

Outpatient medical conditions among children and adults with spina bifida in the United States: Frequency and expenditures

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Accepted 16 July 2010

Abstract. *Objective:* To describe the most prevalent conditions and their associated expenditures for the outpatient care of individuals with spina bifida (SB) of varying ages.

Design: From a large health insurance claims database of people with private insurance, we examined records on outpatient health care received during 2005–2006 for individuals with SB and a matched comparison group. Chronic conditions from the most frequently recorded 4-digit ICD-9-CM codes for individuals with SB were grouped into four categories: cardiovascular disease risk factors, SB secondary conditions, pain, and other symptoms.

Results: Diseases affecting the nervous, genitourinary, and musculoskeletal systems and miscellaneous symptoms (e.g., headache, fever) account for about 70% of outpatient expenditures, excluding those associated with perinatal and congenital conditions. The most common and costly conditions by age group were diseases of the nervous system for children and adults younger than age 30 years and diseases of the musculoskeletal system for adults aged 30–64 years. Individuals with SB had significantly elevated risks for essential hypertension, urinary tract infection, and constipation at young ages and headache, sleep disturbance, and fever throughout the life span.

Conclusions: The frequency of health conditions associated with SB varies across the life span. These conditions should be a priority for further investigations to identify risk factors, treatment and prevention strategies for individuals with SB.

Keywords: Spina bifida, rehabilitation, medical conditions, expenditures

1. Introduction

Spina bifida (SB) is a disabling and potentially lethal condition, particularly in childhood. Improved care has increased the first-year survival rate to 92.1% [1]. Roughly 78% of all individuals with SB now survive to the age of 17 years [2]. As survival has improved, adults now constitute a majority of the population living with SB [3]. Individuals with SB have a greater need for health care across the life span. A previous study of health care expenditures for a privately insured population found that average medical expenditures for

individuals with SB were about \$15,500 per capita per year in 2003 dollars for children and adults. Compared with expenditures for those without SB, average medical expenditures for individuals with SB were 13 times higher for children aged 0–18 years and 3–6 times higher for adults [3].

Individuals with SB experience numerous health complications, but little is known about how the relative frequencies of medical conditions vary across the life span or their implications for medical costs. The ability of healthcare providers to suggest preventive measures, anticipatory guidance, and wellness approaches is constrained by the lack of relevant data [4]. This paper provides an empirical description of the most prevalent conditions for which privately insured individuals with SB of varying ages seek outpatient medical care. We also report the medical care expenditures associated with

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these conditions. Such information may help health-care professionals and individuals with SB anticipate how the condition affects people as they age. It also can help guide decisions on where to direct resources.

2. Methods

2.1. Data source

We used the MarketScan Commercial Claims and Encounters Database for years 2003–2006 in this study. This database was constructed from privately insured, paid medical and prescription drug claims. Several million covered enrollees were listed in this database each year, ranging from approximately 7 million in 2003 to about 16 million in 2006. The enrollees consisted of employees of large U.S. employers, their spouses, and dependent children. MarketScan databases capture their outpatient care, inpatient care and prescription drugs [5]. These data have previously been analyzed to examine medical care expenditures for privately insured individuals with SB [3]. No personal identifiable information was in the database, therefore our analysis does not require IRB approval. In this analysis, we investigate the medical conditions that individuals with SB sought care for. We focused on outpatient services, which include all medical care delivered outside of inpatient hospitalizations. Outpatient expenditures included outpatient surgeries. We also analyzed data on inpatient services, but the small numbers of hospitalizations associated with each diagnosis prevented further analysis. We report here only the results for outpatient encounters and expenditures.

2.2. Study population

We identified enrollees with SB by the presence of the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) code 741. Individuals with this code listed in their primary or secondary diagnoses from either inpatient or outpatient claims from any year during 2003–2005 were categorized as having SB. To fully capture medical care use, we restricted the sample to those who were enrolled during 2005 and 2006 for 2 full years in a fee-for-service plan. We used the fee-for-service criterion because healthcare providers have less incentive to report all services used by patients covered by capitated plans. A comparison group was selected from enrollees in the same database who had no diagnosis of SB re-

ported during 2003–2005, were continuously enrolled for 2 full years during 2005–2006, and were in a fee-for-service plan. The comparison group was matched to individuals with SB at a ratio of 10:1 on the basis of age, sex, and geographic region (Northeast, North Central, South, and West). Because SB diagnoses is the exposure of interest in our analysis as opposed to the outcome, the design is best described as a matched cohort study [6], in which the exposed study subjects (those who had SB) were matched to those without a SB diagnosis.

