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Functional level of lesions scale: Validating fourteen years of research with the National Spina Bifida Patient Registry

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Background: Functional level of lesion (FLOL) is a method for grading the level of neurological function in patients with myelomeningocele and other forms of spina bifida. It has been widely used as an independent variable in studies of spina bifida, but its inter-rater reliability has not previously been tested. The purpose of this study is to measure inter-rater reliability of FLOL testing and compare testing performed by a non-medically trained research associate to testing performed by a pediatric rehabilitation medicine specialist.

Methods: Children in a multi-disciplinary spina bifida clinic underwent FLOL grading by a non-medically trained research associate. On the same day, these children were also graded by a pediatric rehabilitation medicine specialist. Cohen's weighted kappa statistic was used to compare grading, with the rehabilitation medicine specialist considered the gold standard.

Results: A total of 71 patients participated. FLOL was graded for left and right leg for each participant, resulting in 142 measurements. Cohen's weighted kappa was $\kappa=0.809$, with a standard error of 0.034, and 95% CI 0.723-0.875, indicating substantial agreement.

Conclusions: Functional lesion level (FLOL) as performed according to the instructions of the National Spina Bifida Patient Registry by a non-medically trained researcher is a reliable method to grade lower extremity function in spina bifida.

Pelvic fixation techniques for the surgical correction of kyphosis in children with myelomeningocele: An anatomic analysis

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Background: Pelvic fixation methods used in the surgical correction of kyphotic deformity in children with myelomeningocele are designed to accommodate anatomic parameters that are poorly established. This study analyzes the dysplastic pelvic anatomy of this cohort to more accurately determine the feasibility of modern low-profile surgical constructs.

Methods: We measured anatomic parameters relating to pelvic fixation using computed tomography (CT) performed for preoperative evaluation in 17 myelomeningocele children (mean age 8.6 years, range 2.0-14.1 years) with kyphotic deformity and 17 age- and gender-matched controls. The angle of stable screw insertions (SIA) and the distance between the screws at each spinal or pelvic segment (SD) were determined at four common pelvic fixation sites: 1) lumbar vertebrae 5 (L5), 2) posterior superior iliac spine (PSIS), 3) S2-alar-iliac (SAI), and 4) anatomic trajectory (AT). Additional measurements included: the thickness of both sacral ala and the S2 vertebral body, and the sacral width at the SAI site, defined as the surface area available for anchor insertion between the outer border of the spinal canal and the sacroiliac joint.

Results: Mean SIA were similar between the two groups with the exception of the L5 level (kyphosis left: 55°, control left 30°, p=0.000; kyphosis right: 53°, control right: 31°, p=0.000) and right PSIS level (kyphosis: 23°, control: 20°, p=0.034). Mean SD were similar with the exception of the PSIS level (kyphosis: 58 mm, control: 88 mm, p=0.000).

Mean sacral width at the SAI entry site was 20 mm in the kyphosis group and 31 mm in the control group (p = 0.001). Sacral alar thickness on the left and right, as well as sacral thickness at S2, were significantly less in the kyphosis group (left: 13 mm, right: 13 mm, S2: 11 mm) versus controls (left: 25 mm, p=0.000; right: 24 mm, p=0.000; S2: 17 mm, p=0.005). At the SAI site, sacral deficiency or dysplasia in the cohort precluded anchor placement in six patients and required screw placement well medial of the L5 screw insertion in two patients.

Conclusions: Modern low-profile pelvic fixation methods are applicable in the child with myelomeningocele-associated kyphosis if selected to accommodate the individual anatomic parameters. Previously described characteristics of this population—parallel iliac wing angulations and consistently robust sacral ala dimensions—were not noted. SAI fixation was precluded by anatomic deficiencies in some patients. The anatomic trajectory method did provide a reliable and low-profile alternative.

Factors associated with a decline in ambulatory status among children and young adults with spina bifida in the National Spina Bifida Patient Registry

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Background: Using a sample from the National Spina Bifida Patient Registry (NSBPR), we conducted a prospective cohort study to determine factors associated with a decline in ambulatory status among adolescents and young adults living with spina bifida (SB). Particularly, we hypothesized that gains in body mass index (BMI) would be associated with a decline in ambulatory status.

