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Improving bowel management in children with spina bifida

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Background: For patients with spina bifida (SB), achieving adequate bowel management and social continence has been linked to better quality of life as well as higher likelihood of employment as an adult. A metric of success for a working bowel program for patients with SB is the frequency of unplanned bowel movements. Most patients with SB require suppositories, enemas, and/or surgery to achieve continence. In our multidisciplinary SB clinic, we aimed to standardize the approach to developing a bowel management program and by so doing, increase the percentage of children (age 5-14) who are continent for stool to >70%, (i.e., have <1 episode of bowel incontinence per week).
Methods: The approach consisted of two parts: 1) Standardizing a 4-item questionnaire about bowel continence and consistency which was completed at clinic visits and subsequent phone follow up visits in addition to clinic visits. 2) If the patient was not achieving continence, an intervention was offered starting with either oral medication (stimulant and/or osmotic laxatives), and/or suppositories (glycerin or bisacodyl) followed by an escalation to trans-anal irrigation, or surgery for some patients (Malone antegrade continence enema or Chait cecostomy button).
Results: We screened 217 patients. Of these, 119 (55%) met inclusion criteria and agreed to be followed in our study. The majority of those followed (93/119, 78%) had a diagnosis of meningomyelocele. Of those not followed, the majority were already achieving continence with their bowel regimen (71/98, 72%). At the initial visit, only 22/119 (18%) were continent for stool, i.e., NOT having bowel movements outside of the toilet, and the mean number of bowel accidents per week was 9.8. In this study group, 64/119 (54%) patients have completed a one year follow-up. With a graded series of interventions, beginning with suppositories and advancing to high volume enemas, and including planned phone call check ins, for those who have completed one year follow-up, we have increased the proportion who had all bowel movements in the toilet and were accident free to 41% (26/64) (p = 0.005). These patients generally (58%) required enemas or suppositories in order to achieve continence. During a PDSA cycle we revised the criteria for success and began to prospectively evaluate those who had a timed or planned (timed) evacuation either in the toilet or in a diaper/pull-up as being successful. With this approach, 70% (16/23) who have completed one year of follow-up have achieved a successful outcome.
Conclusions: While we were not able to achieve toileted bowel movements in as high a proportion of patients as we desired, we did increase the frequency of predictable or planned bowel movements, e.g., after an enema or suppository, without unplanned bowel movements at other times of the day. Frequent phone follow-up helped to identify barriers to success, such as not understanding how to obtain or use the medication or treatment. An aggressive bowel management program using suppositories and enemas for patients with SB can be effective in achieving social continence.

Perceptions of engaging in social activities reported by adolescents with spina bifida and their parents

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Background: Spina bifida (SB) occurs in approximately 3 of every 10,000 live births in the United States. Little research data are available on adolescents and parents' perceptions and expectations about social functioning of adolescents with disabilities, particularly SB. The aims of this study were to describe (1) the perceptions of adolescents with SB and their parents toward facilitators of and challenges

to the adolescents' social functioning, (2) parents' expectations of social functioning for their adolescents, and (3) adolescents' perceptions of their parents' expectations.

Methods: In this qualitative study, data were collected by conducting semi-structured interviews virtually via Zoom with 20 African American or Native American participants, including 10 adolescents (9 males) with SB and 10 of their parents, (7 fathers).

Results: Themes and subthemes describing participants perceptions were identified. The benefits of adolescents' engaging in social activities and having strong family relationships and support were recognized by both the adolescents and their parents who also identified family, peer and school facilitators. Further, they agreed that the adolescents encountered a variety of SB-related challenges, including stigma and bullying from other children, condition-related challenges such as pain and skin problems and parental protection Participants also agreed on the importance of social life to quality of life.

Conclusions: Healthcare professionals (HCP) should strive to maximize the social participation of adolescents with SB regardless of their physical limitations. In particular, HCP can focus their interactions with parents and adolescents to discuss opportunities for the children's social involvement. Additional research is needed to determine how adolescents and parents can maximize adolescents' engagement in social activities.

Imaging characteristics predicting elevated detrusor pressures in patients with spina bifida

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Background: Patients with spina bifida require urologic follow up with assessments of bladder and renal function. The ideal screening protocol for bladder compliance remains controversial. This study assessed associations between bladder end filling pressure (EFP) and detrusor leak point pressure (DLPP) on urodynamic studies (UDS) and findings from renal bladder ultrasounds (RBUS) and voiding cystourethrograms (VCUG).

Methods: Pediatric spina bifida patients who underwent RBUS and/or VCUG within six months of UDS at a single institution from 2015-2021 were retrospectively reviewed. Demographics, VCUG and RBUS results, and UDS EFPs and DLPPs were recorded. Multiple linear regression analyses and Pearson chi-square tests were conducted to correlate RBUS and VCUG findings with DLPP/EFP.

Results: 129 patients were included. In adjusted analyses, moderate to severe hydronephrosis on RBUS was significantly associated with elevations in mean DLPP/EFPs ($p=0.006$; Table 1). Patients with round bladders had significantly lower mean DLPP/EFP than patients with elongated or conical bladders ($p<0.0001$). The presence of trabeculations was associated with increased mean DLPP/EFPs ($p<0.0001$) and increases in severity of trabeculations were associated with higher DLPP/EFPs ($p<0.0001$). The presence of vesicoureteral reflux (VUR) on VCUG was not associated with significant differences in mean DLPP/EFPs ($p=0.20$).