3. Procedures

As people with SB age, the most frequent conditions for which they seek care may differ. Thus, our analysis was stratified by four age groups: 0–17, 18–29, 30–44, and 45–64 years. We investigated the most prevalent conditions on the basis of the ICD-9-CM codes recorded as primary diagnoses on outpatient claims. If the primary diagnosis was listed as SB (741) or hydrocephalus (331.4), we used the secondary diagnosis. Because this study examined a large number of ICD-9-CM codes, we organized these codes into categories on the basis of the 17 chapters used in the ICD-9-CM (Table 1). We excluded the categories related to pregnancy and congenital anomalies (chapters 11, 14, and 15) and injury and poisoning (chapter 17). The focus of the paper is the investigation of major chronic conditions that persons with SB experience throughout their lifetime after surviving infancy. In addition, most of the claims associated with specific ICD-9-CM codes under the injury and poisoning chapter indicated surgical complications without further detail and hence could not be related to specific secondary conditions. We calculated the percentage of the total outpatient expenditures among the remaining 13 ICD-9-CM chapters.

We chose four major categories for further analyses (diseases of the nervous system and sense organs (chapter 6); symptoms, signs, and other ill-defined conditions (chapter 16); diseases of the musculoskeletal system and connective tissue (chapter 13); and diseases of the genitourinary system (chapter 10), which together accounted for more than 70% of total outpatient expenditures in our exploratory analysis. The first three categories were the most costly categories for children aged 0–17 years, young adults aged 18–29 years, and adults aged 30 years or older, respectively. The fourth category accounted for more than 10% of the total outpatient expenditures for each age group.

Table 1
Percentage distribution of outpatient care payment among the ICD-9-CM chapters for individuals with SB, MarketScan Commercial Claims and Encounters Database, 2005–2006

ICD-9-CM chapters	Percentage of outpatient payment			
	Age group (years)			
	0–17	18–29	30–44	45–64
Total outpatient payment for included chapters	\$7902654	\$2466927	\$4855356	\$7232605
1. Infectious and parasitic diseases (001–139)	1%	2%	1%	0.4%
2. Neoplasms (140–239)	2%	2%	4%	13%
3. Endocrine, nutritional and metabolic disease, and immunity disorders (240–279)	1%	3%	3%	3%
4. Diseases of blood and blood forming organs (280–289)	0.4%	2%	1%	1%
5. Mental disorders (290–319)	3%	4%	3%	1%
6. Disease of the nervous system and sense organs (320–389)	26%	17%	9%	11%
7. Diseases of the circulatory system (390–459)	2%	2%	2%	8%
8. Diseases of the respiratory system (460–519)	14%	5%	4%	3%
9. Diseases of the digestive system (520–579)	5%	3%	4%	5%
10. Diseases of the genitourinary system (580–629)	13%	18%	16%	10%
12. Disease of the skin and subcutaneous tissue (680–709)	3%	6%	4%	2%
13. Disease of the musculoskeletal system and connective tissue (710–739)	11%	16%	30%	27%
16. Symptoms, sign, and other ill-defined conditions (780–799)	17%	22%	19%	16%
Excluded chapters				
11. Complications of pregnancy, childbirth and the puerperium (630–677)				
14. Congenital anomalies (740–759)				
15. Certain conditions originating in the perinatal period (760–779)				
17. Injury and poisoning (800–999)				

We also investigated specific 4-digit ICD-9-CM codes reported as primary outpatient diagnoses during 2005–2006. We first selected all conditions that were recorded for more than 10% of individuals with SB in at least one age category. From this list, we selected chronic conditions which were classified into the following four categories: cardiovascular disease (CVD) risk factors: diabetes (2500), lipid disorders (2720, 2724), hypertension (4011, 4019); SB-associated conditions: compression of brain (3484), urinary tract infection (5990), constipation (5640), intervertebral disc disorders (7221, 7225) and scoliosis (7373); pain: pain in musculoskeletal system (7194, 7231, 7242, 7244, 7245, 7295), headache (7840), chest pain (7860), abdominal pain (7890); and miscellaneous symptom: (7804), including sleep disturbance (7805), fever (7806), fatigue (7807), and symptoms involving respiratory system (7860, 7862). A closer look at conditions under neoplasms suggested that although expenditures were high, they were concentrated among just a few individuals. We chose to analyze conditions that affected at least 10% of individuals with SB and no conditions under chapter neoplasms were selected according to this criterion.

