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Weight Status of Children Participating in the National Spina Bifida Patient Registry

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Abstract

OBJECTIVES: Describe the distribution of weight status categories and determine factors associated with overweight and obesity (OW/OB) in children and adolescents with spina bifida (SB) using the National Spina Bifida Patient Registry.

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All authors conceptualized and assisted in study design. Drs Polfuss, Sawin, Murphy, and Smith, and Ms Liu drafted the initial manuscript, interpreted results, and reviewed and revised the manuscript. Ms Ward, Dr Dosa, Ms Thibadeau, and Dr Wang critically reviewed and edited the manuscript. Ms Liu conducted data management and analyzed the data and Dr Wang replicated the data analysis. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

CONFLICT OF INTEREST DISCLOSURES: K.J.S. is a consultant to the Spina Bifida Association. K.J.S., M.P., and K.S. are co-investigators on the Centers for Disease Control and Prevention National Spina Bifida Patient Registry grant provided to their respective institutions. The other authors have indicated they have no potential conflicts of interest to disclose. 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.

METHODS: Demographic, anthropometric, and clinical data collected from 2009 through 2018 was used to describe the prevalence of OW/OB. The generalized estimating equation model (GEE) identified factors associated with OW/OB among individuals with SB.

RESULTS: Participants (*n* = 7215) were aged 2 to 19 years (mean = 11.1; standard error, 0.06) and 51.4% female. The majority were non-Hispanic white (57.2%) followed by Hispanic or Latino (25.1%) and non-Hispanic Black (7.5%). The myelomeningocele (MMC) subgroup accounted for 76.3%. Most (60.2%) were community ambulators. The overall percentage of OW/OB was 45.2%, with 49.2% of MMC and 32.0% of nonmyelomeningocele OW/OB. Following the Centers for Disease Control Obesity Severity Classification System, 19.7% of MMC were in class 1, 6.6% in class 2, and 3.5% in class 3. Univariate analysis of MMC participants demonstrated demographic (age, sex, race/ethnicity, and clinic region) and clinical variables (functional level of lesion, ambulation, and number of shunt surgeries) were associated with OW/OB. The GEE model showed that OW/OB was independently, and significantly, associated with age, sex, race/ethnicity, lesion levels, and geographic location of the clinics.

CONCLUSIONS: The demographic and clinical factors associated with OW/OB in children and adolescents with SB further our understanding of factors contributing to the higher prevalence of OW/OB in this population and may inform OW/OB prevention and treatment strategies.

Spina bifida (SB), a congenital condition that occurs early in gestation, affects the brain and/or spinal cord and can result in urologic, orthopedic, neurologic, gastrointestinal, cognitive, and mobility impairments.[1] It is estimated that in the United States, 1500 to 2000 infants are born with SB annually and 166 000 individuals live with SB.[2] Associated impairments vary depending on the level of the lesion and the subtype of SB. Myelomeningocele (MMC) is the most common and severe form[1] (Table 1). Overweight and obesity (OW/OB) is a primary concern for individuals with SB because it exacerbates underlying issues (eg, mobility challenges, skin breakdowns) that can impede the individual's ability to self-manage their condition, contribute to obesity-related comorbidities, and/or result in barriers for caregivers.[3]

Preliminary evidence suggests that individuals with SB have a higher prevalence of OW/OB than typically developing (TD) peers.[4–6] However, this evidence is limited by the narrow scope and small sample size of previous studies. Additionally, the prevalence of OW/OB for the different types of SB is unknown. Previously, limited data were available to inform the health care community's efforts to track and effectively intervene to optimize weight management in the population with SB. The focus on children and adolescents is a priority because early onset of OW/OB often continues into adulthood.[7,8] Understanding the factors associated with OW/OB in the SB population provides an opportunity to inform interventions that could reverse emerging unhealthy habits that may solidify with age.[9] In the general US population, OW/OB rates differ based on age, sex, race/ethnicity, and geographic region. Limited information is available regarding the prevalence of OW/OB and its associated risk factors in individuals with SB.

The National Spina Bifida Patient Registry (NSBPR), a collaborative effort between the Centers for Disease Control and Prevention (CDC) and participating centers throughout the United States, was developed to improve the care of individuals with SB.[10] Between 2009 and 2018, the NSBPR collected data from 32 centers, with a centralized data entry and management system that facilitated ongoing quality checks and audits. The large, aggregated NSBPR dataset facilitates the description of all weight status categories, comparison of these categories by type of SB, and identification of factors associated with OW/OB. This information is critical to monitoring OW/OB trends and developing interventions to combat this disabling comorbidity. Thus, the purpose of this study is to describe the distribution of weight status categories in children and adolescents (hereafter referred to as children) with SB (MMC and nonmyelomeningocele [NMMC]) and to identify its related factors. This analysis's primary focus was MMC because it is the most prevalent and severe type of SB.

This study used data from children with SB aged 2 through 19 years, enrolled in the NSBPR from 2009 through 2018, to address 2 research questions:

1. What is the distribution of weight status categories (ie, underweight, normal weight, OW, OB) in children according to type of SB (MMC and NMMC) and age groups (2–5, 6–11, and 12–19 years of age)?
2. Does the distribution of weight status vary by demographic (age, sex, race/ ethnicity, region of clinic,) or clinical factors (functional level of lesion, ambulation status or number of ventriculoperitoneal shunt surgeries)?