Conclusions: Abnormal bladder shape and trabeculations on VCUGs in spina bifida patients had significant associations with increased mean bladder pressures on UDS. Assessment of bladder shape and contour by VCUG may be a valuable screening tool in conjunction with routine RBUS in determining the need for further assessment of bladder pressures in patients with spina bifida.

Implementation of a multicenter skin injury prevention bundle through the National Spina Bifida Patient Registry

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Background: Previous work has shown that targeted health education and self-management can address complications of skin injury among patients with spina bifida (SB). Our objective was to describe the feasibility of a skin injury prevention educational campaign across multiple sites within the National Spina Bifida Patient Registry (NSBPR).
Methods: We analyzed three components of a skin injury prevention bundle that included: (1) SB risk assessment, (2) skin injury assessment, and (3) prevention education. All NSBPR patients who visited a clinic participating in the campaign between November2016 and December 2021 were included. Program participation was defined as exclusive use, mixed use, and no participation. Exclusive use was defined as patients who exclusively used bundle content to complete a component, while mixed use was defined as patients who used bundle content along with other related tools. We examined patient demographic and clinical variables and described overall program participation and participation in each component of exclusive bundle use.
Results: 3,498 patients with SB were identified from 13 participating clinics. Most patients were diagnosed with myelomeningocele (80.2%), 33.8% had sacral level lesions, and 62.1% ambulated to some degree. Among these patients, 56.4% used braces and 29.1%used assistive devices. Exclusive bundle use was reported by 58.7% of patients, while 6.2% of patients reported mixed use, and 35.1%did not participate in any component. Among participants in the exclusive use group, 57.6% completed the prevention education component, 62.1% completed the risk assessment, 49.0% completed the skin assessment, and 43.3% completed all three components.
Conclusions: The use of a skin injury prevention toolkit across the NSBPR is feasible, but opportunities remain for increasing utilization across sites.

Use of a care coordination registry to improve care for high-risk patients at a large multidisciplinary spina bifida center

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Background: Patients with spina bifida require a high level of care coordination. Team members need a way to manage the influx of information from the multidisciplinary discussions that happen in a shared clinical space. A care coordination registry that identifies and tracks high-risk patients would allow for closer monitoring of vulnerable patients.
Methods: A care coordination registry was developed over 15 months by a team that included a complex care pediatrician, a neuropsychologist, a social worker, a nutritionist, an administrative assistant, and nurse coordinators. Tracking measures were considered iteratively and were included if found helpful to coordination. In addition to a weekly coordination meeting, a second weekly meeting with the larger spina bifida team was an opportunity to alert the team to high-risk patients and give clinical updates.
Results: Our registry includes over 480 active patients, representing patients from 33 states and 9 countries. Using an iterative process we identified 6 measures for care coordination, including: 1. high medical complexity, 2. weight concerns, 3. high risk social situation, 4. transition to adult care, 5. upcoming surgery, or 6. active clinical concerns. Over time, 29 patients (6%) were identified as having the highest level of complexity, 20 patients (4%) needed close monitoring for weight, 31 patients (6%) had high risk social situations, and 24 patients (5%) were ready for transfer to adult care. By utilizing the registry during team meetings, on a weekly basis 5-10 patients had status updates shared with the team and 2-5 patients had in-depth team discussions based on clinical concerns.
Conclusions: A continuously updated registry managed by a multidisciplinary team allowed for closer monitoring of patients, more cohesive team-based care, and fewer patient issues "falling through the cracks". This type of registry could support future improvement projects, such as optimization of the transition to adult care or improving pre-surgical management.

A framework for quality improvement in a multidisciplinary spina bifida clinic

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Background: Spina bifida is a complex disease requiring lifelong care to achieve favorable outcomes. Quality improvement (QI) is a method used to standardize care practices to reduce variation, achieve predictable results, and improve outcomes for patients and healthcare organizations. Using a comprehensive QI process, we sought to improve our ability to provide consistent, high-quality care to our patients with spina bifida from the prenatal period until the transition to adult care.
Methods: A range of QI initiatives was implemented throughout 2021. Our goals were enhancing clinic efficiency, provider engagement, program visibility, and community outreach. Specific elements included a pre-clinic huddle, pre-clinic neuropsychology evaluation appointments, enhanced transition to adult care process, quarterly program meetings with clinical/QI/research dashboards, program coordinator conducting prenatal visits and inpatient rounds, a mentorship program, establishing a parent advisor, and inviting our Spina Bifida Wisconsin (SBWI) representative to greet families in the clinic waiting room.
Results: Enhanced clinic efficiency, provider engagement, and community outreach resulted in a 14% increase in spina bifida clinic visits. Patient satisfaction scores averaged 9.7/10 with favorable comments. Our pre-clinic huddle occurred prior to 63% of clinics and was well attended. 29% of the pre-clinic neuropsychology slots were used and overall evaluations increased 24%. Transition documentation was completed on 75% of patients 17 years and older. The quarterly team meeting had an average of 18 participants per meeting. The spina bifida coordinator met with all prenatal patients and rounded on 72% of admitted patients. The mentorship pilot program enrolled 22 families. Finally, a representative from SBWI attended 75% of clinics and spoke with 30 families.
Conclusions: We implemented a bundled approach to QI similar to the bundled interventions used to reduce hospital acquired conditions to address clinic efficiency, visibility, provider engagement, and community outreach. These methods could be implemented by other spina bifida clinics to improve the quality of care and subsequent health outcomes for people with spina bifida.

