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The National Spina Bifida Patient Registry: Profile of a Large Cohort of Participants from the First 10 Clinics

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Abstract

Objective—To use data from the US National Spina Bifida Patient Registry (NSBPR) to describe variations in Contexts of Care, Processes of Care, and Health Outcomes among individuals with spina bifida (SB) receiving care in 10 clinics.

Study design—Reported here are baseline cross-sectional data representing the first visit of 2172 participants from 10 specialized, multidisciplinary SB clinics participating in the NSBPR. We used descriptive statistics, the Fisher exact test, χ^2 test, and Wilcoxon rank-sum test to examine the data.

Results—The mean age was 10.1 (SD 8.1) years with slightly more female subjects (52.5%). The majority was white (63.4%) and relied upon public insurance (53.5%). One-third had sacral lesions, 44.8% had mid-low lumbar lesions, and 24.9% had high lumbar and thoracic lesions. The most common surgery was ventricular shunt placement (65.7%). The most common bladder-management technique among those with bladder impairment was intermittent catheterization (69.0%). Almost 14% experienced a pressure ulcer in the last year. Of those ages 5 years or older with bowel or bladder impairments, almost 30% were continent of stool; a similar percentage was continent of urine. Most variables were associated with type of SB diagnosis.

Conclusion—The NSBPR provides a cross section of a predominantly pediatric population of patients followed in specialized SB programs. There were wide variations in the variables studied and major differences in Context of Care, Processes of Care, and Health Outcomes by type of SB.

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*A list of members of the NSBPR Coordinating Committee is available at www.jpeds.com (Appendix).

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 authors declare no conflicts of interest.

Such wide variation and the differences by type of SB should be considered in future analyses of outcomes.

Spina bifida (SB) is one of the most common causes of disability among children and adolescents in the US and worldwide.[1] Approximately 1500 infants with SB are born yearly in the US,[2] reflecting an overall rate of 3.5 per 10 000[3] and a rate of 4.7, 3.2, and 2.6, respectively, in infants from Hispanic, non-Hispanic white, and non-Hispanic black mothers.[4] Myelomeningocele (MMC) accounts for the majority of individuals with SB identified at birth.[5] SB occurs in the early days of a pregnancy and results in a range of spinal cord and central nervous system impairments that lead to varying degrees of paralysis, limited mobility, impaired sensation, orthopedic problems (scoliosis, congenital hip dysplasia, and clubfeet), and bowel, bladder, and renal impairments.

Most children and adolescents with SB in industrialized countries currently survive, grow up, transition to adulthood, enter the adult health care system, and experience the typical health problems of adults.[6–8] However, data on their care and health status across the life span are limited. To overcome this limitation, and with the long-term goals of improving the health outcomes of people living with SB and building a foundation for ongoing research, the Centers for Disease Control and Prevention (CDC) funded 10 clinics to initiate the National Spina Bifida Patient Registry (NSBPR).[9] The feasibility of the project has now been established, with data collection operationalized at the first 10 clinics and 9 additional clinics.[9]

The purpose of this report is to describe baseline data of the participants enrolled in the registry from the 10 first clinics. A conceptual framework with 3 components was used for this study: Context of Care, Processes of Care, and Health Outcomes.[10] Context of Care included characteristics of the individual (demographic) and their chronic conditions (clinical). Processes of Care were defined as the actions that the individual, family, or health care provider implemented to affect clinical outcomes, such as types of surgeries, procedures, or bowel and bladder management techniques. Health Outcomes included prevalence of pressure ulcers, bowel continence, and bladder continence. Understanding these factors and their interrelationships addresses the long-term goals of the NSBPR. The purpose of this study was to determine the distributions of Context of Care variables (demographic and clinical), Processes of Care (surgeries, bowel and bladder management techniques), and Health Outcomes (pressure ulcers, bowel and bladder continence) of individuals with SB in the NSBPR and to determine whether these variables differ by type of SB.