Methods: Using NSBPR data, we identified all individuals aged 5 years and older whose ambulation status was community ambulator at the time of their enrollment visit. Among them we identified those whose ambulation status was no longer community ambulator (had a partial or total loss of ambulation) in subsequent visits. We used a multivariable Cox Regression model to test the association between the time to decline in ambulatory status and change in BMI. To test the association of BMI change, we used BMI as a time varying covariate in the Cox model. Additional variables included in the multivariable model were age at enrollment, sex, race, functional lesion level, diagnosis (myelomeningocele vs. non-myelomeningocele), and surgical history.

Results: There were 3,032 individuals who were community ambulators at enrollment. Of these, 353 (11.6%) had a decline in ambulation status in subsequent visits. Median (IQR) follow up was 3.0 (1.7,4.8) years. Change in BMI was significantly associated with loss of ambulation (HR 1.02, 95% CI 1.01-1.04, p=0.001). More proximal level of lesion (p< .001), myelomeningocoele diagnosis (p=0.001), greater number of surgeries (p=0.0013), and older age at enrollment (p=0.0038), were also significantly and independently associated with loss of community ambulation status.

Conclusions: A relatively small percentage of children (11.6%) with spina bifida lost the ability to ambulate in the community during the period observed. There are identifiable risk factors associated with this loss, including an increase in BMI. Mmc diagnosis, more proximal level of lesion, total number of surgeries and older age at initial enrollment were also associated with loss of ambulation.

Bracing and ambulatory status in L3 motor level myelomeningocele

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Background: Ambulatory ability of individuals with spina bifida has been associated with neurological level, but there is variability in brace and assistive device (AD) use in these patients. Individuals with L3 motor level may require bracing to ambulate such as hip-knee-ankle-foot orthoses (HKAFO), reciprocating gait orthoses (RGO), knee-ankle-foot orthoses (KAFO), or ankle-foot orthoses (AFO). This study describes brace use and ambulatory status in patients with L3 myelomeningocele.

Methods: Retrospective chart reviews were performed on 307 patients followed by the Spina Bifida clinic at CHOP. Of these, 85 patients (14.5±7.1 years) were classified as having L3 myelomeningocele based on the Broughton Scale. Data collected from annual visits included ambulatory status, highest level of orthosis and AD used.

Results: In cross-sectional data from a younger subset (5y, n=26), 92.3% of patients were ambulatory with AFO use being most common (53.8%), followed by HKAFO(26.9%), KAFO(11.5%), RGO(3.8%) and no bracing(3.8%). In an older group of children (10y, n=26), 92.3% of patients were classified as ambulatory, with AFO use being most common (65.4%), followed by HKAFO(19.2%), KAFO(11.5%), and no bracing (3.8%). Crutches were the most common AD for both age groups (65.3% and 53.8% for 10 and 5, respectively). In a subgroup of 7 patients with longitudinal data from 3-5 years, all who were ambulatory at 5 years old (6/7) were also ambulatory at 3 years old.

Conclusions: Older children demonstrated a lower level of bracing (more AFO use) than younger children with similar motor level. Further study is needed to explore longitudinal relationships and determine the impact of secondary impairments on ambulatory status. This may further impact teenage years and adulthood. These data may inform clinical decision-making on optimal brace recommendations and improve the understanding of ambulatory status in this population as children age.

Exoskeleton assistance improves knee extension during overground walking in spina bifida: A case study

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Background: Our research has previously shown that robotic exoskeletons can improve knee extension and muscle activity in children with crouch gait from cerebral palsy. Here we evaluate the safety, feasibility and effectiveness of exoskeleton assistance in a child with knee extension deficiency from spina bifida.

Methods: Each limb of the NIH pediatric exoskeleton has an actuated knee joint and a passive adjustable ankle. Sensors track the limb to automatically assist knee extension in stance and swing. One participant with L4-5 spina bifida (myelomeningocele; age: 8 years, height: 118 cm; weight: 32.3 kg) completed ten visits after informed consent. Motion capture (Vicon MX) and electromyography (Delsys) were recorded during overground walking with and without the exoskeleton intervention in random order. Primary outcome measures, computed during the last visit, were knee angle and area under curve (AUC) of vastus lateralis (VL) and semitendinosus (ST) EMG linear envelope. Significant differences were assessed using the two standard deviation method.

Results: The exoskeleton applied 0.11 Nm/kg of assistive torque during stance and swing phase knee extension. The participant used a posterior walker with and without the exoskeleton. The exoskeleton intervention significantly increased knee extension at initial contact (without device [left: 14.7±11.3°; right: 26.2±7.3°]; intervention [left: -0.7±1.1°; right: -2.2±1.1°]) and in midstance (without device [left: 10.7±4.0°; right: 23.1±4.1°]; intervention [left: 0.3±1.1°; right: 4.5±1.9°]). AUC of VL and ST muscle activity was significantly reduced during stance phase with the exoskeleton whereas no differences were observed during swing.