METHODS

National Spina Bifida Patient Registry

The centralized data center collects deidentified data from each NSBPR center. After initial enrollment, demographic, social, clinical characteristics, and treatment history are updated annually or biennially. Data collection and transfer procedures were approved by each site's institutional review board and appropriate assents and consents were obtained.

Study Sample

This descriptive cross-sectional study used NSBPR data collected from all eligible individuals attending participating centers from 2009 to 2018. Subjects were excluded from this study if they had missing height or weight ($n = 145$), an extremely low or high body mass index (BMI ≤ 10 kg/m^2 or ≥50 kg/m^2; $n = 46$), or yearly gains in height or weight of more than 3 standard deviations ($n = 3$), because of the concern for data inaccuracy. The final sample included 7215 children aged 2 to 19 years (Fig 1).

Anthropometric Measurements

Per the NSBPR protocol, weight was measured in kilograms on a calibrated scale for children able to stand independently while wearing minimal clothing and with all outerwear removed. For those unable to stand independently, weight was measured using a wheelchair scale. The weights of the chair and clothing or braces were subtracted from the total weight to obtain a "child-only" weight. Standing height (SH), for those who could stand, was measured in centimeters with a stadiometer. For those unable to stand, arm span (AS) was measured (cm), while sitting in a chair with arms extended outward laterally, as a straight line across the child's back from furthest extension of fingers on 1 side of the body to furthest extension of fingers on the opposite side of the body. When SH or AS was not measurable, recumbent length (RL) was measured (cm) as the distance from the crown of the head to the heel of the foot and can be used directly as a proxy for SH.

BMI

BMI was calculated as weight (kg) divided by SH or RL (m) squared. In our sample of 7215 participants, SH was measured in 5128 (71%) and RL in 658 (9.3%) of the participants. For the remaining participants (1419 or 19.7%), AS was the only measure of growth available. A group of 418 patients had both SH and AS measured. From this group, based on previous findings by Shurtleff[11] and Rosenblum,[12] we developed an equation to estimate SH from AS. We used a generalized estimating equation (GEE) model to estimate SH using age, AS, and level of lesion as linear predictors. The modeling resulted in the following equation:

$$\begin{aligned}&\text{Estimated SH(cm)} = 20.2\\&+(0.47*\ \text{Age in years})\\&+(0.80*\ \text{AS in cm})\\&-\begin{cases}10.24, & \text{if Thoracic}\\10.37, & \text{if High lumbar}\\4.46, & \text{if Mid lumbar}\\3.60, & \text{if Low lumbar}\\0, & \text{if Sacral}\end{cases}\end{aligned}$$

Demographic and Clinical Characteristics

Demographic and clinical characteristics were collected. See Fig 2 for categories and definitions.

Statistical Analysis

The sample was divided by SB type (MMC versus NMMC) and children were placed into age groups used by the NHANES of 2 to 5, 6 to 11, and 12 to 19 years of age. To calculate age- and sex-specific BMI percentiles and determine weight status, we used the CDC's equations coded in SAS.[13] From these results, each measure from participants was classified to a weight status category: underweight (<fifth percentile), normal weight (5th to <85th percentile), overweight (85th to <95th percentile), and obese (≥95th percentile).

χ^2 tests assessed the univariate associations between weight status category and each demographic or clinical factor. We dichotomized weight status categories as under/normal weight and OW/OB. To account for the effect of repeated observations of weight status and other time-dependent variables from the same person, we used GEE models with logit link function.[14] The GEE regression models also accounted for correlated data from participants clustered by clinic. Multiple GEE regression models were conducted to test the independent association between weight status and demographic and clinical factors; an independent correlation structure was specified. Statistical tests were all 2-sided, and P values <.05 were considered statistically significant; 95% confidence intervals (CIs) were calculated for odds ratio (OR) estimates. Statistical analyses were performed using SAS version 9.4 (Cary, NC, USA). Per NSBPR protocol, a secondary independent analyst replicated the statistical analysis.

RESULTS

Sample Characteristics

Study participants (*N* = 7215) were aged 2 to 19 years (mean = 11.1, SE = 0.06) with children 12–19 years the largest group at 44.4%, 6–11 years 32.9%, and 2–5 years 22.6%. There were slightly more females (51.4%) than males. Most participants were non-Hispanic white (57.2%) followed by Hispanic or Latino (25.1%) and non-Hispanic Black (7.5%). More than three-fourths of the sample had MMC (76.3%) and the majority (60.2%) was classified as community ambulators (Table 2).