Methods

This descriptive study used baseline data obtained from the first NSBPR visit of the 2172 consented participants who were enrolled between March 2009 and June 2012 at the 10 first clinics. Patients were eligible for inclusion in the registry and in the current analysis if they had 1 of 4 SB types (MMC, meningocele, lipomyelomenigocele, or fatty filum) and received care from one of the participating clinics. The methods for the study, including those to monitor data quality and to obtain the institutional review/ethical board approval, have been reported in a previous publication.[9]

After consent was obtained, clinic personnel used a standardized tool to collect detailed data on 20 core registry questions, each with multiple data elements at all participating clinics.[9] The Initial Encounter Form completed only at the first NSBPR visit included basic demographic and diagnostic information as well as a lifetime history of selected common surgical procedures. The Annual Visit Form, completed at the time of the first and at each subsequent clinic visit, included clinical characteristics, anthropometrics, and insurance status. Data for the previous 12 months also were recorded on all surgeries performed (not just those listed on the initial form), on bowel- and bladder-management techniques currently used, and the targeted outcomes. The functional severity of the neurological impairment (level of lesion: sacral, low-lumbar, mid-lumbar, high-lumbar, and thoracic) was assessed by voluntary movement of hip, knee, or ankle. The analyses used in this study include data from both forms (Initial Encounter and Annual Visit Forms) collected at the first NSBPR visit.

Procedure and Analysis Strategies

Data from participants are collected by a combination of interview and medical record review. The data are entered into a custom-built, web-based SB electronic medical record at the participating clinics and transmitted to a central data center. At regular intervals, the data center, which hosts the web-based application, compiles, deidentifies, and transmits NSBPR data to the CDC for quality control and analysis.[9] Unless otherwise indicated, the full data set from the first 10 clinics was used for all analyses. To account for the effect of normal motor development, the mobility analysis was conducted using only participants aged 2 years and older. The variables “impaired bowel function” and “impaired bladder function” were created to identify those individuals whose SB affects their bowel and bladder functioning (Table I). Those individuals who were continent of stool and urine without using bowel or bladder management techniques were classified as “without impairments”; those with incontinence or who were using a listed technique to promote continence were classified as having “impaired bowel and/or impaired bladder function.” Only data from those with impairments were used to describe the bowel-and bladder-management techniques. To account for development and expectations for socially acceptable continence, the sample of individuals with bowel and bladder impairments was further limited to patients ages 5 years and older for the continence analyses. For the second research question, SB type was collapsed into 2 groups: those with MMC and those with the non-MMC diagnoses (lipoMMC, meningocele, and fatty filum).

Data management and analyses were performed using SAS software 9.3 (SAS Institute, Cary, North Carolina).[11] Associations among categorical variables were examined by the Fisher exact test and χ^2 test, and continuous variables were compared by use of the Wilcoxon rank-sum test. Because of potential concerns regarding selection bias in the enrollment of patients into the NSBPR, data for individuals eligible but not enrolled in the NSBPR in 2012 (n = 311) were compared with data for individuals enrolled in the NSBPR and seen in 2012 (n = 1602). Data on eligible but not-enrolled individuals were only available for 2012, the first year that these data were collected. The 2 groups were compared by clinic for select demographic variables (age, sex, race, ethnicity, type of insurance), select clinical characteristics (diagnosis, level of lesion), and percent of eligible individuals enrolled. The analyses revealed that 2 clinics with the lowest rates of participation (63.2% and 69.2%) had more significant differences in demographic and clinical characteristics between eligible participants and nonparticipants (4 of 7). To determine whether selection bias influenced results for research question 2, analyses were conducted with and without these 2 clinics. Because there were no significant differences by type of SB in the total and reduced sample, the results of the total sample are reported. Although the sample used for the selection bias analysis did not exactly match the study sample for all first visits, it was the only comparison data available on eligible participants and nonparticipants.

