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Age-Specific Probability of 4 Major Health Outcomes in Children with Spina Bifida

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Abstract

Objective: This study aimed to estimate the age-specific probability of 4 health outcomes in a large registry of individuals with spina bifida (SB).

Methods: The association between age and 4 health outcomes was examined in individuals with myelomeningocele (MMC, n = 5627) and non-myelomeningocele (NMMC, n = 1442) from the National Spina Bifida Patient Registry. Sixteen age categories were created, 1 for each year between the ages of 5 and 19 years and 1 for those aged 20 years or older. Generalized linear models were used to calculate the adjusted probability and 95% prediction intervals of each outcome for each age category, adjusting for sex and race/ethnicity.

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Results: For the MMC and NMMC groups, the adjusted coefficients for the correlation between age and the probability of each outcome were −0.933 and −0.657 for bladder incontinence, −0.922 and −0.773 for bowel incontinence, 0.942 and 0.382 for skin breakdown, and 0.809 and 0.619 for lack of ambulation, respectively.

Conclusion: In individuals with SB, age is inversely associated with the probability of bladder and bowel incontinence and directly associated with the probability of skin breakdown and lack of ambulation. The estimated age-specific probabilities of each outcome can help SB clinicians estimate the expected proportion of patients with the outcome at specific ages and explain the probability of the occurrence of these outcomes to patients and their families.

Keywords

spina bifida; bladder incontinence; bowel incontinence; lack of ambulation; skin breakdown

Spina bifida (SB) results from the incomplete closure of the fetal neural tube and affects exposed nerves and, potentially, multiple end organs. Dysfunction is typically more severe with the open type of SB (myelomeningocele [MMC]) than the closed type (non-myelomeningocele [NMMC]). Over time, the impairments from both the congenital malformation and the tethering of nerves related to scarring after initial spinal cord surgery may cause abnormal growth, scoliosis, and end-organ dysfunction, including weakness of the lower extremities, bone and joint deformities, decreased sensation, bladder and bowel incontinence, and sexual dysfunction.[1–3] A 1994–1995 study estimated that 62 per 100,000 Americans were living with SB.[4] Extrapolating this figure to the current US population (331.4 million), the number would be about 205,500 people with SB.

Although adverse health outcomes in people with SB are influenced by the SB type and level of lesion,[5–10] previous studies have also reported that adverse health outcomes are more frequent among individuals with SB who are older, male, without private health insurance, and belong to racial/ethnic minority groups.[11–18] The objectives of this study are to test the strength and independence of the association between age and 4 health outcomes (bladder and bowel incontinence, lack of ambulation, and skin breakdown) and to present the adjusted age-specific probability of each outcome between the ages of 5 and 19 years in easy-to-read charts.

METHODS

The National Spina Bifida Patient Registry (NSBPR) collects data on children, adolescents, and adults attending selected SB clinics in the United States.[19,20] The registry, funded by the Centers for Disease Control and Prevention (CDC), started in 2009 with 10 multidisciplinary clinics. For the study period (2009–2019), up to 37 SB clinics have contributed data to the NSBPR. The NSBPR collects data on carefully selected variables through initial and annual interviews. Except for body measurements, the determination of the level of lesion, and laboratory tests, the interview data are self-reported by the patient or by a proxy (parent or caregiver) to clinicians and staff. When possible, clinical data are verified by physical examination or by the review of medical records. The data include demographic information; surgical procedures (neurologic, orthopedic, and urologic); measures of growth;

results from imaging studies and laboratory analyses; and clinical outcomes (mobility status, continence status, and pressure sores). Clinic and research staff enter collected data into a web-based electronic health record platform. The compiled data are deidentified and transmitted monthly to the federal agency for quality control and analyses. The quality control deals with duplicate data, extreme values, skip patterns, and missing values. The CDC generates monthly data quality reports that go to each clinic for the verification or correction of individual data, if necessary. In addition, every 6 months, each clinic randomly selects 20% of all the individual records it has submitted for that period, and the data are reabstracted and verified by someone other than the initial abstractor. Informed consent or assent to collect and use the data was obtained from each participant. The ways the data are collected, protected, and used were approved by the IRB at each site. For this study, we used data collected at the most recent visit of each participant from 2009 to 2019.

