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Hospitalizations of Adults With Spina Bifida and Congenital Spinal Cord Anomalies

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Abstract

Objective: To examine hospital admission records from a large cohort of persons with spina bifida (SB) with a variety of insurers to provide descriptive detail about adult hospital use for persons with SB and associated disorders in terms of primary diagnosis for hospitalization, age, sex, payer source, lengths of stay, and total charges.

Design: Retrospective secondary data analysis from the Nationwide Inpatient Sample (NIS) from the Healthcare Cost and Utilization Project for 2004 and 2005 of hospitalizations for adults with SB or associated spinal cord anomalies.

Setting: Records from U.S. inpatient hospital admissions.

Participants: Persons with SB age 18 years and older.

Interventions: Not applicable.

Main Outcome Measures: Diagnoses associated with hospitalizations and death.

Results: The most common primary diagnosis for hospitalization was urinary tract infection, followed by complications from devices/grfts/implants and skin wounds. Sepsis accounted for the most deaths. Approximately one third of hospitalizations were for primary diagnoses of potentially preventable conditions. Hospitalizations associated with a primary diagnosis of a potentially preventable condition occurred most often in those less than 51 years of age and in rural or urban nonteaching hospitals.

Conclusions: Reducing the number of secondary medical conditions with proactive and preventative approaches to health care could reduce the morbidity, mortality, and cost for health care for this group.

Keywords

Hospitalization; Prevention & control; Rehabilitation; Spinal dysraphism

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Spina bifida is the most common permanently disabling birth defect in the United States, with a prevalence of over 70,000.¹ Despite advances in preventative folic acid supplementation, the incidence of SB is still 7 out of every 10,000 live births.¹ This condition affects already at-risk populations such as persons from lower socioeconomic status and rural areas at disproportionately high rates.¹ Persons with SB have impaired mobility and experience higher rates of depression and social isolation than many other disability groups.² Unemployment and lack of access to health care are common in this group.³ Many persons with SB have cognitive impairments that impact their ability to initiate and follow through with self-care tasks crucial to their health.⁴ Advancements in medical and surgical care have allowed about 85% of people with SB to live well into adulthood.^{5,6} The prevalence continues to increase because persons are outliving their caregivers.

As youths with disabilities age, they are often discharged from pediatric multidisciplinary clinic settings where they once received comprehensive care and are left to navigate the adult health care world alone.⁷ At the time of this publication, only 4 SB clinics devoted solely to the care of adults currently exist in the entire United States.⁸ At-risk youth with SB are often given little support during the crucial transition from adolescence to adulthood. The knowledge and skills required to treat persons with complex health care needs are often beyond the scope of the primary care physician and must be coordinated by a team of specialists who may be at different institutions.

Young et al⁹ surveyed persons with SB and other disabilities who transitioned from pediatric to adult-centered care and found that adults with SB reported the lowest health scores. In the absence of coordinated care, active medical problems and medications of young adults with disabilities are not regularly reviewed.^{10,11} Admission rates to acute hospitals for adults diagnosed with disabilities in childhood, including SB, are 9 times higher than that of the general population, and 76% do not have or cannot identify a primary care provider.¹²

Prevention of neurologic, musculoskeletal, urologic, and other medical complications is crucial to the care of adults with SB,^{13–16} and little is known about how many of the admissions or deaths of persons with SB are a result of conditions that are potentially preventable. Dosa et al¹⁷ showed that obesity rates of adults with SB are higher than that of the general U.S. population. Nelson et al¹⁸ demonstrated that the prevalence of metabolic syndrome, a constellation of known risk factors for the development of type 2 diabetes, cardiovascular disease, and stroke, is high in obese persons with SB. Causes of death have been sparsely reported in the literature. A retrospective analysis¹⁹ of charts from 1 hospital in the United Kingdom revealed that in many instances, the cause could not be identified, but of the few identifiable cases, renal failure, cardiac complications, and respiratory complications were the top 3 diagnoses associated with mortality.

Kinsman and Doehring²⁰ evaluated admissions of persons with SB to 1 acute care U.S. hospital. Patients were admitted an average 3.6 times over that period, with mean length of stay of 11.2 days. The authors identified potentially preventable secondary conditions such as UTI, kidney stones, skin breakdown, and osteomyelitis that accounted for 47% of admissions, with an average length of stay of 12.5 days.

Ouyang et al²¹ analyzed data from 2001 to 2003 using a database on paid medical and prescription drug claims of persons with SB covered by employer-sponsored insurance programs. Their medical expenditures were 3 to 6 times greater than those of adults without SB, averaging over \$13,000 a year at ages 18 to 44 years, and over \$10,000 a year at ages 45 to 64 years. This study demonstrated significant costs associated with the health care of persons with SB who had employer-sponsored health insurance, but data on adults with other types of insurance coverage are needed.

