Published in final edited form as:
J Pediatr Rehabil Med. 2019 ; 12(4): 361–368. doi:10.3233/PRM-180556.

Differences in continence rates in individuals with spina bifida based on ethnicity

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Abstract

BACKGROUND: Ethnic disparities in continence rates in spina bifida (SB) have been studied regionally but not nationally. National SB Patient Registry (NSBPR) data were analyzed to explore differences in prevalence of bowel and bladder continence and interventions between Hispanics/Latinos and others.

METHODS: Participants 5 to 21 years were categorized into Hispanic/Latino and non-Hispanic/non-Latino. Bladder/bowel continence was defined as dry/no involuntary stool leakage during the

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Conflict of interest
The authors declare no conflicts of interest. 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.

day or none/⩽ monthly incontinence. Chi-square test, Wilcoxon Two Sample Test, and generalized estimating equation (GEE) were used for statistical analysis.

RESULTS: Twenty-five percent of the 4,364 patients were Hispanic/Latino. At their most recent clinic visit, Hispanics/Latinos demonstrated lower rates of urinary continence (38.6% vs. 44.9%; $p = 0.0003$), bowel continence (43.9% vs. 55.8%, $p < 0.0001$), private insurance ($p < 0.0001$), bowel ($p < 0.0001$) or bladder surgeries ($p = 0.0054$), and more vesicostomies ($p = 0.0427$) compared to others. In multiple GEE models, Hispanic/Latino participants demonstrated lower odds of bowel continence as compared to non-Hispanic/non-Latino participants (estimated odds ratio, 0.82, 95% CI, 0.72–0.94, $p = 0.0032$).

CONCLUSIONS: After controlling for covariates, Hispanics/Latinos with SB are less likely to report bowel continence. Clinicians are encouraged to consider the risk of negative health disparities for Hispanic patients with SB and work to mitigate this risk.

Keywords

Spina bifida; myelomeningocele; health disparities; continence; Hispanic; Latino

1. Introduction

Across the United States, approximately 1,500 infants are born each year with spina bifida (SB) [1]. The prevalence of neural tube defects has consistently been shown to be highest among Hispanics [2–4]. The birth prevalence of SB among a subset of states has been reported as 3.80 per 10,000 live births in Hispanics compared to rates of 2.73 and 3.09 per 10,000 live births in non-Hispanic black/African-Americans and non-Hispanic whites, respectively [5].

Berry et al. found that racial and ethnic health care disparities have been reported in studies of children with chronic health conditions including SB [6]. Pertinent to the current study, preliminary findings suggest that there are ethnic disparities in continence outcomes among individuals with SB. In a sample of 70 patients receiving care in a single institution, Chowanadisai et al. found that, as compared to other ethnic groups, Hispanic individuals with spina bifida had a significantly higher incidence of urinary incontinence and a trend toward higher rates of bowel incontinence. In addition, this same population exhibited lower satisfaction with bladder and bowel management strategies [7]. While useful, these findings are limited by the small sample size and recruitment from a single clinic, particularly given recent findings of notable variation in continence reported across multidisciplinary spina bifida clinics [8].

Participants in the Centers for Disease Control and Prevention (CDC)-supported National SB Patient Registry (NSBPR) are an ideal diverse patient population with which to examine disparity issues in a more robust manner compared to extant literature. A study by Schechter et al. used NSBPR data to provide a preliminary analysis of the association between specific demographic variables, including race/ethnicity, and outcomes from the registry [9]. Further, examining data of 1335 participants from the initial 10 participating registry clinics, others found that non-Hispanic or non-Latino Black participants showed the highest rates of bowel and bladder incontinence as compared to Hispanics/Latinos and other participants, even after controlling for spina bifida type, level of lesion, and clinical site [8]. While this study represents an important step forward in better understanding whether continence varies significantly by race/ethnicity, inclusion of only three covariates represents an important limitation given that multiple demographic, condition-specific, and intervention variables are associated with continence [8,10].