Prevalence of Weight Status Categories by SB Type and Age Groups

For the entire sample, 45.2% of children were OW/OB. However, OW/OB prevalence differed by SB type (MMC 49.2% vs NMMC 32%) (Table 3). Children with MMC in the 2- to 5-year age group had the highest prevalence of OW/OB (52.7%) followed by the 6- to 11- and 12- to 19-year age groups (47.4% and 48.9%, respectively) (Table 4). For the NMMC group, the opposite pattern emerged where the 12- to 19-year age group had the highest prevalence (37.5%) followed by 6- to 11- and the 2- to 5-year age groups (29.2% vs 27.4%) (Table 5). For the MMC sample, 5.4% were underweight, 45.3% normal weight, 19.5% OW, and 29.8% OB with 19.8% in obesity class 1, 6.6% in severe obesity class 2, and 3.5% in severe obesity class 3. The NMMC sample had lower frequencies of overweight or obesity, with 5.8% underweight, 62.2% normal weight, 15.7% OW, and 16.2% OB with 9.9%, 3.9%, and 2.5%, respectively, in obesity class 1, 2, and 3 (Table 3). Both groups exceeded the expected 5% for obese category according to the US population charts: nearly 30% for MMC and more than 16% for NMMC.

Differences in Weight Status by Demographic and Clinical Variables—There were differences in the univariate analyses for children with MMC in the weight categories based on demographic (age, sex, and race/ethnicity) and clinical variables (functional level of lesion, ambulation, and number of shunt surgeries) (Table 4). Fewer differences occurred for children with NMMC (Table 5). In the MMC group, more females and children with a ventriculoperitoneal shunt were OW/OB. Weight categories differed significantly by age, race/ethnicity, functional level of lesion, and ambulation in both MMC and NMMC, with the highest percentage of OW/OB in the 2 to 5 year olds (MMC) and 12 to 19 year olds (NMMC) and individuals identified as Hispanic or Latino, followed by non-Hispanic white and non-Hispanic Black. Children with lumbar lesions had the highest OW/OB for MMC (mid-lumbar) and NMMC (high-lumbar) groups. The prevalence of OW/OB differed by ambulation, with household ambulators (MMC) and therapeutic ambulators (NMMC) the highest. There was no difference in distribution of weight categories by clinic region (Tables 4 and 5).

Multivariable GEE Model on OW/OB Status in MMC Sample

The multivariable GEE model identified 4 demographic (age, sex, race/ethnicity, region of clinic) and 1 clinical variable (level of lesion) associated with OW/OB for those with MMC (Table 6). For age, the odds of OW/OB were significantly lower for the 2 older age groups when compared with the 2- to 5-year-old group (6 to 11 year olds: OR, 0.79; 95% CI, 0.72–0.88; $P < .001$; 12 to 19 years old: OR, 0.88; 95% CI, 0.78–0.99; $P = .038$). The odds of OW/OB in females were significantly higher than in males (OR, 1.19; 95% CI, 1.07–1.32; $P = .002$) and in those of Hispanic or Latino ethnicity than non-Hispanic white (OR, 1.65; 95% CI, 1.44–1.88; $P < .001$). In contrast, the odds of OW/OB for those whose race was "other" was significantly lower than non-Hispanic white (OR, 0.78; 95% CI, 0.63–0.96; $P = .02$) and those attending clinics in the western region of the US when compared with those in the Northeast (OR, 0.71; 95% CI, 0.59–0.84; $P \leq .001$). Having a low- (OR, 1.16; 95% CI, 1.01–1.34; $P = .03$), mid- (OR, 1.32; 95% CI, 1.14–1.53; $P \leq .001$) or high-lumbar (OR, 1.45; 95% CI, 1.18–1.78; $P \leq .001$) lesion increased the odds of OW/OB significantly compared with those with sacral lesions.

DISCUSSION

A major finding of this study was the high prevalence of OW/OB among children with SB, especially those with MMC. In this study, almost one-half of the children with MMC were OW/OB, higher than the national OW/OB estimate of 35.1% among TD children 2–19 years of age.[15] Obesity prevalence rates by age group for those with MMC were consistently higher than the general US population ages 2 through 5 (33.4% vs 13.9%), 6 through 11 (28.2% vs 18.4%) and 12 through 19 years (29.2% vs 20.6%) respectively.[16] In addition to obesity-related comorbidities well-described in the general population, children with MMC face additional risks compounded by OW/OB, such as compromised mobility, self-care, and independence. The percentages of those with MMC in each obesity class were also higher than the prevalence rates in US population of children, respectively for class 1 (19.7% vs 12.5%), 2 (6.6% vs 4.1%), or 3 (3.5% vs 1.9%) obesity.[17] The presence of severe obesity in childhood, coupled with diagnosis-specific concerns, may result in a deleterious cycle of further obesity and negative outcomes across the lifespan.

Differences in children's weight status by demographics, age, race/ethnicity, and sex were seen among those with MMC. Somewhat unexpectedly, higher levels of OW/OB were in the 2- to 5-year MMC age group. Toddlers with SB often achieve motor milestones later than TD peers,[18,19] which may contribute to larger percentages of OW/OB. Rates of OW/OB may then decrease because these children age and become more mobile. Inconsistent with findings in TD children, females with MMC in all age groups were more likely to be OW/OB than males.[20] Although TD postpubertal females in the second decade of life are more commonly OW/OB, no differences by sex have been identified in prepubertal children. Some females with MMC enter puberty early, as early as 8 to 10 years of age.[21] This could contribute to pubertal storage of fat cells and increase in OW/OB when compared with same-age males. The differences by age and sex have implications for anticipatory guidance including appropriate nutrition and promotion of early mobility through therapies and at-home physical activities.

