Published in final edited form as:

J Urol. 2018 July; 200(1): 187–194. doi:10.1016/j.juro.2018.02.3101.

Bladder Management and Continence Outcomes in Adults with Spina Bifida: Results from the National Spina Bifida Patient Registry, 2009 to 2015

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Abstract

Purpose: Most children with spina bifida now survive into adulthood, although most have neuropathic bladder with potential complications of incontinence, infection, renal damage and diminished quality of life. In this study we sought to 1) describe contemporary bladder management and continence outcomes of adults with spina bifida, 2) describe differences from younger individuals and 3) assess for association with socioeconomic factors.

Materials and Methods: We analyzed data on bladder management and outcomes in adults with spina bifida from the National Spina Bifida Patient Registry. A strict definition of continence was used. Results were compared to young children (age 5 to 11 years) and adolescents (12 to 19). Statistical analysis compared cohorts by gender, ethnicity, spina bifida type, lesion level, insurance status, educational attainment, employment status and continence.

Results: A total of 5,250 patients with spina bifida were included, of whom 1,372 (26.1%) were adults. Of the adult patients 45.8% did not take medication, but 76.8% performed clean intermittent catheterization. Continence was decreased in adults with myelomeningocele (45.8%) vs those with non-myelomeningocele spina bifida (63.1%, p <0.0001). Continence rates were higher in the older cohorts with myelomeningocele (p <0.0001) but not in those with non-myelomeningocele spina bifida (p 1/4 0.1192). Bladder management and history of urological surgery varied among age groups. On univariate analysis with spina bifida related or socioeconomic variables continence was significantly associated with educational level but on

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No direct or indirect commercial incentive associated with publishing this article.

The corresponding author certifies that, when applicable, a statement(s) has been included in the manuscript documenting institutional review board, ethics committee or ethical review board study approval; principles of Helsinki Declaration were followed in lieu of formal ethics committee approval; institutional animal care and use committee approval; all human subjects provided written informed consent with guarantees of confidentiality; IRB approved protocol number; animal approved project number.

multivariable logistic regression analysis bladder continence was significantly associated with employment status only.

Conclusions: Bladder management techniques differ between adults and children with spina bifida. Bladder continence outcomes were better in adults, with nearly half reporting continence. Continence was significantly associated with employment status in patients age 25 years or older.

Keywords

urinary bladder; neurogenic; spinal dysraphism; urinary incontinence; urination disorders

DUE to medical advancements, nearly all children born with spina bifida survive into adulthood so that today most Americans living with spina bifida are adults. Neuropathic bladder impairment is present in most of these patients, with potential sequelae of incontinence, recurrent urinary tract infections, chronic renal insufficiency and diminished quality of life. ^{2–4} With the increased number of older patients the transition to adult care has become an important component of urological spina bifida care. ⁵

The National Spina Bifida Patient Registry, funded through the Centers for Disease Control and Prevention, began collecting data from multidisciplinary spina bifida clinics across the US in 2009. The primary goals were to describe patients attending those clinics, provide a foundation for research and improve clinical care. Secondarily the registry has enabled collaborative research across multiple time points. The registry includes more than 6,000 cases with sufficient granularity to study bladder management and continence outcomes.

Currently few data are available regarding urological care in adults with SB. We sought to 1) describe contemporary bladder management and continence outcomes in adults with SB, 2) describe differences between adults and younger individuals, and 3) assess for association with socioeconomic factors to improve care and develop realistic expectations for individuals with SB of all ages and their families. We hypothesized that adults would differ from younger patients, and that continence would be associated with better educational and employment outcomes.

METHODS

The NSBPR uses a standardized tool to collect longitudinal data from patients with spina bifida at 26 sites with 6 diagnoses, including MMC, meningocele, lip-omyelomeningocele, split cord malformation, terminal myelocystocele and fatty filum. After local institutional review board approval parents and patients gave informed consent. Enrollment of all eligible patients was encouraged but not required. Baseline demographic and diagnostic information was collected at enrollment, and updated demographic and clinical data were gathered yearly. The data used were obtained at the most recent clinic visit through medical record abstraction and patient interview.