The purpose of our study is to build upon the initial findings of Schechter et al. [9]. Importantly, the NSBPR now includes thousands of patients ages birth through adulthood from 29 sites across the United States. Therefore, a more robust examination of whether Hispanics/Latinos with spina bifida demonstrate differences in bowel and bladder continence, as compared to those of other ethnicities, is now possible. Specifically, we included a broader list of covariates that may affect continence and utilized analytic approaches that account for repeated measurement of the same individuals over time. Based on available literature, we hypothesized that significantly fewer Hispanic/Latino participants experience either bowel or bladder continence.

2. Method

2.1. Data collection and validation

Data were obtained from 29 comprehensive SB clinics (26 sites, three sites included two clinics each, including 6821 patients) participating in the NSBPR, which has been previously described in detail [11]. Briefly, to participate in the registry, clinics must be multidisciplinary, commit to collecting standardized data on specific interventions and outcomes, have a population of a minimum of 200 diagnosis-eligible patients, agree to approach all eligible patients for enrollment into the registry, and report specific individual-level data on those who were eligible but not enrolled.

The Institutional Review Board at each participating registry site approved the procedures of the NSBPR. Participants or their legal guardians provided informed consent; assent was also obtained from minors. Patients diagnosed with myelomeningocele, lipomyelomeningocele, meningocele, fatty/thickened filum, terminal myelocystocele, or split cord malformation were invited to enroll during regularly scheduled clinic visits. Based on chart review and/or interviews with the patient and/or caregiver (an interpreter supported interactions with non-English speaking participants), data were gathered at each annual visit on multiple variables that are considered valid indicators of clinical status, feasible to collect, and definable in a uniform manner. Electronic and manual data quality assurance checks are performed regularly to ensure the quality of data [11].

2.2. Variables included in the current investigation

Patient demographics, disease, and functional characteristics.—For this study, the statistical analysis was restricted to data collected between 2009 and 2015 from 4,364 participants, ages 5.1 to 21.0 years at the time of their last annual visit to a participating SB clinic. The minimum age of 5 years was chosen as urinary continence is likely not consistently emphasized in the study population prior to the age of five. Variables included in this investigation were SB diagnosis (dichotomized to myelomeningocele vs. other diagnoses), age at last visit, sex (male, female), ethnicity using the US Census definition (i.e., Hispanic/Latino vs. non-Hispanic/non-Latino), race (White, Black, Asian, Other), type of insurance (i.e., private vs. non-private), functional level of lesion based on the more affected side (i.e., thoracic, lumbar, sacral), and mobility status (i.e., community ambulator, household ambulator, non-functional ambulator, non-ambulator).

Continence status.—During the first phase of registry data collection (2009–October 2013), urinary continence was defined as being “dry, with or without intervention during the day” and bowel continence was defined as “no involuntary stool leakage, with or without intervention, during the day”. Since October 2013, urinary and bowel continence were quantified using a multiple choice format in response to the following prompt: “Quantify frequency of urinary (stool) incontinence during the day over the last month (‘when not having a urinary tract infection’ for urine and ‘when not ill’ for stool)”. To create a common definition of continence across both phases of the data collection, the six multiple choice response options, which were the same for reporting bladder and bowel incontinence, were dichotomized. Those individuals who reported their incontinence as “never” or “less than once per month” were considered continent (Yes); all others (individuals reporting daily, weekly, or monthly incontinence) were considered incontinent (No). Records with “cannot assess” responses were excluded from the study. Records with any of the following forms of bladder management: urostomy bag, vesicostomy, indwelling catheter, or condom catheter, were assigned “No/incontinent” regardless of the answer to the bladder continence question as these are diversion interventions.