Individuals who identified as Hispanic or Latino had a higher prevalence of OW/OB than their non-Hispanic white or Black counterparts for MMC and NMMC groups. Similarly, CDC data reveal that Hispanic or Latino children have the highest rate of obesity in the general population.[22] However, unlike our study, the CDC data on non-Hispanic Black children reveals a higher prevalence of obesity than the non-Hispanic white population.[22]

Because of the small numbers, our data may not accurately represent the non-Hispanic Black population with SB. The increased prevalence of obesity in the Hispanic/Latino population is consistent with other SB studies that demonstrate disparities in clinical outcomes related to race/ethnicity.[23] The lower odds of being OW/OB in the other race/ethnicity category may, in part, be explained by a large proportion of individuals classified as Asian (38.8%), a group with lower rates of obesity in the general population.[24] Understanding how race/ethnicity is associated with OW/OB may have been clarified if measures of socioeconomic status were available (eg, income) because lower socioeconomic status and obesity have been related in the general population.[25]

Similar to age, sex, and ethnicity, geographic location was significantly associated with OW/OB in the multivariable analysis. Those attending clinics in the West were less likely to be OW/OB when compared with those in the Northeast, Midwest, and South. This difference may be explained by the western climate and culture that support year-round activity for individuals with a physical disability.

Functional level of lesion, ambulation, and shunt status are indicators of SB severity, but only functional level of lesion was related to weight status in the multivariable analysis. However, those with higher (eg, thoracic, high lumbar) lesions are more likely to have the most limited ambulation and a shunt. These severity indicators were related to weight status in the univariate analysis. Because these variables are moderately related to each other, it is possible that ambulation and shunt status did not add significant explanatory power to level of lesion.[26] In addition to weight management challenges encountered by all children,[27,28] these findings support further investigation into unique SB-related challenges. For example, preliminary evidence suggests that individuals with SB have a decreased total energy expenditure consequently influencing the daily energy intake required.[29] In addition, sedentary activity and screen time may be increased from lack of recreational options and time-consuming medical regimens.[3,30] Finally, comfort eating may occur, and role modeling of healthy habits may be challenged because of caregiving-related stress or decreased access to healthier foods.[30,31]

The prevalence of OW/OB and related demographic factors in the NMMC sample resemble TD children, generally increasing from youngest to oldest and highest in the Hispanic or Latino participants. Similarly, the risk for obesity-related health problems is present and indicates the need for increased monitoring and interventions throughout childhood.

Limitations

There are several limitations to our study. The use of BMI to assess adiposity in children with SB has been questioned. Individuals with SB have reduced lean mass; thus, BMI may underestimate weight status.[11,32] However, without alternative options and because of its cost-effectiveness and ease of use in a clinical setting, BMI is widely accepted as a screening tool for OW/OB.[33] Although AS is the recommended alternative for SH in the NSBPR for those unable to stand, it required GEE modeling to create an adjustment for use in the BMI calculation. This is also a strength of the study, but because the equation was based on a limited subsample, it may not be representative of the population and needs validation in future analyses. Overall, the challenges associated with the measurement of height (eg, lack of standardized assessment) for individuals who are unable to stand indirectly affects the reporting of and accuracy of prevalence rates of OW/OB for this population.

Although the NSBPR has specific protocols for anthropomorphic measurements, methodological variations may exist among clinics because of orthopedic impairments of participants. Further, although the NSBPR represents most participants attending centers, the percentage of those participating differs by site. Similarly, the centers may not represent the SB population in the United States, limiting generalizability of the findings. However, the registry provides the largest population of children with SB to date. Longitudinal analysis of data from multiple clinic visits offers a more complete assessment of weight status and its association with covariates. The use of a GEE model enabled us to examine the associations between covariates and weight status while simultaneously capturing the influence of between- and within-subject variation.

CONCLUSIONS

This study documents a high prevalence of OW/OB in children with SB and identifies demographic and clinical factors associated with the higher prevalence. The negative consequences of OW/OB in this population underscore the need for early identification, anticipatory guidance, prevention, and treatment of OW/OB. Further investigation of how unique SB-related challenges influence weight management are warranted.

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Data Sharing Statement:

Deidentified individual participant data will not be made available.

ABBREVIATIONS

AS	arm span
BMI	body mass index
CDC	Centers for Disease Control and Prevention
CI	confidence interval
GEE	generalized estimating equation
MMC	myelomeningocele
NMMC	nonmyelomeningocele
NSBPR	National Spina Bifida Patient Registry
OW/OB	overweight and obesity
OR	odds ratio
RL	recumbent length
SB	spina bifida
SH	standing height
TD	typically developing

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WHAT’S KNOWN ON THIS SUBJECT:

Clinical observations suggest that individuals with spina bifida have a higher prevalence of obesity, which can exacerbate diagnosis-related issues and adds challenges to their self-management such as loss of mobility and skin breakdowns.

WHAT THIS STUDY ADDS:

Using the largest registry of individuals with spina bifida, this study describes the previously unreported prevalence of overweight/obesity in total and by subtype along with the associated demographic and clinical factors among children and adolescents with spina bifida.

