

### **HHS Public Access**

Author manuscript *J Pediatr Rehabil Med.* Author manuscript; available in PMC 2019 July 27.

Published in final edited form as:

J Pediatr Rehabil Med. 2017 December 11; 10(3-4): 335-343. doi:10.3233/PRM-170466.

### Bowel management and continence in adults with spina bifida: Results from the National Spina Bifida Patient Registry 2009–15

John S. Wiener<sup>a,\*</sup>, Kristina D. Suson<sup>b</sup>, Jonathan Castillo<sup>c</sup>, Jonathan C. Routh<sup>a</sup>, Stacy Tanaka<sup>d</sup>, Tiebin Liu<sup>e</sup>, Elisabeth Ward<sup>f</sup>, Judy Thibadeau<sup>e</sup>, David Joseph<sup>g</sup>, National Spina Bifida Patient Registry

<sup>a</sup>Division of Urologic Surgery, Duke University Medical Center, Durham, NC, USA

<sup>b</sup>Department of Urology, Children's Hospital of Michigan, Detroit, MI, USA

<sup>c</sup>Department of Pediatrics, Baylor College of Medicine, Houston, TX, USA

<sup>d</sup>Department of Urology, Vanderbilt University, Nashville, TN, USA

eCenters for Disease Control and Prevention, Atlanta, GA, USA

<sup>f</sup>Carter Consulting, Inc., Consultant to CDC, Atlanta, GA, USA

<sup>g</sup>Department of Urology, University of Alabama at Birmingham, Birmingham, AL, USA

#### Abstract

**INTRODUCTION:** Advances in care have allowed most children with spina bifida (SB) to live to adulthood. The majority have neuropathic bowel dysfunction (NBD), resulting in constipation, incontinence, and diminished quality of life. We sought to 1) describe contemporary NBD management and continence outcomes of adults with SB; 2) describe differences from younger patients; and 3) assess for association with socio-economic factors.

**METHODS:** We analyzed data on NBD management and continence from the National Spina Bifida Patient Registry (NSBPR). Patients were segregated into young children (5–11 years), adolescents (12–19 years), and adults (20 years and older). A strict definition of continence was utilized. Statistical analysis compared cohorts by gender, ethnicity, SB type, lesion level, insurance status, educational attainment, employment status, and continence.

**RESULTS:** A total of 5209 SB patients were included, of whom 1370 (26.3%) were adults. Management and continence varied by age and SB type. Oral medication use did not differ between groups (5.2–6.6%). Suppositories and rectal enemas were used only by 11.5% of adults, which was significantly less than among school-aged children. Antegrade enemas were used by 17.7% of adults which was significantly less than among adolescents (27.2%). Adults were more likely to use digital stimulation or disimpaction or have undergone a colostomy. Bowel continence was reported by 58.3% of overall adult cohort: 55.6% of adults with myelomeningocele and 74.9% with non-myelomeningocele. Bowel continence was significantly associated with employment (*p* 

<sup>\*</sup>Corresponding author: John S. Wiener, Section of Pediatric Urology, P.O. Box 3831, Duke University Medical Center, Durham, NC 27710, USA. Tel.: +1 919 684 6994; Fax: +1 919 681 5507; john.wiener@duke.edu. Conflict of interest None to report.

= 0.0002), private insurance (p = 0.0098), non-myelomeningocele type of SB (p = 0.0216) and educational attainment (p = 0.0324) on univariate analysis but only with employment on multivariable logistic regression (p = 0.0027).

**CONCLUSIONS:** Bowel management techniques differed between adults and younger patients with SB. Bowel continence was reported by over half of SB adults and was associated with socio-economic factors.

#### Keywords

Neurogenic bowel; spina bifida; fecal incontinence

#### 1. Introduction

As the most common permanently disabling birth defect, spina bifida (SB) has traditionally been considered a pediatric condition. Nearly 1,500 children are estimated to be born in the United States (US) with SB without anencephaly each year based on national prevalence studies from the Centers for Disease Control and Prevention (CDC) [1]. However, advances in medical care have enabled nearly all children with SB to now survive into adulthood. In fact, most Americans living with SB are currently adults [2]. Most individuals with SB suffer from neuropathic bowel dysfunction (NBD) manifesting as constipation and fecal incontinence and having a documented negative impact on quality of life [3]. Management of NBD in SB patients has traditionally been conducted by pediatric urologists, pediatric gastroenterologists, developmental pediatricians, and physiatrists, but with more patients reaching adulthood, transition to adult care has become increasingly relevant [4].

