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Association between age of starting clean intermittent catheterization and current urinary continence in individuals with myelomeningocele

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Summary

Introduction—Patients with myelomeningocele often use clean intermittent catheterization (CIC) for renal preservation and to promote urinary continence. While starting CIC at an early age is associated with better renal outcomes, the impact of age of CIC initiation on continence outcomes has not been examined.

Objective—To examine whether earlier CIC initiation is associated with higher likelihood of current urinary continence for patients with myelomeningocele.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jpurol.2022.08.022.

Conflicts of interest

The authors declare no conflict of interests. 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.

Study design—Data of patients aged ≥5 years at last visit were obtained from 35 spina bifida clinics participating in the National Spina Bifida Patient Registry from 2013 to 2018. Sociodemographic characteristics, disease characteristics, and current bladder management strategies were collected. Via univariate and multiple logistic regression models, the latter conducted controlling for all variables associated with current continent status, associations between continence and sociodemographic factors, condition characteristics, and age CIC began (<3 years of age, 3–5 years, 6–11 years, ≥12 years) were analyzed.

Results—Data from 3510 individuals were included (mean age at last visit = 17.0 years, range 5.0–88.7). The sample was evenly distributed by sex (52% female); most individuals were non-Hispanic White (62.6%). The majority of patients (55.2%) started CIC before age 3 years. Continence varied markedly across those who never started CIC (0.6% of patients were continent) and those who started at any age (range 35.3–38.5%). Among those who started CIC, the magnitude of the association was not proportional to age CIC was started. Compared with those who started CIC at age 12 or older, estimated adjusted odds ratio of being continent ranged from 1.04 (6–11 years, 95% CI, 0.72–1.52) to 1.25 (<3 years, 95% CI, 0.89–1.76).

Discussion—Although CIC may be positively associated with achieving urinary continence in individuals with myelomeningocele, we could not demonstrate that younger age at CIC initiation increased the likelihood of achieving this goal. Limitations include lack of data on reason for starting CIC, urodynamic data, and the observational nature of data collection.

Conclusions—Further study is needed addressing limitations of the current investigation to determine if urinary continence outcomes are influenced by the age of starting CIC among patients with myelomeningocele.

Keywords

Myelomeningocele; Urinary continence; Clean intermittent catheterization

Summary of univariate and multiple logistic regressions of age of initial CIC on bladder continence outcome. The National Spina Bifida Patient Registry, 2013–2018 (N = 3510, Age mean = 17.0 years, range 5.0–88.7)

Variables	Crude Odds Ratio (95% CI)	P-value	Adjusted Odds Ratio (95% CI)[a]	P-value
Age of initial CIC		0.67[b]		0.1693[b]
12 and older[a]				
6 to 11	0.95 (0.67–1.36)	0.80	1.04 (0.72–1.52)	0.83
3 to 5	0.87 (0.62–1.23)	0.43	1.05 (0.73–1.52)	0.78
Younger than 3	0.98 (0.72–1.34)	0.90	1.25 (0.89–1.76)	0.20

[a]Reference group.

[b]Overall p-value.

Introduction

Neurogenic bladder is pervasive in spina bifida (SB), particularly its most common form, myelomeningocele [1-3], making it difficult to achieve continence despite advances in

medical and surgical interventions [4]. Extant research provides discrepant estimates of bladder incontinence in people with SB due to variations in continence definitions and data collection methods [5]. However, bladder incontinence is often present in well over half of individuals with SB [2-4,6]. Various sociodemographic (e.g., age, sex, race) and condition-specific (e.g., SB type, functional level of lesion) variables are associated with urinary incontinence [2,7].

Following its introduction in the 1970s, clean intermittent catheterization (CIC) has become standard for many individuals with neurogenic bladder. Benefits of CIC on renal preservation are well established [8-10]. Further, starting CIC before 3 years of age may result in better renal outcomes [11]. However, evidence regarding impact on continence outcomes is less robust. Use of CIC improves continence [4,12-14], although complete continence is not always achieved. There is some evidence that initiating bladder training earlier leads to better outcomes [15]. To date we are unaware of any study that has examined impact of age of starting CIC on continence outcomes.