Demographic and Clinical Variables

Age, sex, race, ethnicity, type of SB (MMC and NMMC [meningocele, lipomyelomeningocele, fatty filum, split cord malformation, and terminal myelocystocele]), and functional level of lesion[5] (thoracic, flaccid lower extremities; high lumbar, hip flexion present; mid lumbar, knee extension present; low lumbar, foot dorsiflexion present; and sacral, foot plantar flexion present). The functional level of lesion was assessed for each lower extremity and classified by the more severely affected side.

Outcomes

Bladder continence status: for version 1 of the questionnaire (2009–2013), the question was “Dry during the day (with or without management)?” Incontinence was defined by an answer of “no.” For version 2 (2014—present), incontinence was defined by an answer of an incontinence event occurring once per month or more. Bowel continence status: for version 1, there was checkbox for “No involuntary leakage during the day, with or without management?” Incontinence was indicated by not checking the box. For version 2, incontinence was defined by an answer of involuntary leakage “once per month” or more. The continent groups included treated and untreated individuals. Ambulation status[5]: community ambulator (able to walk indoors and outdoors for most activities, may need crutches); household ambulator (able to walk only indoors and with apparatus, may use the wheelchair for some indoor activities at home and school and for all activities in the community); therapeutic ambulator (able to walk only during therapy sessions in the school or hospital); and nonambulator (unable to mobilize without a wheelchair). Skin breakdown: for version 1, those who acknowledged to have “had a pressure sore since the last visit” (not counting stage 1 breakdown) were considered to have had a skin breakdown. For version 2, those who acknowledged “having had a skin breakdown in the last year” (not counting stage 1 breakdown) were considered to have had a skin breakdown.

Analytical Sample

From 2009 through 2019, the NSBPR included 10,253 individuals. Children younger than 5 years (n = 2046) were excluded from this analysis because motor testing and determination of continence status are less reliable in this age group.[21] We also excluded participants with missing values in the last visit for any of the variables selected for this study (n = 475).

Compared with included participants, those participants excluded due to missing values had similar distributions of age, sex, and race/ethnicity and a higher proportion of individuals with MMC (84.8% vs 79.6%). Still, the correlations between age and the 4 outcomes of interest were in the same direction for included and excluded individuals, although these correlations were weak for the 2 continence outcomes because of large numbers of missing values for these variables (results not shown). We reported results only among racial/ethnic groups whose numbers were large enough for our analyses (i.e., non-Hispanic White, non-Hispanic Black, and Hispanic). Other racial/ethnic groups were excluded because of their small sample sizes, which total 663 individuals.

Statistical Analyses

We analyzed the data using SAS/STAT software, version 9.4 (Cary, NC).[22] We used logistic regression to calculate odds ratios and 95% confidence intervals (CIs) for the association between selected variables and outcomes. We used generalized linear models to calculate the probability (marginal effect) and 95% CIs of each outcome by age. We divided the sample into 15 age groups, 1 for each year of age from 5 to 19 years. For each age and type of SB, we estimated the probability of each outcome adjusted for sex and race/ethnicity. The group aged 20 years or older was excluded from these age-specific calculations because the age range was too wide. To make the charts, we estimated the probability of each outcome with linear regression models and added the respective prediction intervals (PIs).

RESULTS

Our analytical sample included 7069 individuals, of whom 80% (n = 5627) had MMC and 20% (n = 1442) had other types of SB (NMMC). Table 1 shows that individuals with SB are almost evenly distributed across the 4 age bands (range: 23.4% to 28.0%). Overall, both sexes were similarly represented in the MMC group, but the proportion of females was higher in the NMMC group (56.2% vs 43.8%). The racial/ethnic distributions were similar for both SB groups. In the total sample, the most common functional levels of lesion were sacral (30.7%) and mid lumbar (28.8%). In the MMC group, the most common functional level of lesion was mid lumbar (33.3%), followed by thoracic (20.9%) and sacral (19.7%), whereas a sacral functional level of lesion was most common (73.9%) in the NMMC group (Table 1).

The proportions of individuals with bladder incontinence and bowel incontinence were high in the MMC group (59.6% and 46.9%, respectively). The overall rate of bladder continence without any treatment (0.7%) was much smaller than that of bowel continence without any treatment (31.0%). The percentage of community ambulators among the MMC group (45.8%) was about half of that in the NMMC group (91.5%). In the MMC group, 13.3% reported skin breakdown since the last visit, which doubles the rate observed in the NMMC group (6.0%) (Table 1).

