

# Emergent Care Patterns in Patients with Spina Bifida: A Case-Control Study

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## Abbreviations and Acronyms

CCS = clinical classifications software

ED = emergency department

HCUP = Healthcare Cost and Utilization Project

NEDS = Nationwide Emergency Department Sample

SB = spina bifida

UTI = urinary tract infection

**Purpose:** Individuals with spina bifida are typically followed closely as outpatients by multidisciplinary teams. However, emergent care of these patients is not well defined. We describe patterns of emergent care in patients with spina bifida and healthy controls.

**Materials and Methods:** We reviewed Nationwide Emergency Department Sample data from 2006 to 2010. Subjects without spina bifida (controls) were selected from the sample using stratified random sampling and matched to each case by age, gender and treatment year at a 1:4 ratio. Missing emergency department charges were estimated by multiple imputation. Statistical analyses were performed to compare patterns of care among emergency department visits and charges.

**Results:** A total of 226,709 patients with spina bifida and 888,774 controls were identified. Mean age was 28.2 years, with 34.6% of patients being younger than 21. Patients with spina bifida were more likely than controls to have public insurance (63.7% vs 35.4%,  $p < 0.001$ ) and to be admitted to the hospital from the emergency department (37.0% vs 9.2%,  $p < 0.001$ ). Urinary tract infections were the single most common acute diagnosis in patients with spina bifida seen emergently (OR 8.7,  $p < 0.001$ ), followed by neurological issues (OR 2.0,  $p < 0.001$ ). Urological issues were responsible for 34% of total emergency department charges. Mean charges per encounter were significantly higher in spina bifida cases vs controls (\$2,102 vs \$1,650,  $p < 0.001$ ), as were overall charges for patients subsequently admitted from emergent care (\$36,356 vs \$29,498,  $p < 0.001$ ).

**Conclusions:** Compared to controls, patients with spina bifida presenting emergently are more likely to have urological or neurosurgical problems, to undergo urological or neurosurgical procedures, to be admitted from the emergency department and to incur higher associated charges.

**Key Words:** case-control studies, emergency treatment, spinal bifida cystica

SPINA bifida is a major congenital birth defect in which the neural tube fails to close properly during embryonic development. Although the use of perinatal folic acid supplementation has significantly reduced the birth prevalence of spina bifida, this condition remains the most common permanently disabling birth defect in the United States.<sup>1,2</sup> Furthermore,

an increasingly large number of children with spina bifida are surviving beyond infancy into childhood and adolescence as a result of modern medical and surgical advances.<sup>3</sup>

Because SB affects multiple organ systems, a multidisciplinary approach including neurosurgery, urology, orthopedics and developmental pediatrics is often used to manage these

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cases. However, an aging SB population cannot always be accommodated by traditional pediatric clinics, and coordinating a multidisciplinary transition from pediatric to adult care can be problematic. Adults with SB are reportedly frequent users of acute care hospitals and emergency departments as a major provider of their primary care needs instead of establishing themselves with an adult primary care provider.<sup>4,5</sup> As such, a better understanding of patterns of ED care among individuals with SB is crucial to improve the care (and care transitions) of these often complex cases. We describe emergent care patterns and associated medical charges in patients with SB and healthy controls using a large, population based emergency room encounter registry.

## PATIENTS AND METHODS

### Data Source

We analyzed Nationwide Emergency Department Sample data from 2006 to 2010. NEDS is an all payer database managed by HCUP and sponsored by the Agency for Healthcare Research and Quality. Data in NEDS are from a 20% stratified probability sample of hospital based EDs in the United States based on 5 hospital characteristics, including ownership/profit status, trauma center designation, teaching status, urban/rural location and geographical region. NEDS contains ED visits that do not result in hospitalization and patients who are seen at the ED and subsequently admitted to the same hospital.

NEDS captures patient demographics, clinical features such as acute and chronic diagnostic codes, procedures performed at the ED and subsequent admission, ED disposition and charge data. HCUP has defined post-stratification discharge weights that may be used to estimate nationwide approximations.<sup>6</sup>

### Case and Control Selection

We identified individuals with SB (cases) by ICD-9-CM diagnostic codes 741.X and 756.17 in any diagnosis field. Controls were randomly selected from the overall NEDS cohort using stratified random sampling. Controls were matched to each study subject by age (year), gender and treatment year at a case-to-control ratio of 1:4.

### Covariates for Analysis

Analyzed covariates included basic patient demographics, ie median household income quartiles by zip code, insurance payer (public insurance including Medicare and Medicaid, primary and other), Elixhauser comorbidity index,<sup>7</sup> total charges from ED and subsequent admissions, ED disposition (discharged, admitted, transferred, died, other), and hospital characteristics such as hospital teaching status (metropolitan nonteaching, metropolitan teaching, nonmetropolitan) and geographical region (Northeast, South, Midwest, West).

### Outcome Selection

We defined ED diagnoses and procedures as primary outcomes. Single and multilevel clinical classifications

software was used to define these outcomes, and NEDS chronic disease indication was used to categorize each as acute or chronic. NEDS is structured such that each ED visit/encounter lists the top 15 diagnoses most relevant to that specific visit, ie each diagnosis is simply listed as 1 of 15 diagnoses, and does not necessarily represent a "principal" diagnosis. Acute neurological diagnoses were additionally defined to include neurosurgical device malfunction (ICD-CM-9 diagnosis code 996.2, 996.63 or 996.75) and multilevel CCS diagnosis, "Diseases of the nervous system and sense organs." We defined ventricular shunt procedures as ventricular shunt placement or revision (ICD-CM-9 procedure code 02.3x or 02.4x).

We also examined total charges per ED visit and total hospital charges from the ED and subsequent admission. These charges were reflective of the facility fees associated with each encounter record.

### Statistical Analysis

Bivariate analyses were performed to compare demographics and hospital characteristics of SB cases and controls. We used the Rao-Scott chi-square test, t-test or Wilcoxon rank sum test as appropriate based on data characteristics and distribution. Rates of acute diagnoses and procedures were estimated for cases and controls. All analyses were weighted using HCUP provided estimated weights and estimated covariance matrices to obtain nationwide representation. Generalized estimating equations were used to account for NEDS complex survey design in addition to hospital clustering effects.

Missing charges were treated as missing at random and estimated by multiple imputation methods using other known variables, including patient age, gender, Elixhauser comorbidity index,<sup>7</sup> disposition, insurance, geographical region and injury status. Charges were adjusted to 2010 United States dollars using the Consumer Price Index.<sup>8</sup>

An alpha of 0.05 and 95% confidence intervals were used as criteria for statistical significance. All analyses were performed using SAS®, version 9.3.

## RESULTS

### Demographics

A total of 226,709 SB cases and 888,774 control weighted subjects were identified in the 2006 to 2010 NEDS (table 1). Mean patient age was 28.2 years, and 34.6% of patients were younger than 21. Males constituted 43.4% of the overall cohort. Compared to controls, patients with SB were more likely to have public insurance, to be treated at a metropolitan teaching hospital and to be admitted from the ED.

### Common ED Diagnoses and Procedures

Acute diagnoses in patients with SB were markedly different from controls (see figure). Disorders of the genitourinary system were the most common multilevel CCS category among SB cases, being

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