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Longitudinal Study of Bladder Continence in Patients with Spina Bifida in the National Spina Bifida Patient Registry

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Abstract

Purpose—Achieving bladder continence in individuals with spina bifida is a lifetime management goal. We investigated bladder continence status through time and factors associated with this status in patients with spina bifida.

Materials and Methods—We used National Spina Bifida Patient Registry data collected from 2009 through 2015 and applied generalized estimating equation models to analyze factors associated with bladder continence status.

Results—This analysis included 5,250 participants with spina bifida in a large, multi-institutional patient registry who accounted for 12,740 annual clinic visit records during the study period. At last followup mean age was 16.6 years, 22.4% of participants had undergone bladder continence surgery, 92.6% used some form of bladder management and 45.8% reported bladder continence. In a multivariable regression model the likelihood of bladder continence was significantly greater in those who were older, were female, were nonHispanic white, had a nonmyelomeningocele diagnosis, had a lower level of lesion, had a higher mobility level and had private insurance. Continence surgery history and current management were also associated with continence independent of all other factors (adjusted OR and 95% CI 1.9, 1.7–2.1 and 3.8, 3.2–4.6, respectively). The association between bladder management and continence was stronger for those

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with a myelomeningocele diagnosis (adjusted OR 4.6) than with non-myelomeningocele (adjusted OR 2.8).

Conclusions—In addition to demographic, social and clinical factors, surgical intervention and bladder management are significantly and independently associated with bladder continence status in individuals with spina bifida. The association between bladder management and continence is stronger in those with myelomeningocele.

Keywords

longitudinal studies; spinal dysraphism; urologic surgical procedures

Spina bifida results from an incomplete closure of the neural tube during embryonic development and is usually associated with neurogenic bladder.[1] Achieving bladder continence is a goal for most individuals with spina bifida. Several condition related factors are associated with lower rates of bladder continence, such as myelomeningocele spina bifida diagnosis, a higher lesion level and the presence of shunted hydrocephalus.[2] Achieving bladder continence has a significant impact on quality of life among individuals with spina bifida. Bladder incontinence, independent of fecal incontinence, is a predictor of lower health related quality of life in adults.[3,4] In children continence status does not seem to affect quality of life in the same manner,[5] although continence management broadly affects quality of life at home and at school.[6] In addition to health benefits, children who are continent of urine enjoy greater independenceandopportunitiesforsocialparticipation.[7]

In recent decades the number of interventions available to individuals with neurogenic bladder has grown, resulting in patients undergoing more urological procedures.[8] Reconstructive surgery and medical management are important components of urological care for many individuals with SB.[9,10] However, little is known about bladder continence status through time. The existing literature contains mostly cross-sectional data consisting of continence information at only 1 point in time rather than longitudinally,[11,12] and there is no standard definition of continence used consistently across studies.[13] The paucity of long-term followup for SB related medical and surgical therapies leaves unclear to what degree these interventions affect incontinence through time and makes assessment of the efficacy of these interventions challenging.

We used data from NSBPR to investigate the association between medical and surgical interventions and bladder continence status through time in patients with SB. We hypothesized that reconstructive surgery and medical management aimed at improving bladder continence would be positively associated with continence independent of demographic, social or condition related factors.

MATERIALS AND METHODS

National Spina Bifida Patient Registry

NSBPR is a clinic based registry designed to identify the processes of care and health outcomes in a large sample of individuals with SB. Nine sites (10 clinics, with 1 site including 2 clinics) were funded by CDC to participate in NSBPR to test the feasibility of

using a standard data collection tool to gather longitudinal data from patients having a diagnosis of MMC, meningocele, lipomyelomeningocele or fatty filum between 2008 and 2009.[14] Two additional diagnoses were added in 2013, ie split cord malformation and terminal myelocystocele. By 2015 a total of 26 sites (29 clinics, with 3 sites including 2 clinics each) had joined NSBPR.