Based on limited previous research about the impact of bladder interventions on continence, we hypothesized that earlier CIC initiation would be associated with higher likelihood of current urinary continence.

Materials and methods

Data were obtained from 35 comprehensive SB clinics participating in the National Spina Bifida Patient Registry (NSBPR) from October 2013 through February 2018. Detailed description of the registry has been previously published [16]. Briefly, to participate in the registry, clinics must be multidisciplinary, commit to collecting standardized data on specific interventions and outcomes, and have cared for at least 250 patients with SB in the year prior to applying for inclusion. Patients of all ages are eligible for NSBPR enrollment. At the time of collection of data used in this analysis, clinics were expected to attempt to enroll all eligible participants.

The Institutional Review Board at registry sites approved procedures for the NSBPR. Patients or their legal guardians provided informed consent; youth assent was obtained when appropriate. Those diagnosed with myelomeningocele, lipomeningocele, meningocele, fatty filum, split cord malformation, and terminal myelocystocele are included in the registry. Baseline demographic and diagnostic information was collected at enrollment, and updated demographic and clinical data were gathered at annual visits. Individual data used in the current study are from the most recent clinic visit, obtained through a combination of medical chart review and patient interview.

Participant, condition, sociodemographic, and intervention variables

Only participants with myelomeningocele who responded to the prompt “Age at which CIC was started”, were 5 years of age or older at the time of their last visit, had bladder impairment, and whose data were collected with NSBPR Version 2 were included in this analysis. The age of 5 years has consistently been used as the floor when examining continence outcomes with NSBPR data [2,7,17].

Although uncommon, some individuals with myelomeningocele do not experience neurogenic bladder. Grouping together individuals with and without bladder impairment risks masking outcome differences due to disease characteristic variations. Thus, segregating individuals with and without this impairment is important. NSBPR methods do not allow for objective determination of bladder impairment. Therefore, individuals aged five years and older who were continent without intervention were classified as having “no bladder impairment” and those using current bladder management strategies (scheduled void [yes/no], scheduled catheterization [yes/no], and/or bladder medications [yes/no]) were defined as having “bladder impairment” [3]; only those with impairment were included.

Based on previous research [2,3,7], condition specific variables included in analyses are functional level of lesion (thoracic, high-lumbar, mid-lumbar, low-lumbar, and sacral, based on each lower extremity and classified by the more severe side), ambulation status (community ambulator, household ambulator, therapeutic ambulator, nonambulator) [18], and presence of hydronephrosis.

Sociodemographic variables included age at last visit, sex, race/ethnicity (Non-Hispanic White, Non-Hispanic Black, Hispanic/Latino, and Other), insurance type (private, non-private) and highest educational level achieved.

Finally, to control for the influence of other interventions, data were included on current bladder management strategies (scheduled void/catheterization [yes/no], bladder medications [yes/no]), and history of urologic surgeries [yes/no] (a list of bladder medications prescribed and urologic surgeries tracked in the NSBPR are listed in Appendix I).

Urinary continence

Urinary continence at last visit was classified based on the following item, “Quantify frequency of urinary incontinence during the day over the last month (when not having a urinary tract infection)”. Response options included: (a) patient and/or caregiver unable to provide information; (b) greater than or equal to once per day (daily); (c) less than once per day, greater than or equal to once per week (weekly); (d) less than once per week, greater than or equal to once per month (monthly); (e) less than once per month (less than monthly) and (f) never. Answers of “never” or “less than once per month” were considered as continent; this continence definition has been used with other studies using NSBPR data [17,19,20]. Patients with one of several forms of bladder management were excluded from analyses if they answered in a manner consistent with the study’s definition of being continent, consistent with other NSBPR research [17]: urostomy bag, vesicostomy, indwelling catheter and condom catheter. Those who responded “Unable to provide information” were also excluded from the analysis.

Age of starting CIC

Patients or their legal guardians indicated age at which CIC was started based on pre-defined categories that were grouped as follows: never, younger than 3 years of age, 3–5 years, 6–11 years, and 12 years and older.