Results

Context of Care

The distributions of demographic and clinical characteristics of the total sample of patients are reported in Table I. The mean age of the participants was 10.1 years (SD 8.1) and approximately 85% of them were younger than 18 years of age; the distribution of education levels corresponded with the age distribution. The largest cluster of school-aged participants was in grades 1–8. A majority of participants relied solely on public insurance. The balance had at least some private insurance. Almost 2 of 3 participants were non-Hispanic white, approximately 1 of 15 was non-Hispanic black, and 1 of 4 was Hispanic. Male and female subjects were almost equally represented in this population. As expected, there is wide variation in the number of patients contributed by the sites to the NSBPR.

Of the participants 2 years old or older, just more than one-half primarily walked in the community with or without braces; the rest used a wheelchair for some or all of their mobility. A majority of NSBPR participants had impaired bowel (87.1%) and/or bladder (91.6%) function. When the sample was limited to participants 5 years and older, these impairment percentages still remained high (82.6% and 89.4%, respectively).

Processes of Care

The data on lifetime history of select surgeries, bowel management techniques, and bladder management techniques are reported in Tables II and III. Table II shows that the most common surgery was ventricular shunt placement. Other frequent previous surgeries included procedures to create a stoma for an antegrade continence enema, bladder augmentation, and appendicovesicostomy. Previous surgeries to improve urinary health (eg, vesicostomy) and to facilitate bowel continence (eg, cecostomy button) were reported less frequently.

In addition to the lifetime history of select surgeries, there was a relatively low occurrence of other typical surgeries for individuals with SB in the 12 months before their first visit (Table II). For example, only 67 (3.1%) had a tethered cord release, 33 (1.5%) a tonsillectomy/adenoidectomy, 19 (0.9%) a bladder stone removed, 12 (0.6%) a tracheostomy, 7 (0.3%) a bladder outlet procedure, and 5 (0.2%) a procedure to correct vesicoureteral reflux in the last 12 months. Multiple orthopedic surgical procedures (n = 141) were performed in this time period to correct club foot (n = 36; 1.7%) and other foot/ankle deformities (n = 47; 2.2%), scoliosis (n = 22; 1.0%), hip deformities (n = 18; 0.8%), and knee contractures (n = 16; 0.7%). Some patients had more than one orthopedic procedure performed. Orthopedic procedures occurring early in life included clubfoot repair and hip subluxation/dislocation repairs (median age, 1.2 and 2.2 years, respectively). In contrast, the median age for scoliosis surgery was 11.2 years.

Bowel and bladder management techniques are reported only for those individuals who reported bowel or bladder impairments (Table III). For those with bowel impairments, approximately one-third used no bowel management techniques. Two types of enemas aimed at cleaning the bowel were reported (Table II). The typical way to deliver an enema is transanal or retrograde. These enemas (eg, cone or irritant enema) are delivered by catheter upwards from the rectum. The second type of enema, an antegrade enema, is also delivered by a catheter. However, the catheter is inserted into the colon via the use of a surgically created stoma or device (a cecostomy button) on the abdomen. The stoma/button is connected to a continent pathway proximal to the anus and facilitates emptying of the total colon (Table III). Antegrade enemas typically clean out a larger section of the colon and are used when other bowel management techniques are not successful. In this sample the antegrade enema was used twice as often as the retrograde (irritant and cone) enemas.

For those with bladder impairments, the most common bladder-management technique was intermittent catheterization. A small number reported voluntary/timed voiding, and even fewer participants used an indwelling catheter or a urostomy bag for urine drainage.

Health Outcomes

The 3 health outcomes evaluated in the study (prevalence of pressure ulcers, bowel continence, and bladder continence), are reported in Table IV. A substantial percentage of the sample (13.9%) experienced a pressure ulcer in the previous 12 months. Most of those having pressure ulcers had a single pressure ulcer (n = 277), and a few (n = 25) had multiple pressure ulcers. The pressure ulcers occurred primarily in the lower extremities and pelvis/perineum. A smaller percentage occurred on the trunk, upper extremities, or other areas. The percentages of patients with bowel continence and bladder continence were relatively low.

Differences in Context of Care, Processes of Care, and Health Outcomes by Type of SB

Tables I–IV show that, except for sex and educational level, the distributions of most Context of Care characteristics, Processes of Care variables, and one Health Outcome (pressure ulcer) differed significantly by type of SB (MMC vs non-MMC).