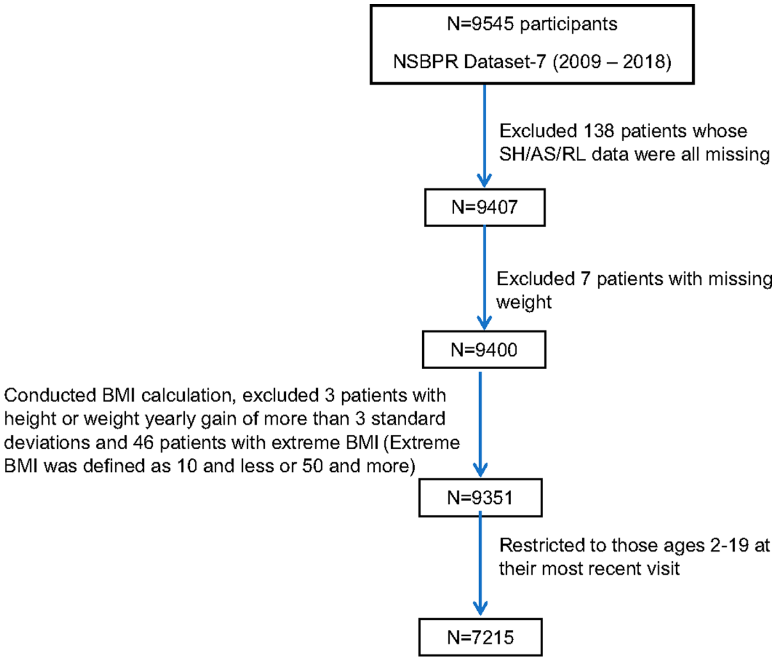
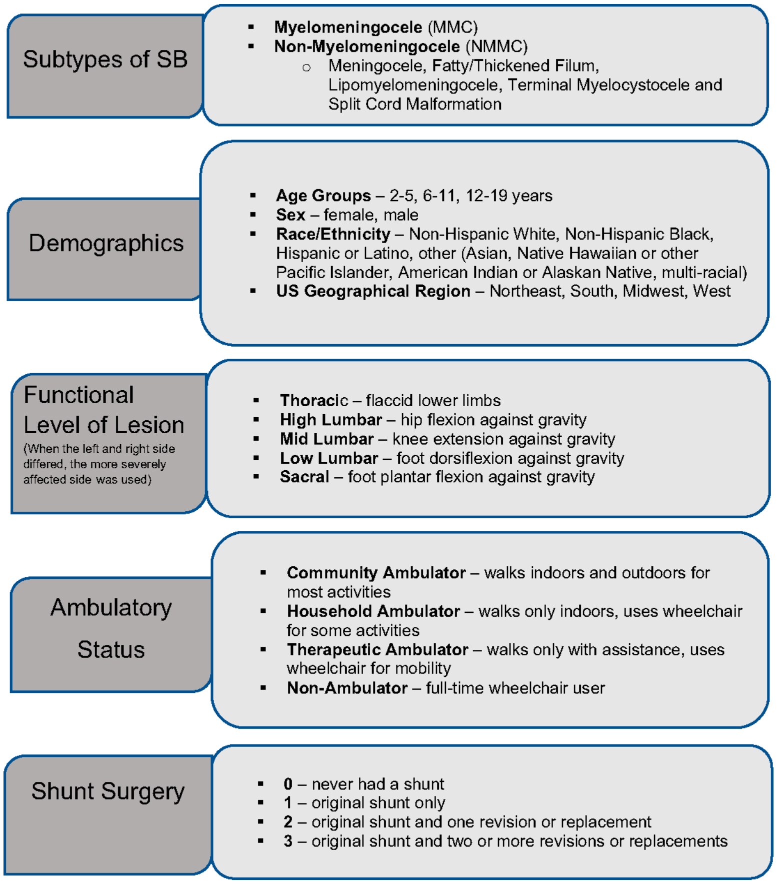


FIGURE 1.

Flowchart illustrating participant selection and inclusion process



Subtypes of SB

- **Myelomeningocele** (MMC)
- **Non-Myelomeningocele** (NMMC)
    - Meningocele, Fatty/Thickened Filum, Lipomyelomeningocele, Terminal Myelocystocele and Split Cord Malformation

Demographics

- **Age Groups** – 2-5, 6-11, 12-19 years
- **Sex** – female, male
- **Race/Ethnicity** – Non-Hispanic White, Non-Hispanic Black, Hispanic or Latino, other (Asian, Native Hawaiian or other Pacific Islander, American Indian or Alaskan Native, multi-racial)
- **US Geographical Region** – Northeast, South, Midwest, West

Functional Level of Lesion
(When the left and right side differed, the more severely affected side was used)

- **Thoracic** – flaccid lower limbs
- **High Lumbar** – hip flexion against gravity
- **Mid Lumbar** – knee extension against gravity
- **Low Lumbar** – foot dorsiflexion against gravity
- **Sacral** – foot plantar flexion against gravity

Ambulatory Status

- **Community Ambulator** – walks indoors and outdoors for most activities
- **Household Ambulator** – walks only indoors, uses wheelchair for some activities
- **Therapeutic Ambulator** – walks only with assistance, uses wheelchair for mobility
- **Non-Ambulator** – full-time wheelchair user

Shunt Surgery

- **0** – never had a shunt
- **1** – original shunt only
- **2** – original shunt and one revision or replacement
- **3** – original shunt and two or more revisions or replacements

FIGURE 2.