Continence surgeries and management.—A history of bladder continence surgery was defined as having undergone one or more of the following procedures, as defined by the Systematized Nomenclature of Medicine (SNOMED): bladder augmentation, appendicovesicostomy, construction of cutaneous stoma of urinary bladder (procedure), closure of cystostomy/vesicostomy, surgical closure of bladder neck/outlet, and bladder neck/outlet operations. A history of bowel continence surgery was defined as having undergone one or more of the following: antegrade continence enema and cecostomy button/ Chait tube. Response options for histories of surgeries were dichotomized to “Yes/No” based on whether any of the aforementioned surgeries had occurred.

Continence management strategies reported at each visit were dichotomized to “Yes/No” depending on whether any techniques were reported as being used currently. Bladder management was defined as using one or more of the following techniques: volitional void in the toilet, clean intermittent catheterization, Crede’s maneuver, indwelling catheter, urostomy bag, condom catheter, and/or taking bladder management medications (anti-muscarinics/anti-cholinergics, alpha-adrenergic antagonists, alpha-adrenergic agonist, beta-adrenergic agonist). Bowel management was defined as using one or more of the following techniques: oral laxative, stool softener, and/or bulking agent/fiber; suppository; standard rectal enema; cone/balloon rectal enema; digital stimulation; timed evacuation; disimpaction; antegrade enema; mini-enemas, pouched fecal diversion; and Peristeen® anal irrigation.

3. Statistical analysis

Based on previous research [8–10], covariates included time-independent variables such as sex, race, and SB diagnosis; and time-dependent variables such as 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 tested using chi-square tests. Associations between continuous independent variables and continence status at last visit were tested using the nonparametric Wilcoxon Two Sample Test.

To account for repeated observations of the continence status and other time-dependent variables in the same person over time, we used generalized estimating equation (GEE) models [12] with logit link function for binomial distribution to examine the association of continence status with selected covariates. These models account for potential correlations among repeated measurements from the same participant and among measurements from participants clustered by clinic. Separate GEE models were developed to test the association between continence status and sociodemographic factors, SB diagnosis, level of lesion, ambulation status, and interventional factors such as history of continence surgeries and management. We selected an exchangeable correlation structure for the GEE models [13,14]. All models incorporated the same independent variables to allow for comparisons of their significance in relation to continence status. Among 4364 eligible participants in the study, 1547 (35.4%) had a single visit and 2817 (64.6%) had multiple visits ranging from 2 to 7.

Statistical tests were all 2-sided, and p values < 0.05 were considered statistically significant; 95% confidence intervals (CIs) were calculated for all point estimates. Statistical analyses were performed by using SAS version 9.3© [15].

4. Results

Table 1 summarizes sociodemographic characteristics, surgical interventions, and management techniques of the 4,364 individuals included in the study based on their last visit. The mean age of participants was 12.89 years and 52.2% were female. Most (78.4%) had myelomeningocele. Approximately 25% were Hispanic/Latino, with similar sex and age distributions for both Hispanic/Latino and non-Hispanic/non-Latino categories. There were no differences by Hispanic/or Latino ethnicity for type of spina bifida, level of lesion, or mobility status. There was, however, a significant difference in health insurance, with 18.2% of Hispanic/Latino patients having private insurance as compared to 58.0% of non-Hispanic/non-Latino patients ($p \leqslant 0.0001$). Significantly fewer Hispanic/Latino patients had a history of bladder continence surgery (18.1%) or bowel continence surgery (11.7%) as compared to non-Hispanic/non-Latino patients (22.1%, $p = 0.0054$, and 25.1%, $p < 0.0001$, respectively), with the exception of vesicostomies. Hispanic/Latino patients were significantly more likely to have had a vesicostomy ($p = 0.0427$) than non-Hispanic/non-Latino patients. Hispanic/Latino patients demonstrated a significantly lower rate of urinary continence (38.6% vs. 44.9%; $p = 0.0003$) and bowel continence (43.9% vs. 55.8%, $p < 0.0001$) than non-Hispanic/non-Latino. Use of bladder management strategies was slightly more common among

Hispanic/Latino patients than non-Hispanic/non-Latino patients. In contrast, there was no difference in use of bowel management techniques between groups.