Differences in demographic characteristics of MMC and non-MMC participants were statistically significant but relatively small (Table I). Patients in the non-MMC group were slightly younger, had larger proportions of patients of “other” race/ethnicity, and had at least some private insurance more often than patients in the MMC group. There were small but statistically significant differences in the relative proportion of MMC vs non-MMC participants at the different SB clinics.

There were a number of significant differences in clinical characteristics (Table I). The majority of the MMC group had functional lesions at the mid-lumbar to thoracic level, whereas the majority of the non-MMC participants had sacral lesions. Approximately 45% of individuals in the MMC group were community ambulators compared with 92.3% in the non-MMC group. Almost 90% of the total MMC group ages 5 and older had bowel impairments compared with just more than one-half of the non-MMC group. Pronounced differences also were found in bladder impairments: almost 95% of MMC participants ages 5 and older reported bladder impairments compared with just greater than 65% of the non-MMC participants.

Processes of Care also varied by type of SB. The lifetime history of select surgeries was significantly different between the MMC and the non-MMC groups (Table II). Participants in the MMC group were generally more likely to undergo surgeries than those in the non-MMC group. This likelihood ranged from 2 times (bladder augmentation) to 18 times (ventricular shunt placement) more likely. The only surgery that was more common in the non-MMC group was colostomy.

There were statistically significant differences between the MMC and the non-MMC participants in the use of 4 of the bowel-management and 3 of the bladder-management techniques (Table III). A greater proportion of individuals in the non-MMC group used no bowel-management techniques despite their bowel impairment compared with the MMC group. A small number (n = 17; 5.7%) of MMC participants who had a surgery to create a stoma or had a cecostomy button inserted were no longer using an antegrade enema as a bowel-management technique. Those in the non-MMC group reported greater rates of either no bladder-management technique or voluntary/timed voiding than those in the MMC group. Although clean intermittent catheterization was used frequently in both groups, the rate in the MMC group was much greater.

Only one health outcome differed significantly by type of SB (Table IV): the 12-month incidence of pressure ulcers in the MMC group was more than double that of the non-MMC group. However, there were no significant differences in the body distribution of these ulcers. Also, there were no statistically significant differences in the prevalence of continence outcomes for those with bowel and bladder impairments. Continence rates were close to 30% in both groups.

Discussion

Our results demonstrate substantial variation in the distribution of variables related to Context of Care, Processes of Care, and Health Outcomes in patients with SB. We also found significant differences in these variables according to SB type (MMC, non-MMC). Most differences in the demographic variables were relatively small. The age distribution of this population is skewed toward younger ages. This finding may be attributable to several factors. Until recently, the SB population was predominantly children and adolescents. In addition, clinics included in the NSBPR are almost exclusively at children’s hospitals. Few clinics in the nation care primarily for adults with SB,[12] and even fewer participate in the NSBPR. Although adults may receive care in some of these programs, transition to adult health care in many clinics is mandatory in early adulthood. Unless the number of programs that provide care to adults with SB is increased in the NSBPR, the ability to understand the trajectory of SB, optimize clinical care, and improve outcomes in adults may be limited.

The distribution of NSBPR participants' ethnic/racial background is similar to other published SB population ethnic/racial distributions[4,13] but differs from that of the general US population. Specifically, the NSBPR population has proportionately more Hispanics (24.2% vs 16.9%), fewer Non-Hispanic blacks (6.6% vs 12.31%), and similar number of Non-Hispanic whites (63.4% vs 63.0%) than what is reported in the US Census.[14]

The relative contribution of genetics, environment, folic acid supplementation, and access to SB subspecialty care on the apparent increased risk in the Hispanic population is largely unknown and deserves further study.[15,16] The impact of folic acid supplementation is particularly salient. This public health intervention seems to have decreased initially the incidence of infants born with SB, but the most recent data indicate that the impact of this intervention may have plateaued.[4,13,17] It is not clear whether this plateau reflects biologic variation in nutritional vulnerability, persisting dietary differences, or social barriers to acceptance of supplementation, each of which would call for a different intervention.