Can the costs be predicted in spina bifida early childhood? Cost prediction using unsupervised machine learning algorithm

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Background: Spina bifida (SB) is a multi-system disorder that can present challenges to healthcare with some suffer from severe impairment. Accurate risk stratification can be instrumental for resource planning. Our objective is to predict the cost in early life of SB patients via a novel approach.
Methods: 2006-2019 Aetna database was queried to extract the SB/MMC cohort. Inclusion criteria included history of myelomeningocele closure and full subscription for the first 5 years of life. Exclusion included lapses in coverage and death before age 5. Cost was extracted by age: first-year cost (1YC, defined as cost aggregated from birth to 1st birthday) and future cost (FC, defined as cost aggregated from 1st to 5th birthday). High-cost group (HCG) and low-cost group (LCG) were classified using KNN algorithm (k=2). Predictive performance of the model was assessed via accuracy, specificity, and sensitivity. Principal component analysis (PCA) using the future annual costs as variables was performed to visualize the group separation by 1YC.
Results: 351 SB patients was initially identified, of which 58 SB (50% female) were included for the final analysis. SB patient clustered in two groups (HCG/LCG) for 1YC and FC separately. Using the 1YC median between HCG/LCG at $22,000, this threshold successfully predicted FC into HCG/LCG with accuracy of 0.86 (95CI: 0.75-0.94), sensitivity at 0.89, and specificity at 0.83. A clear separation of future annual cost groups using PCA by 1YC. For FC, the HCG demonstrated cost sum of $222,183,

while LCG spent $44,550. HCG patients spent more on durable medical equipment, home care/inpatient care, and medications related to end organ failures.
Conclusions: We found a strong association between higher first-year medical expenditure and the higher subsequent future aggregated medical costs for SB patients. This predictive insight can be used to drive targeted intervention, resource allocation, incentives for innovation in providing better care for this complex cohort.

Fostering independence through creation of a skills clinic

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Background: Individuals with spina bifida have many complex needs that often influence the ability to be independent and transition successfully to adult life. It is well documented in the literature that transition is a process not merely a point in time and for individuals with spina bifida begins at birth.
The Spina Bifida Program at Primary Childrens Hospital, Salt Lake City, Utah has developed a clinical road map for care using clinical standards of care based on a developmental approach. Key elements apart from medical interventions include: self care behaviors, bowel and bladder continence and mobility as it relates to becoming independent
These clinical issues are often challenging to address in the multidisciplinary clinic given provider and family concerns with the need to address medical issues and plan intervention related to hydrocephalus, tethered cord syndrome, bladder management and interventions needed to maximize mobility. Once these issues are addressed attention is directed toward assessing independence related to the medical concerns. More often than not clinical time and focus of the family and children limit the ability to adequately address this component of care
Methods: To facilitate an optimum teaching environment a training program has been developed separate from the general multidisciplinary clinic. The program is under the direction of the NP in the Spina Bifida Program and is staffed by clinic nurses, physical therapist, occupational therapist, child life provider and social worker as needed, The goal of the program is to address specific needs related to:

- Bladder: clean intermittent catheterization teaching and training for caregivers
- Self catheterization at appropriate age and development
- Bowel: developing and teaching formal management programs
- Habit training
- Cone enema
- Peristeen
- MACE/miniACE
- Self care skills incorporating assessments and interventions by physical/occupational therapists
- Wheelchair assessments and deliveries
- Durable medical equipment assessments needed for continence and self care

Utilization of standards of care provide the framework for the program addressing expected outcomes at each developmental stage: infancy, toddler, school age, adolescence and young adult. The comprehensive approach addresses physical, developmental and emotional issues
Results: The NP/nursing program formally called Independent Skills Training Program has provided an opportunity to focus on critical needs for fostering interdependence/independence, age and development related. An average of four patients and families are scheduled each clinic for:

- Clean intermittent catheterization teaching
- Self catheterization teaching
- Initiation of bowel management programs
- Postoperative consultation for management of surgical channels: mitrofanoff, MACE, miniAce
- Wheelchair and other durable medical equipment assessments

Nursing team develops a treatment plan utilizing consultations provided by physical and occupational therapists as well as their own assessments. This plan includes follow up telephone consultation provided by the clinic nurses to make adjustments to the program. Families request additional follow up as needs are perceived and are invested in the teaching and training. Therapists work closely with the nursing staff in developing the plan and also request more clinical time as well as close follow up.
Child life is an integral part of the planned intervention during the clinic itself. Anxiety/behavioral concerns are addressed prior to the clinic and intervention provided resulting in a more positive experience for infants, toddlers, and children. Social work consul-

tation is requested for older children and adolescents as needed for support is also available to problem solve funding and resource issues.
Conclusions: The creation of a program specifically developed for training related to major interventions and behavior is critical for achieving interdependence/independence at various stages of development. Separating this from the multidisciplinary clinic has provided opportunities for patients and families to understand these challenges and become involved in well supported programs. Even though this requires additional appointments, families are positive about the individualized care and the ongoing support provided. They are especially positive regarding the collaboration of the training team. Outcome studies are anticipated in the future though currently results are subjective. Press Ganey reports have provided positive feedback from families. Providers in the multidisciplinary clinic (neurosurgery, urology, orthopedics, PM&R) have incorporated referrals to the training program as part of the overall medical plan. Referrals to the program have also been received from community and hospital pediatricians and urologists.