The purpose of this study was to examine hospital admission records from a large cohort of persons with SB with a variety of insurers. Based on the literature from the previous smaller studies mentioned, we hypothesized that UTI would be the most common cause of hospitalization and that renal failure would be the most common cause of death during hospitalization in patients with SB. We anticipated that these findings would hold true regardless of patient age or type of hospital (ie, urban teaching, nonurban teaching, or rural). We also anticipated that about half of admissions and deaths would be a result of potentially preventable secondary medical problems.

We also aimed to provide more descriptive detail about adult hospital use for persons with SB and associated disorders in terms of primary diagnosis for hospitalization age, sex, payer source, lengths of stay, and total charges.

METHODS

The unidentified nature of the data allows this study to be exempt from institutional review board review, as confirmed by the institutional review boards at MetroHealth Medical Center and the University of Pittsburgh. We examined the NIS from the Healthcare Cost and Utilization Project of the Agency for Healthcare Research and Quality to describe hospital use, primary diagnoses, lengths of stay, and total charges for adults with SB and associated disorders. The NIS is a stratified sample of hospital inpatient stays representing approximately 20% of community hospitals in the United States that allows for national estimates. The NIS includes all payer discharge data from over 1000 hospitals in 37 states from nonfederal, short-term general, and specialty hospitals. The NIS excludes short-term rehabilitation, long-term acute care, and psychiatric hospitals as well as substance abuse treatment centers.

We identified hospitalizations by using ICD-9-CM codes for diagnosis of SB (741.0x, 741.9x) or congenital spinal cord anomalies (742.5x) for the years 2004 and 2005. Hospitalizations were included in the analysis for age 18 years and above. We excluded hospitalizations with a primary diagnosis of SB and associated disorders so that the primary diagnosis for hospitalization could be described. Variables extracted from the database for each admission include age, sex, primary diagnosis, payer source, death during hospitalization, length of stay, total charges, and whether the hospital was rural, an urban nonteaching hospital, or an urban teaching hospital. Primary diagnoses were classified using Clinical Classifications Software for ICD-9-CM codes so that a smaller number of meaningful diagnostic categories could be presented.²² We categorized conditions as potentially preventable based on prior literature.²⁰ These conditions included UTI, chronic

ulcer of skin, skin and subcutaneous tissue infection, septicemia, complications or surgery or medical care, pneumonia, infective arthritis or osteomyelitis, and the ICD-9-CM code for indwelling urinary catheter infection (996.64). We categorized hospitalizations as potentially preventable if the primary diagnosis was one of these conditions.

Data were weighted using strata, primary sampling units (hospitals), and sampling weights based on NIS sampling design to determine national estimates. We used a purely descriptive approach to report data; no statistical comparisons were made. The descriptive analyses were completed using SAS version 9.2.^a The top 10 primary diagnoses for hospitalization, age, sex, payer source, death during hospitalization, lengths of stay, and total charges were described for the entire sample and for the sample stratified by age and stratified by type of hospital (rural, urban nonteaching, and urban teaching). The top 10 primary diagnoses for hospitalizations resulting in death were also described. Dually eligible Medicare beneficiaries with Medicaid as a secondary payer were categorized as Medicaid for primary payer.

RESULTS

There were 8118 hospitalizations associated with SB or associated disorders in 2004 and 2005. Of these, 448 had a primary diagnosis of SB and were excluded, leaving 7670 hospitalizations with a secondary diagnosis for SB and associated disorders. This sample represents 37,464 (95% CI, 34,913–40,015) hospitalizations nationally. Average length of stay was almost 7 days, with an average total charge of \$28,918 (95% CI, \$27,367–\$30,469) an admission. Table 1 lists data for the whole sample, table 2 lists data stratified by age, and table 3 lists data stratified by hospital type.

In the unstratified data, 33.8% of admissions (95% CI, 32.5%–35.3%) were a result of potentially preventable conditions. Over the 2-year period, these preventable conditions alone resulted in hospital charges of U.S. \$364 million (95% CI, \$323 million–\$405 million). Hospitalizations associated with a primary diagnosis of a potentially preventable condition resulted in death in 35.7% (95% CI, 27.4%–44.0%) of admissions. Hospitalizations associated with potentially preventable conditions occurred more frequently in those under 51 years of age and in rural and urban nonteaching hospitals (see tables 2 and 3).