Sociodemographic Characteristics

Patients were segregated according to age as school-age (5 to 11 years), adolescent (12 to 19) and adult (20 or older) to compare treatment techniques and outcomes. Race/ethnicity

was classified as nonHispanic white, nonHispanic black, Hispanic or Latino and other. Health insurance was categorized as private or nonprivate. College attendance, graduation rates and current employment status (full-time or part-time vs other, ie not employed, retired, volunteer or occasional worker) were studied in patients age 25 years or older.⁹

SB Lesion Characteristics and Motor Function

SB diagnosis was classified as MMC or nonMMC. Functional lesion level was reported for each lower extremity and defined by the more severe side.

Continence Outcomes

During initial data collection (through September 2013) urinary continence was defined as "dry, with or without interventions, during the day." Later (October 2013 to December 2015) continence was evaluated by multiple choices to "Quantify frequency of bladder incontinence during the day over the last month (when not having a UTI)." Only answers of "Never" or "Less than once per month" were considered as continent. Individuals using one of several forms of bladder management were considered incontinent regardless of their response, including urostomy bag, vesicostomy, indwelling catheter and condom catheter. Responses of "Cannot assess" (90 patients) were excluded.

Management Techniques

Daily antibiotic and antimuscarinic medication usage was analyzed. Surgical history was obtained for bladder augmentation, continent catheterizable urinary channel (Mitrofanoff appendicovesicostomy and Monti reconfigurated small bowel), cutaneous vesicostomy, bladder outlet operation for continence and urinary stone removal. Bladder management techniques were queried and categorized as no management (incontinent in diaper), spontaneous voiding, CIC, indwelling catheter, cutaneous vesicostomy, urostomy (into external appliance), Credé maneuver and condom catheter.

Statistical Analysis

Associations among independent categorical variables were tested using chi-square analysis. Multivariable logistic regression models were used to test the association of bladder continence outcomes with gender, SB type, level of lesion, health insurance type, employment status and educational attainment. Statistical tests were all 2-sided, and p <0.05 was considered significant. Statistical analyses were performed using SAS®, version 9.3.

RESULTS

Demographics

The analysis included 5,250 participants 5 to 83 years old at their last clinic visit through December 2015 (table 1). Adults comprised only 26.1% of the registry participants as clinics at pediatric hospitals represented the majority of enrolled sites. The proportion of females was slightly higher in the 2 younger cohorts and significantly higher in the adult cohort. Racial and ethnic distribution varied with age, with higher proportions of nonHispanic whites in the older groups and a higher proportion of Hispanic/Latinos in the youngest.

There was a larger proportion of adults with MMC and with higher level lesions. The proportion of participants with any private insurance was lower in adults. Patient reported employment status was low, with the majority of adolescents and nearly 1 of 5 adults identifying as students. Slightly more than 1 of 4 adults reported being permanently disabled.

Bladder Management

The proportion of patients using daily antibiotics was low but was increased in adults (table 2). Approximately half of patients used antimuscarinic medication, with decreasing use in older cohorts. Alpha-adrenergic receptor agonist and antagonist medication usage to improve continence or voiding was uncommon and was reported by 6 and 2 patients, respectively.

Analysis of urological surgical history showed an increased prevalence of bladder augmentation, with almost 1 of 4 adults reporting having undergone augmentation. Creation of a continent catheterizable channel (Mitrofanoff or Monti) was greater in adolescents (13.1%) compared to adults (8.1%) and school-age children (7.5%). Proportions of patients with a history of cutaneous vesicostomy or bladder outlet operation were higher in adolescents compared to other age groups. By contrast, history of surgery for stones was more prevalent in adults.

For bladder management choices of "no management" and "spontaneous voiding in toilet" decreased in older age groups. CIC usage was similar in adolescents and adults and was greater than in school-age children. Management by cutaneous vesicostomy decreased with age. Management by indwelling catheter, urostomy bag (incontinent diversion), Credé maneuver or condom catheter was relatively rare but was more common in adults.

Segregation of patients by SB type also demonstrated differences in use of CIC by age (table 3). Overall, 4 of 5 patients with MMC used CIC, with adolescents comprising the highest proportion (83.8%), while only 2 of 5 patients with nonMMC SB performed CIC, with adults comprising the highest proportion (59.5%). Comparison of adults revealed a significant difference only in CIC usage between patients with (79.5%) and without MMC (59.5%, p < 0.0001).

