ episodes. 3. Of 71 individuals who experienced pneumonia or respiratory failure were older at follow-up (p=0.028) and had longer duration of SCI (p=0.002). 4. Those with pulmonary complications had significantly more severe neurologic impairments with lower ASIA Motor scores (p<0.001). 5. Individuals with tetraplegia were more likely than those with paraplegia to have respiratory complications (p=0.003). 6. In addition, respiratory complications most commonly affected those in the more severe injury groups (C1-8) compared with those with less severe injuries (Tl-S5, tetra/para D) (p=0.005). 7. Those with respiratory complications had lower total (p=0.003) and motor (p=0.003) FIM scores. 8. A total of 59 subjects required hospitalizations within 3 yr of their interview and the most common reasons were respiratory disorders *(*N=13).

Table 31. Case reports assessing pneumonia among children with SCI.

Author, Year Country Study Design	Population, Intervention, Outcome Measures
(Warzak et al. 1991) USA Case Report N=1	**Population:** 8 yr, male, C4 tetraplegia SCI, ventilator-dependent. **Intervention:** Information-only procedure involving anxiety-reduction activities including relaxation and cognitive distraction. **Outcome Measures:** Heart rate, mouth noises, and verbalizations during tracheostomy care, ventilation checks, and conversation.

Discussion

There is a significant paucity of information and consensus regarding the management of respiratory insufficiency in the pediatric SCI population. Gilgoff (1988) described attempts to gain ventilator-free time in a group of eight children with high level tetraplegia (C1-2) and no spontaneous breathing by using a neck accessory muscle strengthening program; Seven of the eight children gained 20 min-12 hours of ventilator-free time using this technique and were able to maintain adequate respiratory parameters. While the neurologic level was mentioned in the study report, the severity of and time from injury were not, thus making it hard to predict weaning success extrapolating the data presented. Padman (2003) looked at a cohort of 47 children (split in 2 groups C1-2 and C3-T1) that underwent weaning off the ventilator 10-60 days post injury. While the severity of injury and the exact number of participants in each neurologic level grouping were not specified in the paper, a detailed pathway of care and ventilator weaning for children with tracheostomies was presented. Sixty-three percent of patients were successfully weaned from mechanical ventilation. Taller children with injuries C3-4 or lower and tidal volumes of 18 to 20 cm2/kg were more successfully weaned from mechanical ventilation (assumed to be related to better lung volumes and more motor function). Atelectasis development was a poor predictor factor for weaning and a significant number of children (34%) developed suprastomal granulation tissue that required bronchoscopic removal prior to decannulation.

Vogel (2002b) administered a survey aiming to quantify the prevalence of medical complications to 216 individuals who sustained SCI at age 18 or younger and were at least 24 years of age at interview. 68 of 216 participants experienced pneumonia at least once, and 17 required temporary or chronic ventilation since their injury; of the 68 subjects, 39 experienced one episode, 10 had two episodes, and 19 had more than three episodes. The individuals who experienced respiratory complications were older at follow-up, had longer duration of and more severe SCI, with lower motor and Functional Independence Measure scores. In addition, the most common reason for hospitalization within three years from injury were respiratory disorders (N=13).

Lastly, the role of anxiety awareness and management in the context of SCI related respiratory dysfunction was discussed in a case report of an 8-year-old ventilator-dependent child (Warzak et al. 1991), as well as in a case series involving eight children with SCI (Gilgoff et al. 1988).

5.5.3 Trachea Support

Table 32. Studies assessing trachea support among children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Behl & Watt, 2005) United Kingdom Observational	**Population:** Mean age: 5.9 (1.5-13.8) yr; Gender: males=7, females=2; Mean time since injury: 7 yr.	1. Following rehabilitation and discharge, all children were being ventilated at home on room air; the majority were on mechanical ventilation using the Puritan Bennett Companion 2801 ventilator, one used

N=9	**Intervention:** None. Retrospective Audit. **Outcome Measures:** Inside diameter (ID), outside diameter (OD), lateral tracheal diameter (LTD).	the Breas 501 ventilator with a pressure-limiting valve and one used the Breas 401 ventilator. 2. The IDs of all the tubes used ranged from 4.0 to 7.0 mm in incremental steps of 0.5 mm, and the ODs ranged from 6.0 to 10.7 mm in unequal steps because of material differences. 3. There was a steady increase in tracheostomy tube ID with increasing age ($p<0.01$); this was expressed by the relationship: ID=(agex0.3) + 3.5. 4. OD also related to age ($p<0.01$); this was expressed by the relationship: OD=(agex0.3) + 5.5. 5. LTD was increased with increasing age ($p<0.01$); this was expressed by the relationship LTD=(agex1.2) + 4.6. 6. ID correlated closely with weight ($p<0.01$); this was expressed by the relationship ID=(weightx0.08) + 3.1. 7. OD correlated well with weight ($p<0.01$); this was expressed by the relationship OD=(weightx0.1) + 4.7. 8. LTD also showed good correlation with weight ($p<0.01$); expressed by the relationship LTD=(weightx0.3) + 2.7.

Discussion

Behl (2005) described the long-term tracheostomy tube management in a retrospective cohort of 9 children with ventilator dependency observed over an average of 7 years; they required tracheostomy tube increases about every 2 years. Tracheal size (internal, external and lateral) correlated with age and weight, but the correlation with age was more reliable as the weight was harder to predict because of stunted growth and immobility. In addition, the paper noted that 4/9 children needed tracheostomy dilatation in order to insert the larger tracheostomy tube.

Key Points

Respiratory comorbidities in children with SCI are common and require hospitalized care.

Lung volumes and generated airway pressures depend on age and level and severity of injury.

Pulmonary hygiene, management of anxiety and learning alternative methods of breathing that can offer ventilator free time play important role in the long-term management of respiratory dysfunction associated with SCI.

5.6 Skin Integrity

The physiologic changes that take place after a SCI are varied and have the potential to impact upon almost every body system. In their “Best Practice Guidelines for the Prevention and Management of Pressure Ulcers in People with Spinal Cord Injury,” Houghton and Campbell

(2013) outlined a number of such changes with a direct impact on the skin. These include, but are not limited to, impaired autonomic regulation of subcutaneous blood flow and skin moisture levels, reduced skin temperature reactivity, reduced immune response and changes in connective tissue composition (including changes in extracellular matrix formation and collagen fibre type proportion). Longer term impacts of SCI may also include alterations in metabolic function, muscle mass, and body weight, all of which can affect skin integrity directly or indirectly.

Information about skin complications in SCI is derived largely from work in adults. The scope of skin challenges in pediatric SCI and effective treatment strategies to address them are less well defined. The term "pressure injury" is used to encompass the spectrum of potential damage to the skin and soft tissues as a result of the application of pressure (ranging from subclinical changes prior to ulceration to deep tissue injuries). Although this is the most common skin complication of SCI, there are other potential skin related comorbidities that can arise in the context of pediatric SCD, including self-inflicted wounds and latex allergy. Younger age at time of injury and duration of injury are both documented risk factors for skin complications in adults with SCI (Gélis et al. 2009), and therefore, the risk of pressure injuries in particular may increase as children age with their condition.

Table 33. Studies assessing skin integrity among children with SCI.

Author, Year Country Study Design Sample Size	Study Characteristics	Results
Pressure Injuries		
(McCaskey et al. 2011) USA Case Report & General Review	**Population:** 5 yr female with C3-C4 complete SCI. **Problem:** Pressure Ulcers	1. Article reviews this case report and then provides an excellent general review on pressure ulcers risk factors in pediatrics with considerations for care.
(Vogel et al. 2002b) *Part I* USA Observational N=216	**Population:** Age at injury: 14.1±4.0 yr; Age at interview: 28.6±3.4 yr; Time since injury: 14.2±4.6 yr; Gender: males=150, females=66; Level of injury: tetraplegia=123, paraplegia=93. Severity of injury: C1-4 ABC=41, C5-8 ABC=67, T1-S5 ABC=82, tetra/para D=26. **Intervention:** None. Survey. **Outcome Measures:** Prevalence of pressure ulcerations (PU).	1. PU within the previous 3 yr were experienced by 44% (n=94), of which the mean number of ulcers per subject was 2.5, with 53% reporting 1 ulcer, 17% experiencing 2 ulcers, and 30% reporting > 2 ulcers. 2. Among men, 48% reported PU, in contrast to 33% of the women (p=0.045). 3. PU occurred more commonly in non-white than in white subjects (p=0.04). 4. Individuals who had sports-related SCI were significantly less likely to sustain PU compared with participants with non-sports-related SCI (p=0.033). 5. Those with violence-related SCI were not at greater risk of developing PU compared with those with nonviolent SCI. 6. PU were significantly associated with more severe neurologic impairment as

		measured either by ASIA Motor scores or by injury severity groupings. 7. Mean ASIA Motor score was significantly lower in subjects with PU compared with those without ulcers (p=0.006); however, PU were not more common in those with tetraplegia compared with those with paraplegia. 8. Individuals with PU demonstrated significantly more functional limitation as measured by the FIM. Both the total (p=0.002) and the motor FIM scores (p=0.002) were significantly lower in subjects with PU. 9. PU were not significantly associated with either bladder or bowel incontinence. 10. There was no difference in PU between those with and without bowel incontinence. 11. Subjects who smoked cigarettes or marijuana regularly demonstrated a significantly higher prevalence of PU p=0.01). 12. PU less commonly affected those who drank alcohol at least monthly compared with those who denied drinking alcohol (p=0.031). 13. Development of PU was significantly associated with spasticity (p=0.009). 14. PU were not statistically associated with heterotopic ossification, hip subluxation, hip contractures, or scoliosis.
Traumatic Skin Lesions		
(Almeida et al. 2009) Brazil Case Report N=1	**Population:** Age: 19 mo; Gender: 1 male; Injury etiology: Transverse Myelitis with atrophy C3-T1. **Problem:** Self-injury (biting) to the mouth and bruxism. **Intervention:** Triamcinolone and 3mm thick silicone mouth guard in the maxillary arch.	1. One year post intervention, the patient's lips had completely healed and there was no tooth mobility.
(Colville & Mok, 2003) United Kingdom Case Reports N=2	*Case Report 1:* **Population:** Age: 6 yr; Injury etiology: traumatic, high-level SCI from shrapnel. **Problem:** Self-injury (biting) to the tongue and lips. **Intervention:** Psychologist involvement, psychosocial meetings, play therapy, reassurance, discharge planning.	*Case Report 1:* 1. Behaviour completely abated.

	Case Report 2: **Population:** Age: 12 yr; Injury etiology: SCI requiring spinal fusion and halo traction. **Problem:** Self-injury (biting) to the lips, spitting at nurses, anger, fear of death. **Intervention:** Psychologist and interpreter involvement.	*Case Report 2:* 2. Lip-biting behaviour diminished but child continued to be difficult to manage and did not develop any attachments with ward staff prior to discharge.
(Vogel & Anderson, 2002) USA Case Reports N=4	Case Report 1: Population: Age: 6 yr; Gender: Male; Injury etiology: SCI; Level of injury: complete left C7, right T1. Problem: Picking/scratching nipples. Pt. described them as being "irritated." Intervention: Carbamazepine (10mg/mg/day).	Case Report 1: 1. Significant improvement in in self-injurious behaviour, relapsing only when the medication was stopped/ started (between age 6 and 14 yr).
	Case Report 2: Population: Age: 11 mo; Gender: Male; Injury etiology: SCI at birth; Level of injury: C5. Problem: Biting of the dorsum of both hands and thumb nails. Intervention: Gloves (ages 3-5 yr), 10-15 mg/kg/day Carbamazepine (ages 5-8 yr), 15 mg/kg/day Gabapentin (age 9yr).	Case Report 2: 2. Resolution of symptoms with behaviour only returning when medication was stopped/restarted.
	Case Report 3: Population: Age: 13 yr; Gender: Female; Injury etiology: Transverse Myelitis; Level of injury: left C8, right T1. Problem: Biting to arms and fingers. Pt. attributed this to anxiety and "tingling" to the area. Intervention: Counseling initiated followed by carbamazepine at age 14 yr (100 mg, three times daily), and then gabapentin (300 mg, three times daily).	Case Report 3: 3. Resolution of symptoms with behaviour only returning when medication was stopped/restarted.
	Case Report 4: Population: Age: 17 yr; Gender: Male; Injury etiology: SCI; Level of injury: C5. Problem: Bilateral hand and terminal digit biting. Pt.	Case Report 4: 4. Resolution of symptoms within one year without reoccurring.

	reported the biting helped to move his hands. Intervention: Education, occupational therapy, gloves.	
Latex Allergy		
(Vogel et al. 2002b) *Part I* USA Observational N=216	**Population:** Age at injury: 14.1±4.0 yr; Age at interview: 28.6±3.4 yr; Time since injury: 14.2±4.6 yr; Gender: males=150, females=66; Level of injury: tetraplegia=123, paraplegia=93. Severity of injury: C1-4 ABC=41, C5-8 ABC=67, T1-S5 ABC=82, tetra/para D=26. **Intervention:** None. Survey. **Outcome Measures:** Prevalence of PU (PU), hospitalizations, latex allergy, medical conditions, health insurance	1. 18 individuals reported allergy to latex. 2. Latex allergy was significantly more common in women (16%) than in men (6%) (p=0.017). 3. Latex allergy was reported by 33% of those with SCI related to medical or surgical conditions, in contrast to a 6% prevalence in the other etiology groupings (p<0.001). 4. Latex allergy was also significantly assoc w higher ASIA Motor scores (p=0.003). 5. Latex allergy was more common in those with normal bladder control than those on intermittent catheterization programs or those with indwelling catheters (p=0.005).

Discussion

Pressure injuries are the most common skin-related complication of SCI. In adults, skin conditions are a leading cause of unplanned hospitalization among those with SCI, and the associated costs to the health care system are substantial (DeVivo & Vogel, 2004). In a retrospective survey of 216 individuals with SCI sustained in childhood, 43% of respondents reported having experienced at least one pressure ulcer within the last three years (Vogel et al. 2002b), with almost half of those (47%) indicating that they had experienced two or more pressure ulcers within that time. Factors that were associated with increased rates of ulceration included: male gender, non-white race, non-sports related injury, more severe motor impairment (based on American Spinal Injury Association Impairment Scale motor scores), lower total and motor subscale Functional Independence Measure scores, smoking, and presence of spasticity. Many of these findings are in keeping with the adult literature (Eslami et al. 2012; Gélis et al. 2009). The impact of race on pressure injury risk in adults with SCI has been postulated to relate to health care disparities (Saunders et al. 2015), which were not specifically studied in the survey by Vogel et al.(2002b). In the study by Vogel et al.(2002b), bowel/bladder incontinence, heterotopic ossification, presence of hip contractures or scoliosis and tetra versus paraplegic status did not significantly relate to rate of pressure ulcers. The absence of a link between incontinence and pressure injury is particularly notable as it is frequently cited as a risk factor for pressure injury in adults with SCI (Wilczweski et al. 2012). Given the limitations of this single, survey-based retrospective study of pressure injuries in pediatric SCI, it's unclear if these factors confer less risk in a pediatric population or if the risk associated with these conditions simply hasn't yet been adequately captured by the available literature. It is important to note as well that previous pressure injury has been found to be one of the most consistent risk factors for pressure injury in the adult population (Gélis et al. 2009; Verschueren et al. 2011). That risk has been suggested for people with pediatric SCI by the high frequency of recurrent ulcerations reported in the last 3 years (Vogel et al. 2002b).

Traumatic self-inflicted skin lesions have been reported rarely in both children and adults with SCI (Almeida et al. 2009; Colville & Mok, 2003; Frost et al. 2008; Vogel & Anderson, 2002). In the few pediatric cases presented above, lesions were generally confined to fingers and lips. Cases were described as being linked to one of several factors including dysesthesia, pain or psychological triggers. Accordingly, interventions included the use of physical barriers (mouth guards or gloves), psychological support, or anti-epileptic medications (specifically carbamazepine or gabapentin). Responses to interventions varied, but patients largely improved over time, with relapses occurring in some instances when the medications were stopped.

Latex allergy affects approximately 4.3% of the general population (Wu et al. 2016). It occurs more frequently in children with spinal dysraphism, and has been attributed to repeated exposures to natural rubber latex. Whether or not this allergy is more common in people with SCI is undetermined, but there may be an association with long term catheter use (Monasterio et al. 2000). In the retrospective survey by Vogel et al in 2002, information about latex allergy in individuals with pediatric onset SCI was collected. Approximately 8% of the respondents reported a latex allergy. It was more commonly reported by females but did not appear to be associated with catheter use.

Overall, the literature regarding skin complications in people with pediatric onset SCI is fairly limited. As a result, though some associations can be identified, it's difficult to draw specific conclusions. Pressure injuries are the most common and most concerning skin related complications of pediatric SCI and ongoing efforts to understand contributing factors and reduce rates of pressure injury recurrence are warranted.

Key Points

Pressure injuries are the most common and impactful skin complications of SCI. Risk factors may include previous pressure injury, male gender, non-white race, non-sports related injury, motor severity, Functional Independence Measure score, smoking and spasticity.

Latex allergy may occur at a higher rate amongst people with pediatric SCI than in the general population.

5.7 Cognitive Function

Children with SCI or myelopathy may be at risk of cognitive dysfunction. Little is known about the frequency of cognitive dysfunction post SCI, its etiology, and which cognitive domains are most affected. Cognitive dysfunction may arise from concurrent traumatic brain injury, from the etiology causing myelopathy, such as demyelination or central nervous system inflammation, from systemic effects of treatment for the etiology of SCI such as chemotherapy, and other causes not well-elucidated (Harder et al. 2013; Zonfrillo et al. 2014). Studies characterizing cognitive dysfunction post SCI or post myelopathy are summarized in the Tables below.