Definition of demographic and clinical characteristics included in the study.

TABLE 1

Definitions for Diagnoses Eligible for Inclusion in the NSBPR

Diagnosis	Definition
Myelomeningocele	Open neural tube defect having a visible spinal cord placode on/attached to the skin surface (sacral, lumbar, thoracic).
Meningocele	Spinal fluid and meninges protrude through vertebral opening; no neural elements are included and may or may not be covered by a layer of skin.
Lipomyelomeningocele	Fatty mass attached to the spinal cord arising from the dorsal aspect of the cord (dorsal lipoma); attached directly to the end of the conus medullaris and having a diameter that exceeds the diameter of the conus medullaris (terminal lipoma); involving both the dorsal and terminal ends of the spinal cord (transitional lipoma)
Terminal myelocystocele	A skin covered malformation containing a ‘sac within a sac' (a terminally dilated spinal cord contained with a larger dilated terminal dural sac) with or without an associated lipoma.
Fatty/thickened filum	A thickened filum terminale, with or without fat, associated with the conus medullaris that lies lower than the middle of the second lumbar vertebra.
Split cord malformation	Previously known as diastematomyelia or diplomyelia, malformation containing a doubled spinal cord over a portion of its length.

NSBPR, National Spina Bifida Patient Registry.

TABLE 2

Sample Characteristics by SB Diagnosis

Variables	Overall *n* (%) or statistics (*N* = 7215)	N (%) or Statistics by SB Diagnosis[a] MMC (*n* = 5504)	NMMC (*n* = 1711)
Age at last visit, y			
N	7215	5504	1711
Median	10.9	11.2	9.9
Range[b]	2.0–20.0	2.0–20.0	2.0–20.0
Mean (SE)	11.11 (0.06)	1 1.32 (0.07)	10.46 (0.13)
Sex			
Male	3505 (48.6)	2761 (50.2)	744 (43.5)
Female	3710 (51.4)	2743 (49.8)	967 (56.5)
Race/ethnicity			
Non-Hispanic white	4130 (57.2)	3216 (58.4)	914 (53.4)
Non-Hispanic Black	539 (7.5)	445 (8.1)	94 (5.5)
Hispanic or Latino	1814 (25.1)	1402 (25.5)	412 (24.1)
Other[c]	699 (9.7)	412 (7.5)	287 (16.8)
Refused/unknown	33 (0.5)	29 (0.5)	4 (0.2)
Ambulation status			
Community ambulators	4341 (60.2)	2759 (50.1)	1582 (92.5)
Household ambulators	610 (8.5)	562 (10.2)	48 (2.8)
Therapeutic ambulators	491 (6.8)	470 (8.5)	21 (1.2)
Nonambulators	1773 (24.6)	1713 (31.1)	60 (3.5)
Level of lesion group (*N* = 7212)			
Thoracic	853 (11.8)	832 (15.1)	21 (1.2)
High-lumbar	636 (8.8)	601 (10.9)	35 (2.0)
Mid-lumbar	1935 (26.8)	1775 (32.3)	160 (9.4)
Low-lumbar	1268 (17.6)	1051 (19.1)	217 (12.7)
Sacral	2520 (34.9)	1243 (22.6)	1277 (74.7)
Number of shunt surgeries			

Variables	**Overall *n* (%) or statistics (*N* = 7215)**	**N (%) or Statistics by SB Diagnosis[a]** **MMC (*n* = 5504)**	**NMMC (*n* = 1711)**
0	2772 (38.4)	1157 (21.0)	1615 (94.4)
1	1727 (23.9)	1672 (30.4)	55 (3.2)
2	1194 (16.5)	1173 (21.3)	21 (1.2)
3 or more	1522 (21.1)	1502 (27.3)	20 (1.2)
Region of clinic			
Northeast	962 (13.3)	727 (13.2)	235 (13.7)
South	1708 (23.7)	1380 (25.1)	328 (19.2)
Midwest	2231 (30.9)	1642 (29.8)	589 (34.4)
West	2314 (32.1)	1755 (31.9)	559 (32.7)

[a] NMMC group with 5 diagnoses: meningocele; lipomyelomeningocele; terminal myelocystocele; fatty/thickened filum; split cord malformation.

[b] Inclusion criteria was ≤19 y of age; because of rounding, the range includes 2 through 20 year olds.

[c] Other: 54.2% Asian, 22.9% multiracial, 9.3% other race without specification, 5.2% American Indian or Alaska Native, 1.6% Native Hawaiian/Other Pacific Islander; remainder, incomplete data.

TABLE 3

Weight Categories by Spina Bifida Diagnosis

		N (%) by SB Diagnosis	
Variables	**Overall *n* (%) (*N* = 7215)**	**MMC (*n* = 5504)**	**NMMC (*n* = 1711)**
Underweight	395 (5.5)	296 (5.4)	99 (5.8)
Normal weight	3561 (49.4)	2496 (45.3)	1065 (62.2)
Overweight	1339 (18.6)	1070 (19.4)	269 (15.7)
Obese	1920 (26.6)	1642 (29.8)	278 (16.2)
Obese class 1	1254 (17.4)	1084 (19.7)	170 (9.9)
Severe obesity class 2	431 (6.0)	365 (6.6)	66 (3.9)
Severe obesity class 3	235 (3.3)	193 (3.5)	42 (2.5)

NMMC = group with 5 diagnoses: meningocele; lipomyelomeningocele; terminal myelocystocele; fatty/thickened filum; split cord malformation.

