

**ORIGINAL RESEARCH**

# Factors Associated With Pressure Ulcers in Individuals With Spina Bifida



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**Abstract**

**Objective:** To describe factors associated with pressure ulcers in individuals with spina bifida (SB) enrolled in the National Spina Bifida Patient Registry (NSBPR).

**Design:** Unbalanced longitudinal multicenter cohort study.

**Setting:** Nineteen SB clinics.

**Participants:** Individuals with SB (N=3153) enrolled in 19 clinic sites that participate in the NSBPR.

**Interventions:** Not applicable.

**Main Outcome Measures:** Pressure ulcer status (yes/no) at the annual visit between 2009 and 2012.

**Results:** Of 3153 total participants, 19% (n=603) reported ulcers at their most recent annual clinic visit. Seven factors—level of lesion, wheelchair use, urinary incontinence, shunt presence, above the knee orthopedic surgery, recent surgery, and male sex—were significantly associated with the presence of pressure ulcers. Of these factors, level of lesion, urinary incontinence, recent surgery, and male sex were included in the final logistic regression model. The 3 adjusting variables—SB type, SB clinic, and age group—were significant in all analyses (all  $P < .001$ ).

**Conclusions:** By adjusting for SB type, SB clinic, and age group, we found that 7 factors—level of lesion, wheelchair use, urinary incontinence, shunt presence, above the knee orthopedic surgery, recent surgery, and male sex—were associated with pressure ulcers. Identifying key factors associated with the onset of pressure ulcers can be incorporated into clinical practice in ways that prevent and enhance treatment of pressure ulcers in the population with SB.

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Spina bifida (SB) is a neural tube defect that occurs when the spinal column of a developing fetus does not close properly in utero. It affects approximately 3.1 individuals per 10,000 children and adolescents in 10 regions of the United States according to a

population-based study.<sup>1</sup> Myelomeningocele is the most severe form of SB, in which the vertebrae and spinal canal do not close before birth. Meningocele and lipomyelomeningocele are milder forms. Resulting sequelae of an open neural tube defect may include impairments in mobility, cognition, urinary and fecal continence, and an accumulation of secondary conditions, which may require numerous medical and surgical interventions throughout the life span.<sup>2</sup>

Pressure ulcers result from prolonged pressure to soft tissue, skin, and muscle. They may occur in individuals who have

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impairments in sensation or motor function. Each year, more than 2.5 million people develop pressure ulcers in the United States.<sup>3</sup> Between 1999 and 2005, the overall pressure ulcer prevalence rate was 15% for hospitalized individuals in 9 international pressure ulcer surveys,<sup>4</sup> and 4% in hospitalized children in 2003.<sup>5</sup> In individuals with SB, skin wounds are reported as one of the primary diagnoses associated with hospitalizations.<sup>6</sup> Pressure ulcers can lead to serious complications such as infection, sepsis, leg amputation, and even death.

The annual prevalence rate of pressure ulcers and other causes of skin breakdown in individuals with myelomeningocele reported in the literature for all ages is between 15% and 77%,<sup>7-11</sup> and in adults with SB it is 34%,<sup>12</sup> a much higher rate than in the general population. The wide variations in the rates may be attributed to the differences in population age and inclusion criteria over different studies.

Although there are many published articles describing risk factors for skin breakdown including pressure ulcers, there has been a lack of studies focusing exclusively on this topic in the population with SB. A recent cohort study over a 13-year period found that age, wheelchair use, bare feet, obesity, and reduced executive functioning are key risk factors for wound development.<sup>13</sup> Another small questionnaire-based study of 87 adults with myelomeningocele showed a higher prevalence of pressure ulcers in individuals with memory deficits, Chiari II malformation, and sensory deficit.<sup>14</sup> For young adults with myelomeningocele, the number of ulcers has also been found to be associated with motor and educational level.<sup>15</sup>

Understanding factors associated with pressure ulcers in this population is critical to help them maintain or improve their health. Using results from a prospective study with an adequate sample size will provide a scientific basis to help influence clinical care. This study aims to explore factors associated with pressure ulcers in individuals enrolled in the National Spina Bifida Patient Registry (NSBPR) in the United States between 2009 and 2012.

## Methods

### Study population

The sample is composed of participants with SB from 19 clinic sites who participated in the NSBPR between 2009 and 2012. After institutional review board approval and obtaining informed consent/assent from parents and patients, the clinics collected longitudinal data on individuals with SB.<sup>16</sup> At the initial visit, basic demographic and diagnostic information as well as information on surgical procedures were collected from each patient. At the initial visit and each subsequent annual visit, information on insurance status, anthropometric measurements, surgeries and procedures, education and employment, and treatments and outcomes was also collected. Depending on when a patient was enrolled, a patient may have had from 1 to 4 submitted annual

reports. By the end of 2012, a total of 3738 participants were enrolled in the NSBPR. Of these, 585 participants aged <2 years at enrollment were excluded because mobility status is variable in this age group and for this reason they were not typically evaluated as a cohort. The final analytical data set was composed of 3153 participants' 5593 annual reports (see [supplemental tables S1 and S2](#), available online only at <http://www.archives-pmr.org/>).

## Variables

### SB type and level of lesion

Participants were classified into 2 SB types: myelomeningocele or non-myelomeningocele, which included the diagnoses of meningocele, lipomyelomeningocele, or fatty filum. Each patient's level of lesion was determined on their both right and left sides on the basis of the presence of antigravity strength of muscle groups: hip flexors, quadriceps, dorsiflexors, and plantar flexors. The functional level of lesion was classified into 5 categories—1, sacral, 2, low-lumbar, 3, mid-lumbar, 4, high-lumbar, and 5, thoracic in the order of increasing severity—and used as a continuous variable (1–5) in the analysis. For asymmetric level of lesions, the higher spinal level (ie, more severe) was selected.

### Pressure ulcer status

At each annual visit, participants were asked if there have been any pressure ulcers in the past 12 months or since the previous clinic visit.

### Surgeries

Six surgical types were considered as potential factors. Chiari II decompression and shunt placement surgeries that occurred from birth to the time of the annual visit were considered as (history) binary indicators. Orthopedic, urology, and tethered cord release surgeries that occurred from the 12 months before enrollment to the time of each annual visit were considered as (partial history) binary indicators. Orthopedic surgeries were divided into 2 categories: above the knee and below the knee. Procedures addressing scoliosis, kyphosis, hip flexion contracture, and hip subluxation/dislocation were classified as above the knee procedures. Correction of knee flexion contracture, external tibial torsion, ankle valgus deformity, equinus contracture, clubfoot deformity, congenital vertical talus, and congenital deformity of foot were considered as below the knee procedures. Lastly, to consider the effect of recent hospitalization on pressure ulcers, a summary variable reflecting any recent surgery since the previous annual visit was also created as a binary variable (yes/no).

### Bladder/bowel incontinence

Participants were asked if they were wet during the day with or without interventions for bladder incontinence and if they experienced involuntary stool leakage for bowel incontinence. If they responded yes to either question, they were assigned to the incontinence group for bladder and bowel, respectively.

### Ambulatory ability

Participants were grouped into 4 ambulatory categories and then regrouped into 2 groups: community ambulators or wheelchair users. Community ambulators were defined as those who are able to walk indoors and outdoors for most of their activities regardless of whether they use assistive device or braces. Individuals in this group could use a wheelchair, but only for long trips in the

#### List of abbreviations:

CI	confidence interval
GEE	generalized estimating equation
NSBPR	National Spina Bifida Patient Registry
OR	odds ratio
QIC	quasi-likelihood information criteria
SB	spina bifida

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