Table 34. Studies assessing cognition among children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Zonfrillo et al. 2014) USA Observational N=13,798 (2,952= SCI)	**Population:** Age: 7-18 yr. % Males by injury etiology: TBI=70.0%, Tetraplegia=77.7%, Paraplegia=73.7%, Other=58.4%. Injury etiology: 1) TBI (n=6297); 2) tetraplegia (n=946); 3) paraplegia (n=1244); or 4) other (which included combinations of TBI and SCI, TBI and multiple fracture/ amputation, SCI and multiple fracture/amputation, burns, or other multi-trauma) (n=5311). **Intervention:** None. **Outcome Measures:** Functional Independence Measure (FIM) cognitive subscore.	1. Subjects with tetraplegia and paraplegia as their main injury code had higher levels of cognitive functionality on admission compared with the TBI group. 2. Median admission FIM cognitive subscore for those with tetraplegia or paraplegia was 6, and the majority of these patients improved to 7 on discharge. 3. All injury groups demonstrated improvements in FIM cognitive subscores on discharge from rehabilitation (p<0.0001 for each); children with TBI had more severe discharge cognitive disability compared with those with SCI, burns, or multiple injuries. 4. Subjects with SCI had longer length of stays than those without SCI (p<0.0001). 5. When examining trends over time, there was an overall slight decrease in length of stay (median 15 days in 2002 [IQR 5-29] to median 13 days in 2011 [IQR 8-25 days], p=0.02). 6. The discharge cognitive stages over time have remained stable (median 5 [IQR 4-6]) for 2002-2011.
(Harder et al. 2013) USA Observational N=24	**Population:** Age: 11.5±3.4 (5-18) yr; Gender: males=9, females=15; Injury etiology: Transverse Myelitis; Age of Onset: 9.7±4.8 (1-17) yr; Level of injury: cervical (N=13); Ambulation: normal=46%, abnormal but ambulated independently=79%, bilateral support (i.e., crutches) =29%, wheelchair-bound=8.3%. **Intervention:** None. Neuropsychological evaluation, patient and caregiver surveys. **Outcome Measures:** California Verbal Learning Test, Children's Version (CVLT-C; 5–16 yr and 17-18 yr), Digit Span subtest from the Wechsler Intelligence Scale for Children, Fourth Edition (WISC-IV; 6–16 yr), Wechsler Adult Intelligence Scale,	*Note:* Mildly Impaired (≤1.0 SD from the mean or 16th percentile); Moderately Impaired (≤1.5 SD from the mean or 5th percentile); Severely Impaired (≤2.0 SD from the mean or 2nd percentile). *Fine Motor/Visual-Motor Skills* 1. For the non-dominant hand, mild deficits were observed in 45.5% of subjects, with severe deficits noted in 36.4%; for the dominant hand, mild, moderate, and severe deficits were revealed in 40.9%, 22.7%, and 13.6% of participants, respectively. 2. For graphomotor (i.e., paper/pencil) skills, mild, moderate, and severe deficits in visual-motor integration were observed in 28.6%, 19%, and 4.8%, respectively. 3. The lowest rate of impairment was observed in the area of visual perception (only 4.5% were mildly impaired, none were moderate or severe). *Attention and Executive Function*

	Third Edition (WAIS-III; 17–18 yr), Symbol Search subtest from the WISC-IV/WAIS-IV, Symbol-Digit Modalities Test (SDMT; 8–18 yr), Oral Version, Beery Developmental Test of Visual-Motor Integration, Fifth Edition (VMI-5; 5–18 yr), The Grooved Pegboard (5-18 yr), Trail-Making Test (TMT; 9–18 yr), Letter Fluency subtest from the Delis-Kaplan Executive Function System (DKEFS; 8–18 yr), Pediatric Quality of Life (PedsQL; 5–18 yr) Multidimensional Fatigue Scale, Behavior Assessment System for Children, Second Edition (BASC-2; 5–18 yr), Hauser Ambulation Index, school function, medication use.	4. Approximately 18.2% of participants showed moderate impairment in auditory attention and working memory (i.e., Digit Span), while 40.9% had at least a mild deficit. 5. Parents reported “at-risk” or subclinical attention problems in approximately 30% of participants although no patients demonstrated severe problems in this area, nor did participants’ parents report clinically significant attention problems. 6. While 5.6% of participants showed severe deficits in simple attention (i.e., Trail-Making Test A), 11.1% showed severe deficits in complex attention and sequencing (i.e., Trail-Making Test B). 7. Mild and moderate deficits were noted in the area of verbal fluency for 25% and 20% of the sample, respectively. *Verbal Memory* 8. Deficits in initial free recall (i.e., CVLT-C/II Trial 1) were mildly and moderately impaired at rates of 33.3% and 20.8%, respectively; rates of deficits in free recall decreased with opportunities for rehearsal. 9. Long delay free recall was mildly, moderately, and severely impaired in 25%, 8.3% and 4.2% of participants, respectively. *Processing speed* 10. Mild and moderate deficits in motor-based processing speed were observed at rates of 20% and 10%, respectively; however, when the motor component was removed, moderate and severe impairment were observed at rates of 10% and 5%, respectively.

Table 35. Case reports assessing cognition among children with SCI.

Author, Year Country Study Design	Population, Intervention, Outcome Measures
(Salvato et al. 2017) Italy Case Report N=1	**Population:** 40 mo, female, complete C2 traumatic SCI. **Intervention:** None. Neuropsychological assessment. **Outcome Measure:** Body representation (“Matching Body Parts by Location”), intelligence (Matrix reasoning subtest of the “Wechsler Preschool and Primary Scale of Intelligence Third Edition”)

Discussion

Only two studies have characterized the frequency and types of cognitive dysfunction post SCI. Harder et al. (2013) evaluated cognition in children with transverse myelitis. Although transverse myelitis does not involve brain demyelination, more than half of patients had either mild (40.9%) or moderate (18.2%) attentional dysfunction, nearly half of patients had mild (25%) or moderate (20%) reductions in verbal fluency, and more than half of patients had mild (33.3%) or moderate (20.8%) impairments in verbal memory. Abnormalities were also observed for processing speed and fine motor skills; however, much of this may be attributable to the transverse myelitis and its impact on motor function rather than cognition. Zonfrillo et al. (2014) used a large observational database of children admitted for inpatient rehabilitation. Compared to children with traumatic brain injury, children with SCI (paraplegia and tetraplegia) had higher cognitive functioning at admission and at discharge from inpatient rehabilitation. More than half of children with paraplegia and tetraplegia improved to the highest Functional Independence Measure cognitive subscore on discharge. In a case report of a child with complete C2 tetraplegia, mental body representation was altered compared to age-matched controls (Salvato et al. 2017).

6 Psychosocial Function

The onset of an SCI in infancy, childhood, or adolescence is a life-altering event has major psychosocial implications for survivors. Depression is the most common health conditions in individuals with SCI. In the adult SCI population, it is estimated that 22% of individuals are living with depression (Williams & Murray, 2015). In addition, during inpatient rehabilitation, as many as 42% of individuals with SCI experience depression (Krause et al. 2000). Often closely linked to depression, anxiety is also prevalent among individuals with SCI. According to a meta-analysis by Le and Dorstyn (2016), approximately 27% adults with SCI experience clinically significant symptoms of anxiety. Previous research has found that health complications (e.g., pain), financial strain, unsafe use of alcohol are associated with heightened risks of depression and/or anxiety in individuals with SCI (Budh et al. 2005; Hoffman et al. 2011; Zürcher et al. 2019), whereas factors such as social support, resilience, and community participation serve as protective factors against depression and/or anxiety (Kraft & Dorstyn, 2015; Min et al. 2014; Müller et al. 2015). In terms of interventions various psychological (e.g., cognitive behavioural therapy) and physical interventions (e.g., physical activity courses) have demonstrated effectiveness in treating depression and anxiety in the those with SCI (Burke et al. 2019; Craig et al. 1998; Curtis et al. 2017).

In individuals with and without SCI, levels of depression and anxiety are key determents of life satisfaction, as well as the physical, emotional, and social domains of QoL (Garma et al. 2011; Van Leeuwen et al. 2012). Compared to their counterpart without disabilities, individuals with SCI tend to have lower QoL and decreased life satisfaction (Dijkers, 2005; Evans et al. 1994). It As suggested by Evans et al. (1994), those with more severe injuries are at particularly high risk of having compromised QoL and life satisfaction. The onset of an SCI may also impact the mental and social aspects of life caregivers, especially parents of children with SCI, as the presence of a disability may contradict with their “normal” life that they envisioned for their child (Lynch & Cahalan, 2017). However, the adverse psychological impact of SCI may be buffered by adaptive coping strategies (Chevalier et al. 2009). Coping can be defined as “cognitive and behavioral efforts to manage external and/or internal demands that exceed the resources of the individual" (Kelly, Mulcahey, et al. 2012). In a study by King and Kennedy (1999), the findings demonstrate that group-based interventions aiming to enhance adaptive coping in individuals with SCI may help reduce depression and anxiety.

Research tackling the psychosocial aspect of SCI has primarily focused on the adult population. It is not until recently that the psychosocial aspect of SCI in the pediatric population received growing interests from practitioners and researchers. Given the dynamic nature of childhood of childhood and adolescence, the psychosocial consequences of SCI may have profound developmental implications for the pediatric-SCI population. The purpose of this section is to summarize and review the current evidence related to depression, anxiety, coping, QoL and life satisfactions in the pediatric SCI population.

Table 36. Studies assessing anxiety, depression, coping, life satisfaction and QoL among children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Duzgun Celik et al. 2018) Turkey Observational N=40	**Population:** *Pediatric-sustained SCI (<18 yr):* Age at interview: 23.9±5.8 (18-44) yr; Age at injury: 14.6±2.8 yr; Time since injury: 9.4±6.1 (3-29) yr; Gender: males=13, females=7; Severity of injury: AIS A=10, AIS B=3, AIS C=3, AIS D=4. *Adult-sustained SCI (18+ yr):* Age at interview: 43.9±12.8 (30-79) yr; Age at injury: 33.1±16.6 yr; Time since injury: 8.7±8.0 (1-31) yr; Gender: males=10, females=10; Severity of injury: AIS A=12, AIS B=1, AIS C=5, AIS D=2. **Intervention:** None. Survey. **Outcome Measures:** Craig Handicap Assessment and Reporting Technique (CHART-sf), World Health Organization Quality of Life Scale Short Form (WHOQOL-Bref; four domains including physical, mental, social, and environmental), Beck Depression Inventory (BDI).	1. There was no significant difference in the mean and total CHART-sf scores between the two groups; total CHART-sf scores were not correlated with ASIA scores, complete/incomplete status of patients, depression level or disease duration in either group. 2. For WHOQOL-Bref, only environmental area scores were significantly higher in Group 2 than Group 1 ($p<0.05$). 3. There was no difference in BDI scores between the two groups, and 79% of patients in both groups were within a normal range.
(Morrison et al. 2017) USA	**Population:** *Group 1 (Caregivers with children 1-18 yr; n=178):* Child age at injury:	*Group 1: Data from Caregivers with children 1-18 yr*

Observational N=178 Caregivers of children with SCI	5.8±5.6 yr; Child age at interview: 11.1±5.2 yr; Child gender: males=100, females=78; Level of injury: paraplegia=121, tetraplegia=57; Severity of injury: AIS A=87, AIS BCD=91. *Group 2 (just the children 7-18 yr from the above sample; n=134)*: Child age at injury: 7.3±5.7 yr; Child age at interview: 13.4±3.5 yr; Child gender: males=80, females=54; Level of injury: paraplegia=88, tetraplegia=46; Severity of injury: AIS A=66, AIS BCD=68. **Intervention:** None. Mixed methods. Caregivers answered an open-ended question (qualitative) and completed a survey (quantitative). Children completed surveys only. **Outcome Measures:** *Caregivers*: What has been the most rewarding parenting a child with a SCI. *Children with SCI*: Revised Children's Manifest Anxiety Survey (RCMAS-2-SF), Children's Depression Inventory (CDI-2-SF), Pediatric Quality of Life Inventory 4.0 (PedsQL; Generic Core Scales), Children's Assessment of Participation and Enjoyment (CAPE).	1. Caregivers derive a variety of rewards from parenting their children with SCI including: A. Enhanced Resilience in Child and Self (71.9%) – child's accomplishments, improvement/recovery, school/academic achievements and having a positive/optimistic attitude, etc. B. Stronger Caregiver–Child Relationship (18%) – spending time together, growing close and providing child with emotional assistance. C. Connecting with Others (11.2%) – building relationships with and receiving support with from children and families, with providers and with organizations. D. Learning (9.6%) – learning about new experiences, learning about SCI, learning about the child, learning from the child, the caregiver and child learning from each other and learning to advocate. 2. Just 3.4% of caregivers reported that parenting a child with SCI was like parenting any other child. 3. Just 2.2% reported that there were no rewards to parenting their child with SCI. 4. Caregivers who had children who were older at the time of injury ($p<0.001$) and interview ($p=0.017$) were more likely to report having an enhanced Caregiver–Child Relationship. 5. Caregivers without college exposure ($p=0.034$) and those who were unemployed ($p=0.029$) were more likely to cite Learning as a reward. 6. No other significant relationships emerged between caregiver rewards and sociodemographic variables were found. *Group 2: Caregivers of children 7-18 yr who completed quantitative surveys:* 7. Caregivers whose children scored lower on self-reported school and psychosocial HRQOL were more likely to report 'Resilience in my Child' as a reward ($p<0.05$ for both). 8. Caregivers whose children participated in fewer community activities and participated less often and had lower levels of depressive symptoms reported experiencing an Enhanced Caregiver–Child Relationship ($p<0.05$ for all). 9. Caregivers whose children participated in activities further from home and with a broader group ($p<0.05$ for both) and had higher self-reported psychosocial HRQOL ($p<0.05$) and self-reported and parent-reported school HRQOL ($p<0.001$) were more

		likely to report a Connecting with Others as a reward. 10. No other significant relationships emerged between caregiver reward type and child anxiety, depression, activity participation or quality of life.
(Kelly et al. 2016) USA Observational N=40	**Population:** *Children with SCI:* Age at interview: 11.5±3.2 yr; Age at injury: 4.3±4.2 yr; Gender: males=25, females=15; Time since injury: 6.9±3.9 yr; Level of injury: paraplegia=30, tetraplegia=10; Severity of injury: AIS A=25. *Caregivers:* mothers=34, fathers=3, grandmothers=1, grandfathers=1, aunt=1. **Intervention:** None. Survey. **Outcome Measures:** *Children:* Pediatric Quality of Life Inventory for Health-Related Quality of Life (HRQOL). *Caregivers:* Hospital Anxiety and Depression Scale (HADS), Pennebaker Inventory of Limbic Languidness (PILL), Revised Caregiver Burden Interview, short Form (RCBI), Social Problem-Solving Inventory, revised, short form (SPSI-R:S).	1. Caregiver problem solving alone was related to child physical HRQOL (p<0.01). 2. Caregiver mental health (p<0.01), burden (p<0.05), and problem solving were related to child psychosocial HRQOL (p<0.01). 3. Regression analyses controlling for child age and injury level revealed effective caregiver problem solving (p<0 .001) was significantly related to greater child physical HRQOL. 4. Regression analyses controlling for child age and injury level revealed effective caregiver problem solving (p<0.01) was significantly related to greater psychosocial HRQOL. 5. Problem solving orientation was related to both child physical (p<0.01) and psychosocial HRQOL (p<0.001); having a caregiver who demonstrated a positive, as opposed to negative, problem-solving orientation was related to greater child HRQOL. 6. Problem solving style was related to both physical (p<0.01) and psychosocial HRQOL (p<0.001); caregivers who demonstrated being rational resulted in greater HRQOL among children whereas caregivers who were avoidant resulted in lower HRQOL among children. 7. Caregivers demonstrating impulsivity and/or carelessness was related to kids having lower psychosocial HRQOL (p<0.05) but was not significantly associated with physical HRQOL.
(Ma et al. 2016) Canada Observational N=174	**Population:** *Pediatric-sustained SCI (<19 yr; n=87):* Age: 38.6±12.3 yr; Gender: males=61, females=26; Time post-injury: 24.1±14.0 yr; Level of Injury: C1-4=6, C5-8=35, T1-5=12, T6-L5=34; Severity of injury: complete=41, incomplete=46. *Adult-sustained SCI (19+ yr; n=87):* Age: 39.5±10.9 yr; Gender: males=62, females=25; Time post injury: 12.8±10.0 yr; Level of injury: C1-4=8, C5-8=33, T1-5=11, T6-L5=35. Severity of	1. Compared to adult-sustained SCI, participants with paediatric-sustained SCI reported significantly greater functional independence (FIM motor subscore; p=0.03), less pain (SF-36 pain subscore; p=0.02), and fewer visits to the doctor in the past year (p=0.04). 2. There were no significant differences between adult- or pediatric-sustained SCI groups with respect to perceived health status (SF-36 general health subscore) or depressive symptoms (PHQ-9). 3. Compared to adult-sustained SCI, those with pediatric-sustained SCI reported more minutes of moderate–heavy leisure time physical activity (PARA-SCI; p=0.05), and scored higher on measures of social and

	injury: complete=40, incomplete=45. **Intervention:** None. Secondary analysis of data from the *Study of Health and Activity in People with SCI (SHAPE-SCI)* (Martin Ginis et al. 2008). **Outcome Measures:** Functional Independence Measure (FIM) motor subscale, Short Form 36 (SF-36), number of physician visits, Patient Health Questionnaire 9-item (PHQ-9), Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI), Craig Handicap Assessment and Reporting Technique (CHART), Satisfaction with Life Scale (SWLS)	occupational participation (CHART; p=0.04 and p=0.03, respectively). 4. There were no significant differences between adult- or pediatric-sustained SCI groups with respect to life satisfaction.
(M. Hwang et al. 2015) USA Observational N=159	**Population:** Age at interview: 35.0±6.2 yr; Time since injury: 21.2±7.2 yr; Gender: males=100, females=59; Level of injury: C1-4=24, C5-C8=57, T1-S5=62, other=16; Severity of injury: paraplegia=67, tetraplegia=92. **Intervention:** None. Survey. **Outcome Measures:** Routine medication use, polypharmacy (use of 5+ different medications), secondary health conditions (SHC), Functional Independence Measure, Short Form-12 Health Survey (SF12v2), Craig Handicap Assessment and Reporting Technique (CHART), Patient Health Questionnaire 9-item (PHQ-9).	1. There were no significant differences in the frequency of polypharmacy between men and women (p=0.418), between Caucasians and non-Caucasians (p=0.756) or between those with complete and incomplete injuries (p=0.898). 2. There were significant differences in polypharmacy frequency among the AIS severity groups: C1-4 ABC, 54.2%; C5-8 ABC, 35.1%; T1-S5 ABC, 19.4%; AIS D, 25.0% (p=0.014); polypharmacy was more prevalent in tetraplegia than in paraplegia (p=0.003). 3. Individuals with polypharmacy had significantly older age (p=0.034), longer duration of injury (p=0.017), greater number of SHCs (p<0.001), and higher PHQ-9 total score (p=0.001), but significantly lower FIM motor score (p<0.001), SF12v2 physical component score (p<0.001), CHART physical independence, mobility, occupation and social integration scores (p=0.009, p<0.001, p=0.001, and p=0.037, respectively). 4. Greater number of SHCs, increasing duration of injury and tetraplegia increased odds of polypharmacy (p<0.001, p=0.028, and p=0.010, respectively. 5. Polypharmacy was predictive of decreased CHART mobility scores (p<0.001), decreased SF12v2 physical component scores (p<0.001) and increased PHQ-9 scores (p<0.001) when