In both the MMC and NMMC groups, bladder incontinence was more frequent among 5 to 9 year olds than among the ≥20 year olds, among non-Hispanic Blacks or Hispanics, and in those with levels of lesion above the sacral level (Table 2). The bladder incontinence rate was higher among males than females in the MMC group alone. The bowel incontinence

rate was also higher in both groups among 5 to 9 year olds than among the ≥20 year olds, among males, among Hispanics or non-Hispanic Blacks, and in those with levels of lesion above the sacral level. Skin breakdown in the MMC group was reported less among the 5 to 9 year olds than among the ≥20 year olds, slightly more among males, less among Hispanics, and more in those with levels of lesion above the sacral level. In the NMMC group, skin breakdown was less frequent among 5 to 9 year olds than among ≥20 year olds, similar between males and females, slightly more frequent among non-Hispanic Blacks, and more frequent in those with levels of lesion above the sacral level. Regarding the lack of ambulation, in the MMC group, the frequency of this outcome was lower among 5 to 9 year olds compared with the ≥20 year olds, similar between males and females, higher among non-Hispanic Whites, and higher in those with levels of lesion above the sacral level. In the NMMC group, the frequency of lack of ambulation was also lower among 5 to 9 year olds compared with ≥20 year olds, similar between males and females, higher among non-Hispanic Blacks, and higher in those with levels of lesion above the sacral level.

Multivariable analysis showed similar results for both MMC and NMMC groups (Table 3). The odds of being incontinent of the bladder or bowel were higher at age 5 to 9 years compared with the older groups, lower in females compared with males, higher in non-Hispanic Blacks and Hispanics compared with non-Hispanic Whites, and higher in the higher levels of lesion compared with the sacral level. Regarding skin breakdown and lack of ambulation, the odds of these 2 outcomes were higher for the older groups compared with ages 5 to 9 years and less likely among non-Hispanic Blacks and Hispanics compared with non-Hispanic Whites. The odds were similar for males and females. The results for the univariate analyses were virtually the same (results not shown).

The probability of each outcome, by age and SB type, is shown in Table 4. The correlation coefficients indicated that the association between age and the probability of each outcome can be modeled with a linear regression for the MMC group (absolute value range: 0.81–0.94). For the NMMC group, the correlation coefficients were lower (absolute value range: 0.38–0.77). Graphic representation of the results of linear modeling for all 4 outcomes by age showed steady decreases in the probability of bowel and bladder incontinence and steady increases of the probability of skin breakdown and lack of ambulation with increasing age (Figure 1). For the NMMC group, the trends were similar with lower probabilities at all ages.

DISCUSSION

Here, we showed the strength of the association between age and 4 major health outcomes in individuals with SB, independent of other risk factors. Previous studies with NSBPR data have also examined these associations using odds ratios, but odds ratios as a measure of risk can be challenging for clinicians to communicate because odds ratios are not direct indicators of risk. To facilitate the communication of risk, we converted odds ratios into probabilities of observing a given outcome, adjusting for sex and race/ethnicity, to produce easy-to-read charts. Incidentally, we did not adjust for the level of lesion because the association of the lack of ambulation with the functional level of lesion was so strong that it might largely outweigh the predictive value of other variables in the models.

By modeling the association of the probability of each health outcome with age through linear regression, we were able to create age-specific charts with the probability of each health outcome and its respective PI. With these charts, SB clinics could estimate their expected proportions of patients with a given outcome at specific ages. Clinicians could explain to patients and families the probability of occurrence of an outcome at a given age.

Although the trends with age observed in these outcome charts were expected,[23] we were able to quantify and model them. MMC and NMMC groups showed different relative frequencies of outcomes but similar trends with age, as the former is essentially a more severe manifestation of the latter. The decreasing frequency of bladder and bowel incontinence with age was also expected. As individuals with SB adapt to their social and work environments, they may undergo surgeries and other procedures to achieve continence over time and become more diligent in the regimens required to attain continence. Finally, the parallel increases in the frequency of skin breakdown and lack of ambulation were also expected because, in general, increasing size and weight impairs mobility, and lack of mobility and increasing weight increase the risk for skin breakdown.