Bladder Continence Outcomes

Of the entire cohort 2,284 (43.5%) were considered continent. Interestingly 118 of 293 participants (40.3%) with incontinent forms of bladder management reported continence when asked but were considered incontinent by definition for this analysis. Bladder continence increased with age (36.9% in school-age children, 47.1% in adolescents and 48.2% in adults, p <0.0001). Segregation by SB type (table 3) showed that continence also increased significantly among age groups with MMC, although no statistically significant difference was seen between age groups with nonMMC diagnosis. Of adults continence was lower in those with MMC (45.8%) vs nonMMC SB (63.1%, p <0.0001).

Segregation by Education Level in Adults Age 25 Years or Older

Almost half of patients age 25 years or older pursued post-high school education, with only 1 of 5 attaining a college degree or higher (table 4). Educational attainment did not vary significantly with gender. Employment and private health insurance were associated with higher education, as were nonMMC SB and lower lesion levels. Among the 3 education groups only those with a college degree exceeded 50% continence rate, and continence was significantly associated with education level (p = 0.0077).

Multiple Logistic Regression Models in Adults Age 25 Years or Older

Multiple logistic regression models with SB related and socioeconomic variables demonstrated significant associations between bladder continence and employment status. After controlling for all other variables full-time and part-time workers were more continent than others (p = 0.0232, table 5). Educational attainment was not associated with continence when controlling for other variables.

DISCUSSION

This analysis of bladder management and continence outcomes in SB represents the largest cohort of adults described to date. These data are helpful not only to evaluate current care, but also to provide realistic expectations to younger individuals about future management and outcomes. Furthermore, we noted significant differences among adults compared to younger patients.

Variation in neuropathic bladder dysfunction was expected as the neuropathy associated with SB is a spectrum. Our adult cohort had a greater prevalence of the MMC form of SB and higher lesion level than younger cohorts. This difference could be explained by a tendency of adults with milder forms of SB to be less likely to receive care at multidisciplinary SB clinics.

Overall usage of CIC among adults was 76.8% (79.5% for MMC and 59.5% nonMMC) and bladder continence was 48.2% (45.8% and 63.1% for MMC and nonMMC, respectively). Liu et al noted a similar rate of CIC usage, at 71% in 225 adults with SB, of whom 87% had MMC. ¹⁰ Another study of 65 individuals with SB at 2 adult clinics revealed nearly identical rates of continence (48%) and CIC (77%). ⁵ An international online survey of 518 adults with SB showed similar CIC usage (76%), although bladder continence was notably lower at 23.7%. ¹¹ It is unclear if the lower continence was due to the voluntary and private nature of the online survey or a different definition of continence. Nonetheless, these studies demonstrate that most adults with SB utilize CIC, even with nonMMC defects, and that bladder continence is attainable for a large proportion.

Our adult cohort had a higher proportion of females compared to younger cohorts. This group was less skewed than the adult SB group reported by Liu et al, which was two-thirds female. Perhaps females are more likely than males to seek treatment at NSBPR clinics, or males with SB have decreased longevity compared to females. Nonetheless, no continence differences were associated with gender. We also noted that the racial and ethnic mix of the population with spina bifida in the US has been changing through time, as seen in the 26

NSBPR sites in 20 states. The younger 2 cohorts had proportionally fewer nonHispanic white patients and more Hispanics/Latino patients. This finding likely reflects increased immigration of Hispanic/Latino individuals to the US in recent decades, and this population has a higher incidence of SB and higher birth rates. ¹²

Usage of daily antibiotics was greater in adults. It is not known if this strategy to prevent UTI was begun in these patients when such practice was more common or if they indeed have more UTIs. However, use of antimuscarinic medication was decreased in adults despite improved continence rates and was similar to usage reported by Liu et al (49%). This finding could be related to a higher proportion of patients with a history of bladder augmentation, which typically obviates the need for such medication. The higher proportion of adults who had undergone bladder augmentation may be a reflection of increasing surgical indications with age due to bladder hostility, increasing desire for continence or prior practice patterns that more aggressively relied on augmentation.

The proportions of patients undergoing specific surgeries also could have been affected by prior surgical choices. For instance patients with a vesicostomy do not undergo bladder augmentation and vice versa. Adults underwent fewer surgeries to create continent catheterizable channels compared to adolescents, likely due to the fact that these operations have come into favor only in the last 2 decades. Summers et al noted a similar rate for prior bladder augmentation in their adult clinics (29%). Patients with SB have a greater risk of urolithiasis compared to the general population that increases with age, ¹³ so an increased incidence of stone surgery in adults was not unexpected. The higher proportion of adolescents undergoing bladder outlet surgery for continence may be a reflection of an evolution of more aggressive efforts to help patients with spina bifida attain continence.