Establishing the first community-centered spina bifida research agenda

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Background: The Guidelines for the Care of People with Spina Bifida (Guidelines) identified over 250 research gaps in the care of individuals with Spina Bifida (SB). The community of people living with SB prioritized these research gaps to create a formal research agenda that the SBA could support. Our objective is to present the process and the final research agenda created by individuals with SB, their care partners, clinicians, and researchers.
Methods: A quantitative survey was developed to allow adults with SB and caregivers of those with SB to rank the impact of each of the 27 topical areas of the Guidelines. Survey was sent via SBA's database to English and Spanish-literate individuals. 1607 responses were captured and analyzed. Two focus groups were convened after survey analysis: adults with SB and caregivers of children with SB. Discussion outlines were developed from the results of the survey and were used for known-group validation of the highest-ranked topics. The SBA then solicited caregivers of those with SB, adults with SB, and clinical communities to join its initial Research Advisory Council (RAC). Each group generated a list of top research questions to address the gaps in these highest-ranked impact areas. The SBA led discussion groups for each topic area to rank the proposed questions in order of importance to the SB community and provide content validity. The final SB Research Agenda was created from the final top-ranked questions in each of the six topics.
Results: A ranking of the findings from the quantitative survey identified the two most common topics impacting all surveyed groups were bowel incontinence and urinary incontinence.
Conclusions: A Research Agenda for SB was created to prioritize topic areas of highest impact as ranked by individuals in the SB community to fill the research gaps identified in the Guidelines.

Prevalence and characteristics associated with sleep disordered breathing in patients with spina bifida

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Background: The prevalence of sleep disordered breathing (SDB) in individuals with spina bifida (SB) is between 40 to 80%. SDB is associated with multiple negative health and behavioral outcomes. Timely screening and diagnoses of SDB in children with SB requires understanding associated risk factors. This study's goal was to determine prevalence of SDB, and the risk factors associated with SDB in individuals attending a multidisciplinary SB clinic.
Methods: A retrospective analysis was conducted of patients with SB attending a multidisciplinary SB clinic at a tertiary care pediatric hospital. Clinical and demographic variables are collected at annual

clinic visits and entered in the Center for Disease Control and Prevention's (CDC) National Spina Bifida Patient Registry (NSBPR). Polysomnography (PSG) results, including Apnea Hypopnea Index and Obstructive Index, were extracted from the hospital's Sleep Center Database. Descriptive statistics and chi-square analysis described prevalence of SDB and differences between those with and without a SDB diagnosis.

Results: Of 286 patients identified in the clinic's local NSBPR, most had myelomeningocele (82.5%). 47% were non-ambulators and 38% were community ambulators (Table 1). 71 patients of the 286 completed a diagnostic PSG. Those completing a PSG were more likely to function at thoracic level and be non-ambulators ($p < .001$). 50 of the 71 (70%) patients completing a diagnostic PSG had a SDB diagnosis. Those with SDB diagnosis were more likely to be male ($p = 0.007$) and have no history of shunt revisions ($p = 0.008$) (Table 2).

Conclusions: SDB was common in patients attending SB clinic (70%). Males and those with no history of shunt revisions were more likely to have a SDB diagnosis. Future studies in a larger cohort who received PSGs are needed to better determine SDB prevalence and factors associated with SDB in individuals with SB.

Sleep related breathing disorders in patients with spina bifida repaired pre and postnatally

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Background: Patients with spina bifida (SB) have chemoreceptor dysfunction causing sleep disordered breathing (SDB). Prenatal surgery has improved orthopedic and urological outcomes; however, there are limited data on respiratory outcomes. We examined the SDB in infants who had prenatal vs postnatal closure of their open neural tube defects (NTD). We hypothesized that infants with NTD repaired prenatally will continue to exhibit SDB compared to those repaired postnatally.

Methods: Retrospective study of patients with SB at Children's Hospital Los Angeles from 2015-2021. Data collected included demographic data, timing of NTD closure, associated conditions, polysomnography (PSG), and supplemental oxygen use.

Results: 37 patients, 59% female, had PSG; mean age 5.2±6.3 weeks at PSG. 23/37 had prenatal repair. Age at PSG was not different between the two groups (p=0.78). Gestational age at birth was 35.2±3.4 weeks. Prenatal repair is done between 26-27 weeks gestation; Average age of postnatal repair is 2.0±1.6 days. 30/37 patients had Chiari malformation. 76% of patients required supplemental oxygen based on PSG. There were no differences in SDB between infants following prenatal vs postnatal NTD repair (Table 1).

Conclusions: Patients born with SB have a high prevalence of central and obstructive apneas and significant hypoxemia. Intrauterine or postnatal closure of the defect did not affect the presence or severity of SDB. Although apneas were witnessed in only a few patients, SDB and marked hypoxemia were present in almost all patients, underscoring the importance of surveillance with polysomnography. We speculate that damage to control of breathing occurs before prenatal NTD closure.

Prevalence of elevated blood pressure in a pediatric spinal cord disorders clinic

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Background: Children with spina bifida (SB) are at higher risk for development of hypertension due to multiple etiologies associated with the diagnosis. Prevalence of hypertension ranges from 10-40% in children and young adults with spina bifida compared to 3% in the general population. Accurate assessment of blood pressure in SB patients is required to ensure long term cardiovascular health in this population.