We did not include adults (aged ≥20 years) in the charts for several reasons. Adults have a wide range of ages, and their sample size would have required dividing them into groups so small that the accuracy of the estimation of the probabilities would be compromised. It appears that the associations among outcomes and the variables included in this study are weaker in adults with SB than in children. Most surgeries and procedures that address the outcomes included in this study occur in childhood. Mortality could be higher in adults with SB, leaving survivors with milder forms of the disease and better outcomes. Furthermore, some of the medical and surgical interventions available to attain continence in children with SB over the past 20 years were not available to current-day adults when they were children. Finally, as individuals with SB age, they may develop other conditions that are common in adulthood, which may complicate the identification of trends that are attributable only to SB.

Our findings are consistent with previous NSBPR studies performed using different methodologies. Four outcomes (bladder and bowel incontinence, skin breakdown, and lack of ambulation) are much more frequent among individuals with MMC than among those with other types of SB.[11–13,15,16,23] Age is inversely associated with the frequency of bladder and bowel incontinence [11,13–15,23] and is directly related to the frequency of skin breakdown[11,12,23] and lack of ambulation.[11,18,23] A lower functional level of lesion poses less risk for any of these 4 outcomes than higher levels of lesion; the risk is substantially lower for skin breakdown and lack of ambulation.[11,13–15,18,23] Bladder and bowel incontinence are more likely among males than among females.[11,13–15] Reported sex or racial/ethnic differences in the frequencies of skin breakdown are inconsistent or not statistically significant,[11,12] and one study has reported that the frequency of the lack of ambulation could be higher among males and similar across racial/ethnic groups.[11] Some studies have found bladder or bowel incontinence to be more common among non-Hispanic Blacks[11,13,15] or Hispanics,[17] but other studies have found no racial/ethnic differences for these 2 outcomes.[14,16] This study supports the finding that bladder and bowel incontinence are more frequent among non-Hispanic Blacks and Hispanics, notably in the MMC group.

This analysis has limitations. The data came from individuals who receive their care at select multidisciplinary SB clinics participating in the NSBPR; individuals with SB receiving care in other settings were not represented. Because participation in the registry is voluntary, it is possible that the demographic and disease profiles of participants differed from those who declined to participate. Recall bias of outcome status as reported by the patients or their proxies (parents or caregivers) is possible. Outcome status was characterized as present/absent answers, but the actual status could be more nuanced than that. Clinics may vary in their assessment of these outcomes, but we standardized their definitions according to the answers given in the interview.

Our analysis was cross-sectional, based on reported information at the last visit, but changes in outcomes may vary between clinic visits over time. Changes in the definitions of incontinence during the study period could have affected the reported frequency of continence outcomes. We used a small set of variables in our models, and it is possible that variables not included in the study (e.g., obesity) or not included in the registry (e.g., adherence to treatment) may have affected the results. Combinations of outcomes, which are likely and could be clinically meaningful, were not part of our study. Finally, because the study period was long, it is possible that patients who joined the registry in the early years were different or received different treatments and procedures than patients who joined the registry more recently. Treatments and procedures were not part of our analyses.

The strengths of our analysis derive from characteristics of the NSBPR. This registry collects data from a large and diverse population of individuals with SB from across the United States. About 78% of those invited to participate in the registry accepted the invitation. The data are captured and transferred in standard electronic health record forms specifically designed for the NSBPR. The registry has a central data center with a rigorous data quality control system linked to the data collection at the clinics by secure feedback loops. Individuals joining the registry receive their care at multidisciplinary clinics, giving them access to some of the best assessment and treatments, which generate the data captured in the registry.

CONCLUSION

In individuals with SB, the probabilities of bladder and bowel incontinence are inversely and linearly associated with age. The probabilities of skin breakdown and lack of ambulation are directly and linearly associated with age, independent of sex and race/ethnicity. The large sample size and the significant strength of the associations between age and these outcomes allowed for the creation of charts, with the average probability of each outcome at each year between the ages of 5 and 19 years. These charts may allow clinicians to compare the age-specific distribution of a given outcome in their clinics with our clinic-based reference charts or to get an idea of the expected prevalence of an outcome at a given age as they plan or expand services for patients with SB. For individuals with SB, their families, and caregivers, our charts may help them set their expectations for the status of a health outcome at a given age as they seek care in specialized clinics. Our charts do not provide outcome probabilities for individual patients.

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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.

The data that support the findings of this study are accessed through the sites contributing their data. Restrictions apply to the availability of these data. Interested researchers can contact cdcinfo@cdc.gov.