Conclusions: These results demonstrate the initial safety and effectiveness of a wearable exoskeleton to improve knee extension in a child with spina bifida during overground walking. These benefits, combined with the changes in muscle activity and the possibility to apply resistive torques for strengthening, warrant future investigation of longitudinal exoskeleton use as an assistive and rehabilitation strategy in spina bifida.

Anterior distal femoral hemi-epiphysiodesis for the treatment of knee flexion deformities in children with spina bifida

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Background: Spina Bifida can result in lower extremity muscle imbalance contributing to knee flexion deformities. Children ambulating with knee flexion deformities accelerate degenerative arthritis of the knees, precluding orthotic management, and limiting long term ambulation. Children with Spina Bifida that have active hip flexion and quadriceps, with paralysis of hamstring and gastrocnemius muscles, present with a crouched gait, and progressive knee flexion deformity. Anterior distal femoral hemi-epiphysiodesis allows gradual knee extension and facilitates ground reaction ankle foot orthotic management.

Methods: Anterior distal femoral hemi-epiphysiodesis was performed on 14 children (age 5 to 10 years) with knee flexion contractures exceeding 20 degrees. Guided growth was accomplished with the use of "Eight Plates" and appropriate orthotic management with no restrictions in weight bearing. Thorough examinations were performed every six months monitoring leg lengths and knee extension. These children were followed for over two years with excellent correction of the knee flexion deformities. These children did not require hamstring or iliotibial band lengthening; there was no compromizing functioning muscles.

Results: Minimum two-year follow-up was documented on 14 children with Spina Bifida with knee flexion contractures exceeding 20 degrees. All of the children had improvement of the knee flexion contracture to less than 10 degrees after 2 years. There were minor skin healing problems with no infections. The post-operative protocol was modified with long leg cast immobilization for 3 weeks with resolution of the skin problems. Only one child required implant removal for over correction.

Conclusions: Anterior distal femoral hemi-epiphysiodesis is an effective treatment for correction of knee flexion deformities in children with Spina Bifida. This is an outpatient surgical procedure that does not compromise functioning muscles, facilitates orthotic management, and helps prevent neuropathic knee joint deformities.

Long-term results of posterior medial lateral release for clubfoot deformity in spina bifida

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Background: Clubfoot is estimated to occur in up to 50% of patients with spina bifida (SB), and many of these patients will fail conservative casting and require surgical intervention with posterior medial lateral release (PMLR). While the long-term outcomes of PMLR in idiopathic clubfoot have been established, limited data exists for the outcomes in the SB population.

Methods: A retrospective chart review was performed on cases of PMLR in SB patients from 2007-present, excluding patient with follow-up <3 years. Demographics and surgical outcomes (concurrent procedures, laterality, reoperation rate, and complications) were recorded. Single-factor ANOVA was used to determine associations with rates of reoperation and other variables.

Results: In total, 34 patients with 47 cases of clubfeet treated with PMLR at a major metropolitan children's hospital were identified. Of those, 23 patients with 31 feet were included in the analysis. Average age at time of PMLR surgery was 3.4 years (range: 1.0-8.7). Average length of follow-up was 8.9 years (range: 3.4-14.0). No infections were reported following PMLR. After PMLR, 42% of feet required reoperation at an average of 4.6 years later. Additionally, 19% of feet required two or more reoperations. Of the 13 feet requiring reoperation, 7 feet (23% of total feet) ultimately required talectomy at an average of 4.9 years post-PMLR. Younger age at time of PMLR was associated with increased reoperation rates (p=0.04). Level of spinal lesion, history of tethered cord release, or ventriculoperitoneal shunt were not associated with differences in rate of reoperations after PMLR.

Conclusions: PMLR remains a safe and successful treatment in the short term for clubfoot in SB, but many feet (42%) will require additional procedures at an average of 4.6 years, with talectomy utilized in 23% of feet. These results will help guide/counsel patients and families about the long-term prognosis of treatment for clubfoot in SB.

Home-based virtual reality exergaming to achieve exercise guidelines in children with spina bifida: Feasibility case study

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Background: Access to physical activity among youth with spina bifida (SB) is much lower than it is for children without disability. This study examined the feasibility of a virtual reality (VR) active video gaming system (i.e., bundle of consumer-available equipment) to meet US physical activity guidelines in two youth with SB.