4. Analyses

Among individuals with and without SB, we calculated the percentage of individuals affected by each dis-

ease category. We compared the percentages by using *t*-tests for correlated samples because the sample of individuals with SB and the sample of individuals without SB were matched on several characteristics. We calculated medical expenditures as the sum of insurance plan payments and out-of-pocket copayments and deductibles. We reported average (mean), median, and 95th percentile expenditures among those who sought outpatient care for individuals with and without SB. We used the nonparametric Wilcoxon Signed-Ranks tests to test for differences in median of expenditures between the two groups.

For each of the specific conditions investigated, we reported the percentage of individuals affected by that condition among individuals with SB. We computed the risk ratios by dividing the percentage of individuals with spina bifida who were affected by the percentage of individuals without spina bifida who were affected. By virtue of the perfect matching study design, the confounding by the matching variables was eliminated [6]. We reported the risk ratios and their 95% confidence intervals.

We also reported the mean and median of expenditures associated with outpatient care for individuals with SB after assigning each outpatient encounter to the primary diagnosis. We did not try to model expenditures for the specific conditions investigated because we did not have information on risk factors for these conditions. We provided descriptive information to il-

Table 2
Sample characteristics and outpatient care expenditures for individuals with and without spina bifida (SB), MarketScan Commercial Claims and Encounters Database, 2005–2006

	Age group (Years)				Total
	0–17	18–29	30–44	45–64	
Individuals with SB, N	809	361	456	573	2199
Individuals without SB, N	8090	3610	4560	5730	21990
Demographic characteristics, individuals with and without SB					
Individuals by age group (%)	37%	16%	21%	26%	
Mean patient age (year)	10	23	37	53	29
Female sex (%)	50%	61%	70%	68%	61%
Beneficiary relationship (%)					
Employee	0%	16%	47%	56%	29%
Spouse	0%	9%	37%	43%	20%
Child/other	100%	75%	16%	1%	51%
Region (%)					
Northeast	7%	8%	11%	11%	9%
North Central	34%	32%	31%	30%	32%
South	49%	51%	51%	49%	50%
West	10%	9%	7%	10%	9%
Outpatient medical care, 2005–2006					
Individuals with SB					
Number of individuals receiving outpatient care	799	355	451	572	2177
Average payment per patient	\$ 16020	\$ 10866	\$ 13049	\$ 15285	\$ 14366
Median	7786	5230	7081	9396	7545
95th percentile 48921	35137	42341	47996	46751	
Individuals without SB					
Number of individuals receiving outpatient care	6933	2910	4059	5283	19937
Average payment per patient	\$ 1895	\$ 3009	\$ 4471	\$ 6132	\$ 3716
Median	732	840	1570	2707	1191
95 percentile	6834	11152	16005	20475	13929

illustrate how each of the most frequently occurring conditions compared in terms of outpatient expenditures for individuals with SB.

All analyses were done using SAS 9.1.

5. Results

In total, we identified 2199 individuals with SB who met our sample inclusion criteria and created a matching group of 21,990 individuals without SB (Table 2). Children (aged 0–17 years) accounted for 37% of the sample. Among adults, women outnumbered men. About 51% of the sample consisted of children of beneficiaries, including adult children. Nearly all individuals with SB sought outpatient care during 2005–2006. Approximately 90% of individuals without SB sought outpatient care during the 2-year period. Overall, average expenditures for outpatient care during the 24-month study period were \$14,366 per person with SB and \$3,716 per person without SB.

We compared the percentage of individuals with and without SB who were affected by health conditions in the four major disease categories, as well as the pay-

ments associated with these conditions (Table 3). The category of symptoms, signs, and other ill-defined conditions (ICD-9-CM chapter 16) affected more than 70% of individuals with SB in all age groups. The other two categories that affected more than 70% of individuals with SB were nervous system conditions (ICD-9-CM chapter 6) for children and musculoskeletal conditions (ICD-9-CM chapter 13) for adults aged 45–64 years. Compared with individuals without SB, higher percentages of individuals with SB were affected by conditions in all four categories for all age groups. The differences in percentages of individuals affected were generally greater for children than for adults. In particular, children with SB were 4 times more likely to develop genitourinary conditions and almost 3 times more likely to develop musculoskeletal conditions compared with children without SB.

