

Abstracts

Continence

Using a Decision Tree to Guide Bowel Management in Spina Bifida

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Background When born with Spina Bifida, there are numerous neurologic disorders that accompany this birth defect, including neurogenic bowel. Proactive and systematic, rational approaches can lead to continence and a more functional life style (Doolin, 2007). This presentation will include advances in bowel management options.

Methods Based on the evidence in the literature and expert experience, our approach to bowel management was recognized to be a step by step, individualized approach. This was converted to a decision tree for easy guidance of treatment decisions. The approach includes teaching patients and families normal bowel function, changes resulting from neurogenic bowel, common pitfalls in bowel management, and tips that may improve outcomes. The decision tree starts with dietary management, breaks into a two-fold attack, oral and rectal. One clinic from the National Spina Bifida Patient Registry (NSBPR) data was compared to public data from the NSBPR.

Results Preliminary data from the National Spina Bifida Patient Registry (NSBPR) in 2011 reported bowel continence in 42.1% ($n = 898$) compared to our clinic outcomes of 72.1% ($n = 43$). As the variable of bowel continence has been further defined and further patients were enrolled, the clinic results were comparable to the national reports. Consistency among providers and caregivers is critical to evaluating the management of Spina Bifida.

Conclusions This protocol warrants further evaluation but is offered as a rational, step by step, approach to bowel management in Spina Bifida. It includes the

most recent tools and techniques as well as basic bowel management.

Can Transanal Irrigations Prevent Surgery and Improve Quality of Life in Patients with Organic Defecatory Disorders?

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Background Symptoms of neurogenic bowel are difficult to treat, and may impact quality of life. Malone antegrade colonic enema (MACE) is the gold standard when traditional therapy has failed. The MACE requires surgery which has a potential for associated complications, and is not always successful. Transanal irrigations (TAI) provide a non-surgical option for treatment. Primary aim: to assess effectiveness of TAI in treating patients with organic defecatory disorders referred for MACE or had failed to demonstrate improvement post MACE

Methods $N = 18$ patients that were either referred for MACE (11) or had failed MACE irrigations (7). All participants completed the Fecal Incontinence Quality of Life and the Neurogenic Bowel Dysfunction Scales and an overall satisfaction with their bowel management scale. Study participants received a standardized training session from the same clinician. Participants were evaluated after using Peristeen for at least 2 months using the same instruments listed above. Statistical analysis was performed using t-paired test and chi square.

Results Eighteen subjects with organic defecatory disorders, age ranged from 8–25 years (mean 16.83 ± 5.5). Percentage of patients reporting fecal incontinence went from 77% to 54% ($p = 0.03$) post Peristeen. There was a statistically significant improvement

in bowel control and care, neurogenic bowel dysfunction scores, and overall satisfaction with bowel management scores. Of the 7 patients that failed MACE, all but 1 patient stopped antegrade colonic enemas, and 3 became fully continent with Peristeen. Of the 11 patients referred for MACE surgery 7 became fully continent and none went on to have surgery.

Conclusions Results support the use of Peristeen prior to surgical intervention and in cases where surgical intervention has failed to demonstrate improvement of bowel symptoms.

Differences in Continence Rates in Individuals with Spina Bifida Based on Ethnicity

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Background The prevalence of neural tube defects is highest among Hispanics. Regional studies suggest ethnic disparities in continence rates among individuals with SB; differences have not been studied in a national sample. Participants in the CDC-sponsored National SB Patient Registry (NSBPR) are an ideal sample to explore whether the prevalence of bowel/bladder continence differs for Hispanics compared to others. The goal of this study is to examine whether the prevalence of bowel/bladder continence differs between Hispanics and non-Hispanics and to examine demographic and intervention differences.

Methods Data were extracted from NSBPR for those aged ≥ 5 years for Hispanics and non-Hispanics. Bladder/bowel continence was defined as dry/no involuntary stool leakage during the day or none/ \leq monthly incontinence. Chi-square test was used to examine the association between ethnicity, continence and other factors.