Methods: Two youth with SB—a 12-year-old female and a 13-year-old male; both full-time wheelchair users—participated in a brief, 4-week exercise program using a Quest 1 headset. Other equipment included a Polar H10 (Polar Canada) Bluetooth heart rate monitor, a no-cost mobile phone app (VR Health Exercise Tracker), and 13 games. The intervention was conducted entirely at home due to the coronavirus pandemic in 2019. Participants were instructed to do their best to complete 60 minutes of moderate-intensity VR exercise per day. Exercise duration, intensity, and calories were objectively monitored and recorded during exercise. Fatigue and depression were measured via self-report questionnaires at pre- and postintervention. Participants underwent a semi structured interview with research staff at postintervention.

Results: Participants 1 and 2 completed an average of 281 (SD 93) and 262 (SD 55) minutes of play, respectively. The average minutes of moderate-intensity exercise performed per week for participants 1 and 2 were 184 (SD 103) (184/281, 65.4%) and 215 (SD 90) (215/262, 82.1%) minutes, respectively. One participant had a reduction in their depression score (Quality of Life in Neurological Disorders [Neuro-QoL] test) from baseline to postintervention. Participants noted that they were motivated to exercise due to the enjoyment of the games and VR headset, along with support from a caregiver.

Conclusions: This study demonstrated that two youth with SB who used wheelchairs could use a VR system to independently and safely achieve exercise guidelines at home.

Skills on Wheels: Initial data analyses from a wheelchair skills training program implementation for children with spina bifida

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Background: Many times, when children with Spina Bifida are prescribed wheelchairs, they are measured, fitted, and given some targeted therapy for navigating specific life situations. Occupational participatory goals are at the forefront of much of this work. Oftentimes, however, no regular training is provided to address everyday function and use of the adaptive equipment.

Methods: The Skills on Wheels Training Program builds upon the work of the larger Wheelchair Skills Training Program (WSTP) by focusing the training on pediatric wheelchair users. These children attend a five-week program that incorporates wheelchair skills training from the lower-level skills (e.g., rolling forward) to the higher-level skills (e.g., navigating curbs, ramps, and stairs). Skills on Wheels also incorporates occupational therapy and physical therapy doctoral students in the training. Students participate as trainers and spotters for training.

Results: Caregivers for the children attend programming that involves support groups as well as information sessions about wheelchair care and maintenance. This presentation is focused on the development and assessment of the program specifically for children with Spina Bifida (though the program also serves a variety of diagnoses). Outcome measures focused on pre/post changes of the children's participation, confidence, and wheelchair skills. Findings from the first two years of the program showed that the participants (N=21) increased in all wheelchair skills measured by the Wheelchair Skills Test (WST) with many significant gains. Specifically, a subset of the data related to individuals with Spina Bifida will be presented (N=14).

Conclusions: Participating children also showed significant gains in self-advocacy, community participation, and decreased fear of falling. The resultant program is currently being implemented in Indianapolis as well as the Crann Rehabilitation Centre in Ireland with piloting in other cities.

Association between orthopedic manifestations and tethered cord release in patients with spina bifida: A survival analysis

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Background: Patients with spina bifida are at an elevated risk of developing symptomatic tethered spinal cord. Orthopedic decline is a common manifestation of tethered cord that can be considered an indication for tethered cord release (TCR). The objective of this study is to assess TCR surgeries in patients with spina bifida, comparing those who have undergone orthopedic operations to those with no previous orthopedic intervention, using survival analysis.
Methods: A comprehensive institutional database was queried to identify all children with spina bifida from 2009-2022. Survival analysis was performed to test the association between TCR and history of orthopedic interventions potentially related to tethered cord: cavovarus foot correction or joint contracture release. Data collected includes functional level of lesion (FLOL), ambulatory status, and diagnosis (myelomeningocele vs. other). Kaplan-Meier survival curves and multivariate Cox proportional hazards models were generated.
Results: The total sample included 659 patients. Thirty-four (5.2%) had a history of orthopedic operation, and 625 (94.8%) patients had no history of an orthopedic procedure either before the index TCR or at last-follow-up. Of the 34 patients in the orthopedic group, 3 (8.6%) underwent TCR after the orthopedic operation. Of the 625 patients in the non-orthopedic group, 202 (32.32%) underwent TCR. The adjusted hazards ratio (controlling for FLOL, ambulation, and diagnosis) 3.8 (95% confidence interval 1.2 to 11).
Conclusions: The results indicate that patients who had undergone an orthopedic operation were significantly less likely to have TCR surgery. One possible explanation of this finding might be that orthopedic operations provide a protective effect in that they treat symptoms that might otherwise lead to TCR. Additional study is needed to test this hypothesis and assess for other relationships between lower extremity conditions and TCR.