Methods: The Spinal Cord Disorders Clinic at Arkansas Children's Hospital implemented a standardized blood pressure (BP) measurement protocol based on American Academy of Pediatrics Hypertension guidelines. The protocol includes an electronic alert for BP >90th percentile for age and height or >120/80, measuring mid-arm circumfer-

ence to ensure appropriate cuff size, and manually measuring elevated BP. Data was collected on patients aged 3-21 years seen in the clinic for routine care. Patients were excluded if they did not have a blood pressure recorded with the visit. Prevalence of elevated blood pressure and number of referrals to pediatric hypertension specialist were collected 3 months prior to implementation and 3 months following implementation of protocol.

Results: A total of 88 patients had BP obtained in the clinic prior to implementation, 37% had elevated BP and 21% of those children had received referrals to a pediatric hypertension specialist. Following implementation of standardized BP measurement protocol for 3 months, 115 patients had BP obtained, 13% of children had elevated BP ($p = 0.02$) and 28% of those children received referral to a specialist ($p=0.2$). The protocol was followed appropriately in 56% of patients with elevated BP.

Conclusions: Improved BP measurement accuracy significantly decreased prevalence of elevated BP. Number of referrals to hypertension specialist did not change. Implementation of accurate blood pressure measurement may help identify patients in need of referral to pediatric hypertension specialists and improve health care utilization in this population.

Strategies to improve polysomnography access for children and adolescents with spina bifida: An implementation science approach

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Background: Spina bifida is a complex constellation of conditions resulting from failure of the neural tube to close properly during development. Many associated conditions, such as sleep related breathing disorders (SRBD), are often overlooked, yet can pose serious health consequences if unrecognized. Implementation science is the study of strategies to facilitate the uptake of evidence-based research into regular use. We report the use of implementation science to improve access to polysomnography (PSG), the gold standard for assessment of SRBD in children with spina bifida.

Methods: Our team served 203 individual patients with spina bifida in a pediatric medical center between 2018 and 2021. We utilized implementation science strategies of data management, knowledge sharing and coalition building to improve access to PSG. In 2019we completed a sleep database, followed by administration of pediatric sleep questionnaires at our transdisciplinary specialty clinic. We worked in close collaboration with pulmonology, neurosurgery and otolaryngology to share data trends and provide feedback.

Results: Our most effective strategy was use of pediatric sleep questionnaires to guide referrals to polysomnography, which doubled our completed studies between 2019 (25 studies) and 2020 (52 studies), increasing completed studies from an average of 14.5 per year (2018-2019) to 40.5 per year (2020-2021). Our most common barrier to completed polysomnography completion is canceled or unattended appointments for studies in the 2020-2021 period, compared with lack of referral on the part of provider in 2018-2019, suggesting that knowledge sharing and coalition building were also influential in the increase of completed studies.

Conclusions: Data management and knowledge sharing are powerful techniques. Though sleep questionnaires are not able to predict PSG results, they may improve buy-in and ultimately PSG completion.

Treatment of sleep disordered breathing in individuals with spina bifida

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Background: Treatments for sleep disordered breathing (e.g., tonsillectomy) are effective, however, limited data exists on their effectiveness in individuals with spina bifida (SB) or the impact of common SB-related clinical procedures (e.g., shunt placement) on SDB treatment response. We aimed to determine the impact of SDB treatments and SB-related procedures on the change in apnea-hypopnea

index (AHI) and obstructive index (OI) in individuals with SB.

Methods: A retrospective database analysis and chart review was conducted for patients with myelomeningocele and a diagnosis of SDB attending a multidisciplinary spina bifida clinic at a tertiary care pediatric hospital. Clinical and demographic variables are collected at annual clinic visits and entered in the Center for Disease Control and Prevention's (CDC) National Spina Bifida Patient Registry (NSBPR). Polysomnography (PSG) results were extracted from the hospital's Sleep Center Database and SDB treatments obtained from chart review. Change in AHI, OI, and diagnosis of SDB was analyzed for patients with at least 2 PSGs. We assessed differences between initial and final PSG results using a McNemar test or Wilcoxon signed rank test.

Results: Of 55 eligible patients, most were female (53%), and median age was 1.3 years old at initial PSG and 6.6 at final PSG. 78.2% had obstructive sleep apnea (OSA) and 38% had central apnea (CSA). Between the initial and final sleep studies, there was a significant decrease in the median AHI (13.5 vs 4.0; p <.0001) and OI (7.9 vs 1.7; p <.0001), and in the diagnosis of OSA (78% vs 60%; $p = .04$) and CSA (38% vs 18%; $p = .02$). Specific SDB treatments or SB-related clinical procedures done between PSGs were not associated with statistically significant changes in AHI or OI (Table 1).

Conclusions: AHI, OI, and diagnosis of SDB (OSA or CSA) decreased between initial and final PSGs in patients with SB. Further studies with larger samples of individuals with SB are needed to determine the impact of common SDB treatments or SB-related surgical procedures on changes in AHI, OI, and SDB diagnosis.

A novel resuscitation platform improves respiratory outcome in infants with spina bifida

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Background: Infants with myelomeningocele are at an increased risk for needing respiratory support at birth (Basso da Silva et al, J Perinatal Med 2014). After birth, they are placed on the side-lying or prone position to avoid manipulation of protruding neural elements or fetoscopically repaired wound site. Resuscitation of newborns in such positions can be challenging. A side lying orientation can contribute to ineffective bag mask ventilation or increased difficulty during intubation as airway anatomy is altered. We devised a resuscitation platform that allowed neonatologists to resuscitate infants with myelomeningocele in a supine position.