The differences in average payments between individuals with and without SB (the incremental payment) were highest for nervous system conditions (ICD-9-CM chapter 6) among children and for musculoskeletal conditions (ICD-9-CM chapter 13) among adults older than age 30 years. Genitourinary conditions (ICD-9-CM chapter 10) incurred significantly higher incremental

Table 3
Percentage of individuals with and without spina bifida (SB) affected by specific conditions and the associated payment, by affected body system, MarketScan Commercial Claims and Encounters Database, 2005–2006

Age groups (years)	Percentage of individuals affected ^a		Mean payment (median, 95th percentile) ^b	
	Non-SB <i>N</i> = 21990	SB <i>N</i> = 2199	non-SB	SB
Disease of the nervous system and sense organs (320–389)^c				
0–17	39%	71%	\$457 (\$128, \$1990)	\$3,623 (\$540, \$12634)
18–29	26%	53%	\$1,428 (\$145, \$3127)	\$2,160 (\$322, \$9808)
30–44	31%	55%	\$774 (\$160, \$3106)	\$1,685 (\$424, \$7462)
45–64	37%	66%	\$956 (\$205, \$3747)	\$2,114 (\$456, \$7514)
Diseases of the genitourinary system (580–629)				
0–17	11%	50%	\$492 (\$115, \$2353)	\$2,605 (\$902, \$11094]
18–29	29%	62%	\$1,209 (\$222, \$3435)	\$1,994 (\$548, \$8112)
30–44	40%	61%	\$1,972 (\$267, \$6210)	\$2,817 (\$409, \$8890)
45–64	41%	57%	\$1,338 (\$238, \$4725)	\$2,118 (\$354, \$6779)
Disease of the musculoskeletal system and connective tissue (710–739)				
0–17	20%	56%	\$636 (\$179, \$2606)	\$1,966 (\$501, \$9688)
18–29	27%	53%	\$1,213 (\$309, \$4841)	\$2,017 (\$544, \$6367)
30–44	39%	69%	\$1,680 (\$428, \$7317)	\$4,698 (\$1119, \$15722)
45–64	54%	79%	\$1,870 (\$513, \$7929)	\$4,269 (\$1629, \$17642)
Symptoms, signs, and other ill-defined conditions (780–799)				
0–17	38%	74%	\$581 (\$161, \$2346)	\$2,315 (\$751, \$10311)
18–29	42%	73%	\$844 (\$276, \$3225)	\$2,051 (\$62, \$7461)
30–44	54%	77%	\$1,130 (\$345, \$4715)	\$2,610 (\$1106, \$8879)
45–64	62%	83%	\$1,385 (\$486, \$5911)	\$2,408 (\$1385, \$8654)

^aAll comparisons of differences in percentage affected significant at $p < 0.001$ (matched-pair t-tests).

^bAll comparisons of differences in median payment significant at $P < 0.001$ (Wilcoxon signed-ranks tests).

^cICD-9-CM code.

payments among children than among adults. Symptoms, signs, and other ill-defined conditions (ICD-9-CM chapter 16) among individuals with SB consistently incurred incremental payments of more than \$1,000 per person in each age group.

Table 4 shows the frequencies and adjusted risk ratios of major specific conditions among individuals with SB compared with individuals without SB. One CVD risk factor, essential hypertension, was found to be significantly more common among individuals with SB younger than age 45 years. In contrast, the percent-

ages of individuals affected by diabetes and disorders of lipid metabolism were comparable among those with and without SB in all age groups. Other measures of risk factors for CVD, notably high body mass index and smoking, were not available in the MarketScan Commercial database.