The proportion of individuals with no bladder management decreased with age. This finding may explain why bladder continence improved with age, from 36.9% in school-age children to 48.2% in adults. Bladder continence was significantly greater in adults with nonMMC compared to MMC SB. Adults were more likely to perform CIC and less likely to void spontaneously but CIC was less frequently used by adults with nonMMC SB. However, nearly 7% of all adults had an indwelling catheter or urostomy bag. It is unclear if this finding reflects older practice patterns or aging related sequelae such as progression of incontinence, declining mobility, inability to manage the bladder independently and increasing incidence of pressure ulcers. ¹⁴ Regardless, as more individuals with SB survive further into adulthood, it will be important to determine if forms of bladder management change due to SB related factors or changes in practice paradigms. Inclusion of urodynamic parameters (added to phase 2 of the NSBPR) in future studies should further our understanding of the bladder pathology underlying these findings.

Our socioeconomic findings have implications for the social, educational and vocational development of individuals with SB. We previously analyzed socioeconomic factors in the same adult cohort of patients in the NSBPR and found bowel continence to be associated with higher employment rates and educational attainment on univariate analysis and with employment only on multivariable logistic regression analysis. ¹⁵ In the current analysis of urinary parameters similar statistically significant associations were found between bladder

continence and educational attainment/employment status. These associations were not appreciated on the initial analysis before excluding those with incontinent forms of management. 15

These findings add to the growing body of literature investigating the impact of continence on QOL. Szymanski et al noted that QOL of adult patients with spina bifida was more negatively affected by any bowel incontinence than by low volume bladder incontinence. Similarly Liu et al found that QOL outcomes in 66 adults with SB did not differ based on bladder management techniques. 3

Our study has several potential limitations. As with any large database, errors in patient recall and data entry could have occurred. The NSBPR carefully standardizes data components and collection and has ongoing data quality monitoring. There is potential for selection bias at NSBPR clinics but analyses have revealed no significant differences in eligible, but not enrolled, patients in these clinics. Adults in the registry may not be representative of all adults with SB because they may be receiving more intensive and systematic care in selected clinics than patients receiving care elsewhere. Furthermore, adults attending these clinics may have a higher level of SB related disease burden than those not attending selected clinics. The age distribution of adults in the NSBPR is skewed toward young adults, so these findings may not be representative of older adults with SB. Finally, refinement of the definition of continence during the study period could have impacted the continence outcomes findings.

CONCLUSIONS

This analysis, which is the largest to date of bladder management and continence outcomes in adults with SB, found significant differences compared to adolescents and younger children. Management and outcomes varied by SB type but overall more than three-fourths of adults performed CIC. Bladder continence improved with age for patients with MMC and was significantly associated with employment status. These findings may help guide management of neuropathic bladder in adults with SB and provide realistic goals for younger individuals.

ACKNOWLEDGMENTS

Development of the National Spina Bifida Patient Registry has been successful due to the contributions of members of the NSBPR Coordinating Committee. Members of this committee during 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; Jacob Neufeld, St. Luke's Boise Medical Center, Boise; Robin Bowman, Lurie Children's Hospital of Chicago, Chicago; Karen Ratliff-Schaub, Nationwide Children's Hospital, Columbus; Jim Chinarian, Children's Hospital of Michigan, Detroit; 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; Carlos Estrada, Boston Children's Hospital, Boston, and Michael Partington, Gillette Children's Specialty Healthcare, St. Paul.

Study received institutional review board approval.

Funded by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (Grant 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 and Acronyms

CIC clean intermittent catheterization

MMC myelomeningocele

NSBPR National Spina Bifida Patient Registry

QOL quality of life

SB spina bifida

US United States

UTI urinary tract infection

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Table 1.