		controlling for the number of SHCs, age, duration of injury and AIS severity.
(January et al. 2015) USA Observational N=177	**Population:** *Pediatric-onset SCI*: Age at interview: 33.5±7.1 (19-50) yr; Age at injury: 13.5±4.6 (0-18) yr; Time since injury: 19.5±8.2 (1-43) yr; Gender: males=110, females=67; Severity of injury: tetraplegia=100, complete=125. **Intervention:** None. Survey. **Outcome Measures:** Pittsburgh Sleep Quality Index (PSWI), Short-Form 12 (SF-12) physical subscore, Beck Anxiety Inventory (BAI), Patient Health Questionnaire 9 item (PHQ-9), Satisfaction with Life Scale (SWLS).	1. Half the subjects (51.4%) self-reported poor sleep quality within the last month (51.4%) demonstrating significantly more difficulties than control group norms, but significantly fewer than sleep-disordered patient norms. 2. Subjects with pediatric-onset SCI were comparable to controls in the area of sleep disturbances, and also similar to the sleep-disordered patient group on sleep efficiency and sleep latency scores. 3. Subjects with pediatric-onset SCI were most likely to report difficulty getting to sleep (67.8%) and/or staying asleep (65%) at least once in the last month; bathroom use (40.1%) and sleep interference due to pain (40.1%) were also reported. 4. Older age (p=0.008) and tetraplegia were associated with lower sleep quality (p=0.011) whereas injury etiology, completeness of injury, sex, ethnicity, injury duration, and age of injury were not. 5. Low sleep quality was strongly related to physical functioning (SF-12), both in activity-interfering pain (p<.001) and general health (p<0.001). 6. After controlling for age, injury severity, and physical health components, sleep quality explained a significant portion of the variance in depression (p<0.001) and anxiety (p=0.005), but not in life satisfaction.
(Riordan et al. 2015) USA Observational N=340	**Population:** Age: 13.2.2±3.9 yr; Gender: males=194, females=146; Age at Injury: 8.2±5.8 yr; *Three Level/ Severity Injury Groups:* tetraplegia AIS ABC=96, paraplegia AIS ABC=191, AIS D=53. **Intervention:** None. Survey. **Outcome Measures:** Children's Assessment of Participation and Enjoyment (CAPE), Pediatric Quality of Life Inventory (PedsQL), Revised Children's Manifest Anxiety Scale (RCMAS), Children's Depression Inventory (CDI).	1. Subjects with paraplegia ABC and AIS D injuries participated in more activities than those with tetraplegia ABC (p=0.002 and p=0.018, respectively). 2. There were no significant differences between the participation frequency of subjects with paraplegia ABC and those with AIS D injuries. 3. Subjects with paraplegia ABC reported higher social QOL than those with tetraplegia ABC (p=0.001) and AIS D injuries (p=0.002). 4. There were no differences between subjects in the three neurological impairment categories when examining scores exceeding the clinical cut-off for anxiety or depression.
(Klaas et al. 2014) USA	**Population:** Age: 15.6±2.0 yr; Gender: males=137, females=99; Age at Injury:	1. Girls were significantly more anxious than boys (p=0.030).

Observational N=236	10.6±5.5 yr; Level and Severity of Injury: C1-4 AIS ABC=26, C5-8 AIS ABC=47, paraplegia AIS ABC=120, AIS D=28, missing=15. **Intervention:** None. Survey. **Outcome Measures:** Children's Depression Inventory (CDI), Beck Depression Inventory-II (BDI-II), Revised Children's Manifest Anxiety Scale (RCMAS).	2. There was a significant interaction for child anxiety by child age and sex (p=0.020); older adolescent girls were more anxious than younger adolescent girls and boys and older adolescent boys. 3. Older adolescents (16-17 yr) were significantly more depressed than younger 4. adolescents (12-15 yr) (p=0.040). 5. Regarding depression, there was no significant interaction between child age and sex. 6. Among adolescents (12-17 yr), 16% reported that they think about suicide but would not follow through and 1.1% indicated they wanted to commit suicide. 7. Among 18-yr-olds, 10.9% indicated that they have thought about suicide but would not carry it out, and none responded that they wanted to kill themselves. 8. Among youth overall, 12.4% were receiving counseling services; 17.4% were taking medications for emotional, psychological, or behavioral reasons; and 23.3% were enrolled in counseling and/or taking medications. 9. Older adolescents (23.5%) were significantly more likely to be on medications than younger adolescents (10.1%) (p=0.009].
(Hwang et al. 2014b) USA Observational N=283	**Population:** *Pediatric-onset SCI:* Age: 27.3±3.7 (21-37) yr; Age at injury: 14.5±4.3 (0-18) yr; Time since injury: 12.7±5.0 (4-30) yr; Gender: males=182, females=101; Level of injury: tetraplegia=174; Severity of injury: complete=195; C1-4 AIS ABC=46, C5-8 AIS ABC=110, T1-S5 AIS ABC=99, AIS D=28. **Intervention:** None. Annual interviews. **Outcome Measures:** Satisfaction with Life Scale (SWLS), Short-Form 12 Health Survey (SF-12), Patient Health Questionnaire-9 (PHQ-9), and Craig Handicap Assessment and Recording Technique (CHART).	1. Those attaining a bachelor's degree or higher had increased from 33.2% at the first interview to 47.0% at the last interview; 2. There was no change in the proportion of employed versus unemployed from the first (56.8% versus 43.2%) to last interview (58.1% versus 41.9%) (less than general population estimates); 3. At the last interview, the proportion of employed participants was significantly higher in those with a baccalaureate and post-baccalaureate degrees, whereas the proportion of unemployed individuals was higher in those with a high school diploma. 4. Women and married participants also had higher rates of employment at the last interview than men and single participants, respectively. 5. There was no significant change in employment status over time (OR 1.01, confidence interval (CI) 0.98-1.04). 6. Odds of employment increased over time in participants who were women (1.04, CI 1.00-1.08), married (1.05, CI 1.02-1.08), attained a baccalaureate degree (1.03, CI 1.00-1.07), or post-baccalaureate degree (1.05, CI 1.02-1.08).

		7. Odds of employment decreased over time in participants with occurrence of autonomic dysreflexia (0.80, CI 0.65-0.99), spasticity (0.80, CI 0.59-0.99) or chronic medical condition (0.83, CI 0.71-0.98). 8. Life satisfaction (SWLS) scores increased over time in those who remained employed (1.11, CI 1.01-1.22). 9. Odds of depression (PHQ-9) increased over time in those who remained unemployed (1.13, CI 1.04-1.23).
(January et al. 2014) USA Observational N=214	**Population:** *Pediatric-Onset Adult SCI*: Age: 29.5±5.2 (24-42) yr; Mean age at injury: 13.9±4.4 yr; Gender: males=133, females=81); Level of Injury: tetraplegia=124, paraplegia=90; Severity of Injury: complete=150, incomplete=64. **Intervention:** None. Survey. **Outcome Measures:** Craig Handicap Assessment and Reporting Technique (CHART), Patient Health Questionnaire – 9 Item (PHQ-9), Functional Independence Measure (FIM), Short Form 12 Item Version 2 (SF12v2), Alcohol Use Disorders Identification Test (AUDIT-C).	1. Overall, mean PHQ9 was low at baseline (3.07±0.24); only 8% met the criteria for MDD at any given time point. 2. A much higher percentage reported at least mild symptoms (38%), and 12% endorsed suicidal thoughts at any given time point. 3. Multilevel growth modeling analyses were used to explore depression symptoms across time; several factors emerged as significant predictors of depressive symptoms in the final model: • less community participation (p<0.01); • incomplete injury (p=0.02); • hazardous drinking (p=0.02); • bladder incontinence (p=0.01); • pain (p=0.03) 4. Marriage resulted in decreases in depression scores for individuals (p=0.02).
(Schneider et al. 2014) Switzerland Cohort N=12	**Population:** Age: 7.5 yr; Gender males=10, females=2; Time post diagnosis: 4.2 yr (high grade=2.4 yr, low grade=5.9 yr). **Intervention:** None. Survey sent after patients had microsurgical removal of a primary intramedullary spinal cord tumours (total resection=5, subtotal resection=7). **Outcome Measures:** Pediatric Quality of Life Inventory (PedsQL).	1. Among 10 patients who completed the survey, there were no significant differences in PedsQL scores (child or parent proxy) between the study cohort and values for a normative (healthy) control sample population. *Not significantly powered; authors' power analysis demonstrates a sample of 57 patients is required.
(Harder et al. 2013) USA Observational N=24	**Population:** Age: 11.5±3.4 (5-18) yr; Age at injury: 9.7±4.8 (1-17) yr; Gender: males=9, females=15; Injury etiology: Transverse Myelitis; Level of injury: cervical (N=13); Ambulation: normal=46%, abnormal but ambulated	1. According to parent report on the BASC-2, subjects experienced subclinical (21.7%) or clinical (8.7%) levels of depression in a total of 29% of participants. 2. Of the seven participants who showed elevated symptoms of depression based on parent report, two received referrals for additional cognitive testing.

	independently=79%, bilateral support (i.e., crutches) =29%, wheelchair-bound=8.3%. **Intervention:** None. Neuropsychological evaluation, patient and caregiver surveys. **Outcome Measures:** Behavior Assessment System for Children, Second Edition (BASC-2; 5–18 yr).	3. Of the 11 participants who were prescribed medication (i.e., SSRIs, GABAergic medications, tricyclic antidepressants, and anticholinergic agents), only two were referred for further cognitive testing. 4. No clear association between cognitive dysfunction and mood-related factors or adverse medication side effects.
(Smith et al. 2013) USA Observational N=182	**Population:** Age: 15.9±1.7 (13-18) yr; Gender: males=104, females=78; Level of injury: paraplegia=115, tetraplegia=67; Severity of injury: complete=98, incomplete=84. **Intervention:** None. Survey. **Outcome Measures:** Kidcope, Children's Depression Inventory (CDI), Revised Children's Manifest Anxiety Survey (CMAS), Quality of life (PedsQL). *Note:* "Escape-Oriented Factor" includes distraction, social, withdrawal, self-criticism, blaming others, wishful thinking, resignation and emotion regulation yelling	1. Cognitive restructuring and resignation were the two most frequently used coping strategies reported. 2. In contrast, blaming others and self-criticism were used least frequently. 3. Social support and emotional regulation (calming) were seen as the most effective coping strategies, whereas self-blame and wishful thinking were perceived as least effective. 4. Increased SCI injury duration was associated with lower use of escape-oriented coping strategies. 5. Increased age was associated with increased social withdrawal. 6. Participants with tetraplegia used distraction more often than participants with paraplegia. 7. After controlling for current age, age at injury, sex and injury level, hierarchal linear regression models showed increased scores on the escape-oriented factor were associated with increased anxiety and depressive symptomatology and lower psychosocial QOL ($p<0.001$ for all).
(Castello et al. 2012) USA Pre-Post N=6	**Population:** Age: 16.6±4.4 yr; Gender: males=3, females=3; Time since injury: 3.9±3.1 yr; Level of injury: Cervical=4, Thoracic=2; Severity of injury: AIS A=3, AIS B=1, AIS C=1, AIS D=1. **Intervention:** Functional Electrical Stimulation (FES) cycling. Stimulators were placed on hamstrings, quadriceps and gluteal muscles (45-50 rpm, 250 µs, 33.3 Hz, 70-120 mA). Sessions were 30 min, 3 times per wk over 9 mo.	1. Four of the six participants completed the PedsQL on at least 2 occasions. 2. Mean Psychosocial Health Summary Score for 4 participants at their initial evaluation was 66.67±7.82 (range 61.67-78.33). 3. Post intervention, quality of life increased for 3 of 4 subjects (mean=73.75±11.41, range=60.00-86.67). 4. The mean change from initial to final PedsQL was 7.08±8.21, although change scores ranged from −3.33 to 16.67 (non-significant). 5. Non-significant, positive, correlations were found between change in QOL and both total biking sessions and number of months biked (r_s = 0.60 and r_s = 0.74, respectively).

	Outcome Measures: Pediatric Quality of Life Inventory (PedsQL).	6. Non-significant, positive, correlations were found between initial and final QOL (r_s = 0.60 and r_s = 0.80) and the months post injury.
(Hwang et al. 2012) USA Observational N=215	**Population:** *Pediatric-onset SCI*: Age at interview: 23.3±0.9 yr; Age at injury: 13.2±4.9 yr; Time since injury: 10.3±5.0 yr; Gender: males=126, females=89. Level of injury: tetraplegia=51.6%; Severity of injury: complete=73.5%, C1-4 AIS ABC=11.2%, C5-8 AIS ABC=35.3%, T1-S5 AIS ABC=43.3%, AIS D=8.8%, missing=1.4%. **Intervention:** None. Survey. **Outcome Measures:** Functional Independence Measure (FIM), Satisfaction with Life Scale (SWLS), Short-Form 12 Health Survey (SF-12), Patient Health Questionnaire-9 (PHQ-9) Depression Scale, and Craig Handicap Assessment and Recording Technique (CHART), use of tobacco, alcohol, and marijuana.	1. Prevalence rates of regular substance use were 27.9% for tobacco, 55.4% for alcohol and 10.7% for marijuana (Table 2). These rates are considerably lower than the age-matched general population values. 2. Tobacco use was higher in participants who were unemployed than those employed either full- or part-time (38% versus 21%). 3. Alcohol use was higher in participants who were Caucasian (60 versus 26% non-Caucasian), had a college degree (80% versus 47% no college degree), were employed (70% versus 45% unemployed), had higher annual income (44%, \$10 000 versus 65%, \$10000-29999 versus 77%, >\$30000), were single (59% versus 31% married) and able to drive independently (67% versus 35% cannot drive independently). 4. Marijuana use was more prevalent in males (14% versus 6% female) and those without a college degree (13% versus 2% college degree). 5. There was no significant difference in the prevalence of substance use between those living independently, or in relation to any injury-related factors such as level, severity or duration of injury. 6. Individuals with regular alcohol use had significantly lower incidence of urinary tract infections (64 versus 82%) and chronic medical conditions (11 versus 22%) compared with individuals with no use. 7. Tobacco use was significantly associated with depressive symptoms (PHQ-9; $p<0.05$). 8. Alcohol use was associated with higher socio-cognitive independence (FIM; $p<0.01$), better perceived physical health (SF-12 physical, CHART physical, CHART mobility; $p<0.05$ for all), and increased community participation (CHART social; $p<0.05$). 9. Marijuana use was not associated with any outcome measure. 10. There was no association between SWLS and substance use of any type. 11. Logistic regression indicated that both unemployment and the presence of depressive symptoms contribute independently to tobacco use ($p<0.05$) 12. Logistic regression indicated that having a college degree ($p<0.05$) and being single were

		found to contribute most in predicting regular alcohol drinking (p<0.01), while independent mobility (p<0.01) was also a significant predictor for use. 13. Logistic regression indicated those with a college degree were less likely to use marijuana (p<0.05).
(Boyer et al. 2012) USA Observational N=109	**Population:** *Pediatric-onset SCI*: Age at interview: 17.8±3.7 (11-24) yr; Age at injury: 11.2±5.7 (0-19) yr; Gender: males=59, females=50; Time since injury: 6.6±4.9 (1-23) yr. **Intervention:** None. Survey. **Outcome Measures:** Post Traumatic Stress (PTS) via Post-traumatic Diagnostic Scale and the Child Post Traumatic Stress Disorder Symptom Scale; Family Functioning (FF) via Family Assessment Device; and Functional Independence (FI) via Pediatric Orthopedic Surgeons of North America Pediatric Musculoskeletal Functional Health Questionnaire.	1. Structural equation modeling path analyses were used to test and confirm 3 hypothesized models: A. PTS mediated the relationship between FF and FI; B. The Avoidance symptom cluster of PTS mediated the relationships between PTS reexperiencing symptoms and FI, and between the PTS Arousal symptom cluster and FI; and C. The previous 2 models showed adequate fit to the data when integrated into an overarching model depict the interrelationship of level of SCI (tetraplegia v. paraplegia), FF, PTS symptom clusters, and FI.
(Kelly, Klaas, et al. 2012) USA Observational N=340	**Population:** Group: Children (6-12 yr) =133, Adolescents (13-18 yr) =207. Age: 13.3±3.8 yr. Time since injury: 5.1±4.3 yr, Level of injury: paraplegia=224; Severity of injury: complete=187. **Intervention:** None. Survey. **Outcome Measures:** Children's Assessment of Participation and Enjoyment (CAPE; i.e., participation, diversity, frequency, intensity, context), Pediatric Quality of Life Inventory – Psychosocial Health Scale (PHS) (only emotional, social, school subscales).	1. For children (6-12 yr), Regression analysis showed that *where* children participate (i.e., further from home) positively and significantly predicted QOL subscales after controlling for age, sex, injury level, and injury duration. 2. For adolescents (13-18 yr), regression analysis showed that subject characteristics "*who*" (i.e., being male, having paraplegia, and participating with a more diverse group) positively, and significantly predicted QoL after controlling for child age, sex, injury level, and injury duration.
(Chlan et al. 2011) USA Observational N=298	**Population:** Age: 31.1±5.5 (24-45) yr; Gender: males=184, females=114, Time since injury: 16.6±6.5 (6-38) yr; Level of injury: tetraplegia=165; Severity of injury: AIS A=210.	1. Approximately half (141) of the participants reported that religion is "important to very important" to them. 2. Mean spirituality coping score was 5.14±2.32, range 2-8), with 55% (163) of respondents using spiritual coping "a medium amount to a lot".

