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Comparing binary & ordinal definitions of urinary & stool continence outcomes: Data from the National Spina Bifida Patient Registry

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Summary

Introduction—The National Spina Bifida Patient Registry (NSBPR) assesses bladder and bowel incontinence using ordinal categories, but prior NSBPR analyses employed binary classification. Our aims were to **1**) perform the first NSBPR analysis of bladder and bowel incontinence as ordinal outcomes to compare to the binary definition and subject variables; **2**) explore the

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Disclaimer

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.

Conflict of interest

MSK serves as advisor for Coloplast A/C, Humlebaek, Denmark.

correlation of incontinence with undergarment usage, and **3)** assess incontinence status following continence surgeries.

Methods—Data from NSBPR participants' most recent clinic visit from 2013 to 2020 were analyzed. Ordinal categories of incontinence were compared to previously used binary definitions. Incontinence surgical outcomes were analyzed for those with data at least three months post-operatively. Chi-square tests evaluated associations among categorical variables. Univariate and ordinal logistic regression models were used to test associations of ordinal incontinence status with patient and condition factors. Statistical tests were 2-sided; p values < 0.05 were considered significant.

Results—Analysis of 7217 individuals using ordinal incontinence outcomes showed little difference from previously used binary outcomes. The final multivariable logistic regression models with ordinal multinomial outcomes showed that associations of incontinence with age, sex, race/ethnicity, health insurance, level of lesion, and continence management technique were similar to prior studies. Among those reporting never being incontinent of both bladder and bowel, 14% reported using protective undergarments. Of the 500 individuals who had bladder outlet surgery, 38% reported never being incontinent of urine. Of 1416 individuals who had appendicostomy (ACE) bowel surgery, 48% reported never being incontinent of stool.

Discussion—Our current analysis showed that ordinal continence outcome classification had similar continence findings as previous studies using the binary definition of continence. Expanding the binary definition of continence to include monthly episodes of incontinence did not greatly increase the proportion of continent individuals and, therefore, would have not likely made meaningful differences in continence outcomes in prior NSBPR analyses. However, it is known that even mild incontinence can affect quality of life, therefore, capturing any level of incontinence is of clinical importance. Confirmation of the association of continence outcomes with sociodemographic, condition-related, and interventional factors with both approaches further validates previous analyses using the binary definition of continence.

Conclusion—The previously used binary definition of bladder and bowel continence appears robust. Undergarment choice was a poor surrogate for reported incontinence. After bladder and bowel continence surgeries, 38% and 48%, respectively, reported never being incontinent.

Keywords

Spina bifida; Neurogenic bladder; Neurogenic bowel; National Spina Bifida Patient Registry

Summary Table

Management techniques and incontinence in patients aged 5+ years in the National Spina Bifida Patient Registry, 2013–2019^c.

N (%) by ordinal incontinence status						
Variables	Never	<Monthly	Monthly	Weekly	Daily	P-value
Bladder management	n = 2277	n = 601	n = 409	n = 773	n = 2913	<0.0001^d
No management	41 (7.8)	1 (0.2)	5 (1.0)	6 (1.1)	471 (89.9)	

N (%) by ordinal incontinence status						
Variables	Never	<Monthly	Monthly	Weekly	Daily	P-value
Volitional void	781 (64.2)	88 (7.2)	62 (5.1)	88 (7.2)	197 (16.2)	
Crede	3 (16.7)	2 (11.1)	1 (5.6)	4 (22.2)	8 (44.4)	
CIC urethra	914 (25.9)	382 (10.8)	257 (7.3)	514 (14.6)	1464 (41.5)	
CIC surgical channel	538 (40.0)	128 (9.5)	84 (6.3)	161 (12.0)	433 (32.2)	
Vesicostomy ^d	16 (12.2)	1 (0.8)	1 (0.8)		113 (86.3)	
Urostomy bag ^d	64 (68.8)	6 (6.5)	1 (1.1)	3 (3.2)	19 (20.4)	
Condom catheter					1 (100.0)	
Indwelling catheter ^d	30 (54.5)	3 (5.5)	3 (5.5)	3 (5.5)	16 (29.1)	
Bowel management^b	n = 3196	n = 901	n = 681	n = 863	n = 1131	<0.0001
No intervention	1182 (61.1)	137 (7.1)	113 (5.8)	162 (8.4)	340 (17.6)	
Timed defecation	77 (39.3)	35 (17.9)	16 (8.2)	27 (13.8)	41 (20.9)	
Oral medications only	580 (40.2)	135 (9.4)	124 (8.6)	231 (16.0)	373 (25.8)	
Rectal stimulation	252 (29.9)	134 (15.9)	89 (10.6)	166 (19.7)	202 (24.0)	
Manual disimpaction	30 (31.3)	13 (13.5)	9 (9.4)	19 (19.8)	25 (26.0)	
Retrograde large volume enemas	367 (42.1)	183 (21.0)	144 (16.5)	108 (12.4)	70 (8.0)	
Antegrade enemas	708 (51.0)	264 (19.0)	186 (13.4)	150 (10.8)	80 (5.8)	

^aChi-square test excluded patients with bladder management of vesicostomy, or urostomy bag, or condom catheter, or indwelling catheter.

^bExcluding 136 patients with pouched fecal diversion.

^cThe shaded regions of the table represent what would have been included in the binary definition of continence, with continence being defined as incontinence less than monthly.

^dResponded "Cannot assess": vesicostomy, n=24; urostomy bag, n=23; indwelling catheter, n=13.