TABLE 4

Weight Status Distribution Among Children With MMC

Variables	Overall *n* (%) or Statistics (*N* = 5504)	*N* (%) or Statistics by Weight Status Category			
		Underweight (*n* = 296)	**Normal Weight (*n* = 2496)**	**Overweight (*n* = 1070)**	**Obese (*n* = 1642)**
Age group, y					
2–5	1220 (22.2)	37 (3.0)	540 (44.3)	235 (19.3)	408 (33.4)
6–11	1740 (31.6)	76 (4.4)	840 (48.3)	334 (19.2)	490 (28.2)
12–19	2544 (46.2)	183 (7.2)	1116 (43.9)	501 (19.7)	744 (29.2)
Sex					
Male	2761 (50.2)	194 (7.0)	1259 (45.6)	486 (17.6)	822 (29.8)
Female	2743 (49.8)	102 (3.7)	1237 (45.1)	584 (21.3)	820 (29.9)
Race/ethnicity (*N* = 5475)					
Non-Hispanic white	3216 (58.7)	185 (5.8)	1491 (46.4)	625 (19.4)	915 (28.5)
Non-Hispanic Black	445 (8.1)	33 (7.4)	201 (45.2)	79 (17.8)	132 (29.7)
Hispanic or Latino	1402 (25.6)	57 (4.1)	568 (40.5)	293 (20.9)	484 (34.5)
Other[a]	412 (7.5)	21 (5.1)	223 (54.1)	64 (15.5)	104 (25.2)
Functional level of lesion (*N* = 5502)					
Thoracic	832 (15.1)	91 (10.9)	362 (43.5)	127 (15.3)	252 (30.3)
High-lumbar	601 (10.9)	42 (7.0)	253 (42.1)	106 (17.6)	200 (33.3)
Mid-lumbar	1775 (32.3)	79 (4.5)	776 (43.7)	347 (19.5)	573 (32.3)
Low-lumbar	1051 (19.1)	45 (4.3)	483 (46.0)	216 (20.6)	307 (29.2)
Sacral	1243 (22.6)	39 (3.1)	621 (50.0)	273 (22.0)	310 (24.9)
Ambulation status					
Community ambulators	2759 (50.1)	87 (3.2)	1301 (47.2)	585 (21.2)	786 (28.5)
Household ambulators	562 (10.2)	26 (4.6)	232 (41.3)	118 (21.0)	186 (33.1)
Therapeutic ambulators	470 (8.5)	25 (5.3)	221 (47.0)	82 (17.4)	142 (30.2)
Nonambulators	1713 (31.1)	158 (9.2)	742 (43.3)	285 (16.6)	528 (30.8)
Number of shunt surgeries					
0	1157 (21.0)	48 (4.1)	559 (48.3)	236 (20.4)	314 (27.1)
1	1672 (30.4)	85 (5.1)	727 (43.5)	351 (21.0)	509 (30.4)
2	1173 (21.3)	69 (5.9)	538 (45.9)	217 (18.5)	349 (29.8)

		N (%) or Statistics by Weight Status Category			
Variables	**Overall *n* (%) or Statistics (*N* = 5504)**	**Underweight (*n* = 296)**	**Normal Weight (*n* = 2496)**	**Overweight (*n* = 1070)**	**Obese (*n* = 1642)**
3 or more	1502 (27.3)	94 (6.3)	672 (44.7)	266 (17.7)	470 (31.3)
Region of clinic					
Northeast	727 (13.2)	36 (5.0)	321 (44.2)	136 (18.7)	234 (32.2)
South	1380 (25.1)	84 (6.1)	642 (46.5)	261 (18.9)	393 (28.5)
Midwest	1642 (29.8)	79 (4.8)	714 (43.5)	320 (19.5)	529 (32.2)
West	1755 (31.9)	97 (5.5)	819 (46.7)	353 (20.1)	486 (27.7)

[a] Other: 38.8% Asian, 30.1% multiracial, 13.1% other race without specification, 6.8% American Indian or Alaska Native, 2.4% Native Hawaiian/Other Pacific Islander; remainder, incomplete data.