	Intervention: None. Survey. **Outcome Measures:** Brief Coping with Problems Experienced (Brief COPE), Functional Independence Measure (FIM), Craig Handicap Assessment and Reporting Technique (CHART), Short-Form Health Survey 12 (SF-12) and Satisfaction with Life Scale (SWLS), Importance of Religion (5-pt scale).	3. Importance of religion was positively correlated with age (p<0.01), duration of injury (p<0.01), mental component summary (SF-12; p<0.05) and life satisfaction (SWLS; (p<0.05). 4. Spiritual coping (Bref-COPE) was positively correlated with age (p<0.01), duration of injury (p<0.01) and life satisfaction (SWLS; (p<0.01). 5. Spiritual coping (Bref-COPE) was negatively correlated with FIM motor and CHART occupation (p<0.01 for both). 6. A stepwise regression analysis with life satisfaction (SWLS) as the outcome variable showed the following significant predictors: greater perceived mental health, being married/having domestic partner, greater occupational participation, lower incidence of pain and greater motor functioning (p<0.05 for all; 40% variance explained).
(Garma et al. 2011) USA Observational N=197	**Population:** Age at interview: 12.8±3.7 yr; Age at injury: 6.8±5.6 yr; Gender: males=107, females=90; Time since injury: 6.0±4.7 yr; Level of injury: paraplegia=136, tetraplegia=61. Caregivers: mothers=158, fathers=39 **Intervention:** None. Survey. **Outcome Measures:** Pediatric Quality of Life Inventory (PedsQL) – only the Psychosocial Health Summary Subscale (PHSS) (i.e., emotional, social, school functioning), Revised Children's Manifest Anxiety Survey (RCMAS), Children's Depression Inventory (CDI), Beck Anxiety Inventory (BAI) I or II.	1. Child- and caregiver-report scores on each of the PedsQL subscales and the PHSS from the SCI sample were significantly lower than child- and caregiver-report scores from a normative sample of youth without chronic health conditions (p<.001). 2. With respect to the PedsQL, there was a moderate degree of association between child- and caregiver-reports (.34 - .54); there were 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 where children consistently rated their QOL of life as better than did the caregiver-reporters. 3. Younger age at interview was associated with higher Emotional QoL (PedsQL) in the caregiver-reports (p<0.05), but lower social QoL (PedsQL) in the child-reports (p<p<0.001). 4. Younger age at injury was associated with higher Emotional QoL (PedsQL) (p<0.05). 5. Child and parent-reported anxiety and caregiver depression were significantly related to all aspects of child- and caregiver-report QoL (PedsQL) (p<0.01 for all). 6. QoL (PedsQL) did not vary by gender; however, those with paraplegia had higher social QoL than those with tetraplegia (p=0.046). 7. Regression analyses showed that child mental health significantly predicted child-report QoL (PedsQL) (p<.001), whereas child (p<.001) and caregiver (p<.001) mental health both

		significantly predicted caregiver-report QoL (PedsQL).
(Kelly et al. 2011) USA Observational N=203	**Population:** *Children:* Age at interview: 12.7±3.2 yr; Age at injury: 7.0±5.4 yr; males=108, females=95; Level of injury: paraplegia=142, tetraplegia=61; Severity of injury: complete=102, incomplete=101. *Caregivers*: mothers=158, fathers=29, stepmothers=2, grandmothers=10, aunts=2, grandfathers=2. **Intervention:** None. Survey. **Outcome Measures:** *Caregivers Measures:* Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI). *Child Measures:* Revised Children's Manifest Anxiety Survey (RCMAS), Children's Depression Inventory (CDI), Pediatric Quality of Life Inventory (PedsQL).	1. Caregiver mean BAI score was 8.45±8.43 (0-45) representing the mild range; 16% of caregivers scored in the moderate/severe range. 2. Caregiver mean BDI was 11.37±10.07 (0-49.50) representing the minimal range; 21% of caregivers scored in the moderate/severe range. 3. Among caregivers, 9% scored in the moderate/severe range for both anxiety and depression. 4. Caregiver depression (19% of the variance) was associated with caregivers being female, older child age at injury, and having a child with anxiety and depression (p<0.001). 5. Caregiver anxiety (14% of the variance) was associated with caregivers being female and having a child with anxiety and depression (p<0.001). 6. Child anxiety and depression were each significantly related to less caregiver education, lower-rated child social relationships and increased caregiver anxiety and depression (p<0.01 for all); child anxiety was also related to younger current age and shorter injury duration (p<0.05 for both). 7. Hierarchical regression showed that significant predictors of anxiety (36% of the variance) and depression (26% of the variance) included poor social relationships, caregiver mental health problems and less caregiver education.
(Gorzkowski et al. 2010) USA Observational N=97	**Population:** *Pediatric-onset SCI:* Age at interview: 12.5±3.2 yr; Age at injury: 6.8±5.3 yr; males=0, females=97; Level of injury: paraplegia=79, tetraplegia=18; Severity of injury: complete=50, incomplete=47. **Intervention:** None. Survey. **Outcome Measures:** Children's Assessment of Participation and Enjoyment (CAPE), Children's Depression Inventory (CDI), Pediatric Quality of Life Inventory (PedsQL).	1. On average, subjects participated in 77% of the assessed social activities and 59% of job-related activities; social activities were completed more frequently, further from home, and with a broader group of people than job-related activities. 2. The relationship between social participation context (CAPE social diversity, intensity, with whom, where) and QOL (PedsQL) was mediated by depression (CDI) (p<0.05); a greater social participation context was associated with decreased depression, which was then associated with greater QOL. 3. The relationship between job participation (CAPE diversity and intensity) frequency and QOL (PedsQL) was mediated by depression (CDI) (p<0.05); a greater job participation frequency was associated with decreased

		depression, which was then associated with greater quality of life.
(Anderson et al. 2009) USA Observational N=118	**Population:** Age: 12.3±3.0 yr; Gender: males=61, females=57; Time since injury: 6.4±4.3 (0-16) yr; Level of injury: tetraplegia=89 participants, paraplegia=29; Severity of injury: AIS A=57, AIS B=13, AIS=22, AIS D=17. **Intervention:** None. Interview Survey. **Outcome Measures:** Functional Independence Measure (FIM), Children's Depression Inventory (CDI), Revised Children's Manifest Anxiety Scale (RCMAS), Pediatric Quality of Life Inventory (PedsQL), Children's Assessment of Participation and Enjoyment (CAPE).	1. Mean RCMAS score=9.47±6.31 (13% with clinically significant symptoms of anxiety). 2. Mean CDI score=7.57±6.87 (6% with clinically significant symptoms of depression). 3. Neither anxiety (RCMAS) nor depression (CDI) was statistically associated with demographic factors. 4. Anxiety (RCMAS) was associated with a shorter duration of injury. 5. Depression (CDI) was not associated with injury-related factors but was associated with lower FIM scores. 6. When compared with the outcomes of community participation (CAPE) and quality of life (PedsQL), anxiety (RCMAS) and depression (CDI) were each only associated with community participation, in that the more anxious or depressed children were more apt to do activities closer to their homes rather than at someone else's house or in the community. 7. Lower total quality-of-life (PedsQL) ratings for all subscales were associated with both anxiety (RCMAS) and depression (CDI). 8. Regression showed that anxiety (RCMAS) alone accounted for 56% of the variance in quality of life, whereas depression (CDI) accounted for 3% of the variance in quality of life after controlling for anxiety.
(Chen et al. 2008) USA Observational N=278	**Population:** *Pediatric-onset SCI* (<18 yr): Age: 27.1±3.4 yr; Gender: males=184, females=94; Time since injury: 12.8±4.9 yr; Level of injury: C1-T6=210, T7-S5=68; Severity of injury: complete=189, incomplete=88. **Intervention:** None. Survey at multiple time points over 10 yr. **Outcome Measures:** Functional Independence Measure (FIM), Craig Handicap Assessment and Reporting Technique (CHART), Short-Form 12 (SF-12), and Satisfaction with Life Scale (SWLS).	1. Mean SWLS score for the study population (24.8) was somewhat higher than the mean of 19.4-21.6 from a normative study of persons with adult-onset SCI. 2. Initial life satisfaction (SWLS) was significantly higher for women (p=0.01), those who were married or living with a partner (p<0.01); had college or higher education level (p=0.04); were employed or students (p<0.01); did not use illicit drugs (p<0.01); were free of medical complications in the past year (p=0.02); had higher FIM scores (p<0.01); had higher self-perceived mental health (SF-12; p<0.01)); and had a perfect score in CHART mobility, occupation, and social integration (p<0.01 for all), compared with their counterparts. 3. Initial life satisfaction (SWLS) did not differ by age, race, living situation, age at injury, duration of injury, level and completeness of injury, FIM sphincter control, FIM locomotion,

		SF-12 physical health, or CHART physical independence. 4. On average, SWLS scores increased by 0.14 per year over the course of follow-up (p=0.10), which was significant for those who were employed or students (0.25/yr, p=0.02), lived independently (0.21/yr, p=0.05), had injury level at T7-S5 (0.49/yr, p=0.006), and had medical problems in the past year (0.22/yr, p=0.02). 5. The rate of change in SWLS was not significantly different by sociodemographic variables, presence of medical complications, or physical and psychosocial functioning. 6. Multivariable analysis showed that initial SWLS was significantly associated with sex, marital status, employment status, illicit drug use, FIM motor score, SF-12 mental health, and CHART social integration subscale (p<0.05); rate of change in SWLS was not significantly associated with any factors under investigation.
(Anderson et al. 2007) USA Observational N=232	**Population:** *Pediatric-Onset Adult SCI*: Age: 30.8±5.1 (24-42) yr; Gender: males=145, females=86; Time since injury: 16.1±6.2 yr; Level of injury: tetraplegia=136, paraplegia=96; Severity of injury: complete=159, incomplete=73. **Intervention:** None. Interview Survey. **Outcome Measures:** Functional Independence Measure (FIM), Short-Form-12 (SF12), Craig Handicap Assessment and Reporting Technique (CHART), Satisfaction with Life Scale (SLS), Patient Health Questionnaire 9 Item (PHQQ9).	1. PHQ-9 Depressive Symptom Categories: None=20.7%, Minimal=52.5%, Mild=19.8%, Moderate=5.6%, Moderate-Severe=1.3%, Severe=0.4% 2. There were no significant differences in PHQ-9 based on gender, race, age at injury, age at interview, or duration of injury. 3. There was a significant difference in PHQ-9 between those with complete and incomplete injuries (p=0.013); those with incomplete injuries showed significantly greater PHQ-9 scores than those with complete injuries did. 4. Among those with tetraplegia, individuals with incomplete injuries had significantly greater PHQ-9 scores than those with complete injuries (p=0.036). 5. Among those with paraplegia, there was no significant difference in PHQ-9 scores between those with complete and incomplete injuries. 6. Except for the CHART subscale of physical independence, all the other CHART subscales and total score show significant differences based on PHQ-9 score (p<.05 for all). 7. Greater PHQ-9 scores were associated with less employment, less income, less health-related quality of life as measured by the mental component summary score, and less life satisfaction (p<0.05 for all). 8. Medical complications including pressure ulcers, shoulder pain, and pain at any site were

		associated with greater PHQ-9 scores (p<0.05 for all). 9. Regression analysis showed that factors most predictive of depression were perceived mental health (SF-12), incomplete injuries, and CHART cognition and occupation subscales which accounted for 50% of the variance.
(Abresch et al. 2007) USA Observational N=163 (N=61 SCI)	**Population:** SCI (N=61): Gender: males=24, females=37. Time since injury: >12 mo. Level of injury: T-L2. *Spina Bifida (SB; N=42):* Gender: males=19, females=23. *Obese Controls (N=21):* Gender: males=8, females=13. *Non-Obese Controls (N=39):* Gender: males=19, females=20). **Intervention:** None. Survey. **Outcome Measures:** Pediatric Quality of Life Inventory (PedsQL).	1. SCI and SB subjects had significantly lower sub-scores than CTRL subjects on total (p<0.001), physical (p<0.001), emotional (p<0.01), social (p<0.001), and school (p<0.001) PedsQL domains. 2. Compared to non-obese CTRL subjects, those who were obese had lower sub-scores on the physical (p<0.001), social (p<0.001), and psychosocial (p<0.001) PedsQL domains; there were no significant differences in sub-scores from the emotional and school domains. 3. There were no significant differences between the sub-scores of obese and non-obese subjects with SCI or SB. 4. Total mean PedsQL score of non-obese CTRL subjects was significantly higher than that of the obese control group (p<0.02), which in turn was significantly higher than the SCI group (p<0.02) and the SB group (p<0.02). 5. In comparison with the SB group, the SCI group had significantly higher sub-scores on the social (p<0.001) and school (p<0.001) domains, but similar scores on emotional functioning and total HRQL.
(Anderson et al. 2006) USA Observational N=166	**Population:** Age at injury=14.2±4.0 yr; Gender: males=115, females=51; Level of injury: tetraplegia=106; Severity of injury: AIS A=105. **Intervention:** None. Interview at three different time points. **Outcome Measures:** Craig Handicap Assessment and Reporting Technique (CHART), Short-Form 12 (SF-12), and Satisfaction with Life Scale (SWLS).	Living Status 1. A total of 106 (64%) subjects lived independently at the initial interview and 95 continued to live independently for the remaining 2 follow-up interviews. 2. Of the 60/166 who were not living independently at the first interview, 48/60 (80%) did not live independently at any interview. 3. There were no significant differences between those living independent or dependently with respect to demographic, or body structure and function factors. 4. Those living independently were more functionally independent and have high community participation (CHART total and all subscales except economic self-sufficiency), more likely to be employed, more satisfied with their lives (p<0.030 for all), more likely to be married (p<0.001), less likely to have the

		medical complications of spasticity, pressure ulcers, and severe UTIs ($p<0.050$ for all). 5. Factors most predictive of consistent independent living in the regression were CHART physical independence, mobility, and occupation scores (39% variance). Employment 6. Excluding students and homemakers, there were 113 individuals who completed 3 interviews of which 72 (64%) were employed at the first interview; 60 continued to be employed at the remaining 2 interviews. 7. Of the 41 who were not employed at the first interview, 34 (83%) remained unemployed at all interviews. 8. Those employed at all 3 interviews included a larger percentage of women (81%) than men (57%), a larger percentage of those who were Caucasian (68%) versus other (17%), a larger percentage of those with paraplegia (82%) than tetraplegia (54%), and a larger percentage of those with college degrees (80%) than those with less education (20%). 9. Those employed were more functionally independent and participated more in the community (CHART subscales physical independence, cognitive independence, mobility, and social integration). 10. Those consistently employed were also more likely to be married, to live independently, to have greater life satisfaction, less likely to have spasticity ($p<0.050$ for all). 11. Factors most predictive of stable employment were being female, being Caucasian, having greater cognitive independence and community mobility (CHART), and living independently (71% variance). *Life Satisfaction:* 12. Of the 166 participants, 80 (48%) had good life satisfaction at the first interview, and 64 (84%) continued at the 2 follow-up interviews. 13. A total of 86/166 (52%) had poor life satisfaction at the first interview and 56 (65%) remained dissatisfied at the 2 follow-up interviews. 14. There were differences between those with good or poor life satisfaction with respect to demographic, or body structure and function factors. 15. Factors significantly associated with high life satisfaction scores included functional

		independence, perceived mental health, participation in the community (CHART total and mobility, occupation, and economic self-sufficiency subscales), fewer medical complications (i.e., pressure ulcers, UTIs, and pain), being married, living independently, and being employed. 16. Predictive factors of life satisfaction in a regression were show to be CHART occupation subscale and fewer pressure ulcers (56% variance).
(Anderson & Vogel, 2003) USA Observational N=216* *Same subjects as in (Anderson et al. 2002)	**Population:** *Pediatric-onset* SCI: Age at injury: 14.1±4.0 yr, Age at interview: 28.6±3.4 yr, Time since injury: 14.2±4.6 yr; Gender: males=150, females=66; Level of injury: tetraplegia=22, paraplegia=194. Severity of injury: complete=137, incomplete=78. **Intervention:** None. Survey. **Outcome Measures:** 5-pt rating scale of level of satisfaction on the following domains: transportation in the community, educational achievements, job opportunities, income, recreation and social opportunities, dating opportunities, and sexual experience; Functional Independence Measure (FIM), Craig Handicap Assessment and Reporting Technique (CHART), Short-Form 12 (SF-12), and Satisfaction with Life Scale (SWLS).	1. Highest satisfaction ratings occurred for the domains of transportation, education, and social/recreation; lowest satisfaction ratings occurred for income, job opportunities, and dating opportunities. 2. There were no significant differences in satisfaction ratings for any of the domains with respect to injury severity and gender. 3. In regression modelling, the only demographic factors associated with satisfaction domains were age at interview and gender; women were more satisfied with both income and sexual experiences, and younger age at interview was associated with greater satisfaction with dating opportunities. 4. In regression modelling, perceived health status (SF-12) was predictive for three satisfaction domains (i.e., education, social/recreational opportunities, and sexual experiences). 5. Independent living was associated with three satisfaction domains (i.e., satisfaction with job opportunities, dating, and sexual experiences). 6. Community mobility, frequency of social and recreational activities, and income were each associated with satisfaction in two satisfaction domains. 7. Global life satisfaction, as measured by SWLS, was significantly associated with each of the domain satisfaction ratings (p<0.001) with regression modelling showing the following domains as significant predictors: dating, job opportunities, education, and income (p<0.05 for all).
(Anderson & Vogel, 2002) USA Observational N=195	**Population:** *Pediatric-onset* SCI: Age at injury: 14.1±4.0 yr, Age at interview: 28.7±3.4 yr, Time since injury: 14.6±4.3 yr. Gender: males=134, females=61; Level of injury: tetraplegia=112,	1. Among the sample, 40% (n=78) were unemployed, 51% (n=99) were employed, 6% (n=12) were students, and 3% (n=6) were homemakers. 2. Compared to those unemployed, those who were students, homemakers or employed were significantly less injured (p=0.010), more

	paraplegia=194. Severity of injury: complete=83, incomplete=78. **Intervention:** None. Survey. **Outcome Measures:** Functional Independence Measure (FIM), Craig Handicap Assessment and Reporting Technique (CHART), Short-Form 12 (SF-12), Satisfaction with Life Scale (SWLS).	likely to be living independently (p=0.002), had higher total FIM scores and sub-scores (p=0.001), higher total CHART score and sub-scores (except for social integration) (p<0.05 for all), greater SWLS scores (p<0.001); there was no significant difference between all groups on SF-12. 3. Compared to those employed, those unemployed had lower FIM (total and subscores) (p<0.006 for all), CHART (total and subscores) (p<0.050 for all), SF-12 physical score (p=0.011), SWLS (p<0.001) but not SF-12 mental score.
(Vogel et al. 2002a) Part III USA Observational N=216	**Population:** Age at interview: 28.6±3.4 yr; Age at injury: 14.1±4.0 yr; Time since injury: 14.2±4.6 yr; Gender: males=149, females=67; Level of injury: tetraplegia=57%. **Intervention:** None. Survey. **Outcome Measures:** Functional Independence Measure (FIM), Craig Handicap Assessment and Reporting Technique (CHART), Short-Form 12 (SF-12), Satisfaction with Life Scale (SWLS).	1. Pressure ulcers were statistically associated with employment (p<0.001), independent living (p=0.012), driving (p<0.001), marriage (p=0.020), total CHART score (p=0.007), CHART subscales of economic self-sufficiency, mobility, occupation, physical and social integration (p=0.040, p<0.001, p<0.001, p=0.001 and p=0.002, respectively), mental SF-12 scores (p=0.030), and life satisfaction (p=0.001). 2. Severe UTI was statically associated with employment (p=0.001), independent living (p=0.018), driving (p=0.011), total CHART score (p<0.001), CHART subscales of cognitive, economic self-sufficiency, mobility, occupation and physical (p=0.003, p=0.005, p<0.001, p=0.007 and p=0.001, respectively), SF-12 physical score (p=0.0016), and life satisfaction (p=0.001). 3. Spasticity was statistically associated with employment (p<0.001), independent living (p=0.009), driving (p=0.010), total CHART score (p=0.005), CHART subscales of mobility, occupation and physical (p=0.003, p<0.001 and p=0.001, respectively) SF-12 physical score (p=0.001), and SF-12 mental score (p=0.043). 4. Pain was statistically associated with employment (p=0.030), cognitive CHART subscale (p=0.009), SF-12 mental score (p<0.001), SF-12 physical score (p=0.019), and life satisfaction (p<0.001). 5. Hyperhidrosis was statistically associated with driving (p=0.041), marriage (p=0.043), total CHART score (p=0.025), and occupation CHART subscale (p=0.037). 6. Respiratory complications were statistically associated with employment (p=0.023), physical CHART subscale (p=0.008), and life satisfaction (p=0.030). 7. Shoulder pain was statistically associated with CHART subscales of occupation and physical