By definition, SB-associated conditions occur more frequently among individuals with SB. Compared with individuals without SB, individuals with SB had the highest risk ratio for compression of brain, which was not reported for any individual without SB younger

Table 4

Percentage of individuals with spina bifida (SB) affected by specific conditions and adjusted risk ratios (ARRs) and 95% confidence interval (CI) for individuals with SB compared with individuals without SB, MarketScan Commercial Claims and Encounters Database, 2005–2006

Conditions	Individuals with SB affected by specific conditions (%)				ARR (95% CI) for individuals with SB compared with individuals without SB			
					Age group (years)			
	0–17	18–29	30–44	45–64	0–17	18–29	30–44	45–64
Cardiovascular disease risk factors								
Diabetes mellitus without complications, 2500 ^a	0.6	1.9	5.5	13.3	1.9	1.5	1.2	1.2
					(0.7, 4.8)	(0.7, 3.4)	(0.8, 1.8)	(0.9, 1.5)
Disorders of lipid metabolism, 2720, 2724	0.6	5.0	15.6	34.7	1.1	1.6	1.4	1.1
					(0.5, 2.9)	(1.0, 2.7)	(1.0, 1.8)	(0.9, 1.3)
Essential hypertension, 4011, 4019	1.6	8.6	19.1	37.3	5.7	3.9	1.9	1.2
					(2.9, 11.4)	(2.6, 6.0)	(1.5, 2.5)	(1.0, 1.5)
SB-associated conditions								
Compression of brain, 3484	14.5	8.0	15.8	11.9	ND	ND	863	388
							(120, ∞)	(95, ∞)
Urinary tract infection, 5990	26.5	35.2	26.1	19.5	7.4	6.1	3.4	2
					(6.1, 8.9)	(4.7, 8.0)	(2.6, 4.2)	(1.7, 2.6)
Constipation, 5640	10.9	5.8	2.9	5.2	5.8	4.6	1.6	2.5
					(4.4, 7.5)	(2.7, 7.8)	(0.9, 2.8)	(1.7, 3.8)
Intervertebral disc disorders, 7221, 7225	1.1	4.7	17.8	19.7	9.1	4	5.3	3.7
					(3.7, 22)	(2.3, 7.1)	(4.0, 7.1)	(2.9, 4.6)
Scoliosis, 7373	16.6	8.9	2.6	1.9	19	17	6.8	9.3
					(15, 26)	(9.5, 29)	(3.3, 14)	(4.1, 21)
Pain								
Pain in musculoskeletal system, 7194, 7231, 7242, 7244, 7245, 7295	28.4	36.3	48.9	62.8	2.5	2.4	2.7	3.2
					(2.2, 3.0)	(1.9, 3.0)	(2.2, 3.2)	(2.7, 3.8)
Headache, 7840	18.7	18.6	23.9	20.6	6.6	4.1	4	3.8
					(5.3, 8.1)	(3.0, 5.6)	(3.1, 5.1)	(3.1, 4.8)
Chest pain, 7860	7.3	5.8	10.1	14.7	2.4	2.5	2.2	2
					(1.8, 3.1)	(1.6, 4.1)	(1.6, 3.1)	(1.5, 2.5)
Abdominal pain, 7890	13.7	21.3	26.8	21.8	2.2	2	2.3	1.6
					(1.8, 2.7)	(1.5, 2.7)	(1.8, 2.9)	(1.3, 1.9)
Miscellaneous symptoms								
Dizziness 7804	1.9	2.5	7.9	10.3	2.4	1.2	2.3	2.6
					(1.4, 4.3)	(0.6, 2.3)	(1.6, 3.3)	(1.9, 3.4)
Sleep disturbances 7805	3.3	3.3	9.6	13.3	5	1.7	2.5	2.4
					(3.2, 8.0)	(0.9, 3.1)	(1.8, 3.6)	(1.8, 3.1)
Fever 7806	19.3	7.2	5.3	5.4	2.8	3.3	2.8	3.2
					(2.3, 3.3)	(2.1, 5.1)	(1.8, 4.4)	(2.1, 4.8)
Fatigue 7807	4.6	13.9	17.3	19.2	1.7	2.2	1.8	1.9
					(1.2, 2.4)	(1.6, 3.0)	(1.4, 2.3)	(1.5, 2.4)
Symptoms involving respiratory system, 7860, 7862	16.9	10.8	14.3	23.9	1.8	2	1.5	1.9
					(1.5, 2.2)	(1.4, 2.9)	(1.2, 2.0)	(1.6, 2.4)

ND = not defined because of zero occurrence among the non-SB sample.