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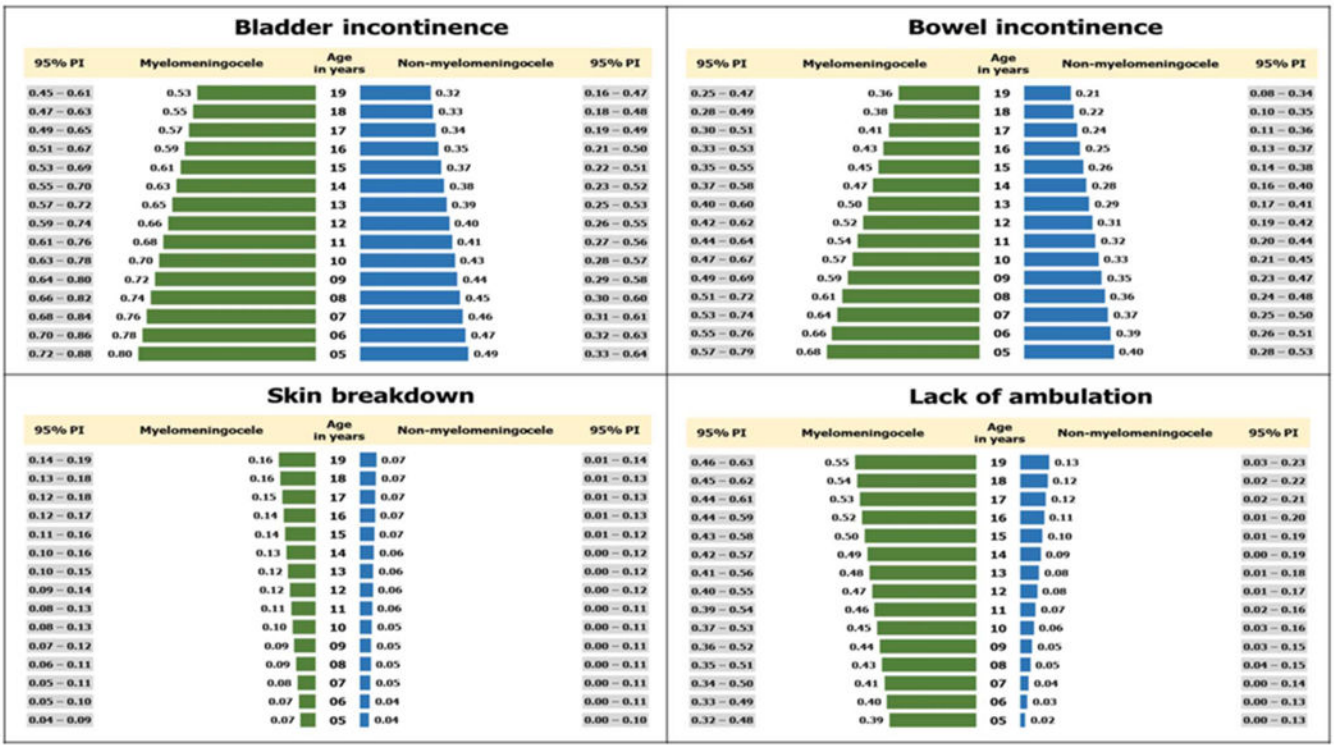

Figure 1.

Modeled probability and 95% prediction interval (95% PI) for 4 major outcomes in patients with spina bifida, by age and spina bifida type, adjusted for sex and race/ethnicity, National Spina Bifida Patient Registry, 2009–2019.

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Table 1.

Distributions of Basic Characteristics of Individuals with Spina Bifida Aged 5 yrs and Older at Their Most Recent Visit, Overall and by the Type of Spina Bifida