Statistical analysis

Associations between categorical variables and categories of age CIC began were examined in bivariate analysis by chi-square test as appropriate. Among patients who started CIC, we performed univariate and multiple logistic regression models to analyze associations between continence and patient sociodemographic factors, categories of age CIC began, and condition characteristics. Regarding categories of age CIC began, first analyses were conducted including all categories. Then, because patients with SB who start CIC prior to age 3 are most likely doing so due to renal factors rather than for continence purposes [21], secondary analyses were conducted excluding the "<3 years of age" category. Estimated odds ratios are presented with 95% confidence intervals. Data management and analyses were performed using SAS software (version 9.4, SAS Institute, Cary, NC). Analyses were replicated and verified by a secondary analyst.

Results

Demographics

Data from 3510 individuals with myelomeningocele aged 5 years and older (Mean = 17.0 years, range 5.0–88.7) were included (Table 1). The sample was evenly distributed by sex (52% female). Most were non-Hispanic White (62.6%). The majority of patients (55.1%) reportedly started CIC when younger than age 3 years of age. Additional demographic and condition-specific data are provided in Table 1. Distribution of bladder continence status by age at last visit and use of CIC is provided in Table 2. Only 0.6% (n = 2) of those who never started CIC were continent, ranging from none to 1.49% across three age groups, whereas continence ranged from 28.52 to 42.73% of patients across age groups at last visit.

Association between urinary continence and age of starting CIC

Excluding those who never started CIC, univariate logistic regression revealed that being continent of urine at the last visit was associated with age at visit, sex, race/ethnicity, highest level of education achieved, insurance type, and current bladder management strategies (Table 3). Odds of being continent at the most recent visit did not vary significantly based on age at which CIC was started.

Multivariable analyses were conducted controlling for all variables except for education and hydronephrosis degree (Table 3). The education variable was highly correlated with age at last visit and was not included in the multivariable model. Hydronephrosis degree was not included in the multivariable model due to significant amount of missing data (Table 1). After controlling for demographic, condition specific, and other intervention variables, urine continence was not significantly associated with age when CIC was started (Table 3). Compared with those who started CIC at 12 years or older, the adjusted odds ratios of being continent were 1.04 for those who initiated CIC 6–11 years of age (95% CI, 0.72 to 1.52), 1.05 for those who initiated CIC 3–5 year old (95% CI, 0.73 to 1.52), and 1.25 for those who started CIC younger than 3 (95% CI, 0.89 to 1.76).

Because initiation of CIC at a young age may be explicitly due to bladder structural and functional characteristics that may impact later continence, multivariable secondary

analysis was conducted comparing those who never started CIC to those who had, excluding participants who started CIC before age 3. Results again show that starting CIC earlier is not significantly associated with greater odds of achieving bladder continence (Table 4). Further, because certain urologic surgeries likely positively impact continence, a subsample 957 patients who never had any urology surgery were analyzed. The “never started CIC” group still had an extremely low continence rate (1.4%) compared with those who started CIC (34.8%). Multivariable logistic regression model showed similar results as the entire study sample. Finally, we examined the subset of 380 patients who had history of urologic surgery and also had appropriate data (i.e., >5 years of age, met definition of bladder impairment, information in dataset Version 2) on continence and CIC usage prior to their urologic surgery, and the finding is consistent with our entire sample (see Appendix II).

Discussion

In individuals with myelomeningocele, starting CIC is often the first step of a program to address urinary continence. We hypothesized that earlier CIC initiation might lead to improved continence. If this hypothesis were true, a relatively simple intervention could decrease the prevalence of urinary incontinence. Continence rates differed markedly based on whether one never started CIC (0.6% of patients were continent) or started CIC at some age (ranging from 35.3 to 38.5% across age groups of starting CIC). While there was a trend toward higher odds of being continent the younger one started CIC, findings did not support the hypothesis that earlier CIC initiation is associated with a higher likelihood of urinary continence.