^a4-digit ICD-9-CM code.

than age 30 years, resulting in infinitely high rate ratios (Table 4). In absolute numbers, the most frequent outpatient diagnosis associated with SB was urinary tract infection (UTI), which affected 20%–30% of this group. Conditions related to spinal cord take different forms at different ages. Children or adolescents are affected frequently by curvature of the spine, whereas adults are more affected by disc disorders.

Pain-related conditions most frequently recorded in outpatient diagnoses include pain in the neck, pain in a

joint, low back pain, radicular syndrome of lower limbs, unspecified backache, pain in limb, headache, chest pain, and abdominal pain. In absolute numbers, the most frequent outpatient diagnosis associated with pain for all age groups was pain in musculoskeletal systems, particularly for adults aged 45–64 years. Compared with those without SB, individuals with SB, particularly children, had the highest risk ratio associated with pain for headache.

Specific conditions within the miscellaneous symp-

Table 5

Average payment associated with outpatient care for specific conditions among individuals with spina bifida (SB), MarketScan Commercial Claims and Encounters Database, 2005–2006

	Mean/median payment associated with outpatient care in dollars			
	Age group (years)			
	0–17	18–29	30–44	45–64
Cardiovascular disease risk factors				
Diabetes mellitus without complications, 2500 ^a	708/321	192/82	511/235	966/448
Disorders of lipid metabolism, 2720, 2724	126/17	114/75	201/123	244/139
Essential hypertension, 4011, 4019	141/98	408/241	383/182	341/212
SB associated conditions				
Compression of brain, 3484	3,371/1,142	1,607/717	2,049/738	2,909/668
Urinary tract infection, 5990	858/252	462/125	511/144	363/92
Constipation, 5640	369/139	404/155	576/165	471/109
Intervertebral disc disorders, 7221, 7225	1,150/707	1,819/788	3,177/825	1,749/913
Scoliosis, 7373	1,293/319	504/239	1,652/297	362/88
Pain				
Pain in musculoskeletal system, 7194, 7231, 7242, 7244, 7245, 7295	737/188	1,262/236	1,705/733	1,473/543
Headache, 7840	1,023/417	1,528/287	2,047/698	1,110/258
Chest pain, 7860	631/98	464/200	770/130	740/265
Abdominal pain, 7890	659/243	814/236	1,040/429	867/267
Miscellaneous symptoms				
Dizziness, 7804	368/270	390/155	581/280	623/187
Sleep disturbances, 7805	2,620/1,772	1,360/1,026	1,723/467	1,592/838
Fever, 7806	449/140	200/96	390/214	1,342/88
Fatigue, 7807	217/147	154/67	271/120	208/117
Symptoms involving respiratory system, 7860, 7862	395/100	333/121	634/128	554/165

^a4-digit ICD-9-CM code.

toms category that we investigated were dizziness, sleep disturbance, fever, fatigue, and respiratory symptoms. Compared with individuals without SB, a higher percentage of individuals with SB in all age groups had a recorded outpatient primary diagnosis of fever, fatigue, and symptoms involving the respiratory system. This group also was more likely to receive outpatient care for sleep disturbance and dizziness; this finding was true for all age groups except young adults. In absolute numbers, fever was the most frequent outpatient diagnosis in this category among children. Among adults, all other symptoms occurred more frequently as people aged, peaking in the 45–64 age group.

Table 5 presents the average expenditures associated with outpatient care for frequently occurring conditions among individuals with SB. Among all conditions, compression of brain incurred the highest treatment expenditures per person for the age groups 0–17 and 45–64 years, and it was second highest for the 18–29 and 30–44 age groups. Intervertebral disc disorders were associated with the highest average outpatient expenditures for the 18–29 and 30–44 age groups and second highest for adults ages 45–64 years. The most common condition, UTI, had relatively low expenditures per person. Among pain categories, headache incurred the highest average treatment expenditure per person for all age groups. Sleep disturbance was the

most expensive diagnosis per affected person among miscellaneous symptoms.

6. Discussion

The increased life expectancy of people with SB highlights the importance of understanding the evolution and management of their health issues over the life span [7]. For individuals with SB, chronic conditions of the nervous system, musculoskeletal system, and genitourinary system, as well as symptoms such as pain and sleep disturbance, account for a major part of their healthcare needs and expenditures. These conditions occur at different times and with varying degrees of severity as people age.