	Overall		Type of Spina Bifida			
			Myelomeningocele		Non-Myelomeningocele	
	n = 7069		n = 5627		n = 1442	
	n	%	n	%	n	%
Age (yr)						
5–9	1765	25.0	1309	23.3	456	31.6
10–14	1653	23.4	1277	22.7	376	26.1
15–19	1670	23.6	1347	23.9	323	22.4
≥20	1981	28.0	1694	30.1	287	19.9
Sex						
Male	3357	47.5	2726	48.4	631	43.8
Female	3712	52.5	2901	51.6	811	56.2
Race/ethnicity						
Non-Hispanic White	4771	67.5	3802	67.6	969	67.2
Non-Hispanic Black	586	8.3	491	8.7	95	6.6
Hispanic	1712	24.2	1334	23.7	378	26.2
Functional level of lesion						
Thoracic	1192	16.9	1174	20.9	18	1.2
High lumbar	650	9.2	626	11.1	24	1.7
Mid lumbar	2035	28.8	1873	33.3	162	11.2
Low lumbar	1021	14.4	848	15.1	173	12.0
Sacral	2171	30.7	1106	19.7	1065	73.9
Bladder continence status						
Continent without treatment	46	0.7	16	0.3	30	2.1
Continent with treatment	3136	44.4	2255	40.1	881	61.1
Incontinent	3887	55.0	3356	59.6	531	36.8
Bowel continence status						
Continent without treatment	2191	31.0	1297	23.0	894	62.0

	Overall		Type of Spina Bifida			
			Myelomeningocele		Non-Myelomeningocele	
	n = 7069		n = 5627		n = 1442	
	n	%	n	%	n	%
Continent with treatment	1844	26.1	1692	30.1	152	10.5
Incontinent	3034	42.9	2638	46.9	396	27.5
Ambulation status						
Nonambulatory	2200	31.1	2144	38.1	56	3.9
Therapeutic ambulatory	382	5.4	363	6.5	19	1.3
Household ambulatory	592	8.4	544	9.7	48	3.3
Community ambulatory	3895	55.1	2576	45.8	1319	91.5
Skin breakdown since the last visit						
Yes	837	11.8	751	13.3	86	6.0
No	6232	88.2	4876	86.7	1356	94.0

National Spina Bifida Patient Registry, 2009–2019.

Table 2.

Proportion of 4 Outcomes Among Individuals with Spina Bifida Aged 5 yrs and Older at Their Most Recent Visit, by Selected Variables and the Type of Spina Bifida

	Myelomeningocele					Non-Myelomeningocele				
	n	% Bladder Incontinence	% Bowel Incontinence	% Skin Breakdown	% Lack of Ambulation	n	% Bladder Incontinence	% Bowel Incontinence	% Skin Breakdown	% Lack of Ambulation
Age (yr)										
5–9	1309	73.0	61.5	8.8	45.0	456	41.7	34.6	4.2	4.6
10–14	1277	64.7	48.2	11.0	48.2	376	38.8	27.1	6.9	7.2
15–19	1347	52.8	38.8	15.6	54.7	323	26.9	19.5	5.9	9.6
≥20	1694	50.9	41.0	16.8	65.5	287	37.6	25.4	7.7	15.3
Sex										
Male	2726	64.6	49.7	14.6	53.7	631	34.7	27.4	5.4	8.4
Female	2901	54.9	44.2	12.2	54.7	811	38.5	27.5	6.4	8.6
Race/ethnicity										
Non-Hispanic White	3802	56.4	43.0	14.4	56.0	969	34.6	25.2	6.0	8.6
Non-Hispanic Black	491	67.4	52.1	14.5	47.9	95	51.6	38.9	6.3	9.5
Hispanic	1334	66.1	56.0	10.0	51.4	378	38.9	30.4	5.8	8.2
Level of lesion										
Thoracic	1174	60.6	52.0	21.2	99.1	18	66.7	61.1	11.1	88.9
High lumbar	626	59.3	54.8	16.1	97.3	24	45.8	41.7	20.8	66.7
Mid lumbar	1873	61.6	46.7	12.2	56.2	162	51.9	35.8	17.3	35.8
Low lumbar	848	63.6	47.6	12.9	20.5	173	46.2	41.6	9.2	9.2
Sacral	1106	52.5	36.6	5.8	4.8	1065	32.3	23.0	3.3	1.6

National Spina Bifida Patient Registry, 2009–2019.

Table 3.