Introduction

Spina bifida (SB) is the most common permanently disabling congenital defect in the US [1]. In 2008, the Centers for Disease Control and Prevention (CDC) developed the National Spina Bifida Patient Registry (NSBPR), a multi-institutional patient registry, as a partnership with selected SB clinics throughout the United States to provide a research platform to improve the care of individuals with SB [2]. Data collection for the NSBPR began in 2009 and involves 35 clinics with over 10,000 participants. From its inception, there have been challenges in the interpretation of some registry variables; thus, as the registry has evolved, data elements have been refined [2].

The initial NSBPR questionnaire only collected binary responses of "continent" and "incontinent" for bladder and bowel outcomes. In 2013, the registry was modified to utilize five-point ordinal responses for frequency of incontinence. Schechter et al. performed the first NSBPR analysis of continence in 1335 individuals from data collected between 2009 and 2012, using the initial binary definitions of bladder incontinence as "any urinary leakage during the day" and bowel incontinence as "any stool leakage during the day" [3]. Using these definitions, 38% and 43% of the cohort reported bladder and bowel continence, respectively. These rates were similar to subsequently published rates from the NSBPR that

compressed newer ordinal incontinence data to define continence as incontinence episodes ‘never’ or ‘less than one incontinent episode a month’ [4,5]. Recent analysis of NSBPR data on bowel incontinence using the binary categorization of continence found 45% had bowel continence [6]. However, compressing ordinal incontinence data into a binary definition may diminish the ability to assess incontinence not captured by strict binary definitions.

More granular reporting of incontinence may be especially important when changing treatment regimens or evaluating surgical interventions to improve continence. Additionally, it is known that bladder incontinence specifically doesn’t have a uniformly negative impact on health-related quality of life in adults and children [7-9]. It is important clinically and in research to compare matched individuals with similar incontinence levels as we are improving management techniques for bladder and bowel incontinence.

This study performed the first detailed NSBPR analysis of bladder and bowel incontinence using the five ordinal choices of incontinence frequency rather than the previously used binary construct. Our primary aim was to see if the prior binary definition was valid in capturing more nuanced patient experience assessed by ordinal choices, with secondary aims of correlating these ordinal data of bladder and bowel incontinence with patient/SB factors and undergarment usage. Finally, we aimed to assess surgical interventions solely performed to achieve continence using ordinal incontinence answers and undergarment selections.

Methods

NSBPR

Between 2008 and 2009, 10 clinics were funded by CDC to participate in the NSBPR to test the feasibility of using a standard data collection tool to gather longitudinal data from participants with SB.¹⁰ Data elements are collected across multiple multidisciplinary SB clinics from patients who have consented to participate in the NSBPR. Demographic, clinical characteristics, and treatment history data are collected during initial enrollment and subsequent annual visits. Data collection for the registry was approved by the Institutional Review Board of each clinic site, and participating individuals provided informed consent. Data are centralized and de-identified prior to analysis.

Data from the most recent clinic visits were analyzed. Inclusion criteria for this study were: individuals 5 years old at the last visit with an annual form completed between 2013 and 2019. Surgical outcome data were analyzed for those individuals who completed an annual form at a minimum of three months after the surgical intervention.

Distribution of incontinence responses

The NSBPR annual form queries the frequency of bladder incontinence during the day over the last month when not having a urinary tract infection. The choices of bladder incontinence frequency on the form are: daily, weekly, monthly, less than monthly, and never. Bowel incontinence over the last month, when not ill, was also quantified using the same scale of frequency.

Bladder management selections are no management, volitional voiding, clean intermittent catheterization (CIC) using the urethra, CIC using a surgical channel, credé, vesicostomy, urostomy bag, condom catheter, and indwelling catheter. Since incontinence outcomes between those who selected CIC plus an indwelling catheter (overnight presumed) and those who selected CIC alone were similar, all such patients were grouped as CIC management alone. Other management combinations were excluded from the analysis. Individuals with vesicostomies, urostomy bags, condom catheters, or indwelling catheters alone were considered to have incontinent bladder management methods and were excluded from regression analysis.

Bowel management selections are manual disimpaction, timed evacuation, digital stimulation, suppository, mini-enemas, standard rectal enema, cone/balloon rectal enema, Peristeen[®] transanal irrigation system (Coloplast A/ C, Humlebaek, Denmark), antegrade enema, and no management. For this analysis, digital stimulation, suppositories, mini-enemas, and standard rectal enemas were grouped as rectal stimulation. Transanal irrigation and cone/balloon rectal enema were grouped as retrograde large-volume enemas. Individuals with colostomies have been considered incontinent by convention since registry initiation because their stool is not contained within the body; therefore, incontinence reporting is not collected on these patients, excluding them from analysis.

Incontinence outcomes after surgical intervention

It was assumed that all individuals who underwent bladder outlet surgery (bulking agent injection, bladder neck reconstruction, sling, closure, and artificial urinary sphincter placement) had bladder incontinence. Procedures to allow antegrade enemas (appendicostomy [antegrade continence enema [ACE] surgery], Chait tube placement or cecostomy (button) creation) were performed for management of neurogenic bowel symptoms. Bowel and bladder incontinence was analyzed in patients following these procedures.

Undergarment use and incontinence

Choices for undergarment use include underwear only, underwear with pad, or protective undergarment (diaper or “pull-up”). Individuals do not specify if the undergarment is used for urine, stool, or both. Distribution of undergarment use by incontinence outcome was analyzed. A subset analysis was conducted of only those meet the definition of being fully continent of urine (selected “never incontinent”) by bowel incontinence selection.