Orthopaedic red flags for tethered cord syndrome

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Background: Manifestations of tethered cord syndrome (TCS) can be neurologic, urologic or orthopaedic, yet little is published regarding orthopaedic red flags precipitating tethered cord release (TCR). We report orthopaedic findings associated with TCS and identify which required further surgical intervention despite TCR
Methods: Survey of all patients from our tertiary referral center enrolled in the National Spina Bifida Patient Registry (NSBPR) who underwent TCR between 2007-2017 yielded 251 patients. Group 1 – fatty filum / low lying cord; Group 2 – lipomyelomeningocele, meningocele, myelocystocele, diastematomyelia, MM manqué; Group 3 –myelomeningocele. Demographic, clinical, and surgical data were collected from NSBPR and patient charts. Indicator for TCR was noted as orthopaedic, urological, both, or asymptomatic. Data was collected on all orthopaedic procedures performed within 18 months of TCR. Statistical analysis was performed using chi square tests for categorical variables.
Results: Indications for TCR included orthopaedic findings in 98/251 (39%) patients: 29% in Group 1, 27% in Group 2, and 69% in Group 3. Symptomatic indicator for TCR was significantly correlated with underlying diagnosis ($p<0.00001$). Figure 1 presents frequency and type of orthopaedic indicator for each group. Average age at first TCR was 4.56, 3.40, and 6.19 years respectively. Of patients who presented

with weakness and decrease on manual muscle test (MMT), 78% in Group 1, 63% in Group 2, and 44% in Group 3 had improvement in MMT at one-year post-TCR. None of the patients requiring second TCR had improvement in MMT. A total of 29 patients (3 in Group 1, 8 in Group 2, and 18 in Group 3) underwent orthopaedic surgery at average 7.8 months post TCR.

Conclusions: The most frequent orthopedic indicator for TCS varies based on underlying diagnosis: gait deviation (Group 1), lower extremity weakness (Group 2), tone abnormality (Group 3). Despite TCR, 30% of patients with orthopaedic manifestations required further surgical intervention for definitive management.

Maximizing ambulatory potential in spina bifida

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Background: Spina Bifida is a complex neurological condition that has associated neural axis deformities, including Arnold-Chiari malformation, hydrocephalus, hydromyelia, diastematomyelia, leptomyelolipoma, and spinal cord tethering. There are associated musculoskeletal deformities from paralysis, spasticity, positioning, and muscle imbalance. Management requires interdisciplinary team including Pediatrics, Nursing, Neurosurgery, Urology, Orthopaedic Surgery, Physical Therapy, Occupational Therapy, Orthotist, Psychologist, Social Worker, and Dietician. The goals of interdisciplinary management is to mainstream children, develop independence, competence in the community, personality development, and transition into adulthood. Evaluations must detect functional deterioration, progressive weakness, spasticity, scoliosis, cognitive impairment, muscle atrophy, neurogenic bladder changes, and progressive musculoskeletal deformities.

Methods: Identify significant physical impairment leading to the inability to maintain ambulatory status. Identify significant physical impairment leading to the inability to maintain independent sitting activities. Define criteria for ambulation including power, range of motion, and crutchable upper extremities. Define criteria for independent sitting activities.

Results: Etiologic factors include anatomic, neurologic, and spinal cord pathology.

Conclusions: Prevention of deformity and loss of functional skills: 1) Early aggressive management 2) Orthotic management coincidental with initiation of ambulatory skills 3) Protect insensate skin 4) Routine thorough neurologic re-evaluation 5) Interdisciplinary care 6) Surgery only to facilitate orthotic management.

Sub-laminar polyester band fixation construct in the treatment of neuromuscular scoliosis

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Background: Spinal deformity correction is a mainstay in the treatment of progressive neuromuscular scoliosis. Sub laminar band constructs offer a fixation method that may be easier to perform and can be placed in spines with hypoplastic pedicles.