Odds of both bowel and bladder continence varied significantly based on a variety of patient, condition-specific, and intervention variables. After adjusting for all other factors in the model, Hispanic/Latino patients still demonstrated significantly lower odds of bowel continence as compared to their non-Hispanic/non-Latino counterparts (Table 3, estimated odds ratio, 0.82, 95% CI, 0.72–0.94, $p = 0.0032$). This pattern was not statistically significant for urinary continence (Table 2, estimated odds ratio, 0.89, 95% CI, 0.77–1.02, $p = 0.0909$).

5. Discussion

Consistent with previous findings [7,9], current results demonstrate disparities in health outcomes for different ethnic groups included in the sample. Specifically, in the univariate analyses, Hispanics/Latinos with spina bifida were significantly less likely to report being continent of bowel and urine than non-Hispanics/Latinos. After controlling for multiple related factors, the results remained statistically significant only for bowel continence. Further, while not the primary focus of the study, disparities in health interventions were also noted, consistent with other studies [16]. Of note, while no differences in the use of bowel management techniques were observed, fewer Hispanic/Latino patients underwent bowel and bladder surgeries and a greater number used bladder management techniques compared to non-Hispanic/non-Latino patients. Inclusion of a large sample recruited from clinics across the US, a standardized definition of continence, and multiple co-variates strengthen confidence in these observations.

The finding of significant health intervention and outcome disparities, weighted toward more negative outcomes for the Hispanic/Latino group, is not surprising given extant literature [17]. Examinations of access, healthcare utilization, and outcomes regularly demonstrate that racial and/or ethnic minorities in the United States fare poorly compared to White/Caucasian individuals [18,19]. Thus, individuals with spina bifida who are members of racial and ethnic minority groups may experience a “third hit” from risk factors that predict their subsequent disparities [16].

This study provides valuable information about disparities in bladder and bowel continence by ethnicity and serves as a starting point to understand and address this phenomenon. While possible explanations for understanding these disparities were not examined in the current study, multiple hypotheses emerge when considering data included and findings observed. First, differing experiences with bladder management techniques and bladder and bowel surgical procedures might be related to variations in access to care or clinical practice across ethnic groups in the United States. Importantly, ethnicity is often correlated with access to and utilization of various types of health care for individuals with special health needs, with gaps in care likely to be greater for Hispanic/Latino children with special health care needs [18]. Second, the finding that Hispanic/Latino participants were much less likely to have private insurance may be a proxy for socioeconomic status, which in turn can influence other variables (e.g., access to resources, physical environmental constraints impacting ability to implement common interventions). Third, goals of treatment may influence variations in outcomes observed. Continence itself may not be a clinical or family priority for a patient with other significant medical or social challenges affecting health [20]. A focus on preservation of kidney function or addressing potential neurologic complications may detract from systematic efforts to help the patient achieve continence. Vesicostomy, although not a continence procedure, is included in our analysis. While it is used as a temporizing measure to protect at-risk kidneys [21,22], it may also be the result of patient/family preference, differences in acceptability of the use of diapers, or other culturally determined factors. Finally, patient and/or family preferences for both care and the outcomes of care may influence observed continence. These preferences may be ethnically derived cultural practices or beliefs [7]. In addition to the obvious benefits of continence related to skin protection and social acceptability, independence in self-care is also a component of continence. Concepts related to dependency and independence by those with chronic conditions may vary by ethnicity and, therefore, impact the ability to achieve continence [23].

It is notable that while Hispanic/Latino patients in our sample have a slightly higher rate of using bladder management techniques, this group has a lower rate of bladder continence. At the same time, while the two groups do not differ significantly regarding bowel management techniques, Hispanic/Latino patients have a much lower rate of bowel continence. Reasons for these findings are not clear, as there is no evidence that those who are Hispanic/Latino experience anatomical differences that would account for differences in the effect of management interventions.