		(p=0.009 and p=0.033, respectively), SF-12 physical score (p=0.002), SF-12 mental score (p<0.001), and life satisfaction (p=0.003). 8. Back pain was statistically associated with economic self-sufficiency CHART subscale (p=0.019), SF-12 physical score (p=0.025), SF-12 mental score (p=0.008), and life satisfaction (p=0.002). 9. Urinary incontinence was statistically associated with cognitive CHART subscale (p=0.013), SF-12 physical score (p=0.045), and SF-12 mental score (p=0.010). 10. Elbow contractures were statistically associated with employment (p=0.049) and driving (p=0.016). 11. Hospitalizations were statistically associated with employment (p=0.047) and CHART subscales of cognitive and economic self-sufficiency (p=0.043 and p=0.017, respectively). 12. Bowel incontinence was statistically associated with independent living (p=0.026). 13. Autonomic dysreflexia was statistically associated with SF-12 physical score (p=0.004). 14. Hip contracture was statistically associated with physical CHART subscale (p=0.044). 15. Ankle pain was statistically associated with SF-12 physical score (p=0.011) and SF-12 mental score (p=0.038). 16. Elbow pain was statistically associated with independent living (p=0.045). 17. Heterotopic ossification was statistically associated with physical CHART subscale (p=0.019).
(Anderson et al. 2002) USA Observational N=216	**Population:** *Pediatric-onset* SCI: Age at injury: 14.1±4.0 yr, Age at interview: 28.6±3.4 yr, Time since injury: 14.2±4.6 yr. Gender: males=150, females=66; Level of injury: tetraplegia=22, paraplegia=194. Severity of injury: complete=137, incomplete=78. **Intervention:** None. Survey. **Outcome Measures:** Functional Independence Measure (FIM), the Craig Handicap Assessment and Reporting Technique (CHART), the Short-Form 12 (SF-12), and	1. SWLS was not significantly associated with gender, duration of injury, or race/ ethnicity. 2. SWLS was significantly associated with both age at injury (p=0.017) and age at interview (p=0.033); SWLS scores for those injured as older adolescents was significantly lower than for those injured at younger ages (p<0.009). 3. Those with paraplegia showed significantly higher SWLS scores than those with tetraplegia (p=0.032). 4. FIM total, motor and cognitive sub-scores were significantly related to SWLS (p<0.001). 5. The total CHART score and all subscale scores (except social integration) were significantly associated with SWLS (p<0.05 for all). 6. Other outcomes statistically associated with higher SWLS scores include higher education, being employed, higher income, living independently, being married, and driving independently (p<0.05 for all).

	the Satisfaction with Life Scale (SWLS).	7. Use of illegal drugs was negatively associated with SWLS (p<0.001). 8. Greater perceived health status (SF-12) was associated with greater SWLS (p<0.001). 9. A greater number of medical complications was associated with less SWLS (p<0.001). 10. Multiple linear model with life satisfaction as the outcome showed the following predictors to be significant: age at injury (p=0.008), CHART mobility (p=0.004), marriage (p<0.001), drug use (p<0.001), medical complications (p<0.05), and SF-12 mental health (p<0.001).
(Kannisto & Sintonen, 1997a) Finland Observational N=408 (N=36)	**Population:** *Pediatric-Onset SCI (N=36):* Age at Injury: 11.3±5.1 yr; Age at evaluation: 31.3±9.9 yr; Time since injury: 20.0±11.2 yr; Gender: males=25, females=11; Severity of injury: complete=28, incomplete=8; Injury etiology: traumatic=30, medical=5, iatrogenic=1. *Controls (N=372):* Age: 16-46 yr. **Intervention:** None. Survey. **Outcome Measures:** 15 Dimensions of Health-Related Quality of Life (15D HRQL): moving, seeing, hearing, breathing, sleeping, eating, communicating, urinary continence, working, social participation, mental functioning, pain, depression, distress and perceived health (level of health status in each); Overall health status measures with the Visual Analogue Scale (VAS).	1. Subjects with SCI assigned higher importance to the 15DHRQL dimensions of mental functioning, communicating, social participation and seeing than the control subjects (p<0.05 for all). 2. The control subjects assigned higher importance to the 15DHRQL dimensions of moving, working, sleeping and eating (p<0.05 for all). 3. The average level of health status score on 15DHRQL for the SCI group was, on average, 0.906±0.058 (range 0.726-0.996, which was significantly different than controls (0.929±0.083; p<0.05); the most marked deviations from the best level of functioning for subjects with SCI occurred on the dimensions of continence, moving, working and pain. 4. The average overall health status scores on the VAS, for subjects with SCI, was 82.3±15.5 (range 35-100); a significant correlation between the HRQL and VAS scores was found (r=0.33; p=0.044).

Discussion

The literature search yielded 35 studies concerning psychosocial adjustment of individuals with pediatric-onset SCI and/or their caregivers; The majority of those were observational studies and utilized self-report survey design.

The prevalence of both depression and anxiety in children with SCI seem to be comparable to that in their typically developing peers and lower than that in adults with SCI (Klaas et al. 2014). In Klass and colleagues' (2014) study with 236 adolescents with SCI, depression and anxiety were present in 5.5% and 10.6% of participants, respectively. In another study involving 24 children with transverse myelitis and their parents, approximately 8.7% of the children experienced clinical levels of depression according to parent-reports (Harder et al. 2013). For adults with pediatric-onset SCI, the overall severity and incidence of depressive symptoms did not differ from those who acquired SCI during adulthood (Ma et al. 2016). Kelly et al. (2011) investigated the incidence of depression and anxiety in 203 primary caregivers of children with SCI and found that 6 and 21% of caregivers scored in the range of moderate or severe anxiety and depression, respectively.

Like in children without disabilities, the incidence of depression and anxiety in children with SCI differ by gender and age. When comparing psychosocial outcomes among adolescents with SCI between ages 12 and 18, Klaas et al. (2014) found that older adolescents were more likely to experience depression than their younger peers. Older Adolescent girls with SCI in particular, were more likely to experience anxiety than their male counterpart and younger girls with SCI. Researchers have also identified various clinical factors associated with depression and/or anxiety in the pediatric SCI population. For example, in children with SCI, shorter duration of injury is associated with occurrence of anxiety (Anderson et al. 2009), and poor social relationships, having a caregiver with mental health problems and having a caregiver with less education predicted both anxiety and depression (Kelly et al. 2011). In adults with pediatric-onset SCI, low levels community participation, polypharmacy (i.e., having to take multiple medications), hazardous drinking, bladder incontinence, and pain have been identified as predictors of depression (M. Hwang et al. 2015; January et al. 2014). Interestingly, adults with pediatric-onset SCI who have incomplete injury seem to be at higher risk of experiencing depression than those with complete injury, and incomplete injury was found to predict depression in two studies (Anderson et al. 2007; January et al. 2014). Furthermore, according to a recent study by January et al. (2015), poor sleep quality may contribute to both depression and anxiety in adults with pediatric-onset SCI. In their work examining predictors of caregiver psychological functioning and relationships between caregiver and child psychological outcomes., Kelly et al. (2011) found that having a child who was older at the time of injury predicted depression among caregivers; in addition, being female and having a child with mental health problems predicted caregiver anxiety and depression.

Depression and anxiety have been linked to a wide range of negative health and social outcomes in the pediatric-SCI population, such as low health-related quality of life (Anderson et al. 2009; Anderson et al. 2007; Garma et al. 2011). As demonstrated by Anderson et al. (2007), depression, in particular, is associated with unemployment, low income, as well as, less life satisfaction in children and adolescents with SCI. Lower depression in children with SCI, on the other hand, is related to favourable outcomes such better parent-child relationship (Morrison et al. 2017). Moreover, it is worth noting that depression and anxiety may impact patterns of community participation in children with SCI. Specifically, children with SCI who are more anxious or depressed are more likely to engage in activities close to their homes rather than at someone else's house or in the community (Anderson et al. 2009)

With respect to life satisfaction, no significant differences have been observed between individuals who acquired SCI during their childhood and those who sustained SCI as adults (Ma et al. 2016). Within the pediatric SCI population, life satisfaction is not significantly associated with gender, duration of injury, or race/ethnicity (Anderson et al. 2002). In their study involving 216 adults with pediatric-onset SCI, Anderson et al. (2002) also found that participants with tetraplegia had significantly lower satisfaction than those with paraplegia, and participants who were injured in their late adolescence had significantly lower life satisfaction than those with earlier onset of injury. In addition, community and occupational participation, being married/having a partner, not using illicit drugs, high perceived mental health, functional independence, and low occurrence of medical complications have been identified as significant predictors of life satisfaction in individuals with pediatric-onset SCI (Anderson et al. 2002; Anderson & Vogel, 2003; Anderson et al. 2006; Chen et al. 2008; Chlan et al. 2011; Vogel et al. 2002a). Anderson and Vogel (2013) investigated domain-specific satisfaction levels in 216 adults with pediatric-onset SCI. The results revealed that the highest satisfaction ratings occurred for the domains of transportation, education, and social/recreation. Dating opportunities, job opportunities, and income, in contrast, had the lowest ratings, but were found to contribute significantly to participants' overall life satisfaction (Anderson & Vogel, 2003). Studies examining longitudinal trend of life stratification in adults with pediatric-onset SCI have shown that life satisfaction tends to increase over time, especially among participants who remained employed (Chen et al. 2008; Hwang et al. 2014b). However, as pointed out by Chen et al. (2008), adults with pediatric-onset SCI who are unsatisfied with life initially are likely to stay unsatisfied over time if the critical factors impeding their levels of life satisfaction remain unchanged or unaddressed.

Previous research has shown that QoL in both children with SCI and adults with pediatric-onset SCI is considerably lower than that in the those without disabilities or chronic conditions (Abresch et al. 2007; Garma et al. 2011; Kannisto & Sintonen, 1997a). Interestingly, as revealed in Kannisto and Sintonen's (1997a) study, individuals with and without pediatric-onset SCI tend to place different emphases when evaluating their QoL. In their sample of 372 adults with pediatric-onset SCI and 36 without disabilities, The SCI group assigned higher importance to the dimensions of mental functioning, communicating, social participation and seeing and lower for moving, working, sleeping and eating compared to participants without disabilities, when assessing their QoL (Kannisto & Sintonen, 1997a). Among children with SCI, those with paraplegia have demonstrated higher QoL, especially the social aspect, than their peers with tetraplegia (Garma et al. 2011; Riordan et al. 2015). Kelly, Klaas et al. (2012) looked at the relationship between participation and QoL in children (between ages 6-12) and adolescents (between ages 13-18) with SCI. The study found that for children, participating in activities further from home predicted higher QoL for children, and participating in activities with a more diverse group predicted higher QoL. These findings suggest that encouraging activity participation outside home may promote QoL of children with SCI, and fostering participation with a more diverse group may improve QoL in adolescents with SCI (Kelly, Klaas, et al. 2012). The role of parental characteristics in influencing the QoL in children with SCI has also been highlighted in the literature. As revealed in a recent study by Kelly et al. (2016), parents' effective problem solving was related to high physical and social health-related quality of life in children with SCI. To date, only one small-scale intervention study targeting QoL in the pediatric SCI population has been conducted. In their pilot study involving six children with SCI, Castello et al. (2012) found that FES cycling exercises was effective in improving QoL in study participants.

Smith et al. (2013) examined coping strategies and their association with psychosocial outcomes in 282 adolescents with SCI and found that cognitive restructuring and resignation were the most frequently used coping strategies among participants, whereas blaming others and self-criticism were the least frequently used. Furthermore, active coping strategies were perceived as effective in reducing SCI-related distress by participants. Escape-oriented coping, in contrast, was linked negative psychosocial outcomes, such as depression and anxiety. (Smith et al. 2013). In adults with pediatric onset SCI, religion has been identified as a commonly used and effective tool of coping. In their sample of 298 adults with pediatric SCI (Chlan et al. 2011), approximately half (55%) of the participants reported using religion as a way of coping. Furthermore, higher perceived importance of religion was linked to higher life satisfaction among study participants.

Overall, while many studies have tackled the psychosocial domain of pediatric SCI, intervention studies focusing on this area are clearly lacking. Moreover, given the influences of caregivers on the well-being of children with SCI, it is important for future clinical interventions aiming to promote psychosocial adjustment in pediatric SCI population to target both children with SCI and their caregivers.

Key Points

Individuals with pediatric-onset SCI have similar levels of depression, anxiety, and life satisfaction compared to the general population; however, the QoL of children with SCI and adults with pediatric-onset SCI is significantly lower than that of individuals without disabilities.

Various demographic and clinical factors, such as age, duration of injury, level of participation, caregiver characteristics, and employment status, have been identified as predictors of depression, anxiety, life satisfaction, and QoL in individuals with pediatric-onset SCI.

Active coping strategies may help offset the adverse psychosocial impact of SCI in the pediatric SCI population.

More intervention studies addressing the psychosocial consequences of pediatric-onset SCI, especially controlled studies, are needed in the future.

7 Community Reintegration

7.1 Play and Participation

Play is the work of children. It is through play and participation that children learn to interact with the world, acquire language, discover their own strengths and weakness, and develop the capacity for self-direction and regulation (Johnson & Klaas, 2007). Mastery over the environment, enhanced socialization, and development of self-concept are critical in maturation and acquisition of cognitive and motor skills. SCI significantly impacts the child's growth and development (Vogel et al. 1997), delaying milestones and creating a downstream impact on overall health, development of disease and comorbidities, functional independence, social isolation, and life satisfaction (Tasiemski et al. 2005). Children with disabilities are at a risk for decreased participation, owing to disruption in motor skills, ease of communication, and access (Brown & Gordon, 1987). Children with physical disabilities, like SCI, are reported to have lower levels of participation, fewer social activities, and spend more time in sedentary activities than their able-bodied peers (Brown & Gordon, 1987). Additionally, they may experience exclusion by their able-bodied peers or environmental barriers limiting their participation in typical childhood activities (Brown & Gordon, 1987). Lack of play and participation has been linked to decreased motor skill acquisition and cognitive development, and greater childhood mental health problems in children with and without disabilities (Brown & Gordon, 1987; Louv, 2008). Issues of play and participation have the potential to compound risks to development, independence, and life satisfaction associated with SCI. Conversely, successful integration in the community and ample play opportunities may mitigate some of the long-term consequences of SCI at all neurological levels.

This module will review the limited data and descriptions of play and community participation in children with SCI and elucidate trends herein. We will review evidence on the impact of play and participation on development and quality of life of children with SCI and the influence of age at onset on patterns of play and participation.

Table 37. Studies examining play and participation of children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Ma et al. 2016) Canada Observational N=174	**Population:** *Pediatric-sustained SCI (<19 yr; n=87):* Age: 38.6±12.3 yr; Gender: males=61, females=26; Time since injury: 24.1±14.0 yr; Level of injury: C1-4=6, C5-8=35, T1-5=12, T6-L5=34; Severity of injury: complete=41, incomplete=46. *Adult-sustained SCI (19+ yr; n=87):* Age: 39.5±10.9 yr; Gender: males=62, females=25; Time since injury: 12.8±10.0 yr; Level of injury: C1-4=8, C5-8=33, T1-5=11, T6-L5=35. Severity of injury: complete=40, incomplete=45. **Intervention:** None. Secondary analysis of data from the *Study of Health and Activity in People with SCI (SHAPE-SCI)* (Martin Ginis et al. 2008). **Outcome Measures:** Functional Independence	1. Compared to adult-sustained SCI, participants with paediatric-sustained SCI reported significantly greater functional independence (FIM motor subscore; p=0.03), less pain (SF-36 pain subscore; p=0.02), and fewer visits to the doctor in the past year (p=0.04). 2. There were no significant differences between adult- or pediatric-sustained SCI groups with respect to perceived health status (SF-36 general health subscore) or depressive symptoms (PHQ-9). 3. Compared to adult-sustained SCI, those with pediatric-sustained SCI reported more minutes of moderate–heavy leisure time physical activity (PARA-SCI; p=0.05), and scored higher on measures of social and occupational participation (CHART; p=0.04 and p=0.03, respectively). 4. There were no significant differences between adult- or pediatric-sustained SCI groups with respect to life satisfaction.