Methods: A retrospective review was conducted of 28 cases of pediatric neuromuscular scoliosis treated with posterior spinal fusion using a predominant sub laminar bands construct from 2013-2016. Preoperative, immediate postoperative, and two-year follow up radiographs and clinical records were reviewed. Correction of coronal and sagittal plane deformity, pelvic obliquity, blood loss, length of surgery, and complications were reviewed from immediate post operative clinical records and radiographs.

Results: Average post-operative and two-year coronal plane correction was 53% (0-92%) and (49%) (range) respectively. Sagittal balance was corrected to within 2 cm of the C7 plumb line in 76% of patients immediately post operatively and maintained at two-year follow up. Average lumbar lordosis angle was unchanged from preoperative x-rays and was within normal range (45°) post operatively and maintained at two-year follow up. Post operative average thoracic kyphosis angle increased by 9° from preoperative imaging (23° to 32°) and was unchanged at two-year follow up. Post operative average pelvic obliquity decreased by 50% from pre-operative x-rays. (14° to 7°) and was unchanged at two-year follow up.

Conclusions: This study investigates outcomes after predominant sub laminar band constructs particularly constructs with sub laminar bands used at the top of the construct. These finding suggest that a predominant sub-laminar polyester band construct with band fixation at the most cephalad level of the construct is a viable option for correction of deformity correction in pediatric patients with neuromuscular causes of scoliosis.

Use of temperature monitoring smart socks for early pressure sore detection by adolescents with spina bifida: A feasibility and accuracy study

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Background: The prevalence of foot pressure injuries in ambulatory pediatric patients with spina bifida (SB) is 14%. Prevention and early detection of pressure sores through monitoring temperature may be vital in this population. The purpose of the study is to determine if continuous temperature monitoring smart socks is feasible in adolescents with spina bifida by obtaining user feedback on comfort and examine if observed temperatures correlated with clinical outcomes.

Methods: A pilot study was conducted on ambulatory SB patients ages 11-21 at Children's Hospital Los Angeles. Participants were provided with temperature monitoring socks for four weeks and completed a satisfaction survey. Data analysis was performed using univariate and multivariate analysis.

Results: There were a total of five participants (3 females, 2 males) with a mean age of 15.8 years (range 13-21) completed the study. All participants identified as Hispanic. Spina bifida functional levels were high (1), mid (1), and low (2) lumbar and sacral (1). Two participants wore braces, three had prior foot pressure ulcers, and two had prior orthopedic surgeries on the feet. The average sock wear was 11.64 hours per day for 4 weeks. Seven days of elevated temperatures were recorded across all participants with the highest temperature recorded at 106.5°F. The mean temperature was 78.9°F with a mean temperature differential between both feet of -1.4°F. The duration of sock wear varied greatly from 31 hours to 596 hours over 4 weeks. Lastly, three of five participants reported that the socks were comfortable and very easy to put on.

Conclusions: Continuous temperature monitoring smart socks are an option for monitoring risk for pressure ulcers in adolescents with SB. Future directions would be to increase sample size, obtain normative data for temperature ranges in this population and correlate to clinical outcomes in the development of foot pressure ulcers.

Intervention with the coop approach leads to a transfer effect over time to untrained goals for children with spina bifida and cerebral palsy

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Background: Interventions used for children with disabilities should yield sustainable results. A previous RCT study showed that intervention with Cognitive Orientation to daily Occupational Performance Approach (CO-OP Approach) was more effective than ordinary treatment in terms of reaching goals and solving problems in new situations for children with spina bifida and for children with CP (1). That study did not report any long-term outcomes. This study investigates effects over time of an intervention with CO-OP Approach in children with spina bifida and children with cerebral palsy regarding goal attainment and transfer effects.

Methods: Second report, evaluating effects over time, from a multi-centre intervention using CO-OP. Thirty-four children (7–16 years, 9 of them had Spina bifida) identified four goals (one untrained to study generalisation and transfer to new activities) and participated in an eleven-session intervention. Assessments were performed at baseline, immediately after the intervention and at three-months follow-up using the Canadian Occupational Performance Measure (COPM) (subjective) and the Performance Quality Rating Scale (PQRS) (objective) as primary outcome measures. Executive function and self-rated competence in daily living were also assessed.

Results: Significant improvements in goal attainment for trained goals, both subjectively and objectively, were demonstrated post-intervention and persisted at follow-up. Significant higher goal attainment over time was also seen in the untrained goals in both subjective and objective assessments. Self-rated competence in general activities of daily living increased slightly and was even higher after three months.