Results A total of 5306 patients ages 5 to 83.7 years were included; 21.5% were identified as Hispanic. There was no difference for SB type or level of lesion. Hispanics were significantly less likely to demonstrate urinary continence (38.7%) compared to non-Hispanics (46.1%; $p < 0.0001$). The same was true for bowel continence; only 43.3% of Hispanics were continent compared to 53.5% of non-Hispanics ($p < 0.0001$). Additional analyses revealed other significant differences: Hispanic patients were younger, less likely to be college educated, more likely to have public insurance, and had fewer bowel or bladder surgeries compared to non-Hispanics (all $p < 0.05$), and were more likely to have vesicostomies ($p = 0.013$).

Conclusions Hispanic patients in the NSBPR are less likely to report bowel and bladder continence, and demographic and intervention differences were noted. Further studies are needed to ascertain causes of these disparities including economics, culture, educational level, and access to and perceptions of care.

Age of Transition to Self-Clean Intermittent Catheterization in Patients with Spina Bifida

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Background Clean intermittent catheterization (CIC) is an integral part of bladder management in Spina Bifida (SB) patients. It is presumed that as these patients age, many become capable of performing CIC independently. The age at which most patients transition to self-CIC is unclear. In this study, we sought to determine at what age most patients transition from caregiver- to self-CIC.

Methods We performed a retrospective cohort study of all patients included in our pediatric and adult University of Alabama at Birmingham and Children's Of Alabama SB registry. We reviewed all patients who were on CIC by caregiver prior to self-CIC. We then reviewed patients with documented ages at the start of caregiver-CIC and those with documented ages of transition to self-CIC. We used these patients to determine the frequencies by age when transition occurs. Patients with incomplete data were excluded.

Results A total of 696 patients were identified, and 378 (54.3%) void via CIC. Of those patients, 206/378 (54.5%) self-CIC, and 112/206 (54.4%) had known

ages when self-CIC began. 64/206 (31.1%) patients had known transitions with accompanying ages from caregiver- to self-CIC and are the focus of the study. 46/64 (71.9%) and 56/64 (87.5%) patients had transitioned to self-CIC by age 10 and 14, respectively. The greatest frequency of transition to self-CIC occurred at 9 years of age with 11/64 (17.2%) patients transitioning.

Conclusions Based on our results, patients between 10–14 years of age who CIC are likely to have transitioned or will transition to self-CIC. This is an important factor for functional independence and will be useful during patient counseling. This timeframe corresponds to the peri-pubertal period when patients may be seeking independence to achieve social continence. Further studies are needed to investigate the factors predicting the transition from caregiver- to self-CIC.

Factors Related to Parent and Child Satisfaction with Bladder and Bowel Programs in Children with SB in the National Spina Bifida Patient Registry (NSBPR)

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Background Frequency of continence and type of bowel or bladder program are collected in the NSBPR. However, we know little about parent and child perceptions of these programs. The purpose of this study was to evaluate the usefulness of added assessment of parent and child satisfaction with bladder and bowel programs.

Methods This descriptive study used data from the NSBPR and additional site-specific data on satisfaction. Sample: The most recent visit from participants in the NSBPR seen in our clinic in 2014 or 2015 ($n = 144$) limited to those over age 5 years of age who had myelomeningocele ($n = 98$). Procedures: Data for the NSBPR was collected at the annual visit using a standardized instrument. Child and parent reported their satisfaction with their bowel and bladder programs, the frequency of CIC and the child's participation with peers. Analyses: Descriptive correlational analyses were conducted. Significance was set at $\alpha = 0.05$.