There were striking differences in the clinical characteristics of the NSBPR population by type of SB but the differences were consistent with previous studies. Most of the non-MMC population had sacral lesions that minimally affected their mobility (walked with no or minor impairment), but many still had bowel and bladder impairments.[18] The frequency of bowel and bladder impairments among individuals in the non-MMC group is 0.6–0.7 times the frequency of impairment in the MMC group. Individuals with impairments generally used a variety of bowel or bladder management techniques, and among those with impairments there was no difference in continence outcomes by type of SB. The MMC population had a wider range of neurologic impairments, lesion levels, bowel and bladder impairments, and methods of mobility. It is also possible that another yet to be identified variable is influencing continence outcomes.

Although mobility is viewed in this study as a clinical characteristic, it could be used in future analyses as an outcome measure to evaluate the success of specific interventions targeted at improving ambulation. Data from this study would support the use of the subsample of those individuals aged 5 and older with bowel or bladder impairments in future examinations of continence. Including individuals without impairments artificially increases the continence rates and results in a false picture of continence success. The definition of continence is also important. The definition used in this study (totally continent in daytime) was needed to quantify the absolute presence or absence of daytime continence across sites and methods of data collection. When this NSBPR definition was used, only a relatively small proportion of those with bladder and/or bowel impairment reported continence. Future versions of the NSBPR should include additional descriptive information to better describe the frequency and quantity of bowel and bladder incontinence.

Further study could better delineate the relationship between specific bowel or bladder management techniques and continence. The establishment of this relationship is important to better understand those individuals that use no intervention or only use voluntary/timed voiding even though they are not successful in achieving bladder continence. Additional data may be helpful to understand the decisions individuals make about bowel- and bladder-management techniques. For some individuals, a flexible school schedule or participation in social activities might have a higher priority than absolute bowel or bladder continence. There also may be differences in the threshold to undergo surgery. It is also possible that those with more paralysis or severe scoliosis or kyphosis are limited in self-care activities and have more challenges with continence.

The NSBPR did not collect data on the issues contributing to the subsequent nonuse of the antegrade enema method in the small group of participants with MMC who had a surgical procedure to create a stoma or place a cecostomy button. Potential problems may have included stoma closure/constriction, discomfort, prolonged time for bowel program, ineffective bowel program, or other unknown causes. The experience of this small but important group should be investigated.

This analysis, like other projects that make use of patient registry data, is limited by potential threats to validity including sampling bias, information bias, or bias that arises from the omission of important data variables in the NSBPR design.[19] It is likely that our patient population, drawn exclusively from those patients attending SB clinics, is not completely representative of individuals with SB who do not attend such clinics. The age distribution is particularly indicative of this bias and reflects the fact that most of the participating clinics have a distinct pediatric orientation. Furthermore, patients with SB at the clinic who are included in the NSBPR may be systematically different than those who are not. There may be differences in demographic characteristics such as race, ethnicity, age, and socioeconomic status, or there may be differences in condition characteristics such as lesion type or level, or overall complexity of condition. The information we could collect regarding non-participants was limited to aggregated data; therefore, we were only able to gauge the potential impact of selection bias but not correct for it. We found that when compared with the rest, 2 NSBPR participating clinics had more statistically significant differences in the select demographic variables and clinical characteristics (ie, age, sex, race, ethnicity, type of insurance, diagnosis, and level of lesion), between eligible participants and nonparticipants, which implies a selection bias. However, our statistical analyses for research question 2 were conducted with and without these 2 clinics, and the results did not change in any substantive way, giving us confidence in our conclusions.

Information bias as the result of variations in accuracy and ascertainment of information about participants is also a potential threat to the validity of analyses based upon registry data. Intense attention was paid to the standardization of data components and data collection both in initial training and in ongoing assessment of clinic personnel. Furthermore, data quality monitoring by the coordinating committee of site Principal Investigators and CDC staff is ongoing.[9] Finally, our standardized data instrument has been revised to ensure consistent interpretation of data fields and complete capture of data. For example, the first version of the instrument limited the number of repeat surgeries that could be reported between annual visits. Although this was a limitation to the analysis, this problem affected a very small percentage of participants and has been corrected in the subsequent version of the instrument.