	Measure (FIM) motor subscale, Short Form 36 (SF-36), number of physician visits, Patient Health Questionnaire 9-item (PHQ-9), Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI), Craig Handicap Assessment and Reporting Technique (CHART), Satisfaction with Life Scale (SWLS)	
(Riordan et al. 2015) USA Observational N=340	**Population:** Age: 13.2.2±3.9 yr; Age at injury: 8.2±5.8 yr; Gender: males=194, females=146; *Three Level/ Severity Injury Groups:* tetraplegia AIS ABC=96, paraplegia AIS ABC=191, AIS D=53. **Intervention:** None. Survey. **Outcome Measures:** Children's Assessment of Participation and Enjoyment (CAPE), Pediatric Quality of Life Inventory (PedsQL), Revised Children's Manifest Anxiety Scale (RCMAS), Children's Depression Inventory (CDI).	1. Subjects with paraplegia ABC and AIS D injuries participated (CAPE) in more activities than those with tetraplegia ABC (p=0.002 and p=0.018, respectively). 2. There were no significant differences between the participation frequency (CAPE) of subjects with paraplegia ABC and those with AIS D injuries. 3. Subjects with paraplegia ABC reported higher social QOL (PedsQL) than those with tetraplegia ABC (p=0.001) and AIS D injuries (p=0.002). 4. There were no differences between subjects in the three neurological impairment categories when examining scores exceeding the clinical cut-off for anxiety or depression (RCMAS and CDI).
(Russell et al. 2015) USA Observational N=199	**Population:** Age at interview: 16.0±1.7 yr; Age at injury: 11.0±5.5 yr; Gender: males=112, females=87; Injury etiology: non-traumatic=41, traumatic=156; Level of injury: tetraplegia=76, paraplegia=123; Severity of injury: AIS A=109, AIS B, C, D=79. **Intervention:** None. Survey. **Outcome Measures:** Children's Assessment of Participation and Enjoyment (CAPE), Pediatric Quality of Life Inventory (PedsQL), Revised Children's Manifest Anxiety Scale (RCMAS), Children's Depression Inventory (CDI), Kidcope.	1. The ineffective copers demonstrated the greatest level of distress, followed by the active copers, the avoidant copers, and the cognitive copers. 2. The cognitive copers had significantly lower mental health symptoms (p<0.001) and significantly higher self-report of emotional QOL (p<0.001) than the ineffective, active, and avoidant copers. 3. The ineffective copers had significantly lower school-related QOL than both the avoidant and cognitive copers (p=0.006). 4. The active coping group was not significantly different from avoidant or ineffective copers on any dimension of QOL or mental health. 5. The active copers participated in activities with significantly greater frequency (p<0.001) than the ineffective and avoidant groups. 6. The avoidant group reported the lowest level of activity enjoyment, with significantly lower activity enjoyment (p=0.010) compared with the active copers.

(Kelly & Vogel, 2013) USA Observational N=410	**Population:** Age at interview: 12.0±4.9 yr; Age at injury: 7.3±6.0 yr; Gender: 231 males, females=179; Severity of injury: AIS A (complete)=226; Level of injury: paraplegia=269. **Intervention:** None. Survey. **Outcome Measures:** Assessment of Preschool Children's Participation (APCP), Children's Assessment of Participation and Enjoyment (CAPE), Pediatric Quality of Life Inventory (PedsQOL), Behaviour Assessment System for Children Second Edition (BASC-2), Revised Children's Manifest Anxiety Scale (RCMAS), Children's Depression Inventory (CDI).	1. Of those with BASC-2 data, 3 (6.5%) children had a clinically significant anxiety score and 4 (8.0%) children had a clinically significant depression score. 2. School-aged children ages 6-12 were most likely to engage in watching TV or a rented movie, playing computer or video games, and playing board or card games and were least likely to do gymnastics or do a paid job. 3. Overall, school-aged children rated their emotional QOL as highest and school QOL as lowest. 4. Of the school-aged children that completed the RCMAS, 9 (7.4%) fell above the clinical cut-off for anxiety and of those that completed the CDI, 5 (4.2%) fell above the clinical cut-off for depression. 5. Younger adolescents ages 13-15 were most likely to engage in watching TV or a rented movie, listening to music, and playing computer or video games and were least likely to be learning to dance, doing gymnastics, and doing martial arts. 6. Overall, younger adolescents rated their social QOL as highest and school QOL as lowest. 7. Of the younger adolescents that completed the RCMAS and CDI, 6 (7.3%) fell above the clinical cut-off for anxiety and 2 (2.4%) above the clinical cut-off for depression. 8. Older adolescents ages 16-18 were most likely to engage in watching TV or a rented movie, listening to music, and talking on the phone and were least likely to be learning to dance, doing gymnastics, and doing martial arts. 9. Overall, older adolescents rated their social QOL as highest and school QOL as lowest. 10. Of the older adolescents that completed the RCMAS, 23 (17.2%) fell above the clinical cut-off for anxiety and of those that completed the CDI, 7 (9%) fell above the clinical cut-off for depression.
(Kelly, Klaas, et al. 2012) USA Observational N=340	**Population:** Group: Children (6-12 yr) =133, Adolescents (13-18 yr) =207. Age: 13.3±3.8 yr. Time since injury: 5.1±4.3 yr, Level of injury: paraplegia=224; Severity of injury: complete=187. **Intervention:** None. Survey. **Outcome Measures:** Children's Assessment of Participation and Enjoyment (CAPE; i.e., participation, diversity, frequency, intensity, context),	1. For children (6-12 yr), Regression analysis showed that *where* children participate (i.e., further from home) positively and significantly predicted QOL subscales after controlling for age, sex, injury level, and injury duration. 2. For adolescents (13-18 yr), regression analysis showed that subject characteristics "*who*" (i.e., being male, having paraplegia, and participating with a more diverse group) positively, and significantly predicted QoL

	Pediatric Quality of Life Inventory – Psychosocial Health Scale (PHS) (only emotional, social, school subscales).	after controlling for child age, sex, injury level, and injury duration.
(Kelly, Mulcahey, et al. 2012) USA Observational N=420	**Population:** Age: 1-18 yr **Intervention:** None. Survey. **Outcome Measures:** Computerized Adaptive Testing (CAT), Children's Assessment of Participation and Enjoyment (CAPE), Revised Children's Manifest Anxiety Scale (RCMAS), Children's Depression Inventory (CDI), Pediatric Quality of Life Inventory (PedsQL), Kidcope.	1. Of those with SCI, 9% scored above the cut-off level that would indicate significant clinical concern, compared with 16% of the normative group. When the group was divided into children (7-12 yr old) and adolescents (13-17 yr old), both groups scored within the average range of anxiety. 2. In the SCI sample, 5% scored above the cut-off that would indicate clinically significant depression compared with 7% in the normative group. 3. 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. 4. Depression, but not anxiety, was associated with decreased community participation. 5. Both increased depression and increased anxiety were associated with decreased QOL. 6. Child mental health significantly predicted self-report QOL, whereas child and caregiver mental health significantly predicted proxy-report QOL. Caregiver mental health was a stronger predictor of how caregivers rated the QOL of their children than child mental health. 7. With regard to psychological outcomes, use of most coping strategies correlated with increased anxiety, increased depression, and decreased QOL. Youth who used cognitive restructuring experienced decreased depression. 8. With regard to frequency of participation, use of self-criticism correlated with less participation, while use of social support was related to increased participation. 9. Youth who reported feeling effective when coping also reported more positive outcomes and more enjoyment while participating.
(Lindwall et al. 2012) USA Observational N=294	**Population:** Age at interview: 13.7±3.5 (7-18) yr; Age at injury: 8.4±5.8 (0-17) yr; Time since injury: 5.4±4.5 (1-18) yr; Gender: males=162, females=132; Level	1. Higher levels of social support and lower levels of self-criticism were associated with higher participation in informal activities ($p<0.01$ and $p<0.05$, respectively).

	of injury: paraplegia=67%, tetraplegia=33%. **Intervention:** None. Survey. **Outcome Measures:** Kidcope, Children's Assessment of Participation and Enjoyment (CAPE).	2. Lower levels of social withdrawal were associated with participation in informal activities with a greater diversity of individuals (p<0.05). 3. Lower levels of blaming others were associated with higher enjoyment of informal activities (p<0.05). 4. Higher levels of cognitive restructuring were associated with participation in formal activities with a greater diversity of individuals and in settings further from home (p<0.05). 5. Frequency of participation and enjoyment in formal activities were not associated with any of the coping variables.
(Klaas et al. 2010) USA Observational N=194	**Population:** *Children:* Age at interview: 13.2±3.7 yr; Age at injury: 7.2±5.7; Gender: males=106, females=88; Level of injury: tetraplegia=57, paraplegia=137. *Caregivers:* mothers=150, fathers=21, grandmother=10, other=13. **Intervention:** None. Survey. **Outcome Measures:** Children's Assessment of Participation and Enjoyment (CAPE).	1. Subjects participated in a mean of 23.83 (43%) (range 9-44) of the 55 activities included in CAPE, of which most activities were sedentary and informal. 2. Subjects participated more often in informal activities (p<0.001) and reported higher levels of enjoyment with these (p=0.046). 3. When participating in formal activities young people (6-12 yr) were more socially engaged (p<0.001) than older subjects (13-18 yr); formal activities were more community-based than activities in the informal domain (p<0.001). 4. Females participated more often in and enjoyed informal activities more than males did (p<0.05). 5. Young people with paraplegia participated more in informal activities (p=0.002). 6. Young people with parents with college experience participated more in formal activities (p=0.009) and reported greater enjoyment in formal activities (p=0.004). 7. There was also a significant interaction of caregiver education by injury level (p=0.034).
(Gorzkowski et al. 2010) USA Observational N=97	**Population:** *Pediatric-onset SCI:* Age at interview: 12.5±3.2 yr; Age at injury: 6.8±5.3; males=0, females=97; Level of injury: paraplegia=79, tetraplegia=18; Severity of injury: complete=50, incomplete=47. **Intervention:** None. Survey. **Outcome Measures:** Children's Assessment of Participation and Enjoyment (CAPE), Children's Depression Inventory (CDI), Pediatric	1. On average, subjects participated in 77% of the assessed social activities and 59% of job-related activities; social activities were completed more frequently, further from home, and with a broader group of people than job-related activities. 2. The relationship between social participation context (CAPE social diversity, intensity, with whom, where) and QOL (PedsQL) was mediated by depression (CDI) (p<0.05); a greater social participation context was associated with decreased depression, which was then associated with greater QOL.

	Quality of Life Inventory (PedsQL).	3. The relationship between job participation (CAPE diversity and intensity) frequency and QOL (PedsQL) was mediated by depression (CDI) ($p<0.05$); a greater job participation frequency was associated with decreased depression, which was then associated with greater quality of life.
(Anderson et al. 2009) USA Observational N=118	**Population:** Age at interview: 12.3±3.0 yr; Gender: males=61, females=57; Time since injury: 6.4±4.3 (0-16) yr; Level of injury: tetraplegia=89, paraplegia=29; Severity of injury: AIS A=57, AIS B=13, AIS C=22, AIS D=17. **Intervention:** None. Survey. **Outcome Measures:** Functional Independence Measure (FIM), Children's Depression Inventory (CDI), Revised Children's Manifest Anxiety Scale (RCMAS), Pediatric Quality of Life Inventory (PedsQL), Children's Assessment of Participation and Enjoyment (CAPE).	1. 13% of the young people with SCI had scores above the clinical cut-off for anxiety, compared with 16% of the RCMAS normative group. 2. 6% of the patients fell above the clinical cut-off range for depression, which is very similarly to the 7% above cut-off in the normative group. 3. Anxiety and depression were each only associated with community participation ($p=0.005$ and $p=0.030$, respectively), in that the more anxious or depressed children were more apt to do activities closer to their homes rather than at someone else's house or in the community. 4. Lower total QOL ratings for all subscales were associated with both anxiety and depression ($p<0.001$). 5. The total CDI and RCMAS scores were significantly correlated with one another ($r=0.742$, $p<0.001$).
(Johnson et al. 2004) USA Observational N=66	**Population:** Age: 16 yr; Gender: males=35, females=31; Age at Injury: 10 yr; Level of Injury: C1-6=19, C7-T6=16, T7-S4=31. Ambulation: Ambulatory=1, Crutches=3, Manual Wheel Chair=45, Power Wheelchair=17. **Intervention:** None. Survey. **Outcome Measures:** Participation in, and satisfaction with, 49 recreational activities.	1. In the mild intensity category of activities, for all levels of injury, the 3 most frequent activities were: listening to music (mean 2.6 h/d); computer use (mean 2.2 h/d); watching television (mean 2.1 h/d. 2. The higher the intensity of activity, the lower the participation rate was among all injury levels. 3. The C7-T6 group spent the most time engaged in recreational activities and also had the highest number of activities participated per year. 4. The T7-S4 had significantly more hours spent in high-intensity activities than did the other 2 groupings. 5. The average number of participants per activity decreased with increasing intensity levels of activity (i.e., mild=35, moderate=22, high=9). 6. Satisfaction scores varied from 3.8 to 4 .3 out of 5 across all activity categories and all injury groupings, indicating a high and consistent satisfaction rate.

Discussion

Literature on play and community participation for people with SCI acquired in childhood is limited. Nearly all studies are low level evidence, observational cohorts, and describe patterns of participation. Nevertheless, there are some lessons to be gleaned from the current body of literature and some considerations for future explorations of the topic.

Persons with SCI acquired in childhood have increased participation and greater functional independence, as compared to those with adult-acquired SCI (Ma et al. 2016). This is good news, as it has the potential to impact the increased morbidity and mortality previously reported for those with pediatric onset SCI (Shavelle et al. 2007). Ma, et al. (2016) suggest that health behaviors and self-management of health increases with experience living with SCI and that the availability of support in school and family settings enhances reintegration and promotes social and occupational participation. Barriers for adults' re-entry to work settings are higher, more costly, and less supported by the community. Additionally, the data suggests that younger age at injury and higher levels of parental education positively impact participation, supporting the assumption that reintegration mediated by family and school resources results in more meaningful and durable participation (Klaas et al. 2010).

Children with paraplegia or incomplete injuries participate in more activities than children with complete tetraplegia (Riordan et al. 2015). The frequency of participation across the groups, however, is not significantly different (Riordan et al. 2015). It stands to reason that, children with greater physical capacities would have a greater range of activities available to them, for reasons related to both motor skills and accessibility. Children with paraplegia also report more participation in informal social activities (Klaas et al. 2010), again likely connected to their decreased need for caregiver support, increased motor skills, and lower community barriers.

The level of activity participation in children with SCI may also be related to their psychological well-being and coping strategies (Anderson et al. 2009; Kelly, Mulcahey, et al. 2012; Lindwall et al. 2012; Russell et al. 2015). For example, depression has been associated with decreased community participation in children with SCI (Kelly, Mulcahey, et al. 2012). In addition, according to Anderson et al. (2009), children with SCI who score high on depression and/or anxiety tend to engage in activities that are close to their homes instead of at someone else's house or in the community. Two studies examined the relationship between coping strategies and activity participation in the pediatric SCI population. In their study involving 199 adolescents with SCI, Russell et al. (2015) found that participants who were categorized as active copers showed significantly greater participation compared to ineffective, avoidant, and cognitive copers. Similarly, Lindwall and colleagues' (2012) work revealed that higher levels of social support and cognitive restructuring and lower levels of self-criticism, social withdrawal, and blaming others predicted favorable participation outcomes in their sample of 299 children with SCI. The authors further suggested that Interventions that encourage higher levels of positive coping strategies and lower levels of negative and avoidant strategies may promote activity participation in youth with SCI.

As indicated in Kelly and colleagues' (2013) study, the types of activities that children with SCI choose to engage in seem to change over time following a developmentally appropriate trajectory. More specifically, in their sample of 410 children with SCI between ages 2 and 18 years, top activity preferences shifted from play and art and crafts for the youngest participants and watching television and playing video and board games for school-aged youth and adolescents to engaging with peers for younger and older adolescents. It is worth noting that the across age groups, the activities that study participants preferred tended to be sedentary in nature. However, the authors pointed out that this pattern may be reflective of a general concern for today's children and youth rather than for those with SCI in particular (Kelly & Vogel, 2013).

This engagement in informal activities may have a particular impact on the acquisition of self-concept and overall mental health for children with SCI. In children without disabilities engagement in informal, unstructured, predominately outdoor play leads to the development of self-direction and regulation (Louv, 2008). These have been linked to self-efficacy, independence, and mental health for typically developing children (Louv, 2008). Informal play and participation is difficult for children with SCI to achieve, and increases in complexity as the child's physical needs increase. Compounding this is a cultural shift toward increasing participation in structured activities, like organized sports, and sedentary activities, like watching television, for all children (Louv, 2008). While this might look like enhanced opportunity for children with SCI—the structured activities offer them support and the sedentary activities reduce physical demands—the lack of unstructured, informal play has a significant negative impact on childhood mental health (Louv, 2008). The data reflects this as high intensity participation, more frequent participation, variable location and peer groups are all associated with decreased depression and improved quality of life for those with pediatric onset SCI (Gorzkowski et al. 2010; Johnson et al. 2004; Kelly, Klaas, et al. 2012; Klaas et al. 2010).

Although participation for children with SCI varies and is promising into adulthood, it is still significantly less than able-bodied age matched peers (Centre, 2013) . These disparities highlight need for more reintegration strategies. Increased participation and engagement in activity have been linked to lower levels of depression in adults and it stands to reason that this would hold for children alike. For this reason, it would benefit the community to study the barriers to participation for children with SCI and interventions aimed at improving rates of participation. The current literature points towards increasing self-efficacy, increasing access to high intensity activity, and diversifying locations and peers as potential points to improve play and community participation in children with SCI. A broader, and perhaps more challenging task, may be to expand unstructured play for children with SCI, so it better matches their non-disabled peers, as a way to recover some of the formative experiences of childhood, so often lost in the case of severe disability. Interestingly, the literature rarely cites access or environmental barriers as impeding participation in children with SCI, suggesting that the classic "where there's a will, there's a way" may support formative experiences for these children. It may be of benefit to assess psychosocial factors, community support, financial resources, familial structures, to see if there are gaps in participation for children with SCI based on these factors.

Future studies may more directly control play and participation schemes to assess near and long-term impacts. Studies may consider using the observational evidence described here to inform design and control variables, like location of participation, peer groups, and play intensity levels. Some of this work may overlap with rehabilitation interventions, particularly when looking at the impact of intensity of participation on independence and quality of life. This has the potential to transition classically rehabilitative interventions to more community settings, like elementary school gym class for example, and offer clinicians and families strategies for successful integration.

Key Points

Evidence for play and participation after pediatric onset SCI is limited to observational studies, descriptive cohorts, and small or single case reports. There have been no interventional studies to date, as assessed by this committee.