Sociodemographic characteristics

For this analysis, age was categorized by: school-aged (5–11 years), adolescent (12–19 years), and adult (over 19 years of age); health insurance status was dichotomized as either having or not having any private insurance. Sex, race, and ethnicity data retained the same categorization as provided in the deidentified dataset.

Spinal cord level of lower extremity motor function

The lowest spinal cord level of lower extremity (LE) motor function on examination was recorded on each side as: thoracic (flaccid lower limb); high-lumbar (hip flexion present);

mid-lumbar (knee extension present); low-lumbar (foot dorsiflexion present); or sacral (foot plantar flexion present). When left and right sides differed, the highest level was used in analysis to represent that individual's overall functional level.

Statistical analysis

Chi-square tests evaluated associations among independent categorical variables. When an expected cell count was ≤ 5 , Fisher's exact method was used to test associations. Univariate and multiple logistic regression models were used to calculate odds ratios, 95% confidence intervals, and P values to test associations of continence outcomes with age, sex, ethnicity, race, level of motor function, health insurance status, and management type. P values < 0.05 were considered statistically significant. Statistical analyses were performed using SAS version 9.4 (Cary, NC, USA).

Results

Study population

A total of 7217 NSBPR participants met the inclusion criteria. Demographic and clinical characteristics are shown in Table 1. Both bladder and bowel incontinence by ordinal choices were statistically significantly different by age groups, sex, race/ethnicity, level of lesion, and insurance status. There were statistically significant differences in the distribution of all five characteristics between the more severe form of SB, myelomeningocele (78.4% of cohort), and less severe forms, non-myelomeningocele (21.4%) (data not displayed).

Continence definition

If the binary definition were expanded to include the "monthly" ordinal response (daily/weekly vs. monthly/less than monthly/never), 0.8–8% more patients would have been classified as continent of urine among the nine forms of bladder management and 6–17% for the seven forms of bowel management (Table 2).

Urinary outcomes

Volitional voiding, urostomy bag, and indwelling catheters were associated with incontinence frequency of "never" in more than 50% (Table 2). Univariate analysis identified that increased odds of better continence were significantly associated with any private insurance, sacral level of LE motor function, non-Hispanic white race/ethnicity, older age, female sex, and volitional voiding (Table 3). Ordinal logistic regression models identified that increased odds of better continence were independently and significantly associated with any private insurance, sacral level of LE motor function, older age, female sex, and management with volitional voiding or CIC surgical channel (Table 4).

Twenty-four percent of individuals who reported never having daytime urinary incontinence reported bladder incontinence overnight (600/2453 individuals) (data not displayed).

Stool outcomes

Antegrade enema was the only form of bowel management associated with incontinence frequency of “never” in more than 50% (Table 2). Univariate analysis identified that increased odds of better continence were significantly associated with any private insurance, sacral level of LE motor function, non-Hispanic white or other race/ethnicity, older age, female sex, and antegrade enemas or no management (Table 5). Multiple ordinal logistic regression identified that increased odds of better continence were noted with any private insurance, non-thoracic level of LE motor function, non-Hispanic white or other race/ethnicity, older age, female sex, and management on antegrade enema, retrograde large volume enemas, or no intervention management (Table 6).

Undergarment use

Of individuals who reported daily bladder incontinence, 78% (1897 out of 2442) also used protective undergarments. For individuals who reported never having bladder incontinence, 23% (516 out of 2236) reported using protective undergarments (Table 7). We found that among the 1701 individuals reporting never having incontinence of either urine and stool, 14% reported using protective undergarments.

Surgical continence outcomes

A total of 656 bladder outlet surgeries were performed in 536 individuals. Of these, 500 had an annual form completed at least three months after their surgery. Bladder incontinence was reported as never occurring in 38%, less than monthly in 9%, monthly in 5%, weekly in 10%, and daily in 38% (Table 8).

1896 Cecostomy button/Chait and ACE procedures were performed in 1600 individuals. Of these, 1416 individuals had a postoperative annual form completed a minimum of 3 months after the surgery date. Bowel incontinence was reported as never occurring in 48%, less than monthly in 19%, monthly in 13%, weekly in 12%, and daily in 8% (Table 8).

Discussion

In a Spina Bifida Association online survey of adults with SB and caregivers, both bladder and bowel incontinence were cited as one of their top five health issues.¹¹ Health-related quality of life has been shown to decrease with increasing amounts of bladder incontinence and with any amount of bowel incontinence [7]. Our current analysis showed that ordinal continence outcome classification had similar continence findings as previous studies using the binary definition of continence [5,6]. Expanding the binary definition of continence to include monthly episodes of incontinence did not greatly increase the proportion of continent individuals and, therefore, would have not likely made meaningful differences in continence outcomes in prior NSBPR analyses. Despite these findings, it is important to keep the ordinal classifications since we know that health-related quality of life outcomes can vary within these ordinal classifications [7,9]. Also, proper monitoring of clinical outcomes for changes over time will be better monitored with ordinal classification. Confirmation of the association of continence outcomes with sociodemographic, condition-

related, and interventional factors with both approaches further validates previous analyses using the binary definition of continence.

Studying patient-reported outcomes yielded interesting findings. The NSBPR researchers, a priori, defined individuals who managed their bladders with vesicostomy, urostomy, condom catheter, or indwelling catheters as incontinent. From the healthcare professionals' perspective, these individuals were classified as incontinent because they do not have volitional control over urination or store urine within their bodies. In this analysis, a majority of individuals with urostomies and indwelling catheters reported that they were never incontinent of urine. From a patient-reported outcome perspective, those with these management forms considered themselves continent, perhaps, because they had found a bladder management option that grants them better containment of their urine.