Demographic and clinical characteristics

		Age Group			
	5-11 Yrs	12–19 Yrs	20 Yrs or Older	Overall/Total No. (%)	p Value (chi-square test)
No. pts	1,993	1,885	1,372	5,250/5,250 (100)	
No. gender (%):					0.0008
Male	968 (48.6)	909 (48.2)	583 (42.5)	2,460/5,250 (46.9)	
Female	1,025 (51.4)	976 (51.8)	789 (57.5)	2,790/5,250 (53.1)	
No. race (%):					<0.0001
NonHispanic white	1,144 (57.4)	1,123 (59.6)	1,073 (78.2)	3,340/5,250 (63.6)	
NonHispanic black	134 (6.7)	151 (8.0)	97 (7.1)	382/5,250 (7.3)	
Hispanic or Latino	480 (24.1)	500 (26.5)	157 (11.4)	1,137/5,250 (21.7)	
Other	225 (11.3)	105 (5.6)	45 (3.3)	375/5,250 (7.1)	
Refused/unknown	10 (0.5)	6 (0.3)	0 (0)	16/5,250 (0.3)	
No. spina bifida type (%):					<0.0001
Myelomeningocele	1,492 (74.9)	1,516 (80.4)	1,185 (86.4)	4,193/5,250 (79.9)	
Other diagnosis	501 (25.1)	369 (19.6)	187 (13.6)	1,057/5,250 (20.1)	
No. level of lesion (%):					<0.0001
Thoracic	193 (9.7)	347 (18.4)	395 (28.8)	935/5,250 (17.8)	
High lumbar	150 (7.5)	163 (8.6)	167 (12.2)	480/5,250 (9.1)	
Mid lumbar	554 (27.8)	502 (26.6)	378 (27.6)	1,434/5,250 (27.3)	
Low lumbar	378 (19.0)	317 (16.8)	152 (11.1)	847/5,250 (16.1)	
Sacral	718 (36.0)	556 (29.5)	280 (20.4)	1,554/5,250 (29.6)	
No. health insurance (%):					0.0003
Any private	974 (48.9)	894 (47.5)	577 (42.1)	2,445/5,247 (46.6)	
Nonprivate	1,017 (51.1)	990 (52.5)	795 (57.9)	2,802/5,247 (53.4)	
No. employment status (%):					<0.0001
Employed full-time	0 (0)	11 (0.6)	185 (13.5)	196/5,250 (3.7)	
Employed part-time	0 (0)	62 (3.3)	235 (17.1)	297/5,250 (5.7)	
Occasional worker	0 0	3 (0.2)	18 (1.3)	21/5,250 (0.4)	
Not employed:					

Some subanalyses had fewer than 5,250 individuals responding to each item.

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Table 2.

Bladder management techniques

		Age Group			
	5-11 Yrs	12-19 Yrs	20 Yrs or Older	p Value Overall/Total No. (%) (chi-square test)	p Value (chi-square test)
No. pts	1,993	1,885	1,372	5,250/5,250 (100)	
No. bladder medications (%):					
Daily antibiotic	190 (11.9)	163 (12.1)	170 (17.4)	523/3,924 (13.3)	<0.0001
Antimuscarinic	853 (53.2)	687 (51.2)	467 (47.7)	2,007/3,924 (51.1)	0.0249
None	695 (43.4)	605 (45.1)	448 (45.8)	1,748/3,924 (44.5)	0.44
No. urological surgical history (%): *					
Bladder augmentation	124 (6.2)	380 (20.2)	316 (23.0)	820/5,250 (15.6)	<0.0001
Mitrofanoff channel	105 (5.3)	150(8.0)	70(5.1)	325/5,250(6.2)	0.0004
Monti channel	50 (2.5)	102 (5.4)	44 (3.2)	196/5,250 (3.7)	<0.0001
Mitrofanoff + Monti	150 (7.5)	247 (13.1)	111 (8.1)	508/5,250 (9.7)	<0.0001
Vesicostomy	90 (4.5)	131 (6.9)	75 (5.5)	296/5,250 (5.6)	0.0043
Bladder outlet operation	47 (2.4)	96 (5.1)	60 (4.4)	203/5,250 (3.9)	<0.0001
Stone surgery removal	25 (1.3)	59 (3.1)	66 (4.8)	150/5,250 (2.9)	<0.0001
No. bladder management (%):					
None/incontinent	247 (12.4)	112 (5.9)	68 (5.0)	427/5,243 (8.1)	<0.0001
Spontaneous void	397 (20.0)	290 (15.4)	143 (10.5)	830/5,226 (15.9)	<0.0001
Clean intermittent catheterization	1,279 (64.8)	1,435 (76.6)	1,047 (76.8)	3,761/5,211 (72.2)	<0.0001
Indwelling catheter	39 (2.0)	35 (1.9)	45 (3.3)	119/5,250 (2.3)	0.0132
Vesicostomy	56 (2.8)	29 (1.5)	22 (1.6)	107/5,241 (2.0)	0.0083
Urostomy bag	3 (0.2)	11 (0.6)	49 (3.6)	63/5,248 (1.2)	<0.0001
Credé	1 (0.1)	4 (0.2)	7 (0.5)	12/5,250 (0.2)	0.0226
Condom catheter	0 (0)	0 (0)	4 (0.3)	4/5,250 (0.1)	0.0035

* Percentages do not total 100 since some individuals were taking multiple medications or underwent multiple surgeries/forms of management.