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Glossary

CDC	Centers for Disease Control and Prevention
MMC	Myelomeningocele
NSBPR	National Spina Bifida Patient Registry
SB	Spina bifida

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Appendix

The development of the NSBPR has been successful because of the contributions of all the members of the NSBPR Coordinating Committee, including: Timothy Brei, MD, FAAP, Riley Hospital for Children, Indianapolis, IN; Heidi Castillo, MD, Cincinnati Children's Hospital Medical Center, Cincinnati, OH; Kurt A. Freeman, PhD, ABPP, Oregon Health & Science University, Portland OR; David Joseph, MD, Children's Hospital of Alabama, Birmingham, AL; Kathleen Sawin, PhD, CPNP-PC, FAAN, Children's Hospital of Wisconsin, Milwaukee, WI; Kathryn Smith, RN, DrPH, Children's Hospital Los Angeles, Los Angeles, CA; Jeffrey Thomson, MD, Connecticut Children's Medical Center, Hartford, CT; William Walker, MD, Seattle Children's Hospital, Seattle, WA; Pamela Wilson, MD, Children's Hospital Colorado, Aurora, CO.

Table I

Context of Care: demographic and clinical characteristics

		By SB type		
Characteristics	**Total, n (%), N = 2172**	**MMC (n = 1763)**	**Non-MMC (n = 409)**	***P* value**[*]
Demographic characteristics				
Age group, y				
Younger than 2	373 (17.2)	300 (17.0)	73 (17.8)	
2 to <5	346 (15.9)	265 (15.0)	81 (19.8)	
5 to <10	454 (20.9)	364 (20.6)	90 (22.0)	
10 to <13	252 (11.6)	207 (11.7)	45 (11.0)	
13 to <18	419 (19.3)	342 (19.4)	77 (18.8)	
18 to <22	210 (9.7)	179 (10.2)	31 (7.6)	
22 or older	118 (5.4)	106 (6.0)	12 (2.9)	.0364
Sex				
Female	1141 (52.5)	909 (51.6)	232 (56.7)	.0618
Race/ethnicity				
Non-Hispanic white	1377 (63.4)	1137 (64.5)	240 (58.7)	
Non-Hispanic black	144 (6.6)	128 (7.3)	16 (3.9)	
Hispanic or Latino	526 (24.2)	426 (24.2)	100 (24.4)	
Other	125 (5.8)	72 (4.1)	53 (13.0)	<.0001
Insurance (N = 2171)				
Any private	1010 (46.5)	788 (44.7)	222 (54.3)	
Nonprivate	1161 (53.5)	974 (55.3)	187 (45.7)	.0005
Site				
1	411 (18.9)	339 (19.2)	72 (17.6)	
2	271 (12.5)	233 (13.2)	38 (9.3)	
3	242 (11.1)	218 (12.4)	24 (5.9)	
4	247 (11.4)	201 (11.4)	46 (11.2)	
5	231 (10.6)	190 (10.8)	41 (10.0)	
6	255 (11.7)	175 (9.9)	80 (19.6)	
7	172 (7.9)	153 (8.7)	19 (4.6)	
8	196 (9.0)	132 (7.5)	64 (15.6)	
9	75 (3.5)	63 (3.6)	12 (2.9)	
10	72 (3.3)	59 (3.3)	13 (3.2)	<.0001
Education level				
Pre-elementary	857 (39.5)	676 (38.3)	181 (44.3)	
Primary/secondary	1205 (55.5)	993 (56.3)	212 (51.8)	
Technical school	8 (0.4)	7 (0.4)	1 (0.2)	
Some college	43 (2.0)	36 (2.0)	7 (1.7)	
College degree	7 (0.3)	6 (0.3)	1 (0.2)	
Advanced degree	4 (0.2)	2 (0.1)	2 (0.5)	
Other	48 (2.2)	43 (2.4)	5 (1.2)	.1523