Similarly, the use of protective undergarments was poorly associated with continence status. The rates of protective undergarment use in this analysis were similar to findings in adults with SB, where 23% reported still wearing undergarments [7]. The incongruent finding of absorbent undergarment use despite reporting continence may arise from the unpredictability of even rare incontinence. NSBPR and the International Children's Continence Society have established the age definition of continence as 5 years of age; many neurotypical children are continent of bladder and bowel by three years of age.^{12, 13} This developmental expectation for continence and resultant incontinence with SB can influence childhood relationships with peers, teachers, and outside caregivers starting in kindergarten. Bladder and bowel incontinence have been described as embarrassing and socially restrictive by children with SB and their families [10]. Absorbent undergarments provide a level of assurance that an incontinent episode can be managed discreetly in a social situation [11]. Incontinence in childhood can affect the achievement of adult developmental milestones [12]. The use of absorbent undergarments despite continence in this subgroup may be a personal choice to prevent social mishaps and loss of self-esteem and dignity.

Bladder incontinence may result from high bladder storage pressures and/or low bladder outlet resistance. The surgical procedures assessed for their effect upon bladder continence for this study addressed low bladder outlet resistance since they are only done to gain continence, unlike bladder augmentation or intradetrusor botulinum toxin injections, which may be done to reduce storage pressures to protect the upper tracts and not solely for continence. Achieving continence in those with low bladder outlet resistance remains a vexing surgical challenge. In this study, bladder outlet procedures reduced incontinence to never in 44% and less than monthly in 10%. This is consistent with recent literature reporting success rates of bladder outlet reconstruction of 54%–68% [13,14]. Our reported outcomes may be suboptimal because they included less invasive procedures for continence that have lower success rates, included multiple institutions with potentially variable experiences, and used patient reports as early as three months after procedures which may not have allowed sufficient time to reach optimal outcomes. Analysis using an extended postoperative period was considered but would have resulted in an unacceptable drop in the cohort size. Nonetheless, individuals should be informed preoperatively that bladder outlet procedures for incontinence may not reliably reduce the frequency of incontinence;

reduction in the quantity of incontinence was not captured in this study, but the NSBPR has recently been modified to begin assessing this variable.

We found that bowel management by antegrade enema was the superior type of bowel management in terms of continence, with incontinence episodes reported as never in 51% and less than monthly in 19%. This included patients with cecostomy buttons/Chait tubes in addition to those undergoing the ACE procedure. Post-operative incontinence findings in ACE patients were very similar at 49% for never and 19% for less than monthly. A recent systematic review reported an 88% rate of bowel continence following the MACE procedure [15]. Continence rates may have been lower in our larger cohort because it was multi-institutional, included data as early as three months post-operatively, and may have queried patient outcomes with a stricter definition.

The findings of our study must be interpreted in the context of study limitations. The NSBPR continues to undergo improvements and modifications to ensure the validity of its data. Whereas clear definitions are provided for the functional outcomes we have analyzed, these are still potentially subject to variation in their reporting and interpretation at different clinics. Data may have been collected in subtly (though significantly) different ways, for example, face-to-face interviews, written survey instruments, or data derived from clinician notes. It is also difficult to differentiate patient-reported responses from care partners' responses when different answers are provided by patients themselves and their care partners, particularly in the pediatric age group. This may create challenges when attempting to compare outcomes among different centers. Of course, choices of responses by participating individuals may be subject to misunderstanding or recall bias. Likewise, selection bias may be a threat to external validity. NSBPR is clinic-based, so it may not represent SB patients who do not attend SB clinics. It is also possible that patients at select NSBPR clinics were not representative of those receiving care at a broader range of SB clinics in general. Regardless, it is sobering to see the continence rates are not particularly high following interventions at these select centers.

The confirmation of the validity of our previously utilized binary definition for bladder and bowel continence being incontinence frequency less than monthly will further inform clinical and academic progress in advancing SB care. The information regarding poor surrogacy of undergarment use for incontinence and surgical outcomes can inform clinicians counseling individuals with SB.

Conclusions

Analysis of ordinal data of bladder and bowel incontinence showed that the previously used binary definition of continence of less than one incontinent episode a month appears appropriate in individuals with SB. Undergarment choice was found to be a poor surrogate for incontinence. After bladder outlet and MACE/ACE surgery, less than half report never having incontinence episodes.

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Table 1

Distribution of key demographic characteristics in patients aged 5+ years by bladder incontinence and bowel incontinence status in the National Spina Bifida Patient Registry, 2013–2019^{*a}.