Institutional review board approval was obtained locally. Informed consent was obtained from participants or parents/guardians. Sites were initially encouraged but not required to enroll all patients with SB. To assess bias, demographic (age, gender, race/ethnicity), social (health insurance status) and condition related data (SB diagnosis, functional level of lesion) variables were collected from those not enrolled. Data were collected by patient interview or questionnaire, or abstracted from the medical chart using standardized data collection forms at enrollment (initial encounter) and followup (annual) visits. Participant data are deidentified and transmitted to CDC for data management and analysis. Numerous systematic procedures are implemented at clinic sites and the CDC Data Management Center to ensure data quality.[14]

For this study we accessed NSBPR data collected at the initial encounter and subsequent annual followup visits for each patient seen from 2009 to 2015. We restricted statistical analysis to data collected from 5,250 participants who were age 5 years or older at the annual visit since bladder continence likely was not consistently emphasized before this age.

Continence Outcome

During the first phase (2009 to October 2013) bladder continence was defined as answering “yes” to the question about being “dry, with or without intervention, during the day.” Subsequently (October 2013 to present) continence was assessed by asking patients to “quantify frequency of urinary incontinence during the day during the last month (when not having a urinary tract infection)” using a multiple-choice format. To create a common definition of continence, we dichotomized the multiple-choice answers. Those who answered “never” or “less than once per month” were considered continent, while those with a greater frequency were considered incontinent. We excluded from analysis patients who answered “cannot assess.”

Sociodemographic Characteristics

Participant age was estimated based on year and month of birth and annual visit. Gender and race/ethnicity data were collected at the initial encounter. Participants were classified by race/ethnicity as nonHispanic white, nonHispanic black, Hispanic or Latino, or other (combined Asian, Native Hawaiian or other Pacific Islander, American Indian or Alaska Native and multiracial). Health insurance information reported at each visit was used to categorize participants into 2 groups, ie any private insurance (commercial, military, regional, etc) and nonprivate insurance (Medicaid, Medicare, charity, etc).

SB Lesion Characteristics and Motor Function

Participants were classified by SB diagnosis into 2 groups, those with MMC and those with nonMMC. Functional lesion level was reported for both sides in 5 categories, ie thoracic

(flaccid lower extremities), high lumbar (hip flexion present), mid lumbar (knee extension present), low lumbar (foot dorsiflexion present) and sacral (foot plantar flexion present). If the lesion differed by side, then the more severe (higher) lesion was used to represent functional lesion level. For this analysis the 3 lumbar categories were combined. Participants were grouped by mobility status into categories of 1) community ambulator, 2) household ambulator, 3) therapeutic ambulator and 4) nonambulator.[15]

Continence Surgeries and Management

A history of bladder continence surgery was defined as having undergone 1 or more procedures performed before the annual visit date, as defined by SNOMED (Systematized Nomenclature of Medicine) terminology. Included procedures consisted of bladder augmentation, appendi-covesicostomy, construction of cutaneous stoma of urinary bladder, bladder outlet operations, closure of cystostomy, bladder reconstruction, surgical closure of bladder neck and/or bladder neck operations.

Bladder management was defined as 1 or more treatments or techniques that included spontaneous void, use of medications (alpha-adrenergic agonist, alpha-adrenergic blocker and antimuscarinics), clean intermittent catheterization, Credé maneuver, condom catheter, urostomy bag, indwelling catheter and vesicostomy. Diaper use was considered as absence of bladder management technique.

Statistical Analysis

Covariates included time independent variables (gender, race/ethnicity and SB diagnosis) and time dependent variables (age, functional level of lesion, health insurance, mobility status, history of continence surgery and management technique). Associations between categorical independent variables and continence status at last visit were evaluated using chi-square tests. Associations between continuous independent variables and continence status at last visit were evaluated using the nonparametric Wilcoxon test.

To account for repeated observations of continence status and other time dependent variables in the same person, we used GEE models to examine the association of continence status with each of the factors described.[16] Participants clustered by clinic were also accounted for as correlated data in the models. We developed separate multiple GEE models to test the independent association between continence status and management strategies, and continence status and surgical procedures, controlling for other factors, using an exchangeable correlation structure for each model.[17,18] We tested the interaction between SB diagnosis and bladder management in a multiple regression model. Statistical tests were all 2-sided, and p values less than 0.05 were considered significant. Statistical analyses were performed using SAS® 9.3 software and R software (R Project for Statistical Computing, http://www.r-project.org), with 95% CIs calculated for all point estimates.