Conclusions CO-OP interventions are effective in achieving and maintaining children's own goals over time. The transfer effect was confirmed by high goal attainment for untrained goals.

1. Peny-Dahlstrand et al. The Cognitive Orientation to daily Occupational Performance (CO-OP) Approach is superior to ordinary treatment for achievement of goals and transfer effects in children with cerebral palsy and spina bifida - a randomized controlled trial. Disabil Rehabil. 2022:1-10

The development of a protocol to evaluate dependent rubor in individuals with spina bifida

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Background: Dependent rubor (DR), feet that turn dark red or purple in a dependent position, and may be cold to touch, are a common concern for parents and patients with Spina Bifida (SB). Though DR may indicate vascular disease in adults, there is no literature on DR in children or young adults with SB. It has been assumed that DR in young individuals with SB is due to autonomic nervous system dysfunction. However, it could be an indication of ischemia and a risk factor for skin breakdown or difficulty healing. This is of particular interest since problems with skin breakdown, particularly in the feet, are a common complication in SB. We report on the development of a protocol for evaluation of DR in SB.

Methods: We queried the literature using search terms rubor, feet, and SB and found no scholarly articles on the subject. A discussion with stakeholders in the pediatric and adult SB clinics at Children's of Alabama and University of Alabama Birmingham disclosed an interest in investigating individuals with DR for possible ischemia. Physicians with interest in wound care and hyperbaric therapy were consulted, and a protocol was developed.

Results: 10-15 children and young adults with SB and DR will undergo measurement of Ankle Brachial Indices (ABI) and non-invasive transcutaneous oxygen measurements (TCOM). ABI and TCOM will be correlated with ambulatory status, functional level of lesion, and history of foot pressure sore. Results will be used to determine if there is an association between DR and ischemia. Patients and caregivers will be counseled on methods to reduce pressure sore development.

Conclusions: A protocol for evaluating DR in individuals with SB has been developed. If the results indicate that feet with DR suffer from ischemia, it could change the clinical care of these individuals regarding care of skin breakdown and performance of elective foot surgery.

Two stage corrective operation for the treatment of pes cavovarus in patients with spina bifida

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Background: Cavovarus has an estimated incidence of 8-17% in patients with spina bifida (SB). The current literature on surgical treatment of cavovarus feet in children and adolescents includes a variety of diagnoses. The authors of this study present the results of a retrospective study performed to assess the radiographic outcomes of two-stage corrective surgery with radical plantar release and osteotomy for pes cavovarus in patients with SB.

Methods: Retrospective chart review was performed on patients with SB with a diagnosis of pes cavovarus at a freestanding children's hospital who underwent surgical correction of the deformity. Patients were excluded for lack of two-stage corrective operation, nonambulatory status, lack of at least six months follow-up, and age >18 years at the time of surgery. Radiographic analysis was performed on 11 patients that had a complete series of weightbearing

X-rays. Preoperative and postoperative radiographic outcome measurements were compared using a two-sample t-test.

Results: Significant changes between the preoperative and postoperative measurements were seen in three commonly used radiographic angles: Meary's angle, the AP talo-first metatarsal (AP TMT1) angle, and the talonavicular coverage. The average Meary's angle was 17.9 ± 13.1 preoperatively and 4.7 ± 10.3 following the second stage of the operation. ($p = 0.016$). The average AP TMT1 angle was 20.6 ± 15.1 preoperatively and 9.3 ± 5.5 postoperatively ($p = 0.011$). The average talonavicular coverage was -10.3 ± 9.6 preoperatively and -3.8 ± 10.1 postoperatively ($p = 0.025$).

Conclusions: The two-stage corrective procedure with plantar release and osteotomy was shown to be effective in correcting radiographic parameters in our cohort of patients with SB with pes cavovarus. Consideration should be given to utilization of the two-stage algorithm presented here in the surgical management of cavovarus feet in patients with SB.

Non-invasive electrical spinal cord stimulation, a new treatment for patients with spina bifida

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Background: Newborns with open spina bifida (SB) are expected to endure lifelong damage to the spinal cord. The resulting loss of sensation and muscle activation as well as neurogenic bladder and bowel dysfunctions are documented in the medical literature. Recovering the ability to the regain some motor, sensory or bowel and bladder control could greatly improve the quality of life and reduce secondary impairments and complications.