Results Participants were 5–23 years of age ($m = 11.6$), 55% female, 83% used CIC for bladder program and 36% used antegrade continent enema for bowel program. Parent and child satisfaction with blad-

der program was high and associated with frequency of urinary incontinence ($r_s = -0.30$; $r_s = -0.26$) and nocturnal incontinence ($r_s = 0.41$; $r_s = 0.36$). Unique relationship for parent was use of undergarments ($r = 0.22$) while child happiness was related to satisfaction ($r_s = 0.24$). Level of lesion, age, type of program, latex allergy and neuropsychological assessment were not significant. A similar pattern emerged with bowel program data.

Conclusions Frequency of incontinence explained a small amount of parent and child satisfaction. A recent study of adults found it was the amount of incontinence not frequency that was related to adult's quality of life. Further investigation of family members' perceptions is indicated.

Urinary Management and Continence Outcomes of Adults with Spina Bifida and Comparison to Children: Findings of National Spina Bifida Patient Registry (NSBPR)

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Background Focused urologic care has been the norm for most Spina Bifida (SB) patients. Little data exist regarding urinary management and outcomes in SB adults and whether they differ from children.

Methods The NSBPR was queried for bladder management, medications, and continence outcomes in those aged ≥ 5 years. Patients were segregated into children, adolescents and adults. Urinary continence was defined as dry during the day with or without intervention.

Results Adults comprised 1405 of 5340 patients and were more likely to be female (57.4%), non-Hispanic white (78.3%), without private insurance (58.4%), have myelomeningocele (MMC) form of SB (86.3%), and have higher lesion level ($p < 0.001$). Compared to children, adults were more likely to be on antibiotics (16.9%) but less likely to be on antimuscarinics (46.2%) ($P < 0.003$). Adults were more likely to be on intermittent catheterization (IC) (76.2%), have an indwelling catheter (3.6%), or have a urostomy (4.2%) (all $p < 0.001$). Adults were more likely to have

had bladder augmentation (23.1%) or stone surgery (4.9%); adolescents were more likely to have had continent catheterizable channel (13.5 vs. 8.8%), vesicostomy (7.3 vs. 5.4%), or bladder outlet procedure (5.2 vs. 4.3) (all $p < 0.01$). 50.9% of adults reported urinary continence—more than adolescents (47.2%) or young children (37.1%) ($p < 0.0001$)

Among MMC patients, adults reported continence more (49.1%) and adolescents were more likely to perform IC (83.3%) ($p < 0.0001$). College degree was attained by 149 of 767 adults aged ≥ 25 years and was associated with greater employment (35.9%), private insurance, non-MMC type, and lower lesion ($p < 0.0001$), but not urinary continence ($p = 0.4$).

Conclusions Adults with SB have differences in urinary management compared to younger patients but are more likely to be dry. Lower lesions were associated with better continence.

Bowel Management and Continence Outcomes of Adults with Spina Bifida: Findings of National Spina Bifida Patient Registry (NSBPR)

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Background Medical advances have greatly extended life expectancy for people with Spina Bifida (SB). Little data exist regarding bowel management and outcomes in SB adults and how they may differ from children.

Methods Using data from the NDBPR in those ≥ 5 years (y), differences in continence among children (5–11 y), adolescents (12–19 y), and adults (≥ 20 y) were analyzed using Chi-square test. 1405 adults, 2015 children, and 1920 adolescents were identified for a total sample of 5340 patients. Bowel continence was defined as no involuntary stool leakage during the day with or without intervention.

Results Adults were more likely to be female, non-Hispanic white, without private insurance, have myelomeningocele (MMC), and have higher lesion level (all $p < 0.001$). Active bowel management was more common in adults (25.5%) ($p = 0.03$). Adults were more likely to use digital stimulation (4.3%), dis-

impaction (3.0%), and standard enema (4.3%) (all $p < 0.008$), but less likely to use suppositories, cone or mini enemas, timed evacuation, or antegrade enemas (all $p < 0.003$). Antegrade enema was the most commonly reported management in all groups (13.1–27.4%) with highest use in adolescents ($p < 0.0001$). Surgical management was more common in adolescents for ACE procedure (24.7%) and cecostomy tube (6.7%) (both $p < 0.0001$); colostomy was more common in adults (4.3%) ($p = 0.0004$).