Although ethnicity was significant in the multivariable analysis of bowel continence, the effect size (odds ratio 1.22, non-Hispanic vs. Hispanic, data not shown) was smaller than a number of other predictors (e.g., age, diagnosis, bowel surgery, sacral lesion). Ethnicity is important to consider but other variables may be even more important in understanding continence in clinical practice.

There are several limitations of this study. This analysis did not link each individual bladder/bowel management technique specifically with continence (e.g., individuals who catheterize four times a day and use an anticholinergic may differ from someone who catheterizes once daily). In addition, information about what types of interventions have been *prescribed* for patients is not gathered as part of NSBPR, only those that are in use; therefore, we cannot factor in adherence or family perceptions of the various treatment modalities. Specifically, current registry data do not allow for examining, or controlling for, level of adherence on continence outcomes. While we assume there may be some impact of language and culture with a minority population being served by majority providers, we did not study this. Finally, as noted above, while differences are observed in continence by ethnicity, the current study does not examine reasons for these differences.

Limitations notwithstanding, the current study adds important findings to the extant literature by confirming disparities in both continence interventions and outcomes. Inclusion of a large sample from clinics across the United States, standardized definitions of interventions and outcomes of interest, and standardized data collection methods add confidence to the results. Future research is necessary to identify the causes of observed disparities, and to develop practices that mitigate and ameliorate their occurrence. This is an important topic for consideration since Hispanics/Latinos have a higher prevalence of neural tube defects than other populations. Our desire is that future research regarding spina bifida will move beyond detecting this disparity to understanding factors that influence disparate health outcomes for Hispanics/Latinos with spina bifida, compared with spina bifida patients of non-Hispanic ethnicity, offering possible solutions and evaluating the impact of various interventions. While the evidence base on this topic grows, clinicians are encouraged to be aware of the risk of negative health disparities for Hispanic patients with SB and are encouraged to institute provider- and clinic-level practices that mitigate this risk.

Acknowledgments

The authors thank the many individuals with SB and their family members who participated in this research, without whom the NSBPR would not be possible. The NSBPR has also been successful because of the contributions of the Centers for Disease Control and Prevention, the Spina Bifida Association, and all members of the NSBPR Coordinating Committee. Members of this Committee during the collection of the data reported are listed in alphabetical order and were Pat Beierwaltes, Children's Hospital of Michigan, Detroit; Timothy Brei, Riley Hospital for Children, Indianapolis; Robin Bowman, Ann and Robert H. Lurie Children's Hospital of Chicago, Chicago; Heidi Castillo, Cincinnati Children's Hospital Medical Center, Cincinnati and Texas Children's Hospital, Houston; James Chinarian, Children's Hospital of Michigan, Detroit; Mark Dias, Hershey Medical Center, Hershey; Brad Dicianno, University of Pittsburgh Medical Center, Pittsburgh; Nienke Dosa, Upstate Golisano Children's Hospital, Syracuse; Carlos Estrada, Boston Children's Hospital, Boston; Kurt Freeman, Oregon Health and Science University, Portland; David Joseph, Children's Hospital of Alabama, Birmingham; Jacob Neufeld, Children's Hospital and Research Center at Oakland, Oakland, University of California at San Francisco Benioff Children's Hospital, San Francisco, and St. Luke's Boise Medical Center, Boise; Joseph O'Neil, Riley Hospital for Children, Indianapolis; Michael Partington, Gillette Children's Specialty Healthcare, St. Paul; Paula Peterson, Primary Children's Medical Center, Salt Lake City; Elaine Pico, Children's Hospital and Research Center at Oakland, Oakland and University of California at San Francisco Benioff Children's Hospital, San Francisco; Karen Ratliff-Schaub, Nationwide Children's Hospital, Columbus; Kathleen Sawin, Children's Hospital of Wisconsin, Milwaukee; Kathryn Smith, Children's Hospital Los Angeles, Los Angeles; Stacy Tanaka, Monroe Carell Jr. Children's Hospital at Vanderbilt, Vanderbilt; Jeffrey Thomson, Connecticut Children's Medical Center, Hartford and Shriners Hospitals for Children Springfield, Springfield; Alex Van Speybroeck, Shriners Hospital for Children, Los Angeles, Los Angeles; William Walker, Seattle Children's Hospital, Seattle; John Wiener, Duke.