The National Spina Bifida Patient Registry (NS-BPR), funded through the CDC, began collecting data from multidisciplinary SB clinics across the US in 2009. Its primary goals were to describe the patients who attend those clinics, to provide a foundation for research, and to improve clinical care [5]. This, in turn, has enabled collaborative research across multiple time points during patients' lives. The data collected are comprehensive, covering multiple organ systems and complications of SB. The registry includes over 6000 patients, 22% of whom are adults, with sufficient granularity to study NBD management and continence outcomes [6].

Currently, there are little data about bowel management and continence outcomes in adults with SB, and these are primarily from single institutional series. The purpose of this descriptive analysis is to characterize current NBD management and associated continence outcomes in a large cohort of adults with SB from across the US. More information is needed to improve care and develop realistic expectations for adults as well as for children with SB and their families.

#### 2. Methods

The NSBPR, a center-based registry implemented and maintained by the CDC, was designed to help describe characteristics of people with SB, processes of care, and health outcomes among a national sample of patients attending SB clinics. Between September

2008 and December 2015, 26 sites (29 multi-disciplinary SB clinics) participated in the NSBPR. Through the use of a standardized data collection tool, longitudinal data were gathered, de-identified, and pooled from patients with 1 of 6 diagnoses: myelomeningocele (MMC), meningocele, lipomyelomeningocele, split cord malformation, terminal myelocystocele, or fatty filum [7].

Local institutional review boards provided approval for study participation, and parents and patients provided informed consent (and assent, as indicated by age) as appropriate. Given that sites were encouraged but not required to enroll all eligible SB patients, aggregate and individual level demographic data on patients not enrolled were collected for comparison. Baseline demographic and diagnostic information was collected through an initial encounter form used at the time of patient enrollment. An annual visit form was used to collect updated information on time-varying demographic and clinical characteristics and treatments at enrollment and at each yearly visit. Patient data were obtained through medical record abstraction and patient interview; after de-identification, data were transmitted to the CDC for management and analysis.

#### 2.1. Sociodemographic characteristics

Patient age was calculated based on birth month and the date of the last annual clinic visit. Patients were segregated by age: school-aged (5–11 years), adolescent (12–19 years), and adult (20 years and older). Gender, race, and ethnicity data were collected at initial encounter. Patients were classified by race/ethnicity as non-Hispanic white, non-Hispanic black, Hispanic or Latino, and other (defined as Asian, Native Hawaiian, or other Pacific Islander, American Indian or Alaskan Native, and/or multi-racial). Health insurance information reported at each visit was categorized into two groups: any private and non-private. Following U.S Census conventions, college graduation rates were examined for individuals aged 25 years and older [8].

#### 2.2. SB Lesion characteristics and motor function

SB diagnosis was classified into two groups: myelomeningocele (MMC) and nonmyelomeningocele. Functional lesion level was reported for each lower extremity: thoracic (flaccid lower extremities); high-lumbar (hip flexion present); mid-lumbar (knee extension present); low-lumbar (foot dorsiflexion present); or sacral (foot plantar flexion present). When the two sides differed, the more severe side was used to represent that patient's functional lesion level.

#### 2.3. Continence outcomes

Bowel continence outcomes were taken from the patient response at the last documented clinic visit. During the first phase of data collection (March 2009–September 2013), bowel continence was defined as "no involuntary stool leakage, with or without interventions, during the day". In phase 2 (October 2013–December 2015), continence was evaluated by multiple choices after asking to "Quantify frequency of stool incontinence over the last month when not ill". To combine the definitions of continence from both phases, the multiple choice answers were converted into a yes/no continence status as follows: the answers of "Never" or "Less than once per month" were considered as continent, and

choices of "Greater than or equal to once per day", "Less than once per day, More than or equal to once per week", or "Less than once per week, greater than or equal to once per month" were defined as incontinent. Those with an answer of "Cannot assess" were excluded from all analyses. Patients managed with ileostomy and colostomy were excluded from continence outcomes analysis.

#### 2.4. NBD management techniques

The registry queried the following forms of NBD management: no management, oral medications, timed evacuation, suppository, standard rectal enema, cone enema, mini enema, antegrade colonic enema, digital stimulation, disimpaction, and other. Registrants were also queried for a history of surgical procedures for NBD management including creation of a channel for antegrade colonic enema (also known as Malone, ACE, or MACE), cecostomy button or tube (including Chait tube), cecostomy button closure, colostomy, and ileostomy.