Variables	N (%) by ordinal bladder incontinence status				N (%) by ordinal bowel incontinence status					
	Never (n = 2282)	<Monthly (n = 604)	Monthly (n = 412)	Weekly (n = 778)	Daily (n = 2938)	Never (n = 3202)	<Monthly (n = 904)	Monthly (n = 682)	Weekly (n = 866)	Daily (n = 1267)
Age group (in years)										
5 to <12	705 (26.8)	187 (7.1)	130 (4.9)	269 (10.2)	1339 (50.9)	991 (38.1)	314 (12.1)	258 (9.9)	368 (14.1)	671 (25.8)
12 to <20	948 (37.7)	216 (8.6)	144 (5.7)	278 (11.1)	926 (36.9)	1320 (53.2)	339 (13.7)	234 (9.4)	263 (10.6)	324 (13.1)
20 or older	629 (33.6)	201 (10.7)	138 (7.4)	231 (12.3)	673 (36.0)	891 (48.5)	251 (13.6)	190 (10.3)	235 (12.8)	272 (14.8)
Sex										
Male	977 (29.5)	239 (7.2)	165 (5.0)	338 (10.2)	1596 (48.1)	1445 (44.1)	407 (12.4)	307 (9.4)	424 (12.9)	693 (21.2)
Female	1305 (35.3)	365 (9.9)	247 (6.7)	440 (11.9)	1342 (36.3)	1757 (48.2)	497 (13.6)	375 (10.3)	442 (12.1)	574 (15.7)
Race/Ethnicity										
Non-Hispanic White	1493 (34.4)	406 (9.4)	264 (6.1)	455 (10.5)	1716 (39.6)	2052 (48.0)	604 (14.1)	462 (10.8)	483 (11.3)	676 (15.8)
Non-Hispanic Black	144 (26.7)	29 (5.4)	35 (6.5)	54 (10.0)	278 (51.5)	228 (42.5)	47 (8.8)	43 (8.0)	82 (15.3)	137 (25.5)
Hispanic or Latino	432 (28.8)	118 (7.9)	70 (4.7)	194 (12.9)	688 (45.8)	606 (41.3)	162 (11.0)	122 (8.3)	234 (16.0)	343 (23.4)
Other	209 (34.0)	48 (7.8)	43 (7.0)	74 (12.1)	240 (39.1)	306 (49.8)	88 (14.3)	51 (8.3)	64 (10.4)	105 (17.1)
Level of lesion group										
Thoracic	278 (23.8)	96 (8.2)	67 (5.7)	136 (11.7)	590 (50.6)	387 (34.2)	173 (15.3)	111 (9.8)	151 (13.3)	311 (27.4)
High-Lumbar	158 (24.9)	59 (9.3)	35 (5.5)	75 (11.8)	308 (48.5)	217 (34.8)	84 (13.5)	65 (10.4)	100 (16.0)	158 (25.3)
Mid-Lumbar	520 (25.9)	178 (8.9)	140 (7.0)	241 (12.0)	929 (46.3)	812 (40.9)	283 (14.3)	233 (11.7)	277 (14.0)	378 (19.1)
Low-Lumbar	290 (28.7)	86 (8.5)	52 (5.2)	107 (10.6)	474 (47.0)	437 (43.8)	139 (13.9)	105 (10.5)	146 (14.6)	171 (17.1)
Sacral	1036 (47.2)	185 (8.4)	118 (5.4)	219 (10.0)	637 (29.0)	1349 (61.8)	225 (10.3)	168 (7.7)	192 (8.8)	249 (11.4)
Health insurance										
Any private	1265 (37.6)	320 (9.5)	206 (6.1)	356 (10.6)	1220 (36.2)	1753 (52.2)	501 (14.9)	347 (10.3)	332 (9.9)	424 (12.6)
Non-private	1017 (27.9)	283 (7.8)	206 (5.7)	422 (11.6)	1718 (47.1)	1448 (40.6)	403 (11.3)	335 (9.4)	534 (15.0)	843 (23.7)

* All p-values were significant at <0.0001 for each variable.

^aThe shaded regions of the table represent what has been previously included in the binary definition of continence (defined as incontinence less than monthly).

Table 2

Management techniques and incontinence in patients aged 5+ years in the National Spina Bifida Patient Registry, 2013–2019^c.

N (%) by ordinal incontinence status						
Variables	Never	<Monthly	Monthly	Weekly	Daily	P-value
Bladder management	n = 2277	n = 601	n = 409	n = 773	n = 2913	<0.0001^a
No management	41 (7.8)	1 (0.2)	5 (1.0)	6 (1.1)	471 (89.9)	
Volitional void	781 (64.2)	88 (7.2)	62 (5.1)	88 (7.2)	197 (16.2)	
Credé	3 (16.7)	2 (11.1)	1 (5.6)	4 (22.2)	8 (44.4)	
CIC urethra	914 (25.9)	382 (10.8)	257 (7.3)	514 (14.6)	1464 (41.5)	
CIC surgical channel	538 (40.0)	128 (9.5)	84 (6.3)	161 (12.0)	433 (32.2)	
Vesicostomy ^d	16 (12.2)	1 (0.8)	1 (0.8)		113 (86.3)	
Urostomy bag ^d	64 (68.8)	6 (6.5)	1 (1.1)	3 (3.2)	19 (20.4)	
Condom catheter					1 (100.0)	
Indwelling catheter ^d	30 (54.5)	3 (5.5)	3 (5.5)	3 (5.5)	16 (29.1)	
Bowel management^b	n = 3196	n = 901	n = 681	n = 863	n = 1131	<0.0001
No intervention	1182 (61.1)	137 (7.1)	113 (5.8)	162 (8.4)	340 (17.6)	
Timed defecation	77 (39.3)	35 (17.9)	16 (8.2)	27 (13.8)	41 (20.9)	
Oral medications only	580 (40.2)	135 (9.4)	124 (8.6)	231 (16.0)	373 (25.8)	
Rectal stimulation	252 (29.9)	134 (15.9)	89 (10.6)	166 (19.7)	202 (24.0)	
Manual disimpaction	30 (31.3)	13 (13.5)	9 (9.4)	19 (19.8)	25 (26.0)	
Retrograde large volume enemas	367 (42.1)	183 (21.0)	144 (16.5)	108 (12.4)	70 (8.0)	
Antegrade enemas	708 (51.0)	264 (19.0)	186 (13.4)	150 (10.8)	80 (5.8)	

^aChi-square test excluded patients with bladder management of vesicostomy, or urostomy bag, or condom catheter, or indwelling catheter.

^bExcluding 136 patients with pouched fecal diversion.