Methods: This presentation's aim is to describe a novel approach to the management of children with SB using non-invasive electrical spinal cord stimulation (niSCS). The presentation will provide an electrophysiological rationale and a description who may benefit from niSCS. It will include a novel testing protocol to test the excitability of the nerves and muscles which allows for objective documentation of progress. Significant portion of the presentation will be the description of five case studies showing significant recovery (i.e., in motor function, sensation, trunk stability, hip dysplasia and bladder function) with the application of the niSCS as part of the physical therapy treatment plan. This recovery is documented in video recordings and medical notes. Managing potential adverse events will also be discussed.

Results: Over 90 patients with SB have been treated with this method by the author so far. The areas of improvement may include increased muscle strength, new movements of the stimulated muscles, improved sensation, circulation and wound healing, reduced constipation and, in a few documented patients, improved urinary control.

Conclusions: niSCS should be considered an effective novel physical therapy method to address a variety of impairments resulting from SB.

Preoperative occupational therapy in children with neurogenic bladder: Improving independence with bladder management

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Background: The purpose of this review was to summarize the current literature on the use of occupational therapy services to facilitate self-catheterization skills in pediatric patients with neurogenic bladder (PNB), and to propose how occupational therapists can partner with urologists to improve surgical decision-making for continent catheterizable channels.

Methods: An extensive literature search was completed in Medline, Pub-Med, Springer, Wiley Online, SAGE publications, PsycInfo, CINAHL, and the American Journal of Occupational Therapy. There were no chronologic restrictions to the search due to a lack of literature. Search parameters were limited to pediatric patients < 22 years, with no restrictions on gender. Initial inclusion criteria included patients with PNB, detailed OT services, and self-catheterization. Articles were excluded if they did not detail OT evaluation/intervention, emphasize independence, or include pediatric patients.

Results: 75 articles were screened, and 47 articles were reviewed. Of the studies reviewed, 1 randomized control trial, 1 literature review, and 2 cohort studies were found. These 4 studies concluded having an OT participate in assessment and training on self-care management led to improvements in bladder function, self-catheterization independence, and/or efficiency of ISC teaching. However, there is a lack of literature detailing the frequency and duration of occupational therapy treatment, recommended timelines to initiate self-catheterization, and predictive factors of independence. No available studies describe indications or standardized methods that exhaust urethral self-catheterization training prior to recommending surgical intervention, or explored occupational therapy evaluations as part of pre-operative assessment for catheterizable channels.

Conclusions: Emerging evidence indicates using occupational therapists to train pediatric patients with neurogenic bladder on self-catheterization can be beneficial and can lead to more efficient bladder management outcomes. Further studies are needed to evaluate the use of occupational therapists in urologic practice, with the aim of prioritizing independence and quality of life.

Ramping up the future of mobility education: A study on the impact of volunteering in a pediatric wheelchair skills training program on OT student learning & professional development

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Background: This study examines occupational therapy graduate student learning and professional development while volunteering at a novel pediatric wheelchair skills training program for wheelchair users with spina bifida and various other conditions. Participation in a wheelchair skills training program by occupational therapy students involved in similar programs has been shown to increase their wheelchair training skills (Coolen et al., 2004; Giesbrecht et al., 2021), but there is little research that currently examines the effect of delivery of a wheelchair skills training program on students' professional development. However, students' participation in other intervention research and service-learning experiences have been found to increase clinical skills, clinical reasoning, and self-efficacy (Maloney et al., 2014; Sanders et al., 2016; Schwartz & Smith, 2015)

Methods: This cross-case comparison study employed a mixed-method design for data collection including web-based surveys, semi-structured interviews, and visual media to investigate: (i) student's self-efficacy in teaching wheelchair skills; (ii) community-mindfulness; and (iii) professional development, including clinical reasoning and recognizing the effects of power dynamics on community access and therapeutic interactions. Data were analyzed using thematic analysis to develop themes and subthemes.

Results: Preliminary data from the questionnaire indicates that students gained understanding of (a) clinical skills and clinical reasoning, such as specific teaching and learning strategies; (b) community mindfulness and self-efficacy, such as understanding the importance of being client-centered in community programs and being able to generalize knowledge and experience gained to participation in future community programs or service; and (c) professional development, including the ability to utilize resources, learn from others, and program development. Further interview and media data analyses will be presented along with preliminary data.

Conclusions: Participating in a pediatric wheelchair skills training intervention program increases future OT's ability to teach wheelchair skills and address community-specific accessibility challenges to best provide services with wheelchair-users with spina bifida.