Guidelines on the age at which to initiate CIC in the SB population are largely driven by concerns for renal preservation. The European Association of Urology (EAU) and European Society for Pediatric Urology (ESPU) recently published joint guidelines stating that CIC should be started as soon as possible after birth [22]. The rationale for this recommendation is to decrease both renal complications and need for later augmentation. In one of the primary studies on which this recommendation is based, treatment was tailored individually over time, and some children were able to stop CIC [9]. The joint guidelines did not offer specific recommendations on when to start CIC again for continence. The International Children’s Continence Society (ICCS) recommends starting CIC at birth if the child cannot empty the bladder spontaneously, with further need for CIC determined at 2–3 months of age with urodynamic and imaging parameters associated with renal deterioration [23]. As with the joint EAU-ESPU guidelines, the ICCS does not have any specific guidelines on when to start CIC for continence. In the United States, the Spina Bifida Association’s Guidelines for the Care of People with Spina Bifida recommend introducing the concept of urinary continence and discussing interest in starting a continence program from 3 years of age onward [24]. This recommendation does not include a specific age for starting CIC in the absence of renal concerns.

Renal indications for starting CIC can occur throughout the lifespan. For continence, one might expect a peak of individuals starting at 3–5 years of age as a part of school readiness preparation with same age non-Spina Bifida peers having completed toilet training. In reality, children continue to start CIC at older ages. In a survey of SB patients/parents in

Turkey, Germany and the Netherlands, 22.4% started CIC at 5 years or older [25]. Our study showed 20% of those who started CIC were 6 years or older.

Even in the absence of improved continence outcomes, early initiation of CIC may offer benefits. Starting CIC is often only the first step in a continence program that may ultimately require medication and surgical intervention. Further, urinary incontinence has been shown to be negatively associated with health-related quality of life (HRQOL) in children as young as 10 years old and this negative association strengthens with increasing age [26]. Additionally, a small Swedish study demonstrated better continence and enhanced social participation in older adolescents with myelomeningocele who self-catheterized compared to an adult cohort who did not participate in a neurogenic bladder program [27].

Earlier initiation of CIC may promote timely independence with toileting skills among those with SB. Two studies with large pediatric samples assessed transition to independence with CIC [28,29]. The mean ages of transition to independent CIC were similar between the studies at 9.45 and 9.7 years of age. Atchley et al. demonstrated that 13% were capable of independent CIC by 5 years of age [29]. Unanswered is the question of whether earlier CIC initiation promotes better independence and adherence to catheterization recommendations.

Contrary to potential benefits of initiating CIC at earlier ages, there is evidence that doing so has some risks. Although CIC increases the risk of bacteriuria, many individuals rarely or never have symptomatic UTIs. However, others have recurrent symptomatic UTIs with significant morbidity. The incidence of outpatient catheter associated UTI (CAUTI) was studied at five pediatric tertiary care academic medical centers in New York City [30]. In the study, 95% of the ambulatory urinary catheter days occurred in children on CIC. Of the outpatient CAUTIs identified, 30-day outcomes included ED visits in 40% of those cases, hospital admissions in 45%, and ICU admissions in 5%. In a study including infants to adults (ages 8 months to 58 years) with SB or tethered cord who performed CIC, Chaudhry et al. found that 25% of the sample experienced frequent UTIs; increasing age was protective against recurrent UTI suggesting caution with starting CIC at younger ages [31]. Other potential complications include urethral trauma and socioeconomic costs (e.g., catheter costs, finding appropriate caregivers who can be trained to catheterize). Consequently, patients, families, and providers must balance potential benefits and risks and individualize the optimal age for starting CIC as part of a continence program.

This study has several limitations. The registry does not allow for determining an indication for starting CIC or receiving bladder surgery. In secondary analyses, we excluded individuals who started CIC prior to 3 years of age because those individuals were not likely to have started CIC as part of a continence program. However, even among individuals who started CIC after 3 years of age, some may have initiated CIC as part of a continence program while others may have started because of renal deterioration risk. Similarly, data are not available on the indication or bladder surgery. While selected bladder surgeries, such as bladder augmentation or Botulinum Toxin, chemodenervation injection, theoretically may affect continence, we cannot assert that each occurred specifically to improve this outcome. If the ratio of these indications was not constant across the different age groups for initiating CIC, true differences in continence outcomes may have been more difficult to observe.