Odds Ratios and 95% Confidence Intervals (95% CIs) for 4 Outcomes Stratified by Key Variables

	Myelomeningocele							
	Bladder Incontinence		Bowel Incontinence		Skin Breakdown		Lack of Ambulation	
		95% CI		95% CI		95% CI		95% CI
Age at visit (yr)								
5–9	Referent	—	Referent	—	Referent	—	Referent	—
10–14	0.67	0.56–0.79	0.57	0.48–0.67	1.29	0.99–1.68	0.98	0.79–1.21
15–19	0.39	0.33–0.46	0.36	0.31–0.43	1.83	1.43–2.34	1.19	0.96–1.47
≥20	0.38	0.32–0.44	0.41	0.35–0.48	1.74	1.37–2.20	1.34	1.08–1.65
Sex		95% CI		95% CI		95% CI		95% CI
Male	Referent	—	Referent	—	Referent	—	Referent	—
Female	0.69	0.62–0.77	0.83	0.74–0.92	0.77	0.66–0.90	0.95	0.81–1.10
Race/ethnicity		95% CI		95% CI		95% CI		95% CI
Non-Hispanic White	Referent	—	Referent	—	Referent	—	Referent	—
Non-Hispanic Black	1.62	1.32–1.99	1.51	1.24–1.83	1.06	0.81–1.40	0.74	0.56–0.97
Hispanic	1.42	1.24–1.63	1.70	1.49–1.94	0.68	0.55–0.84	1.03	0.86–1.24
Functional level of lesion		95% CI		95% CI		95% CI		95% CI
Sacral	Referent	—	Referent	—	Referent	—	Referent	—
Low lumbar	1.59	1.32–1.92	1.57	1.30–1.90	2.47	1.79–3.42	5.07	3.67–7.01
Mid lumbar	1.55	1.32–1.81	1.62	1.38–1.89	2.21	1.65–2.95	25.44	19.02–34.04
High lumbar	1.47	1.19–1.80	2.38	1.93–2.92	3.01	2.16–4.20	705.90	404.90–1231.00
Thoracic	1.83	1.53–2.18	2.42	2.02–2.88	3.98	2.97–5.33	1972.00	1024.00–3798.00
	Non-Myelomeningocele							
	Bladder Incontinence		Bowel Incontinence		Skin Breakdown		Lack of Ambulation	
		95% CI		95% CI		95% CI		95% CI
Age at visit (yr)								
5–9	Referent	—	Referent	—	Referent	—	Referent	—
10–14	0.84	0.63–1.12	0.64	0.47–0.88	1.52	0.81–2.83	1.07	0.53–2.13
15–19	0.48	0.35–0.66	0.42	0.30–0.59	1.20	0.61–2.37	1.70	0.87–3.36
≥20	0.75	0.55–1.04	0.57	0.40–0.81	1.36	0.70–2.64	1.82	0.93–3.55

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	Myelomeningocele							
	Bladder Incontinence		Bowel Incontinence		Skin Breakdown		Lack of Ambulation	
		95% CI		95% CI		95% CI		95% CI
Sex		95% CI		95% CI		95% CI		95% CI
Male	Referent	—	Referent	—	Referent	—	Referent	—
Female	1.15	0.92–1.44	0.96	0.76–1.23	1.18	0.74–1.86	0.89	0.56–1.40
Race/ethnicity		95% CI		95% CI		95% CI		95% CI
Non-Hispanic White	Referent	—	Referent	—	Referent	—	Referent	—
Non-Hispanic Black	1.90	1.23–2.93	1.73	1.10–2.71	1.02	0.42–2.50	0.99	0.40–2.47
Hispanic	1.18	0.92–1.53	1.21	0.92–1.60	1.04	0.61–1.77	1.26	0.73–2.17
Functional level of lesion		95% CI		95% CI		95% CI		95% CI
Sacral	Referent	—	Referent	—	Referent	—	Referent	—
Low lumbar	1.81	1.30–2.52	2.49	1.77–3.51	2.94	1.58–5.45	6.20	3.06–12.56
Mid lumbar	2.39	1.70–3.37	2.06	1.44–2.97	5.94	3.47–10.17	32.30	18.02–57.88
High lumbar	1.80	0.79–4.13	2.61	1.13–6.05	7.42	2.59–21.25	116.00	43.28–311.00
Thoracic	4.70	1.72–12.86	6.73	2.54–17.82	3.24	0.71–14.85	464.20	97.08–2220.00

National Spina Bifida Patient Registry, 2009–2019. Multivariable analysis.

Table 4.

Probability and 95% Confidence Interval (95% CI)[a] of 4 Major Outcomes in Spina Bifida Individuals by Age and 2 Types of Spina Bifida: Myelomeningocele (MMC) and Non-Myelomeningocele (NMMC).