Bowel continence was higher in adolescents and adults vs. children (56.1–56.5% vs. 43%) ($p < 0.0001$). Continence for adults with MMC and non-MMC types of SB was 53.3% and 73.4%, respectively.

Conclusions More than 50% report of SB adults report bowel continence. Management strategies in adults differ from younger patients. Future analysis with longitudinal data may provide more informative results.

Bowel Incontinence in Adults with Spina Bifida

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Background We have shown that in adults with SB, bowel incontinence more frequently than monthly is significantly and independently associated with self-identification as “permanently disabled.” The purpose of this study is to perform a detailed evaluation of bowel continence and bowel management in adults.

Methods We collected data pertaining to stool continence and bowel management for patients seen in our adult SB clinic using variables collected as part of the NSBPR. We then performed univariate and multivariate analyses to determine association between clinical and demographic variables and frequency of stool incontinence. We report what interventions are used by individuals who report an active bowel management regimen.

Results One hundred ninety-three individuals are included (63% female), 87% have a diagnosis of myelomeningocele. 27.5% individuals report at least weekly stool incontinence while 37.8% report never having stool incontinence. Comparing individuals who have stool incontinence at least weekly to those with less frequent incontinence, having a bowel management program (OR 3.8 $p = 0.00$), and any post-secondary education (OR 2.5 $p = 0.026$) are statis-

tically significantly and independently associated. Diagnosis of myelomeningocele ($p = 0.039$) and employment status ($p = 0.029$) were significant in univariate analysis. One hundred forty-two individuals report having a bowel management program (72.4%). The most common components of a bowel management program are antegrade enema (ACE) (23.2%), oral stool softener (19.7%), suppository (14.7%), and colostomy (6.3%).

Conclusions We identified factors associated with bowel incontinence in individuals with SB and characterized bowel management techniques. While our data show an increased percentage of our adult patients on a bowel management program when compared to our pediatric patients, future efforts should continue to emphasize the importance of establishing a bowel program early given the importance of bowel continence for adults with Spina Bifida.

Variation in Surgical Management of Neurogenic Bowel among Centers Participating in National Spina Bifida Patient Registry

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Background Optimal management of neurogenic bowel in patients with Spina Bifida (SB) remains

controversial. Surgical interventions may be utilized to treat constipation and provide fecal continence, but their use may vary between SB treatment centers.

Methods We queried the National Spina Bifida Patient Registry (NSBPR) to identify patients who underwent bowel procedures. We abstracted demographic characteristics, SB type, functional level, concurrent bladder surgery, mobility, education, and NSBPR clinics to determine whether any of these factors were associated with rates of interventions for management of neurogenic bowel. Multivariable logistic regression with adjustment for selection bias was performed.

Results We identified 5,528 patients with SB enrolled in the 2009–14 NSBPR. Of these, 1088 (19.7%) underwent procedures for neurogenic bowel, including 957 (17.3%) ACE / cecostomy tube and 155 (2.8%) ileostomy/colostomy patients. Procedure rates range from 12.1–37.9% among the 19 clinics. Procedures were more likely in patients who were older, white, non-ambulatory, with high-level, myelomeningocele lesion, with private health insurance (all $p < 0.001$), and female ($p = 0.006$). On multivariable analysis, NSBPR clinic and older age (both $p < 0.001$) were the most significant predictors of surgery. White race ($p = 0.002$), non-ambulatory status ($p = 0.011$), higher lesion level ($p < 0.001$), private insurance ($p = 0.002$) and female gender ($p = 0.015$) were also associated with increased odds of surgery.

Conclusions There is significant variation in rates of procedures to manage neurogenic bowel among NSBPR clinics. In addition to SB-related factors such as mobility status and lesion type/level, non-SB-related factors such as patient age, gender, race and treating center are also associated with the likelihood of undergoing neurogenic bowel intervention.