Lower urinary tract characteristics vary widely in individuals with myelomeningocele. Accordingly, the degree of intervention required to achieve continence also varies. For CIC to help achieve urinary continence, the bladder must be able to fill with low pressures and the bladder outlet must have sufficient resistance. Urinary continence is most difficult to achieve in an individual whose bladder neck is incompetent. Even at an experienced center, only 75–81% were able to achieve a 4-h dry interval after bladder neck reconstruction [32]. The NSBPR has not been able to categorize the heterogeneity of lower urinary tract characteristics well. Urodynamic parameters were previously collected by chart review from each site; however, concerns about data quality limit the use of these data. In this study, hydronephrosis is the only variable assessed to evaluate differences in anatomy among the groups. It is a yet unanswered question whether earlier initiation of CIC could potentially improve long term bladder compliance and detrusor overactivity and lead to better continence outcomes.

There are other study limitations beyond the absence of reason for starting CIC and urodynamic data. Importantly, while the NSBPR uses a standardized definition for the variable of “Age at which CIC was started”, patient/caregiver interpretation of the meaning of that item cannot be ascertained. Given that some patients with myelomeningocele may initiate and discontinue CIC over the course of the lifespan, it is possible that participants did not appreciate that this item was prompting for the age of starting long-term use. Also, in adult patients, initiation of CIC may have occurred decades prior and retrospective recall of CIC start date may be incorrect. As an additional limitation, NSBPR participation does not require clinics to ascribe to any particular intervention practices, but rather document current interventions and outcomes. As a result, considerable variability across sites regarding indications for starting CIC, particularly for continence, is likely. As a related issue, registry sites were given guidance on preferred methods of gathering information (interview, medical record review), but methods were not mandated; thus, data ascertainment method variation may impact results. Finally, study data were contributed by a group of primarily academic medical centers with clinics providing a range of multidisciplinary services. This may or may not impact access and adherence to CIC and may not be universally representative of SB care.

Conclusions

Although CIC may be positively associated with achieving urinary continence in individuals with myelomeningocele, our study could not demonstrate that younger age at CIC initiation increased the likelihood of achieving this goal. Given continued difficulties with urinary incontinence for many with myelomeningocele despite improvements in medical and surgical interventions, continued study is warranted, particularly as it relates to age of CIC initiation and continence outcomes. Analysis of data on bladder continence gathered via the NSBPR offers a unique opportunity to improve upon methods of previous research (e.g., standardized definition of continence, data from multiple clinical sites contributing to both a larger sample and potentially greater patient representation, ability to consider correlates to continence). However, as the NSBPR is a registry documenting existing care and outcomes over time, analysis is limited to data available. Prospective studies, such as the CDC-funded Urologic Management to Preserve Initial Renal Function Protocol for Young Children with

Spina Bifida [33], are warranted to determine the impact of age at initiation of CIC on urinary continence.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Distribution of key demographic and clinical characteristics of myelomeningocele patients aged 5+ years with bladder impairment according to age of initial CIC in the National Spina Bifida Patient Registry, 2013–2018.