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Table 1

Patient characteristics, surgical interventions, and management techniques, National Spina Bifida Patient Registry (2009–2015)

Variables	**Overall *n* (%) or statistics (*N* = 4364)**	***N* (%) or statistics by ethnicity**		***P*-value**
		Hispanic or Latino (*n* = 1092)	**Not Hispanic or Latino (*n* = 3272)**	
Age at visit (years)*				
N	4364	1092	3272	
Median	12.6	12.8	12.5	
Range	5.1–21.0	5.1–21.0	5.1–21.0	
Mean (SE)	12.89 (0.07)	13.01 (0.14)	12.85 (0.09)	0.31
Age group (years)				
5–11	2002 (45.9)	480 (44.0)	1522 (46.5)	
12–21	2362 (54.1)	612 (56.0)	1750 (53.5)	0.1505
Sex				
Male	2087 (47.8)	537 (49.2)	1550 (47.4)	
Female	2277 (52.2)	555 (50.8)	1722 (52.6)	0.31
Race group (*N* = 4313)				
White	3542 (82.1)	927 (88.0)	2615 (80.2)	
Black	343 (8.0)	16 (1.5)	327 (10.0)	
Asian	182 (4.2)	4 (0.4)	178 (5.5)	
Other	246 (5.7)	106 (10.1)	140 (4.3)	< 0.0001
Spina bifida type				
Myelomeningocele	3421 (78.4)	863 (79.0)	2558 (78.2)	
Other diagnosis	943 (21.6)	229 (21.0)	714 (21.8)	0.58
History of vesicostomy*				
Yes	271 (6.2)	82 (7.5)	189 (5.8)	
No	4093 (93.8)	1010 (92.5)	3083 (94.2)	0.0427
History of bladder continence surgery*				
Yes	922 (21.1)	198 (18.1)	724 (22.1)	
No	3442 (78.9)	894 (81.9)	2548 (77.9)	0.0054
Any bladder management technique (*N* = 4340)*				
Yes	4002 (92.2)	1018 (93.8)	2984 (91.7)	

Variables	Overall *n* (%) or statistics ($N = 4364$)	*N* (%) or statistics by ethnicity		*P*-value
		Hispanic or Latino ($n = 1092$)	Not Hispanic or Latino ($n = 3272$)	
No	338 (7.8)	67 (6.2)	271 (8.3)	0.0220
History of bowel continence surgery*				
Yes	950 (21.8)	128 (11.7)	822 (25.1)	
No	3414 (78.2)	964 (88.3)	2450 (74.9)	< 0.0001
Any bowel management technique ($N = 4361$)*				
Yes	2817 (64.6)	687 (62.9)	2130 (65.2)	
No	1544 (35.4)	405 (37.1)	1139 (34.8)	0.1883
Functional level of lesion*				
Thoracic	655 (15.0)	169 (15.5)	486 (14.9)	
Lumbar	2315 (53.0)	577 (52.8)	1738 (53.1)	
Sacral	1394 (31.9)	346 (31.7)	1048 (32.0)	0.88
Mobility status*				
Community ambulators	2594 (59.4)	650 (59.5)	1944 (59.4)	
Household ambulators	327 (7.5)	83 (7.6)	244 (7.5)	
Non-functional ambulators	295 (6.8)	71 (6.5)	224 (6.8)	
Non-ambulators	1148 (26.3)	288 (26.4)	860 (26.3)	0.98
Health insurance ($N = 4361$)				
Any private	2095 (48.0)	198 (18.2)	1897 (58.0)	
Non-private	2266 (52.0)	892 (81.8)	1374 (42.0)	< 0.0001
Urinary continence outcome ($N = 4302$)				
Continent	1865 (43.3)	420 (38.6)	1444 (44.9)	
Incontinent	2438 (56.7)	669 (61.4)	1769 (55.1)	0.0003
Bowel continence outcome ($N = 4163$)				
Continent	2196 (52.8)	466 (43.9)	1730 (55.8)	
Incontinent	1967 (47.2)	595 (56.1)	1372 (44.2)	< 0.0001