	Bladder Incontinence				Bowel Incontinence				Skin Breakdowns				Lack of Ambulation			
Age (yr)	**MMC**	**95% CI**	**NMMC**	**95% CI**	**MMC**	**95% CI**	**NMMC**	**95% CI**	**MMC**	**95% CI**	**NMMC**	**95% CI**	**MMC**	**95% CI**	**NMMC**	**95% CI**
5	0.80	0.75–0.84	0.45	0.34–0.57	0.74	0.68–0.79	0.40	0.29–0.52	0.07	0.04–0.10	0.04	0.01–0.11	0.43	0.37–0.49	0.05	0.02–0.14
6	0.75	0.69–0.80	0.45	0.35–0.56	0.65	0.59–0.71	0.40	0.30–0.52	0.08	0.05–0.12	0.04	0.01–0.11	0.43	0.37–0.49	0.04	0.01–0.11
7	0.75	0.70–0.80	0.48	0.38–0.59	0.64	0.58–0.69	0.33	0.24–0.44	0.09	0.06–0.13	0.04	0.02–0.11	0.40	0.34–0.46	0.06	0.02–0.13
8	0.74	0.69–0.79	0.47	0.37–0.58	0.63	0.57–0.68	0.42	0.32–0.53	0.08	0.05–0.12	0.07	0.03–0.14	0.44	0.38–0.51	0.07	0.03–0.14
9	0.74	0.68–0.79	0.42	0.32–0.52	0.56	0.49–0.62	0.36	0.26–0.46	0.10	0.07–0.15	0.03	0.01–0.09	0.45	0.39–0.52	0.03	0.01–0.09
10	0.72	0.66–0.77	0.47	0.35–0.59	0.61	0.55–0.67	0.37	0.26–0.50	0.09	0.06–0.13	0.04	0.01–0.13	0.40	0.34–0.47	0.07	0.03–0.17
11	0.71	0.66–0.77	0.47	0.36–0.58	0.52	0.46–0.58	0.36	0.26–0.47	0.12	0.09–0.17	0.09	0.05–0.18	0.49	0.43–0.55	0.06	0.03–0.14
12	0.71	0.65–0.76	0.40	0.28–0.53	0.49	0.43–0.55	0.28	0.18–0.41	0.10	0.07–0.14	0.06	0.02–0.16	0.48	0.43–0.54	0.10	0.04–0.21
13	0.58	0.52–0.64	0.45	0.34–0.57	0.44	0.38–0.50	0.22	0.14–0.34	0.12	0.08–0.17	0.04	0.01–0.11	0.41	0.35–0.47	0.07	0.03–0.15
14	0.67	0.61–0.73	0.36	0.25–0.49	0.50	0.43–0.56	0.29	0.19–0.41	0.11	0.08–0.16	0.11	0.06–0.22	0.52	0.45–0.58	0.09	0.04–0.19
15	0.60	0.54–0.66	0.32	0.22–0.44	0.39	0.32–0.45	0.20	0.12–0.31	0.15	0.11–0.20	0.03	0.01–0.11	0.48	0.42–0.55	0.10	0.05–0.20
16	0.56	0.50–0.62	0.26	0.16–0.40	0.37	0.31–0.43	0.18	0.10–0.32	0.15	0.11–0.20	0.09	0.04–0.20	0.48	0.42–0.54	0.02	0.00–0.13
17	0.53	0.47–0.58	0.23	0.15–0.34	0.45	0.39–0.50	0.20	0.12–0.30	0.14	0.11–0.18	0.07	0.03–0.14	0.56	0.51–0.61	0.07	0.03–0.15
18	0.59	0.53–0.66	0.32	0.20–0.46	0.42	0.36–0.49	0.27	0.16–0.42	0.16	0.12–0.21	0.04	0.01–0.15	0.54	0.47–0.60	0.15	0.07–0.28
19	0.52	0.46–0.59	0.46	0.32–0.61	0.42	0.35–0.49	0.30	0.19–0.46	0.18	0.13–0.23	0.08	0.03–0.21	0.58	0.51–0.64	0.22	0.12–0.37
R[b]	−0.933		−0.657		−0.922		−0.773		0.942		0.382		0.809		0.619	

National Spina Bifida Patient Registry, 2009–2019.

[a] Adjusted for sex and race/ethnicity.

[b] Correlation coefficient for the correlation between age and the probability of outcome.