Methods: A custom resuscitation platform composed of medical grade acrylic board with a 5 x 2.5" linear cutout in the center and covered by foam and waterproof lining was designed for resuscitation of infants with myelomeningocele. This allowed for infants to be placed supine during resuscitation without pressure or trauma to the spinal defect. This retrospective study compares the resuscitative efforts and respiratory outcome of infants born with myelomeningocele at a single center from August 2020 to August 2022, with or without the use of the customized resuscitation platform. Student t-test was used to compare continuous variables and Fisher exact test to compare categorical variables. Statistical significance was set at p<0.05.

Results: Overall, 24 patients were resuscitated during the designated time period. Thirteen and eleven patients were resuscitated before and after the introduction of the customized platform, respectively. There were no significant differences in mean gestational age (35.3 vs. 35.6 weeks), birthweight (2583 vs. 2476 grams), or Apgar score at 1 minute (6 vs. 7) and 5 minutes of life (8 vs. 9), all p>0,05. In comparing resuscitative efforts before and after introduction of the customized platform, there was no difference in CPAP use (71.4% vs. 36%, p=0.1), significantly more positive pressure ventilation use (46.2 vs. 0%, p=0.02), and more RDS (69.2 vs. 18.2%, p=0.02). Of note, one infant who was intubated in the side-lying position prior to introduction of the customized platform suffered from complications of pneumomediastinum.

Conclusions: There was a reduction in the positive pressure ventilation during resuscitation and respiratory distress syndrome after introduction of the customized resuscitation platform. Resuscitation of newborns with spinal defects in the supine position may improve respiratory transition from intrauterine to extrauterine life. Further studies are needed to validate this finding.

COVID-19 vaccination in individuals with spina bifida

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Background: Vaccine hesitancy remains an obstacle in curtailing the Covid-19 pandemic. No studies to date have examined COVID-19 vaccination practices in people with spina bifida (SB). Understanding the factors driving vaccination beliefs and behavior is critical for guiding messaging, targeting barriers, and implementing vaccination strategies. Our objective was to conduct a national survey of individuals with SB and their care partners to assess COVID-19 vaccination behaviors and vaccine uptake.
Methods: We created a survey to assess current vaccination status, general perceptions towards vaccinations, and barriers within the SB community. Surveys were administered via the Spina Bifida Association. Chi-squared and independent-sample t-tests were used to analyze the relationship between vaccine uptake and demographics. Multivariable logistic regression was used to test which predictors impacted the odds that of having received a vaccine.
Results: 1,145 participants reported their COVID-19 vaccine status. Majority reported being vaccinated (n=896, 78.3%). Children reported significantly lower vaccine uptake (n=156, 51.1%) when compared to adults with SB (n=551, 88.5%), and care partners responding for individuals over 18 (n=182, 87.1%). The most common reasons for not getting vaccinated were concern about vaccine safety (n=109, 43.8%) and efficacy (n=85, 34.1%). The most common reasons for getting a vaccine were concerns about getting COVID-19 (n=629, 70.2%), a desire to not transmit COVID-19 (n=478, 53.3%), desire to prevent spread of COVID-19 (n=466, 52.0%), clinician recommendation (n=382, 42.6%) and being in a high-risk group (n=358, 40.0%). Healthcare professional recommendations played a significant (OR 2.77 $p<0.001$) role in vaccination.
Conclusions: About 1:5 individuals with SB have not received any COVID-19 vaccine. Health providers play a critical role in COVID-19 vaccination messaging and should emphasize vaccine safety and efficacy.

Six-minute walk test in ambulatory children with spina bifida

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Background: Children with spina bifida (SB) with higher functional lesion levels walk less than those with lower functional lesion levels (mid lumbar=knee extension present, low lumbar=ankle dorsiflexion present, and sacral=plantarflexion present). Physical, environmental, and social determinants impact access to opportunities to support active lifestyles. The six-minute walk test (6MWT) assesses functional exercise capacity in numerous chronic conditions, but normative scores do not exist for SB. This study aims to determine reference values of 6MWT scores (average feet walked and standard deviation [SD] according to an age- and gender-matched reference population) across SB lesion levels, and to assess for differences in 6MWT scores using insurance type as proxy for social determinants.
Methods: 140 children (65 F, 75 M) ages 11.7±3.3 (from 6.0 to 17.9) years with SB (myelomeningocele, meningocele, myelocystocele, lipomeningocele) with mid lumbar (n=43), low lumbar (n=27), and sacral (n=70) lesion levels performed a 6MWT at a single tertiary care pediatric hospital. Physical therapists instructed children to walk as far as able for 6 minutes according to a standardized protocol modified from the American Thoracic Society. Children used their own assistive and orthotic devices. Pulse oximetry monitored heart rate (HR) and oxygen saturation levels.
Results: 6MWT scores increased with lower lesion levels ($p<0.0001$). The average 6MWT score for mid lumbar level was 766±407 ft (-6.9±2.5 SD), low lumbar level was 1163±268 ft (-4.9±1.2 SD), and sacral level was 1428±275 ft (-3.8±1.6 SD). Each lesion level was different across all levels in a pairwise comparison ($p<0.001$). Children with mid lumbar SB also had higher resting HR ($p<0.01$), lower height percentile ($p<0.01$), and higher weight percentile ($p=0.047$) than children with sacral SB. Increased age was moderately correlated with

increased 6MWT scores among low lumbar lesion levels (r=0.56, p<0.01), but not among mid lumbar and sacral levels (Figure). Children with public insurance walked significantly fewer feet than children with private insurance (p=0.046).
Conclusions: Normative 6MWT scores across SB functional levels can provide clinicians a reference to guide intervention. Poverty (public insurance as proxy) was a significant factor in decreased functional walking capacity in this cohort. The relationship between social determinants and walking capacity in children with spina bifida merits further study to maximize opportunities for activity.