Table 3.

Bladder management and continence outcomes by SB type

		Age Group	•		
	5-11 Yrs	12 –19 Yrs	20 Yrs or Older	5-11 Yrs 12-19 Yrs 20 Yrs or Older Overall/Total No. (%) (chi-square test)	P Value (chi-square test)
No. pts	1,993	1,885	1,372	5,250/5,250 (100)	
No. bladder management by CIC (%):					
Myelomeningocele	1,141 (77.1)	1,141 (77.1) 1,261 (83.8)	937 (79.5)	3,339/4,193 (80.2)	<0.0001
Nonmyelomeningocele	138 (27.9)	174 (47.3)	110 (59.5)	422/1,057 (40.3)	<0.0001
No. bladder continence (%):					
Myelomeningocele	432 (29.0)	638 (42.1)	543 (45.8)	1,613/4,193 (38.5)	<0.0001
Nonmyelomeningocele	304 (60.7)	249 (67.5)	118 (63.1)	671/1,057 (63.5)	0.1192
All pts	736 (36.9)	887 (47.1)	661 (48.2)	2,284/5,250 (43.5)	<0.0001

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Table 4.

Demographics and continence outcomes in patients older than 25 years with SB by education level

		Education Level			
	High School or Less	Technical School or Some College	College or Higher	Overall	p Value (chi-square test)
No. pts	402	195	143	740	
No. gender (%):					0.75
Male	163 (40.5)	83 (42.6)	55 (38.5)	301 (40.7)	
Female	239 (59.5)	112 (57.4)	88 (61.5)	439 (59.3)	
No. employment (%):					<0.0001
Full-time or part-time	108 (26.9)	64 (32.8)	85 (59.4)	257 (34.7)	
Other	294 (73.1)	131 (67.2)	58 (40.6)	483 (65.3)	
No. health insurance (%):					<0.0001
Any private	110 (27.4)	73 (37.4)	94 (65.7)	277 (37.4)	
Nonprivate	292 (72.6)	122 (62.6)	49 (34.3)	463 (62.6)	
No. SB type (%):					<0.0001
Myelomeningocele	372 (92.5)	171 (87.7)	111 (77.6)	654 (88.4)	
Other diagnosis	30 (7.5)	24 (12.3)	32 (22.4)	86 (11.6)	
No. level of lesion (%):					<0.0001
Thoracic	166 (41.3)	40 (20.5)	33 (23.1)	239 (32.3)	
High lumbar	47 (11.7)	25 (12.8)	12 (8.4)	84 (11.4)	
Mid lumbar	98 (24.4)	67 (34.4)	45 (31.5)	210 (28.4)	
Low lumbar	40 (10.0)	23 (11.8)	14 (9.8)	77 (10.4)	
Sacral	51 (12.7)	40 (20.5)	39 (27.3)	130 (17.6)	
No. bladder continence (%)	155 (38.6)	92 (47.2)	75 (52.4)	322 (43.5)	0.0077

Table 5.

Odds association of bladder continence with key characteristics of patients older than 25 years with SB, based on multivariable logistic regression

	OR (95% CI)	p Value
Gender:		0.34
Male	Referent	
Female	1.16 (0.86, 1.57)	
Employment:		0.0232
Full-time/part-time	Referent	
Other	0.69 (0.49, 0.95)	
Health insurance:		0.29
Any private	Referent	
Nonprivate	0.84 (0.60, 1.17)	
Spina bifida type:		0.90
Myelomeningocele	Referent	
Other diagnosis	1.03 (0.62, 1.71)	
Level of lesion:		0.1057
Thoracic	Referent	
High lumbar	0.99 (0.59, 1.65)	
Mid lumbar	1.09 (0.74, 1.16)	
Low lumbar	1.00 (0.58, 1.71)	
Sacral	1.83 (1.83, 2.95)	
Education:		0.23
High school or less	Referent	
Technical school or some college	1.31 (0.91, 1.87)	
College or higher	1.33 (0.87, 2.02)	