^cThe shaded regions of the table represent what would have been included in the binary definition of continence, with continence being defined as incontinence less than monthly.

^dResponded "Cannot assess"; vesicostomy, n = 24; urostomy bag, n = 23; indwelling catheter, n = 13.

Table 3

Summary of univariate logistic regression on binary and ordinal^d bladder continence outcome excluding patients without bladder management in the National Spina Bifida Patient Registry, 2013–2019.

Variables	N (%) (Total N = 6449)	Binary ^c		Ordered	
		Odds Ratio ^e (95% CI)	P-value	Odds Ratio ^e (95% CI)	P-value
Age at last visit					
5 to <12 ^a	2302 (35.7)		<0.0001 ^b		<0.0001 ^b
12 to <20	2363 (36.6)	1.55 (1.38–1.74)	<0.0001	1.58 (1.42–1.76)	<0.0001
20 or older	1784 (27.7)	1.41 (1.25–1.60)	<0.0001	1.47 (1.31–1.65)	<0.0001
Gender					
Male ^a	2970 (46.1)				
Female	3479 (53.9)	1.34 (1.22–1.48)	<0.0001	1.39 (1.27–1.53)	<0.0001
Race/Ethnicity (21 missing)					
Non-Hispanic White ^a	4046 (62.9)		<0.0001 ^b		<0.0001 ^b
Non-Hispanic Black	453 (7.0)	0.69 (0.56–0.84)	0.0002	0.74 (0.62–0.88)	0.0009
Hispanic or Latino	1381 (21.5)	0.76 (0.67–0.86)	<0.0001	0.77 (0.69–0.86)	<0.0001
Other	548 (8.5)	0.95 (0.80–1.14)	0.61	1.02 (0.87–1.20)	0.82
Level of lesion					
Thoracic ^a	1073 (16.6)		<0.0001 ^b		<0.0001 ^b
High-Lumbar	583 (9.0)	1.14 (0.92–1.40)	0.23	1.11 (0.92–1.34)	0.26
Mid-Lumbar	1844 (28.6)	1.15 (0.98–1.35)	0.0804	1.18 (1.03–1.36)	0.0173
Low-Lumbar	915 (14.2)	1.32 (1.10–1.58)	0.0030	1.26 (1.07–1.49)	0.0048
Sacral	2034 (31.5)	2.68 (2.30–3.12)	<0.0001	2.70 (2.36–3.10)	<0.0001
Health insurance (1 missing)					
Any private ^a	3145 (48.8)				
Non-private	3303 (51.2)	0.64 (0.58–0.71)	<0.0001	0.66 (0.60–0.72)	<0.0001
Bladder management^f(340 missing)					
Volitional void ^a	1216 (19.9)		<0.0001 ^b		<0.0001 ^b
Credé	18 (0.3)	0.15 (0.05–0.43)	0.0004	0.17 (0.07–0.39)	<0.0001

Variables	N (%) (Total N = 6449)	Binary ^c		Ordered	
		Odds Ratio ^e (95% CI)	P-value	Odds Ratio ^e (95% CI)	P-value
CIC urethra	3531 (57.8)	0.23 (0.20–0.27)	<0.0001	0.22 (0.19–0.25)	<0.0001
CIC surgical channel	1344 (22.0)	0.39 (0.33–0.46)	<0.0001	0.37 (0.32–0.43)	<0.0001

^aReference group.

^bOverall p-value.

^cBinary outcome defines reporting incontinence frequency of Never and Less than monthly to be continent, and Monthly, Weekly, and Daily to be incontinent.

^dOrdered bladder incontinence frequency: 1 = Never, 2 = Less than monthly, 3 = Monthly, 4 = Weekly, 5 = Daily.

^eOdds ratio of having lower order of bladder incontinence frequency.

^fExcluded: Vesicostomy, Urostomy bag, Condom catheter, and Indwelling catheter, n=340.

Table 4

Summary of multivariable logistic regression on binary and ordinal^d bladder continence outcome excluding patients without bladder management in the National Spina Bifida Patient Registry, 2013–2019 (n = 6088^f).

Variables	Binary ^c		Ordered	
	Odds Ratio ^e (95% CI)	P-value	Odds Ratio ^e (95% CI)	P-value
Age at last visit		<0.0001 ^b		<0.0001 ^b
5 to <12 ^a				
12 to <20	1.71 (1.50–1.94)	<0.0001	1.73 (1.55–1.94)	<0.0001
20 or older	2.02 (1.74–2.33)	<0.0001	2.12 (1.86–2.40)	<0.0001
Gender				
Male ^a				
Female	1.38 (1.23–1.53)	<0.0001	1.42 (1.29–1.56)	<0.0001
Race/Ethnicity		0.0173 ^b		0.0822 ^b
Non-Hispanic White ^a				
Non-Hispanic Black	0.76 (0.61–0.95)	0.0145	0.84 (0.69–1.02)	0.0748
Hispanic or Latino	0.86 (0.75–1.00)	0.0474	0.88 (0.77–1.00)	0.0451
Other	0.83 (0.68–1.01)	0.0646	0.89 (0.75–1.06)	0.1945
Level of lesion		<0.0001 ^b		<0.0001 ^b
Thoracic ^a				
High-Lumbar	1.24 (0.99–1.55)	0.0656	1.21 (1.00–1.48)	0.0538
Mid-Lumbar	1.12 (0.94–1.33)	0.21	1.13 (0.98–1.32)	0.0973
Low-Lumbar	1.24 (1.01–1.51)	0.0374	1.17 (0.98–1.40)	0.0790
Sacral	1.84 (1.54–2.21)	<0.0001	1.82 (1.55–2.14)	<0.0001
Health insurance				
Any private ^a				
Non-private	0.78 (0.70–0.88)	<0.0001	0.80 (0.72–0.89)	<0.0001
Bladder management^f		<0.0001 ^b		<0.0001 ^b
Volitional void ^a				
Credé	0.15 (0.05–0.44)	0.0005	0.16 (0.07–0.37)	<0.0001

Variables	Binary ^c		Ordered	
	Odds Ratio ^e (95% CI)	P-value	Odds Ratio ^e (95% CI)	P-value
CIC urethra	0.27 (0.23–0.31)	<0.0001	0.25 (0.22–0.29)	<0.0001
CIC surgical channel	0.43 (0.36–0.52)	<0.0001	0.39 (0.33–0.47)	<0.0001

^aReference group.