#### 2.5. Statistical analysis

Associations among independent, categorical variables were tested for statistical significance using chi-square tests. Univariate and multivariable logistic regression models were used to test the associations of bowel continence outcomes at last clinic visit with gender, SB type, level of lesion, health insurance type, employment status, and educational attainment among all individuals aged 25 years and older with complete data. Statistical tests were all 2-sided, and p values < 0.05 were considered significant. Statistical analyses were performed using SAS version 9.3.

#### 3. Results

#### 3.1. Demographics

A total of 5209 registry participants aged 5–83 years at their last clinic visit through December 2015 were included in the analyses (Table 1). The proportion of females was slightly higher than males in the two younger cohorts: school-aged and adolescents, but this difference was significantly greater in the adult cohort. Race and ethnicity distribution varied between age groups with the proportion of non-Hispanic whites decreasing in younger age groups (78.0% of adults to 57.1% of school-aged children) while the proportion of Hispanic/ Latinos increased (11.7% of adults to 26.3% of adolescents and 24.3% of school-aged children). There was a larger proportion of adults with MMC as well as with higher level of lesions. The proportion of participants with any private insurance declined from the schoolaged to the adult group. A minority of patients with SB were employed; only 12 (0.6%) adolescents and 182 (14.0%) adults worked full time, while 63 (3.4%) adolescents and 235 (18.1%) adults worked part time. A total of 1742 (93.3%) of adolescents and 271 (20.9%) adults reported themselves as students, and 362 (27.9%) adults identified themselves as permanently disabled.

#### 3.2. NBD management

Reported use of oral medication usage was low and not different between cohorts (Table 2). Use of timed evacuation and suppositories decreased with age groups and was lowest among adults. Standard rectal enemas were used proportionally less by adolescents than school-

aged children and adults, and use of cone and mini enemas was higher in school-aged children than among adolescents and adults. Antegrade enemas through a surgically created channel or cecostomy button/tube were used by more than 25% of adolescents, but usage was significantly lower in adults and younger children. Digital stimulation, disimpaction, and other forms of bowel management were utilized by small numbers of patients, but all were used more commonly by adults than other age groups.

A significantly larger proportion of adolescents had undergone surgery for creation of an antegrade colonic enema channel or cecostomy button/tube to allow bowel management by antegrade enema. Colostomy had been performed on 135 individuals with a higher prevalence among adults. Age at the time of colostomy was available for 97 individuals. Fifty-eight of those with a colostomy had MMC with a mean age at time of colostomy of 13.4 years (SE = 1.5, median 13.0; range 0–46.4). Thirty-nine patients with colostomy had non-MMC diagnosis with a mean age at time of colostomy of 2.9 years (SE = 1.3, median 0.0; range 0–38.6). Overall, 14 (26.4%) of all adults with colostomies at a known age had them performed in adulthood (mean and median age = 31.3 and 29.4 years). Fifteen patients had undergone ileostomy (five patients had both ileostomy and colostomy), and age at surgery was known in ten. Of the six with MMC, the mean and median ages of surgery were 7.9 and 8.6 years (range 0–12.2); whereas, of the four with non-MMC type of SB, all were performed soon after birth.

#### 3.3. NBD continence outcomes

After exclusion of colostomy and ileostomy patients, 2707 (53.5%) individuals of all ages reported bowel continence (Table 3). The continence rate was similar in adults and adolescents (58.3–58.6%) and was significantly greater than among school-aged children. A similar trend was noted when patients were segregated by MMC and non-MMC forms of SB, but continence rates were relatively lower in the MMC cohort. Limiting analysis to only adults, non-MMC patients had a significantly higher continence rate than MMC patients (p < 0.0001).

#### 3.4. Segregation by education level in adults aged 25 years or older

A minority (19.5%) of adults older than 25 years and older had attained a college degree or higher (Table 4). The higher female to male ratio among all adults with SB did not vary significantly with education level. Employment and private health insurance status were associated with higher education, as were non-MMC type of SB and lower lesion levels. Bowel continence was reported by 55.1% of all adults aged 25 years and older and was significantly associated with educational attainment. Those with a college degree or higher had a higher continence rate of 62.3% versus those with some post-secondary education (58.6%) or no post-secondary education (50.7%).