Rates of autism in children with spina bifida higher than general population

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Background: Children with spina bifida have abnormal central nervous system (CNS) development, related to failure of the neural tube to close. The formation of the CNS and subsequent development lends itself to common neuropsychological patterns, such as higher verbal IQ relative to overall IQ. Given that spina bifida is an anomaly of CNS development and autism is a developmental disorder of the CNS, it is reasonable to surmise that some etiologies for these conditions may overlap. For instance, both have increased likelihood of neuronal migration anomalies. Those with autism are more likely to have spina bifida than typical peers, but the converse relationship has not been studied.
Methods: We present a retrospective review of 218 individuals with spina bifida served in our transdisciplinary clinic from 2017-2022, aged 18 months to 21 years of age. Electronic medical record (EMR) review of those meeting inclusion criteria were evaluated for formal documentation of autism diagnosis in available EMR (2017 onward).
Results: Based on CDC data, the rate of autism is 1/44 (2.3%), significantly lower than the rate in our sample 10/218 (4.6%, p= 0.0219). Of those patients with comorbid autism and spina bifida, 7 were biological males and 3 female, a rate of 6.4% and 2.8%. The CDC data for the general population indicate a rate of 3.7% in males and 0.9% in females.
Conclusions: Though previously published research has indicated those with autism are more likely to have spina bifida, the converse has not been evaluated. This may have devasting effects, including delayed autism diagnosis and management. This relationship must be further studied to guide future evaluations and interventions.

Educational value of medical students' experience as counselors in a medically complex spina bifida summer camp

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Background: Children with complex medical needs account for 40% of healthcare utilization within the pediatric population (1). Exposure to this population is imperative in the development of clinical and interpersonal communication skills for healthcare trainees. Prior research shows that medical camps provide students with a non-traditional means to pediatric clinical exposure (2,3,4,5,6,7). Fourteen rising second-year medical students participated as counselors at Camp Patrick, a week-long summer camp for children with Spina Bifida (SB). We hope to promote the role that medical camps play in clinical learning by evaluating the educational value and student comfort in working with individuals with disabilities.
Methods: For purposes of program evaluation, a survey was constructed with 26 multi-format questions evaluating student experiences at Camp Patrick. The participant response rate was 13 out of 14.
Results: 69.2% reported that their clinical expectations for camp were exceeded. 76.9% and 92.3% did not have previous experience with urinary catheterization or bowel flush programs respectively. Par-

ticipants benefited most from opportunities that included: hands-on procedural experience, improving interpersonal communication skills, and the development of empathy. Only 30% of students felt prepared for their clinical role as counselors. Respondents reported a new understanding that the campers have impressive levels of independence and are invaluable in directing their own care. They also developed new empathy for the campers' daily time-consuming care needs.

Conclusions: Camp Patrick served as an impactful non-traditional clinical experience for medical students, as 69.2% reported this experience exceeded their expectations and 92.3% would recommend the experience to other medical students. It was determined that additional pre-camp clinical training specific to SB for medical students would maximize their learning experience. Overall, 84.6% of students reported increased comfort in working with individuals with disabilities in the pediatric population.

Risk factors for unanticipated hospitalizations in children and youth with spina bifida at an urban children's hospital: A cross-sectional study

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Background: Spina bifida (SB) is a condition resulting from the improper closure of the neural tube and vertebral column during fetal development. While patients' life expectancy and quality of life have improved dramatically due to medical advances, children continue to experience health-related issues that often require hospitalizations.

The association among sociodemographic and clinical characteristics with potentially preventable hospitalizations (PPH) in children and youth with myelomeningocele type SB were investigated in this cross-sectional study.

Methods: Chart reviews and data extraction were conducted on 108 children and youth, ages 1 month to 21 years admitted for PPH in a regional children's academic medical center between May 2017 and July 2019.

Sociodemographic variables included sex, age, type of insurance and ethnicity. Clinical variables included level of lesion, ambulation status, shunt dependency and selected diagnostic categories. Univariate, bivariate and multivariate analyses were conducted to identify factors associated with PPH.

Results: Factors associated with PPH included being male, ages 5 to 18 years, low lumbar level lesions, non-ambulatory, with public insurance, Hispanic and shunt dependent. Most hospitalizations (73%) were for neurologic or urologic conditions. Factors independently associated with PPH were ethnicity for urologic conditions, being ambulatory for metabolic conditions, and age for gastroenterology conditions.

Conclusions: Selected demographic and clinical variables were found to be associated with PPH of children and youth with myelomeningocele-type SB. The most common reasons for PPH were shunt malfunctions and urinary tract infections, consistent with other studies.