Selection Bias Analysis

Given that clinics are not required to enroll all patients with SB, it is possible that enrollment was not random.[12] Therefore, we used previously described methods to assess selection bias in enrollment.[19,20] With data of EAE participants at the last contact we built a logistic

regression model predicting actual continence status from selected variables (age, gender, race/ethnicity, health insurance status, SB diagnosis, functional level of lesion) and estimated the probability of bladder continence. According to this probability, we randomly assigned a continence status (yes/no) to each ENE patient using a Bernoulli trial.[21] This step is repeated 10,000 times for each ENE individual. EAE and ENE samples were then combined into a single data set for the enrollment bias analysis.

Selection bias is suspected if enrollment varies significantly across the strata of a predictor variable. To test for bias, for each continence status (yes/no) separately we used logistic regression to model the likelihood of enrollment according to the characteristics shown to be significantly associated with continence in our previous models. In the absence of selection bias the likelihood of enrollment would be the same for each continence status, ie the likelihood ratio would be 1. This ratio is called the ratio of selection probability ratios. Adjusted OR is then calculated by dividing the observed OR for being continent by the RSPR. If the RSPR is different from 1, then the adjusted OR will reflect the magnitude of the bias.

RESULTS

Longitudinal Data Collection of Bladder Continence Status

Demographic and clinical characteristics at last visit of 5,250 participants 5 years old or older are summarized in table 1. Between 2009 and 2015 NSBPR recorded 12,740 visits from study participants whose bladder continence status was documented. Of the 1,865 patients with a single visit the prevalence of bladder continence was 42.4%. Of the 3,385 participants with 2 or more annual visits 1,166 (34.4%) remained incontinent for the followup period of study, 781 (23.1%) remained continent and 1,438 (42.5%) experienced changes in continence status. There was a total of 7,490 return visits in participants with 2 or more annual visits. A change from incontinence to continence since the previous visit was reported in 15.7% of these visits, and the opposite change, from continence to incontinence, in 11.9%. Among all participants 45.8% reported bladder continence at the most recent visit.

Univariate GEE Analysis

When the 9 independent variables were tested separately, all were significantly associated with bladder continence (supplementary table 1, http://jurology.com/). The odds of continence were higher in individuals who were older, female, were nonHispanic white or other race/ethnicity, had been diagnosed with nonMMC, had a history of continence surgery, were using a management technique, had a lower lesion level, were ambulatory or had private health insurance.

Multiple GEE Regression Models Analysis

In multiple regression models all associations remained statistically significant (table 2). The odds of continence increased in individuals using vs not using bladder management techniques (OR 3.8, 95% CI 3.2–4.6). Likewise, the odds of continence increased in those who reported a history of continence surgery (OR 1.9, 95% CI 1.7–2.1).

The interaction term between SB diagnosis and bladder management was significantly associated with continence status (p = 0.006). Therefore, we used separate models for MMC and nonMMC groups. Continence was more likely among those with either diagnosis who reported following a bladder management strategy, although the magnitude of the association was different (MMC OR 4.6, 95% CI 3.6–6.0; nonMMC OR 2.8, 95% CI 2.1–3.7).

Selection Bias Analysis

Using 2015 clinic visit data, 3,808 EAE participants and 1,321 ENE individuals were included in this analysis. After running the full model we observed a significant lack of fit (Hosmer-Lemeshow test, p = 0.01). Therefore, we tested a reduced model by excluding race/ethnicity and level of lesion.

RSPR was nearly 1 for all variables examined (supplementary table 2, http://jurology.com/). Therefore, the observed OR for bladder continence was not significantly different from the enrollment adjusted odds. Thus, for these variables there was no detectable selection bias in our sample.