^bOverall p-value.

^cBinary outcome defines reporting incontinence frequency of Never and Less than monthly to be continent, and Monthly, Weekly, and Daily to be incontinent.

^dOrdered bladder incontinence frequency: 1 = Never, 2 = Less than monthly, 3 = Monthly, 4 = Weekly, 5 = Daily.

^eOdds ratio of having lower order of bladder incontinence frequency.

^fExcluded: Vesicostomy, Urostomy bag, Condom catheter, and Indwelling catheter.

Table 5

Summary of univariate logistic regression on binary and ordinal^d bowel continence outcome excluding patients with pouched fecal diversion in the National Spina Bifida Patient Registry, 2013–2019 (n = 6772^f).

Variables	N (%) (Total N = 6772)	Binary ^e		Ordered	
		Odds Ratio ^e (95% CI)	P-value	Odds Ratio ^e (95% CI)	P-value
Age at last visit					
5 to <12 ^a	2568 (37.9)		<0.0001 ^b		<0.0001 ^b
12 to <20	2448 (36.1)	2.04 (1.82–2.29)	<0.0001	2.06 (1.86–2.28)	<0.0001
20 or older	1756 (25.9)	1.79 (1.58–2.03)	<0.0001	1.85 (1.66–2.07)	<0.0001
Gender					
Male ^a	3195 (47.2)				
Female	3577 (52.8)	1.24 (1.12–1.36)	<0.0001	1.24 (1.14–1.36)	<0.0001
Race/Ethnicity (25 missing)					
Non-Hispanic White ^a	4171 (61.8)		<0.0001 ^b		<0.0001 ^b
Non-Hispanic Black	525 (7.8)	0.63 (0.52–0.75)	<0.0001	0.65 (0.55–0.76)	<0.0001
Hispanic or Latino	1449 (21.5)	0.65 (0.57–0.73)	<0.0001	0.65 (0.58–0.73)	<0.0001
Other	602 (8.9)	1.07 (0.89–1.28)	0.46	1.02 (0.87–1.20)	0.80
Level of lesion					
Thoracic ^a	1080 (15.9)		<0.0001 ^b		<0.0001 ^b
High-Lumbar	598 (8.8)	0.94 (0.77–1.15)	0.58	1.02 (0.85–1.22)	0.86
Mid-Lumbar	1947 (28.8)	1.20 (1.03–1.39)	0.0191	1.30 (1.14–1.49)	0.0001
Low-Lumbar	984 (14.5)	1.29 (1.09–1.54)	0.0037	1.41 (1.21–1.65)	<0.0001
Sacral	2163 (31.9)	2.47 (2.12–2.88)	<0.0001	2.80 (2.44–3.22)	<0.0001
Health insurance (1 missing)					
Any private ^a	3297 (48.7)				
Non-private	3474 (51.3)	0.53 (0.48–0.58)	<0.0001	0.55 (0.51–0.61)	<0.0001
Bowel management^f					
Manual disimpaction ^a	96 (1.4)		<0.0001 ^b		<0.0001 ^b
No intervention	1934 (28.6)	2.64 (1.75–4.00)	<0.0001	2.95 (2.04–4.26)	<0.0001

Variables	N (%) (Total N = 6772)	Binary ^c		Ordered	
		Odds Ratio ^d (95% CI)	P-value	Odds Ratio ^e (95% CI)	P-value
Timed defecation	196 (2.9)	1.64 (1.00–2.69)	0.0477	1.48 (0.95–2.29)	0.0804
Oral medications only	1443 (21.3)	1.21 (0.80–1.83)	0.37	1.24 (0.86–1.80)	0.25
Rectal stimulation	843 (12.4)	1.04 (0.68–1.59)	0.85	1.04 (0.71–1.51)	0.85
Retrograde large volume enemas	872 (12.9)	2.11 (1.38–3.22)	0.0006	2.06 (1.41–2.99)	0.0002
Antegrade enemas	1388 (20.5)	2.88 (1.90–4.38)	<0.0001	2.72 (1.88–3.93)	<0.0001

^aReference group.

^bOverall p-value.

^cBinary outcome defines reporting incontinence frequency of Never and Less than monthly to be continent, and Monthly, Weekly, and Daily to be incontinent.

^dOrdered bowel incontinence frequency: 1 = Never, 2 = Less than monthly, 3 = Monthly, 4 = Weekly, 5 = Daily.

^eOdds ratio of having lower order of bowel incontinence frequency.

^fPouched fecal diversion excluded due to missing data on bowel incontinent frequency (n = 136).

Table 6

Summary of multivariable logistic regression on binary and ordinal^d bowel continence outcome excluding patients with pouch fecal diversion in the National Spina Bifida Patient Registry, 2013–2019 (n = 6746).