As hypothesized, the most common primary diagnosis for hospitalization was UTI (10.2%), followed by complications from devices/grfts/implants (9.1%) and wounds (5.9%). Within the device/grft/implant complication group, 53% (46.5%–59.5%) were a result of shunt problems, but this group also included complications from other devices such as bladder catheters, arteriovenous fistulas, and joint prostheses. Sepsis accounted for the most deaths (18.8%), followed by pneumonia (9.4%) and respiratory failure (7.0%). Contrary to our hypothesis, renal failure was the seventh most common diagnosis associated with death, accounting for 2.5% of cases.

^a.Supplier
SAS Institute Inc, 100 SAS Campus Dr, Cary, NC 27513.

When stratified by age, UTI, device/graft/implant complications, and issues related to skin integrity accounted for most hospitalizations for those between ages 18 and 64 years. Spondylosis, intervertebral disk disease, and other sources of back pain were most common (5.4%) in the group 51 to 64 years old. In the group 65 years and older, the 3 most common diagnoses were pneumonia, anemia, and congestive heart failure.

DISCUSSION

This study reveals that approximately one third of total admissions of adults with SB are a result of potentially preventable conditions, primarily infections. A slightly higher proportion (35.7%) of hospitalizations resulting in death have a primary diagnosis of a potentially preventable condition. Interestingly, hospitalizations associated with a potentially preventable condition increased as age decreased. More research is needed to determine whether lack of preventative care in the crucial transition period between pediatric and adult care explains these findings. Also, hospitalizations associated with potentially preventable conditions occurred more often in rural and urban nonteaching hospitals. This may reflect the higher acuity conditions for those who are older or who are receiving care in urban teaching hospitals. While charges billed for these conditions were in excess of \$360 million, the actual cost and reimbursements are likely less, but still represent an enormous opportunity for improvement. Reducing the number of secondary medical conditions with proactive and preventative approaches to health care could potentially improve outcomes for these patients. Physiatrists in particular can play an important role in the coordination of care for these persons given their training in managing complex, chronic disabilities such as SB.¹⁴ We have published a comprehensive review of the care of the adult with SB.¹⁴

The results support our hypothesis and corroborate results of prior smaller studies that UTI is the most common cause of admission. Wounds remain in the top 3 diagnoses on admission. Complications caused by shunt problems account for about 5% of the remaining cases. The results did not support our hypothesis that renal failure would account for most deaths; in fact, infectious etiology including sepsis (including urosepsis) and pneumonia were the most common cause not only of morbidity but also of mortality.

When stratifying by age, the most common etiologies for admission were strikingly different for the oldest cohort, 65 years and older, than for the other age groups, with over 20% of admissions resulting from cardiovascular and pulmonary complications. Cerebrovascular accident accounted for almost 3% of admissions for the oldest cohort and 6.5% of deaths in the entire sample but is previously unreported in the literature for this population. Given the significant risk of additional long-term disability from cardiovascular and cardiopulmonary events, physicians should be attuned to identifying and treating modifiable risk factors in this population. Also of note is that spondylosis emerged as being common in the group 51 to 64 years old, but there is very little reported on degenerative joint disease and back problems in the SB population.¹⁴ More research on outcomes and the role of interventional and nonsurgical approaches to back pain is clearly needed in this population.

When stratifying by hospital type, UTI and issues related to skin integrity were common across groups. Pneumonia was more common at rural hospitals, and more shunt-related

complications were seen at urban teaching hospitals, suggesting many of the complex neurosurgical cases may have been recognized more readily at larger institutions or may have been referred there from outlying areas.

Many patients in this cohort may have been admitted for debility. Approximately 2% to 4% of admissions of those 51 years and older were coded as admissions for adjustments to a prosthesis or device, or for deconditioning type diagnoses, including the ICD-9-CM code of V57.89, which is “other: multiple training or therapy.” These admissions were acute hospitalizations and not admissions to inpatient rehabilitation. More research is needed to delineate common diagnoses associated with acute inpatient rehabilitation in this population.