### 3.5. Univariate and multivariable logistic regression models in adults aged 25 years or older

Univariate logistic regression models showed that employment (p = 0.0002), health insurance (p = 0.0098), SB type (p = 0.0216) and educational attainment (p = 0.0324) were significantly associated with bowel continence. On multivariable logistic regression, full- or

part-time employment was the only variable with a statistically significant association with bowel continence (Table 5).

#### 4. Discussion

Using data from the NSBPR, we herein report the largest analysis of bowel management and continence outcomes in adults with SB to our knowledge. The findings are important not only to evaluate care of SB adults but also to provide realistic expectations to SB children and their families about future management. Clinical care is continually evolving in all areas of medicine, and SB care is no different; we noted significant differences in management and outcomes in adults compared to school-aged children and adolescents, as newer procedures and management techniques have been developed.

The adult SB population is heterogeneous in terms of SB type and lesion level, so variation in NBD was expected. Our adult cohort had a larger proportion of individuals with the MMC form of SB and higher lesion levels than younger cohorts. It is unknown if this difference was related to the fact that adults with milder forms of SB are less likely to receive care at multidisciplinary SB clinics participating in the NSBPR or if there has been a recent trend to include more children with non-MMC diagnosis in SB clinics. The reported bowel continence rate for adults with SB was 58.3% (55.6% for MMC and 74.9% for non-MMC). An international on-line survey of 518 SB adults showed a lower bowel continence rate of 44.6% [9]. It is unclear if lower continence rates were due to the voluntary and private nature of the on-line survey. Nonetheless, it is clear that bowel continence is attainable for a large proportion of adults with SB.

Our cohort of adults had a higher proportion of females compared to younger cohorts. This was less skewed than others have reported; Liu et al. [10] had a two-thirds female distribution in their analysis of 225 adults with SB. Females are known to be more diligent about routine health care [11], and this may explain the greater preponderance of females attending SB clinics in the registry. Alternatively, females may simply be more likely than males to seek treatment at NSBPR or other SB clinics, or males with SB may be more likely to expire at younger ages than females. Despite this difference, no difference in bowel continence was associated with gender. We also noted that the racial and ethnic mix of the population of SB patients in the US has been changing over time, as seen in our 26 sites in 20 states. The younger two cohorts in the registry had proportionally fewer non-Hispanic whites and more Hispanics/Latinos. This likely reflects increased immigration of Hispanics/Latinos to the US in the past several decades, and this population is known to have a higher incidence of SB and higher birth rates [12].

Management of NBD showed different care patterns across age groups. Interestingly, continence was similar at 58% in both adults and adolescents. Use of timed evacuation, suppositories, and mini-enemas all declined with increasing patient age; it may be that these interventions may become less effective or require greater assistance as individuals age. Digital stimulation and disimpaction were used more frequently by adults and could be a reflection that these are older forms of management or that adults are less bothered by these techniques. Colostomy is typically a last resort in bowel management and is often done to

Wiener et al.

manage severe sacral skin ulcers; its greater prevalence in adults was not unexpected as adults are known to have significant morbidity and mortality from skin ulcers [13,14]. The use of antegrade enema was significantly greater in adolescents, and the higher rates of procedures to allow this was accordingly higher in this cohort. These age differences are likely explained by the fact that these procedures only came into widespread practice over the last two decades. Further study is needed to see if this surgical trend will lead to improved bowel continence rates in adults in the future.

The unique socio-economic findings of this analysis have many important implications for the social, educational, and vocational development of individuals with SB, as well as their daily personal hygiene. Adults with SB were less likely to have private insurance compared to younger patients. This is not unexpected as patients are no longer covered by their parents' insurance at older ages. Furthermore, SB appears to negatively affect educational and employment attainment which is a major determinant of health insurance status for adults. We found that 46% of participants aged 25 years or older had attended some college, and 19% had at least a college degree; this compares to 59% of all American adults aged 25 or older attending some college and 33% achieving a bachelor's degree [8]. Educational attainment in adults with SB was further noted to significantly impact employment and insurances status. Conversely, we noted that the more severe end of the SB spectrum manifested in MMC and higher levels of lesion was associated with lower educational attainment. A total of 38.4% of our adult SB cohort reported full or part time employment which was similar to 34% noted by Liptak et al. [15]. Finally, we noted an association between educational status and bowel continence. To investigate the association of socioeconomic and disease factors with bowel continence, controlling for confounding variables, we used multivariable logistic regression. The only statistically significant association noted was between bowel continence and employment status. In a similar analysis of bladder continence in the same cohort, we found no association with these same factors [16]. It has been suggested that bladder incontinence (particularly low-volume) may be less impactful than bowel incontinence. Szymanski et al. [9], in fact, noted that quality of life of adult SB patients was more negatively affected by bowel than bladder incontinence. The directionality of the relationship between bowel continence and educational attainment and employment is not known; are people that are more motivated to successfully use a bowel program to attain continence also more motivated to complete college and gain employment or does the presence of the bowel incontinence reflect social and/or diseaserelated factors that prevent college attendance/completion or employment? Clearly, further study is needed.