Variables	Binary ^c		Ordered	
	Odds Ratio ^e (95% CI)	P-value	Odds Ratio ^e (95% CI)	P-value
Age at last visit		<0.0001 ^b		<0.0001 ^b
5 to <12 ^a				
12 to <20	2.20 (1.94–2.49)	<0.0001	2.20 (1.97–2.45)	<0.0001
20 or older	2.35 (2.03–2.71)	<0.0001	2.48 (2.18–2.81)	<0.0001
Gender				
Male ^a				
Female	1.21 (1.09–1.34)	0.0004	1.22 (1.11–1.34)	<0.0001
Race/Ethnicity		0.0032 ^b		0.0024 ^b
Non-Hispanic White ^a				
Non-Hispanic Black	0.76 (0.62–0.92)	0.0056	0.75 (0.63–0.90)	0.0018
Hispanic or Latino	0.88 (0.76–1.01)	0.0669	0.88 (0.78–0.99)	0.0345
Other	1.16 (0.96–1.41)	0.1250	1.08 (0.92–1.28)	0.34
Level of lesion		<0.0001 ^b		<0.0001 ^b
Thoracic ^d				
High-Lumbar	1.09 (0.89–1.35)	0.40	1.22 (1.02–1.47)	0.0320
Mid-Lumbar	1.37 (1.16–1.61)	0.0001	1.50 (1.30–1.73)	<0.0001
Low-Lumbar	1.57 (1.30–1.89)	<0.0001	1.74 (1.48–2.05)	<0.0001
Sacral	3.17 (2.67–3.77)	<0.0001	3.61 (3.10–4.21)	<0.0001
Health insurance				
Any private ^a				
Non-private	0.64 (0.57–0.71)	<0.0001	0.67 (0.61–0.74)	<0.0001
Bowel management		<0.0001 ^b		<0.0001 ^b
Manual disimpaction ^a				
No intervention	1.84 (1.20–2.83)	0.0053	2.09 (1.43–3.04)	0.0001

Variables	Binary ^c		Ordered	
	Odds Ratio ^e (95% CI)	P-value	Odds Ratio ^e (95% CI)	P-value
Timed defecation	1.33 (0.79–2.22)	0.28	1.22 (0.78–1.90)	0.38
Oral medications only	0.98 (0.63–1.50)	0.91	1.03 (0.70–1.49)	0.89
Rectal stimulation	1.07 (0.69–1.66)	0.76	1.14 (0.78–1.67)	0.50
Retrograde large volume enemas	2.07 (1.33–3.22)	0.0013	2.18 (1.48–3.20)	<0.0001
Antegrade enemas	2.46 (1.60–3.79)	<0.0001	2.50 (1.71–3.64)	<0.0001

^aReference group.
^bOverall p-value.

^cBinary outcome defines reporting incontinence frequency of Never and Less than monthly to be continent, and Monthly, Weekly, and Daily to be incontinent.

^dOrdered bowel incontinence frequency: 1 = Never, 2 = Less than monthly, 3 = Monthly, 4 = Weekly, 5 = Daily.

^eOdds ratio of having lower order of bowel incontinence frequency.

Undergarment use and incontinence status among those who used some sort of management in the National Spina Bifida Patient Registry, 2013–2019^b.

Table 7

Variables	N (%) by ordinal incontinence status					P-value
	Never	<Monthly	Monthly	Weekly	Daily	
<i>Bladder incontinence</i>						
Undergarment use	n = 2236	n = 600	n = 404	n = 767	n = 2442	<0.0001
Not Asked	78 (3.5)	31 (5.2)	8 (2.0)	16 (2.1)	41 (1.7)	
Protective undergarment ^a	516 (23.1)	219 (36.5)	198 (49.0)	489 (63.8)	1897 (77.7)	
Underwear with pad	210 (9.4)	150 (25.0)	77 (19.1)	142 (18.5)	308 (12.6)	
Underwear only	1432 (64.0)	200 (33.3)	121 (30.0)	120 (15.6)	196 (8.0)	
<i>Bowel incontinence</i>						
Undergarment use	n = 2014	n = 764	n = 568	n = 701	n = 927	<0.0001
Not Asked	68 (3.4)	13 (1.7)	13 (2.3)	11 (1.6)	13 (1.4)	
Protective undergarment ^a	831 (41.3)	428 (56.0)	364 (64.1)	555 (79.2)	808 (87.2)	
Underwear with pad	358 (17.8)	134 (17.5)	91 (16.0)	59 (8.4)	42 (4.5)	
Underwear only	757 (37.6)	189 (24.7)	100 (17.6)	76 (10.8)	64 (6.9)	

^aDiaper, pull-up, Attends.

^bThe shaded regions of the table represent what would have been included in the binary definition of continence, with continence being defined as incontinence less than monthly.

Incontinence status after bladder and bowel continence surgery in the National Spina Bifida Patient Registry, 2013–2019^a.

Table 8

	N	N (%)by ordinal incontinence status				
		Never	<Monthly	Monthly	Weekly	Daily
Post bladder surgery ^b	500	188 (37.6)	43 (8.6)	27 (5.4)	52 (10.4)	190 (38.0)
Post bowel surgery ^c	1416	686 (48.4)	267 (18.9)	181 (12.8)	163 (11.5)	119 (8.4)

^aThe shaded regions of the table represent what would have been included in the binary definition of continence, with continence being defined as incontinence less than monthly.

^bIncluded bulking agent injection, bladder neck reconstruction, sling, closure, and artificial urinary sphincter placement.

^cIncluded appendicostomy (antegrade continence enema [ACE]), Chait tube placement or cecostomy creation (ACE).