TABLE 5

Weight Status Distribution Among Children with NMMC

Variables	**Overall *n* (%) or Statistics (*N* = 1711)**	**N (%) or Statistics by Weight Status Category**			
		Underweight (*n* = 99)	**Normal Weight (*n* = 1065)**	**Overweight (*n* = 269)**	**Obese (*n* = 278)**
Age group, y					
2–5	413 (24.1)	28 (6.8)	272 (65.9)	62 (15.0)	51 (12.3)
6–11	637 (37.2)	33 (5.2)	418 (65.6)	90 (14.1)	96 (15.1)
12–19	661 (38.6)	38 (5.7)	375 (56.7)	117 (17.7)	131 (19.8)
Sex					
Male	744 (43.5)	42 (5.6)	448 (60.2)	116 (15.6)	138 (18.5)
Female	967 (56.5)	57 (5.9)	617 (63.8)	153 (15.8)	140 (14.5)
Race/ethnicity (*N* = 1707)					
Non-Hispanic white	914 (53.5)	53 (5.8)	574 (62.8)	147 (16.1)	140 (15.3)
Non-Hispanic Black	94 (5.5)	6 (6.4)	55 (58.5)	18 (19.1)	15 (16.0)
Hispanic or Latino	412 (24.1)	13 (3.2)	224 (54.4)	76 (18.4)	99 (24.0)
Other[a]	287 (16.8)	27 (9.4)	210 (73.2)	26 (9.1)	24 (8.4)
Functional level of lesion (*N* = 1710)					
Thoracic	21 (1.2)	7 (33.3)	10 (47.6)	1 (4.8)	3 (14.3)
High-lumbar	35 (2.0)	3 (8.6)	17 (48.6)	7 (20.0)	8 (22.9)
Mid-lumbar	160 (9.4)	9 (5.6)	101 (63.1)	21 (13.1)	29 (18.1)
Low-lumbar	217 (12.7)	17 (7.8)	130 (59.9)	34 (15.7)	36 (16.6)
Sacral	1277 (74.7)	62 (4.9)	807 (63.2)	206 (16.1)	202 (15.8)
Ambulation status					
Community ambulators	1582 (92.5)	80 (5.1)	998 (63.1)	254 (16.1)	250 (15.8)
Household ambulators	48 (2.8)	2 (4.2)	29 (60.4)	6 (12.5)	11 (22.9)
Therapeutic ambulators	21 (1.2)	3 (14.3)	8 (38.1)	2 (9.5)	8 (38.1)
Nonambulators	60 (3.5)	14 (23.3)	30 (50.0)	7 (11.7)	9 (15.0)
Number of shunt surgeries					
0	1615 (94.4)	90 (5.6)	1013 (62.7)	251 (15.5)	261 (16.2)
1	55 (3.2)	6 (10.9)	29 (52.7)	12 (21.8)	8 (14.5)
2	21 (1.2)	1 (4.8)	10 (47.6)	4 (19.0)	6 (28.6)

		N (%) or Statistics by Weight Status Category			
Variables	**Overall *n* (%) or Statistics (*N* = 1711)**	**Underweight (*n* = 99)**	**Normal Weight (*n* = 1065)**	**Overweight (*n* = 269)**	**Obese (*n* = 278)**
3 or more	20 (1.2)	2 (10.0)	13 (65.0)	2 (10.0)	3 (15.0)
Region of clinic					
Northeast	235 (13.7)	20 (8.5)	136 (57.9)	42 (17.9)	37 (15.7)
South	328 (19.2)	24 (7.3)	203 (61.9)	42 (12.8)	59 (18.0)
Midwest	589 (34.4)	30 (5.1)	385 (65.4)	94 (16.0)	80 (13.6)
West	559 (32.7)	25 (4.5)	341 (61.0)	91 (16.3)	102 (18.2)

[a] Other: 76.3% Asian, 12.5% multiracial, 3.8% other race without specification, 2.8% American Indian or Alaska Native, 0.4% Native Hawaiian/Other Pacific Islander; remainder, incomplete data

TABLE 6

Summary of Multivariable GEE Model on Overweight/Obese Weight Status Among MMC Participants (5474 Participants With 15 360 Visits)

Variables	Odds Ratio (95% CI)	*P* Value
Age group, y		<.001[a]
2–5[b]		
6–11	0.79 (0.72–0.88)	<.001
12–19	0.88 (0.78–0.99)	.04
Sex		
Male[b]		
Female	1.19 (1.07–1.32)	.002
Race/ethnicity		<.001[a]
Non-Hispanic white[b]		
Non-Hispanic Black	1.01 (0.83–1.23)	.92
Hispanic or Latino	1.65 (1.44–1.88)	<.001
Other[c]	0.78 (0.63–0.96)	.02
Functional level of lesion		<.001[a]
Sacral[b]		
Low-lumbar	1.16 (1.01–1.34)	.03
Mid-lumbar	1.32 (1.14–1.53)	<.001
High-lumbar	1.45 (1.18–1.78)	<.001
Thoracic	1.17 (0.95–1.45)	.13
Ambulation status		.18[a]
Community ambulators[b]		
Household ambulators	0.93 (0.80–1.07)	.31
Therapeutic ambulators	0.90 (0.76–1.07)	.23
Nonambulators	0.84 (0.72–0.98)	.03
Number of shunt surgeries		.62[a]
0[b]		
1	1.11 (0.95–1.30)	.18

Variables	Odds Ratio (95% CI)	*P* Value
2	1.08 (0.91–1.28)	.37
3 or more	1.08 (0.91–1.27)	.38
Region of clinic		<.001[a]
West[b]		
Northeast	1.42 (1.19–1.69)	<.001
South	1.18 (1.02–1.37)	.02
Midwest	1.34 (1.16–1.54)	<.001

[a] Overall *P* value.

[b] Reference group.

[c] Other: 38.8% Asian, 30.1 multiracial, 13.1 other race without specification, 6.8 American Indian or Alaska Native, 2.4 Native Hawaiian/Other Pacific Islander; remainder, incomplete data.