Variables	Overall n (%) (N = 3510)	N (%) by age (years) CIC began					P-value
		Never (n = 324)	Younger than 3 (n = 1937)	3 to 5 (n = 612)	6 to 11 (n = 455)	12 and older (n = 182)	
Age (years) group							
5 to <12	1321 (37.6)	178 (54.9)	808 (41.7)	237 (38.7)	98 (21.5)		
12 to <20	1221 (34.8)	79 (24.4)	635 (32.8)	216 (35.3)	227 (49.9)	64 (35.2)	
20 or older	968 (27.6)	67 (20.7)	494 (25.5)	159 (26.0)	130 (28.6)	118 (64.8)	<0.0001
Sex							
Male	1686 (48.0)	190 (58.6)	842 (43.5)	313 (51.1)	240 (52.7)	101 (55.5)	
Female	1824 (52.0)	134 (41.4)	1095 (56.5)	299 (48.9)	215 (47.3)	81 (44.5)	<0.0001
Race/Ethnicity (N = 3497)							
Non-Hispanic White	2189 (62.6)	177 (55.3)	1285 (66.5)	376 (61.6)	241 (53.1)	110 (60.4)	
Non-Hispanic Black	296 (8.5)	58 (18.1)	101 (5.2)	54 (8.9)	52 (11.5)	31 (17.0)	
Hispanic or Latino	790 (22.6)	59 (18.4)	452 (23.4)	125 (20.5)	118 (26.0)	36 (19.8)	
Other	222 (6.3)	26 (8.1)	93 (4.8)	55 (9.0)	43 (9.5)	5 (2.7)	<0.0001
Education (N = 3441)							
Elementary and below	1239 (36.0)	173 (55.3)	758 (39.9)	219 (36.1)	88 (19.9)	1 (0.6)	
Middle school	480 (13.9)	36 (11.5)	269 (14.2)	87 (14.3)	83 (18.7)	5 (2.8)	
High school	1188 (34.5)	70 (22.4)	610 (32.1)	196 (32.3)	201 (45.4)	111 (62.4)	
Advanced post high school	534 (15.5)	34 (10.9)	263 (13.8)	105 (17.3)	71 (16.0)	61 (34.3)	<0.0001
Level of lesion							
Thoracic	700 (19.9)	54 (16.7)	392 (20.2)	108 (17.6)	93 (20.4)	53 (29.1)	
High-Lumbar	399 (11.4)	33 (10.2)	233 (12.0)	65 (10.6)	48 (10.5)	20 (11.0)	
Mid-Lumbar	1187 (33.8)	98 (30.2)	678 (35.0)	215 (35.1)	148 (32.5)	48 (26.4)	
Low-Lumbar	554 (15.8)	53 (16.4)	313 (16.2)	94 (15.4)	70 (15.4)	24 (13.2)	
Sacral	670 (19.1)	86 (26.5)	321 (16.6)	130 (21.2)	96 (21.1)	37 (20.3)	0.0015
Health insurance							
Any private	1574 (44.8)	128 (39.5)	901 (46.5)	280 (45.8)	196 (43.1)	69 (37.9)	
Non-private	1936 (55.2)	196 (60.5)	1036 (53.5)	332 (54.2)	259 (56.9)	113 (62.1)	0.0367

Variables	Overall n (%) (N = 3510)	N (%) by age (years) CIC began					P-value
		Never (n = 324)	Younger than 3 (n = 1937)	3 to 5 (n = 612)	6 to 11 (n = 455)	12 and older (n = 182)	
Current bladder management (N = 3501)							
None	240 (6.9)	178 (55.1)	36 (1.9)	13(2.1)	6(1.3)	7 (3.9)	
CIC only	869 (24.8)		469 (24.3)	166 (27.2)	150 (33.1)	84 (46.4)	
CIC + Rx[a]	2070 (59.1)		1296 (67.0)	408 (66.8)	285 (62.9)	81 (44.8)	
Other[b]	322[c] (9.2)	145 (44.9)	132 (6.8)	24 (3.9)	12 (2.6)	9 (5.0)	<0.0001
Bladder continence							
Yes	1194 (34.0)	2 (0.6)	736 (38.0)	216 (35.3)	170 (37.4)	70 (38.5)	
No	2316 (66.0)	322 (99.4)	1201 (62.0)	396 (64.7)	285 (62.6)	112 (61.5)	<0.0001
History of urology surgery							
No	957 (27.3)	138 (42.6)	485 (25.0)	166 (27.1)	112 (24.6)	56 (30.8)	
Yes	2553 (72.7)	186 (57.4)	1452 (75.0)	446 (72.9)	343 (75.4)	126 (69.2)	<0.0001
Most recent degree of kidney hydronephrosis (N = 3120)							
None	2679 (85.9)	257 (89.9)	1496 (85.6)	456 (87.0)	341 (83.6)	129 (83.8)	
Mild (SFU1–2)	328 (10.5)	23 (8.0)	195 (11.2)	44 (8.4)	49 (12.0)	17 (11.0)	
Moderate (SFU 3)	78 (2.5)	3 (1.0)	40 (2.3)	17(3.2)	12 (2.9)	6 (3.9)	
Severe (SFU 4)	35(1.1)	3 (1.0)	17 (1.0)	7(1.3)	6(1.5)	2(1.3)	0.38

Abbreviations: CIC = Clean Intermittent Catheterization, Rx = prescribed medication, SFU = Society of Fetal Urology grading system.

[a]1945 (94%) patients in this group were taking anticholinergic medication at the time of their last visit.

[b]Included Crede, cystectomy, indwelling catheter, spontaneous void, vesicostomy, urostomy bag, urinary diversion, Rx, and one or more of them in combination.

[c]Note that only 3(0.9%) patients in this group were continent of bladder.