Our study was subject to limitations. As with any large database, errors in patient recall and data abstraction and entry may have occurred. The NSBPR carefully standardized data components and collection and has ongoing data quality monitoring between participating clinics and CDC staff [5]. There is a potential for selection bias within the enrolled clinics, but sensitivity analyses have shown no significant differences in eligible, but not enrolled, patients in these clinics. (manuscript in preparation) Adults enrolled in the registry may not be representative of all adults with SB in the US because they may be receiving more intensive and systematic care in multidisciplinary clinics selected by the CDC to participate in the NSBPR than patients receiving care at other SB clinics or elsewhere. It is not known if

the type of SB clinic matters as the NSBPR includes a mix of pediatric only, adult only, and all age clinics. Furthermore, adults attending these clinics may have a higher level of SBrelated disease burden than those not attending specialty clinics. This may be more pronounced for less affected non-MMC patients who may not seek medical care if having no problems. The age distribution of adults studied is skewed towards young adults, so these findings may not be representative of older adults with SB.

#### 5. Conclusions

This largest analysis to date of NBD bowel management and continence outcomes in adults with SB revealed significant differences compared to adolescents and younger children with SB, as well as differences based on SB type. Bowel continence was noted to be superior in adults and better in those with less severe forms and lower lesion level of SB. Bowel continence was significantly associated with employment status and educational attainment on univariate analysis, but only employment on multivariable logistic regression analysis. These findings should help guide management of NBD in adults with SB and provide realistic goals for counseling of younger patients.

#### Acknowledgments

The development of the National Spina Bifida Patient Registry has been successful due to the contributions of all the members of the NSBPR Coordinating Committee. Members of this committee during the collection of the data reported here were William Walker, Seattle Children's Hospital; Kathryn Smith, Children's Hospital, Los Angeles; Kurt Freeman, Oregon Health and Science University; Pamela Wilson, Children's Hospital Colorado; Kathleen Sawin, Children's Hospital of Wisconsin and Froedtert Hospital, Milwaukee (adult clinic); Jeffrey Thomson, Connecticut Children's Medical Center, and Shriners Hospital for Children, Springfield; Heidi Castillo, Children's Hospital Medical Center, Cincinnati, and Texas Children's Hospital, Houston; David Joseph, Children's Hospital of Alabama; Jacob Neufeld, St. Luke's Boise Medical Center, Boise; Robin Bowman, Lurie Children's Hospital of Chicago; Karen Ratliff-Schaub, Nationwide Children's Hospital, Columbus; Jim Chinarian, Children's Hospital of Michigan, Detroit; John Wiener, Duke University Medical Center, Durham; Mark Dias, Hershey Medical Center, Hershey; Joe O'Neil, Riley Hospital for Children, Indianapolis; Alex VanSpeybroeck, Shriners Hospital for Children, Los Angeles; Brad Dicianno, Children's Hospital of Pittsburgh, and University of Pittsburgh Medical Center, (adult clinic) Pittsburgh; Paula Peterson, Primary Children's Medical Center, Salt Lake City; Elaine Pico, UCSF, San Francisco, and Children's Hospital and Research Center, Oakland; Nienke Dosa, Upstate Golisano Children's Hospital, Syracuse; Stacy Tanaka, Monroe Jr. Carrell Children's Hospital at Vanderbilt, Nashville; Carlos Estrada, Boston Children's Hospital, Boston; Michael Partington, Gillette Children's Specialty Healthcare, St. Paul.

