

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

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

Conclusions: In addition to demographic, social and clinical factors, surgical intervention and bladder management are significantly and independently

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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Study received institutional review board approval.

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associated with bladder continence status in individuals with spina bifida. The association between bladder management and continence is stronger in those with myelomeningocele.

Key Words: 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 independence and opportunities for social participation.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 non-Hispanic white,

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