Study Limitations

We recognize several limitations to this study. First, using secondary data to identify hospitalizations for persons with SB or congenital spine anomalies using a secondary diagnosis creates the potential for underestimating prevalence of hospital use for this group. A comorbid diagnosis of SB or congenital spine anomaly might not be listed if the provider or coder listed only secondary diagnoses salient to the reason for admission. However, this study indicates that when SB or congenital anomalies are listed as a comorbid diagnosis, the primary diagnoses associated with the hospitalization are for reasons often considered preventable with appropriate ambulatory care. It has been suggested that the clinical prominence of SB and congenital disorders may improve comorbid diagnosis coding compared with less prominent comorbidities, although this has never been studied to our knowledge.²³ Second, the unit of analysis for the NIS is the hospitalization and not the individual. Multiple hospitalizations by the same person could thus be present within the data. It is not possible to estimate how often repeat admissions occur within the data. Because of a lack of independence of observations, we have chosen not to compare statistically age or hospital groups according to occurrences of preventable conditions and thus have used a descriptive approach. More work is needed on datasets for which observations are independent and other possible confounders such as history of hydrocephalus and motor level, which can be indicators of disease severity, or other comorbid conditions can be considered. While these issues limit the conclusions that can be drawn about the risk of hospitalization faced by those with SB and congenital spine anomalies, the results are still representative of hospitalizations occurring within this group and thus provide insight about where efforts might be best spent for prevention of hospitalization.

CONCLUSIONS

In a nationally representative sample of hospitalizations for adults with SB or other congenital spinal cord anomalies, UTI, complications of devices/implants/grafts, and skin wounds are the most common primary diagnoses associated with hospitalizations. More compelling, this study reveals that approximately one third of total admissions of adults with SB are a result of potentially preventable conditions such as infections or complications of medical or surgical care not related to shunts. Reducing the number of secondary medical

conditions with proactive and preventative approaches to health care could reduce the morbidity, mortality, and cost for health care for this group.

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List of Abbreviations

CI	confidence interval
ICD-9-CM	<i>International Classification of Diseases–9th Revision–Clinical Modifications</i>
NIS	Nationwide Inpatient Sample
SB	spina bifida
UTI	urinary tract infection

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Table 1:**Data From the Unstratified Sample**

Variable	Value	95% CI
Sample size (n)	7670	
National estimate sample size (n)	37,464	34,913–40,015
Demographics		
Mean age (y)	40.2	39.4–41.0
% Women	55.9	54.2–57.5
Insurance type (%)		
Medicare	28.5	26.5–30.6
Medicaid	41.0	38.8–43.3
Private	25.6	24.0–27.2
Other	4.8	4.3–5.4
Hospitalization information		
% Died	1.5	1.3–1.8
Mean length of stay (d)	6.9	6.6–7.2
Mean total charges (\$)	28,918	27,367–30,469
Primary diagnoses for hospitalizations (%)		
UTI *	10.2	9.1–11.2
Complication device, implant, or graft	9.1	8.0–10.2
Chronic ulcer of skin *	5.9	5.2–6.5
Skin and subcutaneous tissue infection *	4.7	4.1–5.3
Septicemia *	4.3	3.7–4.8
Complications of surgery or medical care *	3.2	2.8–3.7
Pneumonia *	2.6	2.2–3.1
Infective arthritis or osteomyelitis *	2.4	2.1–2.8
Calculus of urinary tract	2.3	1.8–2.8
Spondylosis	2.3	1.9–2.8
Diagnoses resulting in death (%)		
Septicemia *	18.8	11.7–25.9
Pneumonia *	9.4	4.6–14.2
Respiratory failure	7.0	2.8–11.2
Acute cerebrovascular disease	6.5	2.3–10.8
Complication of device, implant, or graft	4.7	1.1–8.4
Aspiration pneumonitis	3.7	0.01–7.5
Acute renal failure	2.5	0.0–5.4
Complication of surgery or medical care *	2.4	0.03–4.7
Pericarditis, endocarditis, myocarditis; cardiomyopathy	2.4	0.2–4.6
Acute myocardial infarction	2.6	0.0–5.6

* Indicates diagnoses categorized as potentially preventable.

Table 2:

Data for Entire Population, Stratified by Age

Variable	Age 18–35y		Age 36–50y	
	Value	95% CI	Value	95% CI
Sample size (n)	3625		2153	
National estimate sample size (n)	17,688	(16,002–19,374)	10,548	(9616–11,480)
Demographics				
Mean age (y)	26.2	(25.8–26.6)	42.1	(41.9–42.4)
% Women	55.90	(53.5–58.4)	54.20	(51.1–57.3)
Insurance type (%)				
Medicare *	14.40	(12.0–16.8)	28.60	(25.2–31.9)
Medicaid *	51.60	(48.5–54.6)	42.10	(38.4–45.8)
Private *	28.20	(25.7–30.7)	24.70	(22.1–27.2)
Other *	5.80	(5.0–6.7)	4.70	(3.7–5.7)
Hospitalization information				
% Admitted to rural hospital	11	(8.3–13.7)	13.10	(9.9–16.2)
% Admitted to urban nonteaching hospital	31.60	(27.9–35.3)	38.10	(34.1–42.0)
% Admitted to urban teaching hospital	57.40	(53.0–61.8)	48.80	(44.4–53.3)
% Died	0.90	(0.6–1.2)	1.50	(1.0–2.1)
Mean length of stay (d)	7.1	(6.7–7.5)	6.9	(6.4–7.5)
Mean total charges (\$)	30,269	(28,158–32,380)	28,197	(25,894–30,500)
Primary diagnoses for hospitalizations (%)				
Complication device, implant, or graft	12.6	(10.7–14.5)	10.3	(8.3–12.4)
UTI	12.2	(10.6–13.9)	8.0	(6.6–9.4)
Chronic skin ulcer	6.8	(5.7–7.8)	6.0	(4.9–7.1)
Skin and subcutaneous tissue infection	5.4	(4.5–6.4)	5.0	(4.0–6.0)
Septicemia	4.0	(3.2–4.8)	5.1	(3.9–6.2)
Complications of surgery or medical care	3.4	(2.7–4.0)	4.0	(3.1–4.9)
Calculus of urinary tract	3.2	(2.3–4.0)	2.9	(2.2–3.6)
Infective arthritis or osteomyelitis	3.0	(2.4–3.6)	2.7	(1.9–3.6)

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Abbreviations: CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease.

* Insurance missing for each group: 18–35y, n=5; 36–50y, n=4; 51–64y, n=2; 65y+, n=1.

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Table 3:

Data for Entire Population, Stratified by Hospital Type

Variable	Rural		Urban Nonteaching		Urban Teaching	
	Value	95%CI	Value	95%CI	Value	95%CI
Sample size (n)	920		2830		3920	
National estimate (n)	4692	(3875–5509)	13,575	(12,508–14,642)	19,197	(17,028–21,365)
Demographics						
Age (y)	43.2	(41.1–45.2)	42.7	(41.7–43.7)	37.8	(36.5–39.0)
% Women	52.8	(47.4–58.1)	55	(52.2–57.7)	57.3	(55.0–59.5)
Insurance type (%)						
Medicare *	31.9	(27.1–36.7)	31.4	(28.6–34.3)	25.7	(22.5–28.9)
Medicaid *	49.3	(43.4–55.2)	39.4	(36.3–42.5)	40.2	(36.7–43.7)
Private *	14.8	(11.6–17.9)	24.3	(21.7–26.9)	29.1	(26.7–31.5)
Other *	3.9	(2.4–5.6)	4.9	(4.0–5.8)	5	(4.2–5.7)
Hospitalization information						
% Died	1.4	(0.6–2.2)	1.2	(0.8–1.6)	1.8	(1.4–2.2)
Length of stay (d)	5.2	(4.4–6.0)	7.1	(6.5–7.7)	7.2	(6.8–7.6)
Total charges (\$)	14,228	(11,871–16,585)	30,341	(27,872–32,811)	31,553	(29,204–33,901)
Primary diagnoses for hospitalizations						
UTI	12.5	(10.8–14.3)	10.9	(9.3–12.5)	12.5	(10.8–14.3)
Skin and subcutaneous tissue infection	8.4	(7.3–9.5)	6.8	(5.6–7.9)	8.4	(7.3–9.5)
Pneumonia	5.6	(4.7–6.4)	6.0	(4.7–7.3)	5.6	(4.7–6.4)
Chronic skin ulcer	4.4	(3.6–5.1)	5.3	(4.4–6.2)	4.4	(3.6–5.1)
Complication of device, implant, or graft	4.0	(3.1–4.8)	5.0	(4.1–5.9)	4.0	(3.1–4.8)
Septicemia	4.0	(3.3–4.8)	3.1	(2.4–3.9)	4.0	(3.3–4.8)
Fluid and electrolyte disorders	3.2	(2.3–4.0)	3.0	(2.4–3.7)	3.2	(2.3–4.0)
Other GI disorders	2.4	(1.8–3.1)	2.4	(1.7–3.1)	2.4	(1.8–3.1)
COPD	2.2	(1.7–2.7)	2.5	(1.8–3.1)	2.2	(1.7–2.7)

Variable	Rural		Urban Nonteaching		Urban Teaching			
	Value	95%CI	Value	95%CI	Value	95%CI		
Intestinal obstruction	2.0	(1.4–2.5)	Complications of surgery or medical care	2.3	(1.7–2.9)	Epilepsy	2.0	(1.4–2.5)
% Potentially preventable	37.7	(32.6–42.8)		36.8	(34.6–39.0)		30.9	(29.1–32.6)

Abbreviations: COPD, chronic obstructive pulmonary disease; GI, gastrointestinal.

* Missing observations for insurance: rural, n=2; urban nonteaching, n=5; urban teaching, n=5.