Funded by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (1UO1DDD000744.01). The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

#### Abbreviations

CDC	Centers for Disease Control and Prevention
MMC	myelomeningocele
NBD	neuropathic bowel dysfunction
NSBPR	National Spina Bifida Patient Registry
SB	spina bifida

#### References

- Parker SE, Mai CT, Canfield MA, et al. Updated National Birth Prevalence estimates for selected birth defects in the United States, 2004–2006. Birth Defects Res A Clin Mol Teratol 2010; 88(12): 1008. [PubMed: 20878909]
- [2]. Ouyang L, Grosse SD, Armour BS, et al. Health care expenditures of children and adults with spina bifida in a privately insured US population. Birth Defects Res A Clin Mol Teraol 2007; 79(7): 552.
- [3]. Rocque BG, Bishop ER, Scogin MA, et al. Assessing health-related quality of life in children with spina bifida. Journal of Neurosurgery: Pediatrics 2015; 15(2): 144. [PubMed: 25415252]
- [4]. Summers SJ, Elliott S, McAdams S, et al. Urologic problems in spina bifida patients transitioning to adult care. Urology 2014; 84(2): 44.
- [5]. Thibadeau JK, Ward EA, Soe MM, et al. Testing the feasibility of a National Spina Bifida Patient Registry. Birth Defects Res A Clin Mol Teratol 2013 1; 97(1): 36. [PubMed: 23125114]
- [6]. Sawin KJ, Liu T, Ward E, et al. The National Spina Bifida Patient Registry: profile of a large cohort of participants from the first 10 clinic. J Pediatr 2014; 166(2): 444. [PubMed: 25444012]
- [7]. Schechter MS, Liu T, Soe M, et al. Sociodemographic attributes and spina bifida outcomes. Pediatrics 2015 4; 135(4): e957–64. [PubMed: 25780069]
- [8]. Ryan CL, Bauman K. Educational attainment in the United States 2015. U.S. Census Bureau, 3 2016 http://www.census.gov/content/dam/Census/library/publications/2016/demo/p20-578.pdf.
- [9]. Szymanski KM, Cain MP, Whittam B, et al. All incontinence is not created equal: impact of urinary and fecal incontinence on quality of life in adults with spina bifida. J. Urol 2017; 197(3): 885. [PubMed: 28131501]
- [10]. Liu JS, Greiman A, Casey JT, et al. A snapshot of the adult spina bifida patient high incidence of urologic procedures. Cent European J Urol 2016; 69(1): 72.
- [11]. Thompson AE, Anisimowicz Y, Miedema B, et al. The influence of gender and other patient characteristics on health care-seeking behavior: a QUALICOPC study. BMC Fam Pract 2016; 17(3): 38. [PubMed: 27036116]
- [12]. Canfield MA, Mai CT, Wang Y, et al. The association between race/ethnicity and major birth defects in the United States, 1999–2007. Am J Pub Health 2014; 104(9): e14.
- [13]. Kim S, Ward E, Dicianno B, et al. National Spina Bifida Patient Registry. Factors associated with pressure sores in individual with spina bifida. Arch Phys Med Rehabil 2015; 96(8): 1435.
   [PubMed: 25796136]
- [14]. Cai B, McDermott S, Wang Y, et al. Skin Ulcers and Mortality Among Adolescents and Young Adults With Spina Bifida in South Carolina During 2000–2010. J Child Neurol 2016; 31(3): 370–7. [PubMed: 26239488]
- [15]. Litpak GS, Robinson LM, Davidson PW, et al. Life course health and healthcare utilization among adults with spina bifida. Dev Med Child Neurol 2015; 58(7): 714. [PubMed: 26526690]
- [16]. Wiener JS, Suson KD, Castillo J, et al. Bladder management and continence outcomes in adults with spina bifida: results from the National Spina Bifida Patient Registry 2009–15. Third World Congress on Spina Bifida San Diego CA 3 18, 2017.

~
₽
-
<u> </u>
The second secon
_
0
$\mathbf{O}$
<
ົ
_
_
7
Ē
7
SNI
lusc
SNI
lusc
IUSC
nuscri

Distribution of key demographic and clinical characteristics of patients with SB according to age in the National Spina Bifida Patient Registry, 2009–15