DISCUSSION

We longitudinally analyzed changes in continence status in a large sample of patients with SB. The continence status for slightly more than half remained steady, although 43% changed continence status, with similar numbers going from incontinence to continence and vice versa. Continence was associated with demographic, social and condition related factors. Those using a bladder management technique or reporting a history of continence surgery were more likely to be continent of urine. However, since our analysis was not designed to temporally associate interventions with changes in continence, causality cannot be inferred.

Our results highlight the dynamics of changes in continence through time as well as the importance of surgical and management techniques in attaining continence. In addition to the large sample size, the longitudinal nature of our data allowed us to use GEE models to examine the associations between covariates and continence status, and to simultaneously capture the influence of between and within subject variation in risk factors on continence. Furthermore, NSBPR prospectively captured demographic, condition related and management data that are more extensive than in comparable retrospective studies. We believe that longitudinal analysis of multiple clinic visits may offer a more complete assessment of bladder continence than analysis of just a single (most recent) visit per participant, which may be more subject to recall bias.

We found that the magnitude of the association between bladder management and continence status varies significantly according to SB diagnosis. Those with MMC were 4.6 times and nonMMC 2.8 times more likely to be continent if they were following a bladder management strategy. This finding is consistent with the expectation that neurogenic bladders are likely more common and more severe in individuals with MMC,[22] and, therefore, more frequently require interventions to attain continence.

We recognize several limitations of our study. First, continence status was reported by the patient or the parent/guardian, or obtained from a questionnaire/clinic note, which could introduce recall or collection bias. In addition, the data do not allow us to address the reasons for the change in continence status, although we believe that multiple followup visits provide a more informative picture of factors involved in continence than a cross-sectional analysis at a single point. Furthermore, our results may not be generalizable to individuals with SB outside NSBPR, ie continence and its management may differ between those who do and do not attend SB clinics. Finally, despite a meticulous protocol and dedicated quality control efforts, abstraction of the history of surgeries from medical records, including the timing and sequence, may have been incomplete or unverifiable for some participants.

Notwithstanding the limitations, our results add important information to extant literature on bladder continence in individuals with SB as the first study to include a multisite large sample with a longitudinal design with comprehensive data collection and rigorous analyses. In the future we hope to associate longitudinal data with specific interventions, such as clean intermittent catheterization, medical therapy and surgical intervention, to determine their causality regarding continence, as well as to seek associations with social, demographic and condition related factors.

CONCLUSIONS

Multiple demographic, social and clinical factors are significantly and independently associated with bladder continence status in patients with SB. However, the beneficial effects of surgical procedures and management strategies on achieving bladder continence appear to be independent of these factors. For management strategies this association appears to be stronger in individuals with MMC vs nonMMC.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations and Acronyms

CDC	Centers for Disease Control and Prevention
EAE	eligible and enrolled
ENE	eligible nonenrolled
GEE	generalized estimating equation
MMC	myelomeningocele
NSBPR	National Spina Bifida Patient Registry
RSPR	ratio of selection probability ratios
SB	spina bifida

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Table 1

Demographic and clinical characteristics of patients age 5 years or older with spina bifida at last visit