Persons with pediatric-onset SCI are more likely to report greater functional independence, less pain, and less comorbidities requiring medical intervention as compared to persons with adult-onset SCI. Additionally, they are more likely to participate in moderate to heavy physical activity and a greater variety of social and occupational activities.

Children with paraplegia (all AIS) and AIS D tetraplegia participate in a greater variety of activities at higher intensities than persons with tetraplegia (AIS ABC), but at the same frequency; satisfaction with participation is equally high across both groups.

Greater variety in location of participation (i.e., away from home) and peer group positively impacts quality of life, after controlling for age, sex, level of injury and chronicity.

More than half of caregivers report at least one obstacle limiting their child's participation. Community and disability-related factors are the most likely obstacles to be reported. Obstacles are more likely to be reported for younger children and children in more rural settings.

Persons with pediatric-onset SCI are more likely to participate in informal activities, than formal activities. Satisfaction with participation in these activities is more likely to be higher in younger children, females, and children with paraplegia.

Children with SCI who have a greater variety of social activities are more likely to report greater participation, less depression, and higher quality of life.

7.2 School

Every child has the right to learn. However, many children with SCI are not receiving equal education opportunities due to their disability status and lack of accessibility within the school system. Inadequate access to quality education have long-lasting and pervasive impact on children's social development, as well as their abilities to lead a fulfilling live and contribute to their community in adulthood (UNICEF, 2021).

To return to school is a primary rehabilitation goal for children and adolescents who have sustained an SCI and is key to smooth transition into adulthood; High educational attainment has been shown to predict positive employment outcomes later in life in those with SCI (Anderson & Vogel, 2002; Hwang et al. 2014b). When returning to school after acquiring an SCI, children may experience various challenges related to physical accessibility, psychological adjustment, and social participation. For example, they may need to cope with changes in their self-image and role in school as a result of the changes in their physical abilities; in addition, inadequate awareness and knowledge about SCI among teachers and peers may hinder their full participation in school activities, such as sports and school trips (Knight, 2008; Mulcahey, 1992). This section presents an overview of the existing evidence on school re-entry in children with SCI.

Table 38. Studies assessing school among children with SCI.

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Harder et al. 2013) USA Observational N=24	**Population:** Age at interview: 11.5±3.4 (5-18) yr; Age at injury: 9.7±4.8 (1-17) yr; Gender: males=9, females=15; Injury etiology: Transverse Myelitis; Level of injury: cervical (N=13); Ambulation: normal=46%, abnormal but ambulated independently=79%, bilateral support (i.e., crutches) =29%, wheelchair-bound=8.3%. **Intervention:** None. Neuropsychological evaluation, patient and caregiver surveys. **Outcome Measures:** Academic performance at school.	1. Parents reported that 33% of subjects were below average or failing performance in one of four academic domains.
(Massagli et al. 1996) USA Observational N=53	**Population:** Age at Injury: 9.2 (0-17) yr; Gender: males=33, females=20; Injury etiology: SCI=43, Transverse Myelitis=7, Skeletal Dysplasia=1, Other=2; Time since injury: 9.4 (0-26) yr; Level and severity of injury:	*Primary School Subjects (n=12)* 1. All subjects were enrolled in school full-time; 9 were qualified for special education services and they received special services that included an aide (58%), a full-time private RN (8%), and physical or occupational therapy (75%). 2. Almost all (n=11) participated in physical education and all participated in recess and field trips.

	complete paraplegia=17, incomplete paraplegia=8, complete tetraplegia=17, incomplete tetraplegia=11. **Intervention:** None. Survey. **Outcome Measures:** School placement, cumulative and most recent term grade point average (GPA), use of services (e.g., physical or occupational therapy, an aide, or nurse) and assistive technology, highest level of education achieved by each parent. Self-ratings on performance in discussions, group activities, homework, test completion, independent study, behavior; teacher reports on school program, type of classroom setting, changes in class requirements for the student, use of transition services, and use of assistive technology in the classroom, student performance; attendance, grades, transition planning.	3. The most common modifications reported by the students and teachers were allowance of extra time to complete in-class work (33%), and a change in location (17%) due to lack of access. 4. The median values for self-ratings by students ranged from 4 to 6, and by teachers of the students from 4.5 to 5.5 (not significantly different). *Secondary School Subjects (N=19)* 5. Two subjects attended school part-time and the rest went full-time. 6. Six students were qualified for special education services; special services provided to secondary students included an aide (32%), a full-time private RN (10%), physical or occupational therapy (16%), and classes related to vocational preparation (26%). 7. Only 9 participated in physical education, and 6 reported that they did not participate in class field trips. 8. Modifications provided for these students included extra time to complete in class work (42%), location change (26%), and alternate assignments (21%). 9. Eighty-five percent of secondary students, including both who were ventilator-dependent, planned to attend college. 10. Mean grade point average (GPA) for these 19 students was 3.05. 11. Students had a mean of 23 absences per school year, but school absences did not appear to influence the previous term GPA. 12. Class ranks were available for 11 students for which 45% were in the top quartile and 18% in each of the other 3 quartiles. 13. Both students and teachers rated all performance measures a median of 5, (no significant difference). *Post-Secondary Subjects (N=22)* 14. Only 2 (9%) of the 22 postsecondary subjects did not complete high school; 50% were currently in college, 32% had completed college, and 18% had never attended college. 15. Compared to secondary students, these students reported similar modifications in their school work but with greater frequencies: extra time to complete work and tests (68%), a location change (50%), and alternate assignments (32%).

		16. Those in college anticipated working in such jobs as pharmacist, lawyer (n = 2), engineer (n = 2), teacher, personnel manager, accountant, and social worker. 17. Two students were ventilator-dependent; one anticipated a job in psychological counseling and the other was uncertain. 18. Actual jobs held by those who had completed or never attended college included engineer, photographer, insurance agent, computer operator, ranch foreman, teacher, homemaker (n=2), and rehabilitation counselor (subject who was ventilator-dependent). 19. Five postsecondary subjects lived with family, 1 lived in a nursing home, 4 lived away from family with an aide, and the rest lived independently. 20. The level of SCI was not related to whether or not a working age subject had ever been employed in a minimum wage job: 11 of 20 with paraplegia versus 6 of 17 with tetraplegia bad ever been employed (p=0.23).
(Graham et al. 1991) USA Observational N=13	Population: Age at injury: 12-19 yr; Gender: males=12, females=1; Level of injury: tetraplegia=6, paraplegia=7. Intervention: None. Survey and Interview. Outcome Measures: personal care needs, asking for and receiving help in school, perceived attitudes of classmates and teachers, availability of counseling services, and participation in extracurricular activities. Responses to the following questions: 1) How do you feel other students perceive you and your disability? 2) Do you have problems with other students because of your disability? 3) How did your parents react regarding your return to school? 4) Do you participate in school activities?”	*Of total sample (N=44), 11 dropped out of school before their injury; 5 refused to return to school after their injury; 5 already had graduated from high school; and 2 had educational services provided at home; 21 patients returned to school of which data is presented here for 13 who agreed to participate.* 1. No student felt that able-bodied students had poor attitudes or unfriendly toward them. 2. Male students enjoyed the positive attention from others, particularly from female peers. 3. Those reluctant to ask for help excluded themselves from activities (to appear independent); those with paraplegia often stated they did not need help in school. 4. Parents wanted students to go to school and accepted no excuses except actual physical illnesses. 5. All schools attended were (mostly) wheelchair accessible; one had to be assisted up a steep ramp, one student blamed the school for not providing a wheelchair accessible location and he dropped out of school in last term. 6. Educational and vocational counseling was very limited. 7. Three students with tetraplegia had a note-taker assigned; tape recorders were also used to take notes. 8. None of the students were required to attend physical education class; leisure activities involving able-bodied and disabled were lacking.

		9. Reasons for non-participation in other extra-curricular activities were a) the long school day, b) the rigid transportation schedule, c) homework and personal care schedules, and d) fear of crowds and violence. 10. Males with paraplegia had no problems with personal care. 11. Bladder and bowel accidents were not a major concern; only three students reported accidents which were a source embarrassment. 12. While few problems were expressed initially, follow-up reports revealed a dropout rate for this group of 38% (5 of the 13). 13. The five students who dropped out of regular day schools all did so in the 11th grade and had been shooting victims. 14. Four of the six students who graduated from regular high school programs also enrolled in colleges. 15. One student died in the senior high school term from a subsequent gunshot wound. 16. The youngest student, who was 12 yr old when injured, still is attending school.

Discussion

Three studies were identified from our literature search, all of which were observational studies and originated from the USA. Topics examined include school performance, recommendation for the school re-entry process, laws and legislations**,** services by physical or occupational therapist, assistive technology, and children's subjective experiences with the re-entry process.

Massagli (1996) conducted the largest study to date on educational achievement and vocational participation in 53 children and adolescents post SCI. primary school, secondary student, postsecondary students who acquired SCI before age 18 and their teachers were surveyed. Content analysis of school records were also performed. Overall, students with SCI demonstrated adequate academic performance and school participation. This was reflected in students and teachers' ratings on the students' performance and participation, as well as the high post-secondary school enrollment rate (82%) among the high school graduates. Harder and colleagues' (2013) study, in contrast, indicated that many students with SCI may experience challenges in the academic aspect of school life. Specifically, in their study, 33% of parents of children and adolescents with SCI indicated that their child experienced school problems, defined as below average of failing performance in one of four academic domains. However, it should be noted that these caregiver reports were based on a non-standardized and non-validated school history questionnaire on academic functioning. Therefore, this finding should be interpreted with caution.

Challenges related to school participation encountered by children with SCI were noted in two of the three studies (Graham et al. 1991; Massagli et al. 1996). For participants in Massagli and colleagues' (1996) study, especially those who were attending secondary school, participation in physical education was limited. Likewise, Graham and colleagues' (1991) study revealed a lack of availability of accessible leisure activities for adolescents with SCI. Interestingly, although peers' negative attitudes towards people with disabilities have frequently been identified as barriers to school participation in the literature, no participants in Graham and colleagues' (1991) study reported their able-bodied peers having poor attitudes or being unfriendly towards them.

Not surprisingly, the services that children with SCI receive and require in school setting depend on their age and developmental stages. In Massagli and colleagues' (1996) study, it was found that primary school students with SCI received more support by physical and occupational therapy services than secondary school students, whereas secondary and postsecondary students required more modifications of the curriculum and daily activities, possibly due to increased complexity of school work and less direct support received. As noted by Massagli et al. (1996), adolescents with SCI may benefit from transition planning services, such as employment counselling, within the school setting. However, such services for this population were found to be inadequate for study participants (Graham et al. 1991; Massagli et al. 1996)

As Mulcahey (1992) pointed out, successful rehabilitation efforts entail not only improvements in functional independence but also successful community reintegration that allows the individuals to resume meaningful lifestyles. Given the significance of school in children's everyday life, this calls for more research, especially intervention studies, on the topic of return-to-school in the pediatric SCI population. Furthermore, in order to improve the quality of research in this field, multicentre studies are needed to increase the sample size, as SCI in children and adolescents are rare in many countries.

Key Points

Experts in the field has identified the process of re-entry to school the main issue for children and adolescents with SCI.

However, evidence in this field is lacking, which highlight the need of more and methodological sound research. School settings and programs, study populations need to be defined. Outcome measures need to be validated and standardized.

There is a challenge in obtaining good quality data due to the relatively low incidence of pediatric SCI, which calls for more multicentre studies nationally and internationally to direct best practice.

7.3 Employment

According to the Universal Declaration of Human Rights by the United Nations (1948), the right to work is a universal human right. *Employment* can be defined as "engaging in all aspects of work, as an occupation, trade, profession or other form of employment, for payment or where payment is not provided, as an employee, full or part time, or self-employed" (Organization, 2001). The value of employment and its benefits on the individual's daily functioning and psychosocial well-being has been well documented in the literature. Past research has shown that active participation in the workforce can lead to increased independence and social integration, greater life satisfaction, and improved quality of life in those with SCI (Hess et al. 2004; Ottomanelli & Lind, 2009).

Most people with SCI are capable of contributing to their communities through employment post injury and can benefit greatly from vocational rehabilitation (Bickenbach et al. 2013). However, their potential to participate in the workforce is often hampered by various physical and social barriers. As suggested in a report from the Spinal Cord Injury Research Evidence on work and employment post-SCI in the adult population, facilitators and barriers to return-to-work following SCI consist of both modifiable and non-modifiable factors and are situated at both at the individual and systemic levels (Escorpizo R, 2018).

Demographic and clinical characteristics, such as being male and Caucasian, earlier onset of injury, lower injury severity, and higher pre-injury education participation in the workforce , have been identified as non-modifiable personal factors that increase the likelihood of employment post-SCI; post injury factors such as lower occurrence of health complications, higher level of education, functional independence, and desire to work are modifiable personal characteristics that predict better vocational outcomes. Within the broader social environment, access to assistive devices and transportation, workplace accommodations, as well as adequate social support, serve as facilitators of return-to-work following SCI, while inadequate financial assistance, negative societal attitudes people with disabilities, and lack of environmental accessibility contribute to negative vocational outcomes (Anderson & Vogel, 2002; Miriam Hwang et al. 2015; Vogel et al. 1998).

In Western society where autonomy, independence and productivity are highly valued during late adolescence and young adulthood, it is especially important to create an environment that enables young people living with SCI to thrive in the workforce. In this section, we review current evidence on employment in individuals with pediatric-onset SCI and identify gaps in the existing literature.

Table 39. Studies assessing employment among children with pediatric-onset SCI

Author, Year Country Study Design Sample Size	Population Intervention Outcome Measure	Results
(Miriam Hwang et al. 2015) USA Observational N=461	Population: *Pediatric-onset SCI:* Age at interview: 32.3±5.8 (22-50) yr; Age at injury: 14.2±4.4 (0-18) yr; Gender: males=290, females=171; Time since injury: 18.1±6.6 (6-43) yr; Level of injury: paraplegia=210, tetraplegia=251; Severity of injury: C1-4 AIS ABC=65, C5-8	1. Individuals with paraplegia were more likely to be employed than those with tetraplegia (p=0.001). 2. There was no difference in employment rates between males and females (p=0.741). 3. Married individuals were significantly more likely to be employed than single individuals (p=0.001).

	AIS ABC=160, T1-S5 AIS ABC=189, AIS D=43, missing=4. Intervention: None. Cross-sectional data from a larger longitudinal study. Outcome Measures: Standard Occupational Classification (SOC) system.	4. Those who were able to drive were more likely to be employed than those who did not drive (p<0.001). 5. Education, Legal, Community Service, Arts, and Media Occupations were most prevalent (30.2%), followed by Management, Business, and Financial Occupations (21.1%), Computer, Engineering, and Science Occupations (10.6%), and Office and Administrative Support Occupations (10.0%). 6. There was a similar proportion of men and women who were employed in the Management, Business, and Financial Occupations (men, 20.4%; women 22.7%) and Education, Legal, Community Service, Arts, and Media Occupations (men, 30.1%; women, 30.3%). 7. There was a higher proportion of women than men who were employed in the Healthcare Practitioners and Technical Occupations (men, 0.9%; women, 9.1%) and the Office and Administrative Support Occupations (men, 6.2%; women, 16.7%). 8. Men were predominant in the Farming, Fishing, and Forestry Occupations (men, 3.5%; women, 0%); Construction and Extraction Occupations (men, 2.7%; women, 0 %); Installation, Maintenance, and Repair Occupations (men, 2.7%; women, 0%); Production Occupations (men, 4.4%; women, 1.5%); and Transportation and Material Moving Occupations (men, 0.9%; women, 0%). 9. There was a similar proportion of individuals in the tetraplegia and paraplegia groups working in the Education, Legal, Community Service, Arts, and Media Occupations (tetraplegia 30.6%; paraplegia 29.8%) and Healthcare Practitioners and Technical Occupations (tetraplegia 3.5%; paraplegia 4.3%). 10. The distribution of parttime versus full-time employment within each SOC group revealed a higher prevalence of fulltime employment in all SOC groups except for the Service Occupations and Sales and Related Occupations, which displayed similar proportions between the employment intensity groups. 11. Approximately one-half of individuals with a postbaccalaureate or a professional degree were employed in the Education, Legal, Community Service, Arts, and Media