[*] At last visit.

Table 2

Summary of multivariable regression – GEE model for urinary continence, National Spina Bifida Patient Registry (2009–2015)

Variables	**Odds ratio (95% CI)**	***P* -value**
Age at visit		
5 year increase	1.38(1.30–1.47)	< 0.0001*
Sex		
Male†		
Female	1.36(1.22–1.52)	< 0.0001*
Ethnicity		
Non-Hispanic†		
Hispanic or Latino	0.89 (0.77–1.02)	0.0909
Race		0.0007*‡
White†		
Black	0.66 (0.53–0.82)	0.0002*
Asian	1.22 (0.91–1.62)	0.1845
Other	0.94 (0.73–1.21)	0.62
Spina bifida type		
Myelomeningocele†		
Other diagnosis	2.49 (2.13–2.91)	< 0.0001*
History of bladder continence surgery		
No†		
Yes	1.73 (1.51–1.98)	< 0.0001*
Any bladder management		
No†		
Yes	8.42(6.44–11.02)	< 0.0001*
Level of lesion		< 0.0001*‡
Thoracic‡		
Lumbar	0.94 (0.80–1.11)	0.48
Sacral	1.39(1.13–1.71)	0.0018*
Mobility status		0.0006*‡
Community ambulators†		
Household ambulators	0.97 (0.82–1.14)	0.68
Non-functional ambulators	0.84(0.69–1.01)	0.0605
Non-ambulators	0.72 (0.62–0.85)	< 0.0001*
Health insurance		
Any private†		
Non-private	0.74 (0.66–0.83)	< 0.0001*

[†] Reference group;

[‡] Overall *p*-value.

Table 3

Summary of multivariable regression – GEE models for bowel continence National Spina Bifida Patient Registry (2009–2015)

Variables	Odds ratio (95% CI)	*P*-value
Age at visit		
5 year increase	1.55 (1.47–1.64)	< 0.0001
Sex		
Male[†]		
Female	1.18 (1.06–1.30)	0.0017
Ethnicity		
Non-Hispanic[†]		
Hispanic or Latino	0.82 (0.72–0.94)	0.0032
Race		0.1459[‡]
White[†]		
Black	0.82 (0.67–0.99)	0.0423
Asian	1.15 (0.87–1.53)	0.33
Other	1.00(0.79–1.27)	0.99
Spina bifida type		
Myelomeningocele[†]		
Other diagnosis	2.18 (1.87–2.53)	< 0.0001
History of bowel continence surgery		
No[†]		
Yes	1.96 (1.72–2.25)	< 0.0001
Any bowel management		
No[†]		
Yes	1.06(0.96–1.17)	0.26
Level of lesion		< 0.0001[‡]
Thoracic[†]		
Lumbar	1.22 (1.04–1.45)	0.0176
Sacral	1.71 (1.39–2.11)	< 0.0001
Mobility status		< 0.0001[‡]
Community ambulators[†]		
Household ambulators	0.87 (0.73–1.03)	0.1015
Non-functional ambulators	0.73 (0.60–0.88)	0.0009
Non-ambulators	0.65 (0.56–0.76)	< 0.0001
Health insurance		
Any private[†]		
Non-private	0.63 (0.56–0.70)	< 0.0001

[†] Reference group;

[‡] Overall p-value.