		Bladder Continence Status		
	Overall	**Continent**	**Incontinent**	**p Value**
Age at visit (yrs):				<0.001
Median (range)	14.6 (5.1–83.7)	16.0 (5.1–75.2)	13.3 (5.1–83.7)	
Mean ± SE	16.60 ± 0.14	17.69 ± 0.21	15.68 ± 0.18	
No. age at visit/total No. (%):				<0.001
5 to Less than 12 yrs	1,993/5,250 (38.0)	758/1,993 (38.0)	1,235/1,993 (62.0)	
12 to Less than 20 yrs	1,885/5,250 (35.9)	919/1,885 (48.8)	966/1,885 (51.2)	
20 Yrs or older	1,372/5,250 (26.1)	725/1,372 (52.8)	647/1,372 (47.2)	
No. gender/total No. (%):				<0.001
Male	2,460/5,250 (46.9)	1,008/2,460 (41.0)	1,452/2,460 (59.0)	
Female	2,790/5,250 (53.1)	1,394/2,790 (50.0)	1,396/2,790 (50.0)	
No. race/total No. (%):				<0.001
NonHispanic white	3,340/5,234 (63.8)	1,634/3,340 (48.9)	1,706/3,340 (51.1)	
NonHispanic black	382/5,234 (7.3)	135/382 (35.3)	247/382 (64.7)	
Hispanic or Latino	1,137/5,234 (21.7)	449/1,137 (39.5)	688/1,137 (60.5)	
Other	375/5,234 (7.2)	179/375 (47.7)	196/375 (52.3)	
No. spina bifida type/total No. (%):				<0.001
Myelomeningocele	4,193/5,250 (79.9)	1,722/4,193 (41.1)	2,471/4,193 (58.9)	
Other diagnosis	1,057/5,250 (20.1)	680/1,057 (64.3)	377/1,057 (35.7)	
No. history of bladder continence surgery/total No. (%):				<0.001
Yes	1,178/5,250 (22.4)	653/1,178 (55.4)	525/1,178 (44.6)	
No	4,072/5,250 (77.6)	1,749/4,072 (43.0)	2,323/4,072 (57.0)	
No. any bladder management technique/total No. (%):				<0.001
Yes	4,833/5,221 (92.6)	2,321/4,833 (48.0)	2,512/4,833 (52.0)	
No	388/5,221 (7.4)	69/388 (17.8)	319/388 (82.2)	
No. functional level of lesion/total No. (%):				<0.001
Thoracic	935/5,250 (17.8)	390/935 (41.7)	545/935 (58.3)	
Lumbar	2,761/5,250 (52.6)	1,109/2,761 (40.2)	1,652/2,761 (59.8)	
Sacral	1,554/5,250 (29.6)	903/1,554 (58.1)	651/1,554 (41.9)	
No. mobility status/total No. (%):				<0.001
Community ambulator	2,923/5,250 (55.7)	1,495/2,923 (51.1)	1,428/2,923 (48.9)	
Household ambulator	398/5,250 (7.6)	153/398 (38.4)	245/398 (61.6)	
Nonfunctional ambulator	345/5,250 (6.6)	130/345 (37.7)	215/345 (62.3)	
Nonambulator	1,584/5,250 (30.2)	624/1,584 (39.4)	960/1,584 (60.6)	
No. health insurance/total No. (%):				<0.001
Any private	2,445/5247 (46.6)	1,254/2,445 (51.3)	1,191/2,445 (48.7)	
Nonprivate	2,802/5247 (53.4)	1,148/2,802 (41.0)	1,654/2,802 (59.0)	

Data from National Spina Bifida Patient Registry, 2009 to 2015.

Table 2

Data obtained through multivariable GEE modeling for urinary continence in 5,220 patients

	OR (95% CI)	p Value
Age at visit: 5-yr increase	1.1 (1.1–1.2)	<0.001
Gender:		<0.001
Male	Reference	
Female	1.3 (1.2–1.5)	
Race/ethnicity:		0.001
NonHispanic white	Reference	
NonHispanic black	0.7 (0.5–0.8)	<0.001
Hispanic or Latino	0.9 (0.8–1.0)	0.045
Other	1.0 (0.8–1.2)	0.92
Type of SB diagnosis:		<0.001
MMC	Reference	
NonMMC	2.3 (2.0–2.6)	
History of bladder continence surgery:		<0.001
No	Reference	
Yes	1.9 (1.7–2.1)	
Any bladder management:		<0.001
No	Reference	
Yes	3.8 (3.2–4.6)	
Level of lesion:		<0.001
Thoracic	Reference	
Lumbar	0.9 (0.8–1.0)	0.044
Sacral	1.2 (1.0–1.5)	0.029
Mobility status:		<0.001
Community ambulator	Reference	
Household ambulator	0.9 (0.8–1.0)	0.166
Nonfunctional ambulator	0.8 (0.7–0.9)	0.007
Nonambulator	0.7 (0.6–0.8)	<0.001
Health insurance:		<0.001
Any private	Reference	
Nonprivate	0.7 (0.7–0.8)	

Data from National Spina Bifida Patient Registry, 2009 to 2015.