Table 2

Distribution of bladder continence status by age at visit and CIC usage. The National Spina Bifida Patient Registry, 2013–2018.

	N	N (%) of being continent of bladder, subgroup n	
		Never started CIC (n = 324)	Started CIC (n = 3186)
Age group (years)			
5 to <12	1321	1 (0.56), n = 178	326 (28.52), n = 1143
12 to <20	1221	0 (0), n = 79	481 (42.12), n = 1142
20 or older	968	1 (1.49), n = 67	385 (42.73), n = 901

Table 3

Summary of univariate and multiple logistic regressions on bladder continence outcome. The National Spina Bifida Patient Registry, 2013–2018.[a]

Variables	Crude Odds Ratio (95%CI)	P-value	Adjusted Odds Ratio (95% CI)[b]	P-value
Age at visit		<0.0001[d]		<0.0001[d]
5 to <12[c]				
12 to <20	1.82 (1.53–2.17)	<0.0001	1.73 (1.43–2.08)	
20 or older	1.87 (1.56–2.25)	<0.0001	1.69 (1.37–2.09)	
Gender				
Male[c]				
Female	1.42 (1.23–1.64)	<0.0001	1.37 (1.18–1.60)	<0.0001[d]
Race/Ethnicity		<0.0001[d]		0.0082[d]
Non-Hispanic White[c]				
Non-Hispanic Black	0.83 (0.62–1.09)	0.1790	0.98 (0.72–1.33)	0.88
Hispanic or Latino	0.64 (0.53–0.77)	<0.0001	0.72 (0.59–0.89)	0.0017
Other	0.68 (0.49–0.92)	0.0143	0.74 (0.53–1.03)	0.0778
Education		<0.0001[d]	Not Applicable	
Elementary and below[c]				
Middle school	1.34 (1.06–1.69)	0.0156		
High school	1.90 (1.59–2.28)	<0.0001		
Advanced post high school	2.11 (1.69–2.63)	<0.0001		
Level of lesion		0.24[d]		0.0654[d]
Thoracic[c]				
High-Lumbar	1.31 (1.01–1.71)	0.0417	1.43 (1.08–1.90)	0.0124
Mid-Lumbar	1.02 (0.83–1.25)	0.84	1.04 (0.84–1.30)	0.71
Low-Lumbar	1.10 (0.86–1.40)	0.46	1.19 (0.91–1.54)	0.20
Sacral	1.14 (0.91–1.44)	0.26	1.23 (0.95–1.58)	0.1137
Health Insurance				
Any private[c]				
Non-private	0.66 (0.57–0.76)	<0.0001	0.69 (0.59–0.82)	<0.0001

Variables	Crude Odds Ratio (95%CI)	P-value	Adjusted Odds Ratio (95% CI)[b]	P-value
Current bladder management (excluding none[f])		<0.0001[d]		<0.0001[d]
CIC only[c]				
CIC + Rx	0.65 (0.55–0.76)	<0.0001	0.68 (0.57–0.80)	
Other[e]	0.01 (0.00–0.04)	<0.0001	0.01 (0.00–0.05)	
Age of initial CIC		0.67[d]		0.1693[d]
12 and older[c]				
6 to 11	0.95 (0.67–1.36)	0.80	1.04 (0.72–1.52)	0.83
3 to 5	0.87 (0.62–1.23)	0.43	1.05 (0.73–1.52)	0.78
Younger than 3	0.98 (0.72–1.34)	0.90	1.25 (0.89–1.76)	0.20
History of urology surgery				
No[c]				
Yes	1.16 (0.99–1.37)	0.0729	1.16 (0.97–1.39)	0.0969
Hydronephrosis degree		0.20[d]	Not Applicable	
None[c]				
Mild (SFU1–2)	1.25 (0.98–1.59)	0.0764		
Moderate (SFU 3)	1.26 (0.79–2.02)	0.33		
Severe (SFU 4)	1.39 (0.69–2.82)	0.35		

Abbreviations: CIC = Clean Intermittent Catheterization, Rx = prescribed medication, SFU = Society of Fetal Urology grading system.

[a] The Never started CIC group was excluded.

[b] 3107 patients with non-missing data were included in the multiple regression model.