		By SB type		
Characteristics	**Total, n (%), N = 2172**	**MMC (n = 1763)**	**Non-MMC (n = 409)**	***P* value**[*]
Clinical characteristics				
Mobility status age 2 and older (n = 1782)				
Community ambulators	961 (53.9)	651 (45.0)	310 (92.3)	
Household ambulators	147 (8.2)	140 (9.7)	7 (2.1)	
Nonfunctional ambulators	145 (8.1)	137 (9.5)	8 (2.4)	
Nonambulators	529 (29.7)	518 (35.8)	11 (3.3)	<.0001
Functional LOL[†]				
Thoracic (flaccid lower extremities)	330 (15.2)	325 (18.4)	5 (1.2)	
High-lumbar (hip-flexion present)	211 (9.7)	204 (11.6)	7 (1.7)	
Mid-lumbar (knee extension present)	581 (26.7)	543 (30.8)	38 (9.3)	
Low-lumbar (foot dorsiflexion present)	393 (18.1)	343 (19.5)	50 (12.2)	
Sacral (foot plantar flexion present)	657 (30.2)	348 (19.7)	309 (75.6)	<.0001
Bowel function				
Impaired bowel function, total sample[‡]	1891 (87.1)	1618 (91.8)	273 (66.7)	<.0001
Impaired bowel function, ages 5 and older[§]	1200 (82.6)	1059 (88.4)	141 (55.3)	<.0001
Bladder function				
Impaired bladder function, total Sample[**]	1989 (91.6)	1693 (96.0)	296 (72.4)	<.0001
Impaired bladder function, ages 5 and older[§]	1299 (89.4)	1133 (94.6)	166 (65.1)	<.0001

LOL, level of lesion.

[*] *P*-value for difference between type of SB (MMC vs non-MMC).

[†] LOL is collected for both right and left side of the body; n = 128 with differences by side of the body. Reported here is the side with the most severe impairment.

[‡] Individuals are classified as having impaired bowel function if they are have involuntary release of stool or use an intervention (bowel-management technique) to prevent involuntary release of stool.

[§] Subsample of all participants ages 5 or older = 1453.

[**] Individuals are classified as having impaired bladder function if they are have involuntary release of urine or use an intervention (bladder-management technique) to prevent involuntary release of urine.

Table II

Process of Care: lifetime history of select surgeries

Surgeries	Total sample, n (%), N = 2172	By SB type MMC (n = 1763)	 Non-MMC (n = 409)	*P* value[*]
Neurosurgery				
Ventricular shunt placement	1427 (65.7)	1409 (79.9)	18 (4.4)	<.0001
Chiari decompression	159 (7.3)	156 (8.8)	3 (0.7)	<.0001
Bladder surgeries				
Bladder augmentation	261 (12.0)	235 (13.3)	26 (6.4)	<.0001
Appendicovesicostomy (Mitrofanoff)	204 (9.4)	189 (10.7)	15 (3.7)	<.0001
Ileovesicostomy (Monti)	74 (3.4)	72 (4.1)	2 (0.5)	<.0001
Vesicostomy	114 (5.2)	109 (6.2)	5 (1.2)	<.0001
Bowel surgeries				
Creation of ACE stoma[†]	276 (12.7)	259 (14.7)	17 (4.2)	<.0001
Cecostomy button or rube[‡]	23 (1.1)	22 (1.2)	1 (0.2)	.1032
Colostomy	40 (1.8)	25 (1.4)	15 (3.7)	.0064

ACE, antegrade continent enema.

[*] *P* value for difference between type of SB (MMC vs non-MMC).

[†] Surgical procedures that create a stoma for an antegrade continent enema, including an appendicocestomy, a Malone antegrade continent enema procedure, or any procedure that uses a bowel segment to create a stoma to the bowel through which an antegrade enema can be delivered.

[‡] A procedure in which a plastic “button” is inserted to create a channel for an antegrade continent enema.