		Age grou	Age group (commn 70)		
Variables	Overall patients (%) (N = 5209)	5-11 ( <i>n</i> = 1958)	12-19 ( <i>n</i> = 1881)	20 and older $(n = 1370)$	P-value*
Sex					
Male	2434 (46.7)	946 (48.3)	906 (48.2)	582 (42.5)	
Female	2775 (53.3)	1012 (51.7)	975 (51.8)	788 (57.5)	0.0012
Race/ethnicity					
Non-Hispanic white	3310 (63.5)	1118 (57.1)	1124 (59.8)	1068 (78.0)	
Non-Hispanic black	377 (7.2)	127 (6.5)	154 (8.2)	96 (7.0)	
Hispanic or Latino	1130 (21.7)	476 (24.3)	494 (26.3)	160 (11.7)	
Other	376 (7.2)	227 (11.6)	103 (5.5)	46 (3.4)	
Refused/unknown	16 (0.3)	10~(0.5)	6 (0.3)	0	< 0.0001
Spina bifida type					
Myelomeningocele	4156 (79.8)	1463 (74.7)	1513 (80.4)	1180 (86.1)	
Other diagnosis	1053 (20.2)	495 (25.3)	368 (19.6)	190 (13.9)	< 0.0001
Level of lesion group					
Thoracic	926 (17.8)	181 (9.2)	350 (18.6)	395 (28.8)	
High-lumbar	482 (9.3)	149 (7.6)	167 (8.9)	166 (12.1)	
Mid-lumbar	1413 (27.1)	543 (27.7)	496 (26.4)	374 (27.3)	
Low-lumbar	838 (16.1)	370 (18.9)	316 (16.8)	152 (11.1)	
Sacral	1550 (29.8)	715 (36.5)	552 (29.3)	283 (20.7)	< 0.0001
Health insurance $(N = 5206)$					
Any private	2428 (46.6)	961 (49.1)	893 (47.5)	574 (41.9)	
Non-private	2778 (53.4)	995 (50.9)	987 (52.5)	796 (58.1)	0.0001

# Table 2

Distribution of NBD management techniques among patients with SB according to age in the National Spina Bifida Patient Registry, 2009–15

Age group (% within each age group)

	Overall patients (%) $(N = 5209)$	5-11 ( <i>n</i> = 1958)	12-19 ( <i>n</i> = 1881)	20 and older $(n = 1370)$	P-value <sup>A</sup>
Bowel management *					
Oral medications	316 (6.1)	121 (6.2)	124 (6.6)	71 (5.2)	0.24
Time evacuation	189 (3.6)	82 (4.2)	78 (4.1)	29 (2.1)	0.0023
Suppository	247 (4.7)	121 (6.2)	85 (4.5)	41 (3.0)	< 0.0001
Standard enema	175 (3.4)	75 (3.8)	43 (2.3)	57 (4.2)	0.0047
Cone enema	310 (6.0)	209 (10.7)	55 (2.9)	46 (3.4)	< 0.0001
Mini enema	164 (3.1)	103 (5.3)	48 (2.6)	13 (0.9)	< 0.0001
Antegrade enema	999 (19.3)	250 (12.8)	508 (27.2)	241 (17.7)	< 0.0001
Digital stimulation	158 (3.0)	50 (2.6)	48 (2.6)	60 (4.4)	0.0033
Disimpaction	108 (2.1)	26 (1.3)	41 (2.2)	41 (3.0)	0.0038
Other	67 (1.3)	18 (0.9)	20 (1.1)	29 (2.1)	0.0059
Bowel surgical history					
Antegrade colonic enema (Malone) channel creation	908 (17.4)	218 (11.1)	456 (24.2)	234 (17.1)	< 0.0001
Cecostomy button	268 (5.1)	68 (3.5)	124 (6.6)	76 (5.5)	< 0.0001
Cecostomy button closure	6 (0.1)	1 (0.1)	0	5 (0.4)	0.0058
Colostomy	135 (2.6)	38 (1.9)	44 (2.3)	53 (3.9)	0.0018
lleostomy	15 (0.3)	9 (0.5)	4 (0.2)	2 (0.1)	0.1879

J Pediatr Rehabil Med. Author manuscript; available in PMC 2019 July 27.

<sup>A</sup>Chi-square test.

### Table 3

Bowel continence outcomes among patients \* with SB segregated by SB type in the National Spina Bifida Patient Registry, 2009–15

	A	ge group (%	Age group (% continent in each age group)	acn age group)	
P	atients (%)	5-11	Patients (%) 5-11 12-19	20 and older P-value**	P-value <sup>**</sup>
Overall cohort ( $n = 5064$ )	2707 (53.5)	866 (45.2)	2707 (53.5) 866 (45.2) 1074 (58.6)	767 (58.3)	< 0.0001
Myelomeningocele ( $n = 4064$ )	1989 (48.9)	1989 (48.9) 550 (38.1)	809 (54.4)	630 (55.6)	< 0.0001
Non-myelomeningocele ( $n = 1000$ )	718 (71.8)	718 (71.8) 316 (67.1)	265 (76.6)	265 (76.6) 137 (74.9)	0.0070
* Excluding patients with history of colostomy and/or ileostomy.	omy and/or ile	eostomy.			
** Chi-square test.					