[c] Reference group.

[d] Overall p-value.

[e] The None management group (n – 240) was excluded since all patients in this subgroup were incontinent.

[f] Included Crede, cystectomy, indwelling catheter, spontaneous void, vesicostomy, urostomy bag, urinary diversion, Rx, and one or more of them in combination.

Table 4

Summary of univariate (n = 1249) and multiple (n = 1216) logistic regressions on bladder continence outcome. The National Spina Bifida Patient Registry, 2013–2018 (excluded Never started CIC and CIC started <3 years groups).

Variables	Crude Odds Ratio (95% CI)	P-value	Adjusted Odds Ratio (95% CI)[a]	P-value
Age at visit		<0.0001[c]		<0.0001[c]
5 to <12[b]				
12 to <20	2.22 (1.63–3.02)	<0.0001	2.14 (1.53–2.99)	<0.0001
20 or older	2.35 (1.71–3.23)	<0.0001	2.28 (1.58–3.30)	<0.0001
Gender				
Male[b]				
Female	1.30 (1.03–1.63)	0.0273	1.31 (1.02–1.67)	0.0319
Race/Ethnicity		0.0020[c]		0.1175[c]
Non-Hispanic White[b]				
Non-Hispanic Black	0.74 (0.50–1.08)	0.1180	0.81 (0.53–1.23)	0.32
Hispanic or Latino	0.57 (0.42–0.76)	0.0002	0.66 (0.47–0.93)	0.0174
Other	0.78 (0.51–1.20)	0.26	0.93 (0.58–1.47)	0.74
Education (32 missing)		<0.0001[c]	Not Applicable	
Elementary and below[b]				
Middle school	1.15 (0.75–1.74)	0.52		
High school	2.23 (1.64–3.05)	<0.0001		
Advanced post high school	2.27 (1.58–3.26)	<0.0001		
Level of lesion		0.66[c]		0.42[c]
Thoracic[b]				
High-Lumbar	1.36 (0.88–2.10)	0.1652	1.39 (0.87–2.20)	0.1649
Mid-Lumbar	1.11 (0.80–1.54)	0.55	1.12 (0.79–1.59)	0.54
Low-Lumbar	1.23 (0.83–1.83)	0.29	1.34 (0.87–2.04)	0.1801
Sacral	1.18 (0.82–1.69)	0.37	1.37 (0.92–2.03)	0.1189
Health Insurance				
Any private[b]				

Variables	Univariate Odds Ratio (95% CI)	P-value	Multiple Odds Ratio (95% CI)[a]	P-value
Age of initial CIC		0.66[c]		0.69
12 and older[b]				
6 to 11	0.95 (0.67–1.36)	0.80	1.12 (0.76–1.65)	0.57
3 to 5	0.87 (0.62–1.23)	0.43	1.18 (0.80–1.74)	0.40
History of urology surgery				
No[b]				
Yes	1.44 (1.10–1.88)	0.0083	1.32 (0.99–1.77)	0.0557
Hydronephrosis degree		0.0979[c]	Not Applicable	
None[b]				
Mild (SFU1–2)	1.61 (1.08–2.40)	0.0185		
Moderate (SFU 3)	0.97 (0.48–1.98)	0.94		
Severe (SFU 4)	1.63 (0.59–4.55)	0.35		
Non-private	0.71 (0.57–0.90)	0.0045	0.79 (0.61–1.02)	0.0758
Current bladder management (excluding none[d])		<0.0001[c]		<0.0001[c]
CIC only[b]				
CIC + Rx	0.54 (0.42–0.69)	<0.0001	0.57 (0.44–0.74)	<0.0001
Other[e]	0.02 (0.00–0.18)	0.0003	0.02 (0.00–0.18)	0.0003

Abbreviations: CIC – Clean Intermittent Catheterization, Rx = prescribed medication, SFU = Society of Fetal Urology grading system.

[a] 1566 patients with non-missing data were included in the multiple regression model.

[b] Reference group.

[c] Overall p-value.

[d] The None management group (n = 240) was excluded since all patients in this subgroup were incontinent.

[e] Included Crede, cystectomy, indwelling catheter, spontaneous void, vesicostomy, urostomy bag, urinary diversion, and one or more of them in combination.