Standardized screening for sleep disordered breathing in a multidisciplinary spina bifida clinic

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Background: Sleep disordered breathing (SDB), including central and obstructive sleep apnea (OSA), is estimated to occur in >40% in children with spina bifida (SB). SDB results in various negative physical and neurocognitive outcomes. The *Guidelines for the Care of People with SB* recommend screening all children attending multidisciplinary SB clinics for SDB using a standardized assessment tool. The Pediatric Sleep Questionnaire (PSQ) is a validated symptom-based assessment tool for OSA screening in the general pediatric population. The accuracy of

the PSQ, however, in identifying SDB in children with SB is unknown. We assessed the feasibility of implementing a validated SDB screening questionnaire in a SB clinic.

Methods: Through a collaborative process with the SB clinic interdisciplinary team and hospital sleep center, we implemented screening for SDB at all SB clinic visits. All children ages 0 to 22 attending the SB clinic were provided the 22-item Sleep-Related Breathing Disorder Subscale of the PSQ. Forms were reviewed by developmental clinicians and patients referred to sleep center based on PSQ score and clinical history. Number of patients eligible for screening were tracked and basic demographic data and PSQ results entered in REDCap. Frequencies of completed PSQ's and positive PSQ scores (i.e., answered 'yes' to >.33 of total questions answered) were calculated. For those ages 2 to 18, research staff reviewed polysomnogram records for an SDB diagnosis.

Results: Between 12/14/2020 to 06/28/2021, 162/181 patients attending the SBC completed the PSQ. 36/162 (22%) screened positive (Table 1). Upon chart review of available PSG data, 37 (23%) of those screened had a SDB diagnosis, and 14 of the 36 (39%) with a positive PSQ had a documented diagnosis of SDB. Of the 110 patients between age 2 to 18 years old completing a PSQ, 30 (27%) scored above the .33 cut-off. 25 of 110 (23%) had an SDB diagnosis, while 13 of these 25 (52%) had negative PSQ screen. An additional 411 PSQ's have been completed since July 2021.

Conclusions: Implementation of a 22-item parent-report screening tool in a busy multidisciplinary SB clinic is feasible and can promote standardized screening and referral for SDB. Next steps will be to determine the sensitivity and specificity of the PSQ in identifying those with SDB by comparing to polysomnogram results (the gold standard for SDB diagnosis) in a cohort of children with SB.

Virtual "peleton" home exercise program to promote adaptive cycling along the Erie Canal

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Background: Physical activity is the key to wellness for people with spina bifida. Effective physical activity programs (a) incorporate goal-setting, (b) provide a way to monitor progress, and (c) are offered in group settings for accountability. The "Canalway Challenge" is a state-funded health promotion initiative that encourages people across New York State to discover the 360-mile Erie Canalway. It offers interactive maps for tracking miles, social media for group challenges, and a finisher kit with a bandana, mileage car magnets, and stickers for successful participants.

Methods: In Summer 2022 our spina bifida center collaborated with the Canalway Challenge to record "point of view" videos of fifteen one-mile-long segments of trail. Each mile-long segment offers approximately 6 minutes of adaptive cycling video, with ambient sounds and coaching narrated by our team. In 2023 these videos will be linked to a "February Fifteen" challenge. We will recruit participants via our Spina Bifida Center's Facebook Page. Ergometers will be offered as an incentive for adolescents to create groups at school.

Results: We will evaluate the Canalway Challenge as a goal-setting tool for health promotion at our center. The comparison group will be participants in other areas of the state who enroll and view the videos. We will evaluate goal attainment for all participants with site analytics as well as vis a vis age, sex, SES and shunt status, and self-reported physical activity at time of recruitment. We will develop a follow up survey to track whether the Challenge was effective in promoting adaptive cycling along the Erie Canal during Summer 2023.

Conclusions: Goal setting is an important feature of successful physical activity programs for people with spina bifida. The February Fifteen Canalway Challenge is an inclusive health promotion campaign that encourages cyclists of all abilities to enjoy outdoor recreation.

Facilitating quality spina bifida care and functional outcomes: Integration of research approaches into clinical care workflows

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Background: Functional outcomes optimization for individuals with Spina Bifida (SB) is a priority of providers, families, and patients. Several SB medical factors have been associated with various functional outcomes. Past research activities required chart review for extraction of relevant data. EMR optimization can allow for automated data extraction, increasing efficiency of quality improvement initiatives and clinical research. The Children's Wisconsin (CW) Spina Bifida Clinic attempted to capitalize on this opportunity by integrating clinical data collection procedures into typical clinical workflows.

Methods: The CW SB Clinic team met to review SB medical variables of interest identified in prior research (e.g., level of lesion, need for shunt, shunt revisions, etc.). These variables were reviewed by a national consortium of pediatric neuropsychologists involved in provision of care and assessment of outcomes in children and adolescents with SB. Once relevant variables were confirmed, an EMR template/flowsheet was developed and integrated into the clinical documentation workflow. Flowsheet variables are directly extracted from the EMR and uploaded into a database platform allowing for rapid examination of clinical quality initiatives and specific research questions.

Results: Within the first 3 months of implementation, 75 SB Clinical flowsheets were completed. Completion of this flowsheet takes approximately 15 minutes at this stage but has standardized clinical documentation of SB medical variables and has provided a tabulated form of clinical variables that can be reviewed quickly.

Conclusions: This quality improvement project will improve maintenance of clinical information, reduce gaps in care and facilitate research projects to improve the quality of care in patients with SB. Next steps include consideration of additional essential variables and partnering with multisite collaborators to implement such procedures in their clinics which will allow for more robust investigations into best practices and how to optimize outcomes and independence for individuals with SB across the country.