# Table 4

Demographics and clinical characteristics and continence outcomes in adults \* with SB aged 25 and older segregated by education level in the National Spina Bifida Patient Registry, 2009-15

			Education level		
Variables	Overall patients (%) (N = 708)	High school or less $(n = 379)$	Tech school or some college $(n = 191)$	College or more $(n = 138)$	P-value*
Sex					
Male	282 (39.8)	151 (39.8)	79 (41.4)	52 (37.7)	
Female	426 (60.2)	228 (60.2)	112 (58.6)	86 (62.3)	0.80
Employment $(n = 653)$					
Full-time or part-time	251 (38.4)	108 (30.8)	60 (34.3)	83 (65.4)	
Other	402 (61.6)	243 (69.2)	115 (65.7)	44 (34.6)	< 0.0001
Health insurance					
Any private	264 (37.3)	99 (26.1)	71 (37.2)	94 (68.1)	
Non-private	444 (62.7)	280 (73.9)	120 (62.8)	44 (31.9)	< 0.0001
SB type					
Myelomeningocele	621 (87.7)	348 (91.8)	167 (87.4)	106 (76.8)	
Other diagnosis	87 (12.3)	31 (8.2)	24 (12.6)	32 (23.2)	< 0.0001
Level of lesion group					
Thoracic	221 (31.2)	146 (38.5)	42 (22.0)	33 (23.9)	
High-lumbar	83 (11.7)	47 (12.4)	24 (12.6)	12 (8.7)	
Mid-lumbar	201 (28.4)	96 (25.3)	64 (33.5)	41 (29.7)	
Low-lumbar	76 (10.7)	40 (10.6)	22 (11.5)	14 (10.1)	
Sacral	127 (17.9)	50 (13.2)	39 (20.4)	38 (27.5)	< 0.0001
Bowel continence outcome					
Yes	390 (55.1)	192 (50.7)	112 (58.6)	86 (62.3)	
No	318 (44.9)	187 (49.3)	79 (41.4)	52 (37.7)	0.0318

J Pediatr Rehabil Med. Author manuscript; available in PMC 2019 July 27.

\*\* Chi-square test.

# Table 5

Odds of bowel continence according to key characteristics of 653 patients \* with SB aged 25 years and older in The National Spina Bifida Patient Registry, 2009-2015

	CITIVALIAN ALIAN		TATALLA TAULA TAULA LEGI CONTA	
	Odds ratio (95% CI)	P-value	Odds ratio (95% CI)	P-value
Gender		0.3280		0.5735
${ m Male}^{ au}$				
Female	1.16 (0.86, 1.57)		$1.10\ (0.80, 1.51)$	
Employment group		0.0002		0.0027
Full/part time ${}^{\!\!\!\!\!\!/}$				
Other	$0.54\ (0.39,\ 0.75)$		0.59~(0.42, 0.83)	
Health insurance		0.0098		0.3688
Any private $^{ au}$				
Non-private	$0.67\ (0.48,\ 0.91)$		0.85 (0.60, 1.21)	
Spina bifida type		0.0216		0.1344
Myelomeningocele $^{\dagger}$				
Other diagnosis	1.74 (1.09, 2.79)		1.52 (0.88, 2.61)	
Level of lesion		0.2469		$0.7160^{\ddagger}$
Thoracic $^{\dagger}$				
Lumbar-high	0.77 (0.47, 1.28)		0.78 (0.46, 1.34)	
Lumbar-mid	1.14 (0.78, 1.68)		1.11 (0.74, 1.67)	
Lumbar-low	0.97 (0.58, 1.64)		$0.90\ (0.51,1.59)$	
Sacral	1.44 (0.92, 2.24)		1.13(0.68, 1.89)	
Education		0.0324		$0.4439^{\ddagger}$
High school or less $^{ au}$				
Technical school or some college	1.38 (0.97, 1.96)		1.28 (0.88, 1.86)	
College or more	1.61 (1.08, 2.40)		1.13 (0.72, 1.78)	