Table III

Process of Care: bowel and bladder management techniques

Management techniques	**Total, n (%)**[*]	**By SB type**		***P* value**[†]
Impaired bowel function (n = 1891)		MMC, n = 1618 (%)[*]	Non-MMC, n = 273 (%)[*]	
No bowel technique used	655 (34.6)	510 (31.5)	145 (53.1)	<.0001
Oral medications	679 (35.9)	602 (37.2)	77 (28.2)	.0041
Antegrade enema[‡]	279 (14.8)	261 (16.1)	18 (6.6)	<.0001
Manual stimulation	116 (6.1)	111 (6.9)	5 (1.8)	.0005
Suppository	109 (5.8)	97 (6.0)	12 (4.4)	.33
Cone saline enema[§]	74 (3.9)	68 (4.2)	6 (2.2)	.13
Irritant enema[§]	55 (2.9)	52 (3.2)	3 (1.1)	.0523
Other	97 (5.1)	79 (4.9)	18 (6.6)	.24
Impaired bladder function (n = 1989)		MMC, n = 1693 (%)[*]	Non-MMC, n = 296 (%)[*]	
No bladder technique used	390 (19.6)	290 (17.1)	100 (33.8)	<.0001
Clean intermittent catheterization	1373 (69.0)	1244 (73.5)	129 (43.6)	<.0001
Voluntary/timed voiding	154 (7.7)	98 (5.8)	56 (18.9)	<.0001
Vesicostomy	63 (3.2)	54 (3.2)	9 (3.0)	1.00
Indwelling catheter	17 (0.9)	15 (0.9)	2 (0.7)	1.00
Urostomy bag	7 (0.4)	6 (0.4)	1 (0.3)	1.00
Credé	1 (0.1)	1 (0.1)	0 (0.0)	1.00

[*] Participants may use more than one management technique; thus, total percentages may be greater than 100%.

[†] *P* value for difference between type of SB (MMC vs non-MMC).

[‡] An enema given via an opening to the bowel on the abdomen, proximal to the rectum.

[§] An enema given retrograde or upwards from the rectum.

Table IV

Health Outcomes: pressure ulcer prevalence, bowel continence, and bladder continence

		By SB type		
Outcomes	**Total, n (%)**	**MMC, n (%)**	**Non-MMC, n (%)**	***P* value**[*]
Pressure ulcer prevalence[†]	302 (13.9)	275 (15.6)	27 (6.6)	<.0001
Pressure ulcer location				
Trunk/upper extremity	28 (9.3)	27 (9.8)	1 (3.7)	
Lower extremity/foot	184 (60.9)[‡]	162 (58.9)	22 (81.5)	
Posterior pelvis/perineum	73 (24.2)[§]	69 (25.1)	4 (14.8)	
Multiple locations—other combinations[**]	17 (5.6)	17 (6.2)		.1223
Continence[††]				
Bowel continence[‡‡]	356 (29.7)	315 (29.7)	41 (29.1)	.92
Bladder continence[§§]	391 (30.1)	347 (30.6)	44 (26.5)	.32

[*] *P* value for difference between type of SB (MMC vs non-MMC).

[†] Total sample N = 2172; MMC = 1763, Non-MMC = 409; 302 reflects 277 participants who had a single pressure ulcer and 25 who had 2–3 pressure ulcers.

[‡] Participants had pressure ulcers on both lower extremity and foot.

[§] Four participants had pressure ulcers on both posterior pelvis and perineum.

[**] A total of 17 participants had 2–3 pressure ulcers reflecting other combinations; 8 on trunk + foot or posterior pelvis; 7 on foot + posterior pelvis or other; 2 on the lower extremity + posterior pelvis or head.

[††] Defined as continence during the day for those who have impaired bowel or bladder function.

[‡‡] Subsample of participants age 5 and older with impaired bowel function; total n = 1200; MMC 1059; non-MMC = 141 (Table I).

[§§] Subsample of participants age 5 and older with impaired bladder function; total n = 1299; MMC 1133; non-MMC = 166 (Table I).