		Occupations (49.1%), with Management, Business, and Finance Occupations (21.1%) and Healthcare Practitioners and Technical Occupations (10.5%) following in frequency. 12. For those with a baccalaureate degree, Management, Business, and Finance Occupations (32.7%) and Education, Legal, Community Service, Arts, and Media Occupations (28.8%) were most prevalent, followed by Computer, Engineering, and Science Occupations (9.6%) and Office and Administrative Support Occupations (9.6%). 13. Among individuals with an associate's degree or technical training, Education, Legal, Community Service, Arts, and Media Occupations (17.9%) were most frequent, followed by Computer, Engineering, and Science Occupations (16.1%) and Office and Administrative Support Occupations (16.1%), whereas Production Occupations (33.3%) and Service Occupations (16.7%) were most prevalent in participants whose final diploma was from high school or a GED. 14. Data on job satisfaction were available for 82 of the 219 employed individuals and revealed that 77 (94%) were at least moderately satisfied with their occupation and 5 (6%) reported some degree of dissatisfaction.
(Hwang et al. 2014b) USA Observational N=283	Population: *Pediatric-onset SCI:* Age at interview: 27.3±3.7 (21-37) yr; Age at injury: 14.5±4.3 (0-18) yr; Gender: males=182, females=101; Time since injury: 12.7±5.0 (4-30) yr; Level of injury: tetraplegia=174; Severity of injury: complete=195; C1-4 AIS ABC=46, C5-8 AIS ABC=110, T1-S5 AIS ABC=99, AIS D=28. Intervention: None. Annual interviews. Outcome Measures: Satisfaction with Life Scale (SWLS), Short-Form 12 Health Survey (SF-12), Patient Health Questionnaire-9 (PHQ-9), and Craig Handicap Assessment and Recording Technique (CHART).	1. Those attaining a bachelor's degree or higher had increased from 33.2% at the first interview to 47.0% at the last interview. 2. There was no change in the proportion of employed versus unemployed from the first (56.8% versus 43.2%) to last interview (58.1% versus 41.9%) (less than general population estimates). 3. At the last interview, the proportion of employed participants was significantly higher in those with a baccalaureate and post-baccalaureate degrees, whereas the proportion of unemployed individuals was higher in those with a high school diploma. 4. Women and married participants also had higher rates of employment at the last interview than men and single participants, respectively. 5. There was no significant change in employment status over time (OR 1.01, confidence interval (CI) 0.98-1.04). 6. Odds of employment increased over time in participants who were women (1.04, CI 1.00-1.08), married (1.05, CI 1.02-1.08), attained a

		baccalaureate degree (1.03, CI 1.00-1.07), or post-baccalaureate degree (1.05, CI 1.02-1.08). 7. Odds of employment decreased over time in participants with occurrence of autonomic dysreflexia (0.80, CI 0.65-0.99), spasticity (0.80, CI 0.59-0.99) or chronic medical condition (0.83, CI 0.71-0.98). 8. Life satisfaction (SWLS) scores increased over time in those who remained employed (1.11, CI 1.01-1.22). 9. Odds of depression (PHQ-9) increased over time in those who remained unemployed (1.13, CI 1.04-1.23).
(Hwang et al. 2012) USA Observational N=215	Population: *Pediatric-onset SCI*: Age at interview: 23.3±0.9 yr; Age at injury: 13.2±4.9 yr; Gender: males=126, females=89. Time since injury: 10.3±5.0 yr; Level of injury: tetraplegia=51.6%; Severity of injury: complete=73.5%, C1-4 AIS ABC=11.2%, C5-8 AIS ABC=35.3%, T1-S5 AIS ABC=43.3%, AIS D=8.8%, missing=1.4%. Intervention: None. Survey. Outcome Measures: Functional Independence Measure (FIM), Satisfaction with Life Scale (SWLS), Short-Form 12 Health Survey (SF-12), Patient Health Questionnaire-9 (PHQ-9) Depression Scale, and Craig Handicap Assessment and Recording Technique (CHART), use of tobacco, alcohol, and marijuana.	1. Prevalence rates of regular substance use were 27.9% for tobacco, 55.4% for alcohol and 10.7% for marijuana (Table 2). These rates are considerably lower than the age-matched general population values. 2. Tobacco use was higher in participants who were unemployed than those employed either full- or part-time (38% versus 21%). 3. Alcohol use was higher in participants who were Caucasian (60 versus 26% non-Caucasian), had a college degree (80% versus 47% no college degree), were employed (70% versus 45% unemployed), had higher annual income (44%, $10 000 versus 65%, $10000-29999 versus 77%, >$30000), were single (59% versus 31% married) and able to drive independently (67% versus 35% cannot drive independently). 4. Marijuana use was more prevalent in males (14% versus 6% female) and those without a college degree (13% versus 2% college degree). 5. There was no significant difference in the prevalence of substance use between those living independently, or in relation to any injury-related factors such as level, severity or duration of injury. 6. Individuals with regular alcohol use had significantly lower incidence of urinary tract infections (64 versus 82%) and chronic medical conditions (11 versus 22%) compared with individuals with no use. 7. Tobacco use was significantly associated with depressive symptoms (PHQ-9; $p<0.05$). 8. Alcohol use was associated with higher socio-cognitive independence (FIM; $p<0.01$), better perceived physical health (SF-12 physical, CHART physical, CHART mobility; $p<0.05$ for all), and increased community participation (CHART social; $p<0.05$).

		9. Marijuana use was not associated with any outcome measure. 10. There was no association between SWLS and substance use of any type. 11. Logistic regression indicated that both unemployment and the presence of depressive symptoms contribute independently to tobacco use (p<0.05). 12. Logistic regression indicated that having a college degree (p<0.05) and being single were found to contribute most in predicting regular alcohol drinking (p<0.01), while independent mobility (p<0.01) was also a significant predictor for use. 13. Logistic regression indicated those with a college degree were less likely to use marijuana (p<0.05).
(Anderson et al. 2006) USA Observational N=166	Population: Age at injury=14.2±4.0 yr; Gender: males=115, females=51; Level of injury: tetraplegia=106; Severity of injury: AIS A=105. Intervention: None. Interview at three different time points. Outcome Measures: Craig Handicap Assessment and Reporting Technique (CHART), Short-Form 12 (SF-12), and Satisfaction with Life Scale (SWLS).	*Living Status:* 1. A total of 106 (64%) subjects lived independently at the initial interview and 95 continued to live independently for the remaining 2 follow-up interviews. 2. Of the 60/166 who were not living independently at the first interview, 48/60 (80%) did not live independently at any interview. 3. There were no significant differences between those living independent or dependently with respect to demographic, or body structure and function factors. 4. Those living independently were more functionally independent and have high community participation (CHART total and all subscales except economic self-sufficiency), more likely to be employed, more satisfied with their lives (p<0.030 for all), more likely to be married (p<0.001), less likely to have the medical complications of spasticity, pressure ulcers, and severe UTIs (p<0.050 for all). 5. Factors most predictive of consistent independent living in the regression were CHART physical independence, mobility, and occupation scores (39% variance). *Employment:* 6. Excluding students and homemakers, there were 113 individuals who completed 3 interviews of which 72 (64%) were employed at the first interview; 60 continued to be employed at the remaining 2 interviews.

		7. Of the 41 who were not employed at the first interview, 34 (83%) remained unemployed at all interviews. 8. Those employed at all 3 interviews included a larger percentage of women (81%) than men (57%), a larger percentage of those who were Caucasian (68%) versus other (17%), a larger percentage of those with paraplegia (82%) than tetraplegia (54%), and a larger percentage of those with college degrees (80%) than those with less education (20%). 9. Those employed were more functionally independent and participated more in the community (CHART subscales physical independence, cognitive independence, mobility, and social integration). 10. Those consistently employed were also more likely to be married, to live independently, to have greater life satisfaction, less likely to have spasticity ($p<0.050$ for all). 11. Factors most predictive of stable employment were being female, being Caucasian, having greater cognitive independence and community mobility (CHART), and living independently (71% variance). *Life Satisfaction:* 12. Of the 166 participants, 80 (48%) had good life satisfaction at the first interview, and 64 (84%) continued at the 2 follow-up interviews. 13. A total of 86/166 (52%) had poor life satisfaction at the first interview and 56 (65%) remained dissatisfied at the 2 follow-up interviews. 14. There were differences between those with good or poor life satisfaction with respect to demographic, or body structure and function factors. 15. Factors significantly associated with high life satisfaction scores included functional independence, perceived mental health, participation in the community (CHART total and mobility, occupation, and economic self-sufficiency subscales), fewer medical complications (i.e., pressure ulcers, UTIs, and pain), being married, living independently, and being employed. 16. Predictive factors of life satisfaction in a regression were show to be CHART occupation subscale and fewer pressure ulcers (56% variance).

(Anderson & Vogel, 2002) USA Observational N=195	**Population:** *Pediatric-onset* SCI: Age at injury: 14.1±4.0 yr, Age at interview: 28.7±3.4 yr, Gender: males=134, females=61; Time since injury: 14.6±4.3 yr. Level of injury: tetraplegia=112, paraplegia=194. Severity of injury: complete=83, incomplete=78. **Intervention:** None. Survey. **Outcome Measures:** Functional Independence Measure (FIM), Craig Handicap Assessment and Reporting Technique (CHART), Short-Form 12 (SF-12), Satisfaction with Life Scale (SWLS).	1. Among the sample, 40% (n=78) were unemployed, 51% (n=99) were employed, 6% (n=12) were students, and 3% (n=6) were homemakers. 2. Gender ratio of students (33% female) was similar to those employed (35% female) and significantly higher than those unemployed (20% female) ($p<0.001$). 3. Compared to those unemployed, those who were students, homemakers or employed were significantly less injured ($p=0.010$), more likely to be living independently ($p=0.002$), had higher total FIM scores and sub-scores ($p=0.001$), higher total CHART score and sub-scores (except for social integration) ($p<0.05$ for all), greater SWLS scores ($p<0.001$); there was no significant difference between all groups on SF-12. 4. More women (69%) than men (51%) were employed ($p=0.030$); genders were approximately equal for full-time employment but more women were employed part-time than men. 5. No significant differences in rate of employment by race, age at interview, age at injury, or duration of injury. 6. Individuals with SCI from medical and/or surgical causes were more likely to be employed (85%) than were those with other etiologies (54%; $p=0.030$). 7. Individuals with paraplegia were more likely to be employed than were those with tetraplegia (66% versus 49%, $p=0.027$) but this trend was significant for women only. 8. Compared to those employed, those unemployed had lower FIM (total and subscores) ($p<0.006$ for all), CHART (total and subscores) ($p<0.050$ for all), SF-12 physical score ($p=0.011$), SWLS ($p<0.001$) but not SF-12 mental score. 9. With respect to medical complications, compared to those employed, those unemployed had greater spasticity ($p=0.001$), severe urinary tract infections ($p<0.001$), respiratory complications $p=0.044$), pressure ulcers ($p<0.001$) and days hospitalized ($p=0.013$). 10. The regression model for the outcome employment demonstrated four significant predictors: total yr of education $p<0.001$), community mobility ($p<0.001$), functional independence ($p=0.037$), and decreased medical complications ($p=0.017$).

Kannisto & Sintonen (1997b) Finland Observational N=408 $N_{(SCI)}$=36 $N_{(PS)}$=372 SCI – Spinal Cord Injury PS – Population Sample	**Population:** (SCI) Mean age=31.3±9.9yr.; Gender: males=25, females=11; Level of injury: Complete tetraplegia=3, Incomplete tetraplegia=5, Complete paraplegia=25, Incomplete paraplegia=3; Level of severity: AIS A=28, B/C/D=8; Time since injury=20.0±11.2yr. (PS) Demographic characteristics not reported for PS group. **Intervention:** None – observational, outcomes compared to general population sample. **Outcome Measures:** Health-Related Quality of Life (HRQL (15D – 15 multiple-level dimensions)) and average importance of HRQL dimensions.	1. HRQL score of the SCI group was significantly lower than that measured in the population sample. 2. Average importance weights assigned by the SCI group differed significantly ($p<0.05$) from those assigned by the general population group on several dimensions: 1) SCI group higher for mental functioning, communicating, social participation, and seeing; 2) SCI group lower for moving, working, sleeping, and eating.
Vogel et al. (1998) USA Observational N=81(46) *Of the original sample, 30 were lost to follow-up and 4 died	**Population:** Mean age=27.2±1.8yr.; Gender: males=31, females=15; Level of injury: C4-T12; Level of severity: AIS A=26, B=9, C=8, D=3; Time since injury: Not reported. **Intervention:** None – observational. **Outcome Measures:** A structured questionnaire including physical, psychosocial, and medical information. The Craig Handicap Assessment and Reporting Technique and two measures of life satisfaction were also administered.	1. 54% of participants were employed: Full time, 39%; Part-time, 15; Unemployed, 46%. 2. 48% of participants lived independently. 3. 15% of participants were married. 4. Life satisfaction was associated with education, income, satisfaction with employment, and social and recreational opportunities.
(Massagli et al. 1996) USA Observational N=53	**Population:** Age at Injury: 9.2 (0-17) yr; Gender: males=33, females=20; Injury etiology: SCI=43, Transverse Myelitis=7, Skeletal Dysplasia=1, Other=2; Time since injury: 9.4 (0-26) yr; Level and severity of injury:	*Post-Secondary Subjects (N=22)* 1. Only 2 (9%) of the 22 postsecondary subjects did not complete high school; 50% were currently in college, 32% had completed college, and 18% had never attended college. 2. Compared to secondary students, these students reported similar modifications in their school work but with greater

	complete paraplegia=17, incomplete paraplegia=8, complete tetraplegia=17, incomplete tetraplegia=11. **Intervention:** None. Survey. **Outcome Measures:** School placement, cumulative and most recent term grade point average (GPA), use of services (e.g., physical or occupational therapy, an aide, or nurse) and assistive technology, highest level of education achieved by each parent. Self-ratings on performance in discussions, group activities, homework, test completion, independent study, behavior; teacher reports on school program, type of classroom setting, changes in class requirements for the student, use of transition services, and use of assistive technology in the classroom, student performance; attendance, grades, transition planning.	frequencies: extra time to complete work and tests (68%), a location change (50%), and alternate assignments (32%). 3. Those in college anticipated working in such jobs as pharmacist, lawyer (n = 2), engineer (n = 2), teacher, personnel manager, accountant, and social worker. 4. Two students were ventilator-dependent; one anticipated a job in psychological counseling and the other was uncertain. 5. Actual jobs held by those who had completed or never attended college included engineer, photographer, insurance agent, computer operator, ranch foreman, teacher, homemaker (n=2), and rehabilitation counselor (subject who was ventilator-dependent). 6. Five postsecondary subjects lived with family, 1 lived in a nursing home, 4 lived away from family with an aide, and the rest lived independently. 7. The level of SCI was not related to whether or not a working age subject had ever been employed in a minimum wage job: 11 of 20 with paraplegia versus 6 of 17 with tetraplegia bad ever been employed (p=0.23).

Discussion

To date, no intervention studies on work and employment in individuals with pediatric onset SCI have been conducted; all eight studies summarized above are observational studies. Among those, all but one originated from the United States, and six were conducted within a single pediatric specialty hospital system for children and adolescents with SCI (Shriner's Hospital). Participants involved in the studies were primarily young adults with pediatric-onset SCI. Overall, the employment rates in study participants with pediatric-onset SCI ranged from 47.5% to 64% (Anderson & Vogel, 2002; Anderson et al. 2006; Miriam Hwang et al. 2015), which is higher than that in the adult-onset population but significantly lower the employment rate in age-matched general population (Lidal et al. 2007; U.S. Bureau of Labor Statistics, 2013). In the most recent study examining the occupational characteristics of adults with pediatric-onset SCI using the 2010 Standard Occupational Classification system, Hwang and colleagues (2015) found that 219 of 461 participants were employed in a variety of occupations, with education, law, community service, arts, and media occupations being the most common.

Similar to findings from studies conducted with individuals who acquired SCI as adults, Secondary health conditions, such as occurrence of AD, spasticity, pressure ulcers, and respiratory complications, were found to decrease the odds of employment for persons with pediatric-onset SCI (Anderson & Vogel, 2002; Anderson et al. 2006; Hwang et al. 2014b). level of injury was found as a predictor of employment outcomes among those with pediatric onset SCI. More specifically, those with paraplegia were more likely to be employed compared to those with tetraplegia (Miriam Hwang et al. 2015; Massagli et al. 1996). Interestingly, unlike those who acquired SCI later in life, males with pediatric onset SCI were no more likely to be employed compared with their female counterpart (Miriam Hwang et al. 2015). Not surprisingly, high household income, functional independence, community mobility, and active community participation were identified as facilitators to employment (Vogel et al.1998; Anderson & Vogel, 2002; Anderson et al. 2006; Hwang et al. 2014b; Vogel et al.1998; Anderson et al. 2002).

As suggested by Massagli et al. (1996), the overall education attainment is high among those with pediatric-onset SCI. In addition, high levels of education, especially completion of post-secondary education, seem to predict positive employment outcomes (Anderson & Vogel, 2002; Hwang et al. 2014b; Miriam Hwang et al. 2015; Kannisto & Sintonen, 1997a; Massagli et al. 1996; Vogel et al. 1998). However, despite their high level of educational achievement, the employment prospect and outcomes in individuals with pediatric-onset SCI are much less positive than those in those without disabilities (Kannisto & Sintonen, 1997a). In their study involving 46 young adults with pediatric-onset SCI, Vogel et al. (1998) found that the employment rate of participants with pediatric-onset SCI (full time or part time) was 54%, which was considerably lower than that of the general population (84%). Findings from Hwang and colleagues' (2014b) work which took a closer look at the relationship between levels of education and employments rates in adults with pediatric-onset SCI may help explain the discrepancy in employment prospect between those with and without pediatric-onset SCI. The study revealed that although the employment rate in participants with baccalaureate or higher degree (71.3%) were similar to the employment rate in the general population with same level of education (76%), the employment rates in participants with a high school diploma and some college/associate's degree were considerably lower than that in the general population with the same education attainment. This difference may be attributed to the nature of the work available for individuals with a high school diploma or associate's degree, which often require activities than may be too physically demanding for those with SCI (Hwang et al. 2014b).

It is worth noting that employment may be associated with psychosocial well-being. Several studies demonstrated that life satisfaction was rated higher among participants with pediatric onset SCI who were employed, compared to those who were unemployed (Anderson & Vogel, 2002; Anderson et al. 2006; Hwang et al. 2014b; Vogel et al. 1998). In addition, for participants who were employed, the levels of life satisfaction tended to increase over time (Miriam Hwang et al. 2015). Hwang et al. (2012) examined self-reported data on substance abuse in young adults with pediatric-onset SCI in the United States. Logistic regression indicated that unemployment was a contributor to tobacco use and depression in participants. Interestingly, the study also showed that alcohol use was more prevalent among participants who were employed than those who were unemployed (Hwang et al. 2012).

No studies identified from our literature search investigated the role of socio environmental factors in shaping employment outcomes in individuals with pediatric-onset SCI, representing a notable gap in the literature. Moreover, with the lack of intervention studies, the evidence concerning the employment outcomes of those with pediatric onset SCI are primarily drawn from observational studies, making it challenging to establish guidelines for clinical practice. If the ultimate goal of rehabilitation for children and adolescents who sustain a SCI is to assure that they grow up to lead productive and satisfying lives, more research on vocational rehabilitation and educational planning in adolescents and youth with SCI is needed in the future.

Key Points

Despite their high educational attainment, the employment rate of individuals with pediatric-onset SCI is considerably lower than that of the general population.

High level of education, high household income, functional independence, community mobility, and active community participation facilitate employment in individuals with pediatric-onset SCI; high injury severity and frequent occurrence of health complications hinder employment in this population

While the existing observational studies offer valuable insight into the facilitators and barriers of employment in individuals with pediatric onset SCI, high-quality intervention studies are needed in this area.

Future research needs to explore the roles of environmental factors in shaping employment outcomes in individuals with pediatric-onset SCI.

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Abbreviations

AIS	American Spinal Injury Association Impairment Scale
AD	Autonomic Dysreflexia
BMI	Body Mass Index
BMC	Bone Mineral Content
BMD	Bone Mineral Density
CVS	Cardiovascular
FES	Functional Electrical Stimulation
HO	Heterotopic Ossification
STAMP	Screening Tool for the Assessment of Malnutrition in Pediatrics
SCD	Spinal Cord Dysfunction
SCI	Spinal Cord Injury
SCI/D	Spinal Cord Injury/Dysfunction
UTI	Urinary Tract Infection
UDS	Urodynamic Studies
VTE	Venous Thromboembolism