Among the most frequently occurring conditions and symptoms, our study found that compression of the brain was the most costly diagnosis for all age groups. It affected more than 10% of individuals with SB at all ages except those aged 18–29 years. This elevated pressure in the brain can be a sign of shunt malfunction [8]. The most costly diagnosis within the pain category, headache, is also a common symptom of shunt malfunction [8]. This area needs further study.

CVDs are among the leading causes of death and the most costly conditions in the general U.S. population.

Individuals with chronic physical conditions may be at increased risk of developing CVDs because of physical inactivity [9]. Our analysis showed that conditions related to clinically ascertained CVD risk factors, including diabetes, disorders of lipid metabolism, and essential hypertension, are among the most frequently occurring conditions among individuals with SB. However, compared with individuals without SB, only the risk for essential hypertension was significantly elevated for individuals with SB. One possible explanation is that diabetes and lipid disorders are more likely to be identified if a patient sees a primary care physician rather than a specialist. If we know provider type, we could better assess the differences of these disorders among individuals with or without SB. However, such information is not available from our dataset. Although provider type is a field, it is inconsistently recorded; often “physician” is listed without distinguishing primary care from specialists. It has previously been reported that adolescents and young adults with SB have average values of lipid and lipoproteins comparable with those in the general population, and a higher proportion of adolescent males with SB have hypertension [9]. Our study provides partial support for these findings.

Our findings suggest that for individuals with SB aged 45 years and older, selected CVD risk factors, including diabetes, disorders of lipid metabolism, and essential hypertension, are comparable with those of individuals without SB. However, our sample of adults with SB who were privately insured is likely not representative of the entire adult population with SB. It is also possible that individuals with SB and early onset CVD risk factors did not survive to become older adults. Another possible explanation is that adults without SB catch up to individuals with SB in terms of CVD risk as they age.

Diseases of the urinary system contribute significantly to the medical impact of SB. UTI was among the most frequently recorded diagnoses for outpatient visits. UTI is classified as an ambulatory care-sensitive condition (ACSC) for which timely ambulatory treatment might prevent hospitalizations [10,11]. However, it has not been established that ACSC hospitalizations can be reduced through ambulatory care or what strategies can be effective in reducing ACSC hospitalizations [12]. Future research is needed to identify strategies to reduce UTI and inpatient admissions for individuals with SB [11].

Pain was among the most frequently coded diagnoses for all age groups, including headache, pain in limb, joint, neck, back, chest, and abdomen. These findings

were consistent with a previous analysis of pain in 68 children and adolescents with SB, in which the authors found pain occurred most frequently in the head, back, abdomen, neck, shoulder, legs, and hands [13]. Unmanaged pain has a substantial negative impact on quality of life among children and adolescents with SB [14] and their parents [15]. Future research is needed to improve our understanding of the mechanisms of pain among individuals with SB and the efficacy of pain management strategies for this population.

Symptoms such as fever, fatigue, dyspnea, cough, and sleep disturbance that may be associated with underlying conditions are frequently recorded as primary diagnoses for individuals with SB seeking outpatient care. These symptoms also account for a large portion of total outpatient payments. Currently, the magnitude of this problem has not received enough clinical attention. Research on how these symptoms are associated with specific conditions such as shunt malfunction and how they can be effectively prevented and treated for individuals with SB is needed.

This study has several limitations inherent to analyses of administrative claims data. First, because no medical records could be accessed, diagnoses based on billing codes cannot be validated and do not necessarily accurately reflect the medical conditions for which individuals were treated or sought treatment. Second, no information was available on other important determinants of health status, including physical activity, overweight, smoking, race/ethnicity, or socioeconomic status. Similarly, no information was available on limitations in activity or participation. Third, the sample of adults was selective for those in private employment, although the majority of adults in the sample were dependents of employees. Individuals with SB who are employed, especially older adults, may be healthier than the overall population with SB, and their medical care may not be representative of all adults with SB. Fourth, the cross-sectional design of this study does not allow for investigation of patterns of emergence and changes over time for conditions associated with SB, which would require a cohort study.

7. Conclusions

Medical conditions for which individuals with SB seek care are diverse and costly. Consequently, lifetime care coordination and close follow-up are needed. Among children with SB, shunt-related neurological conditions are prevalent. Diagnoses such as pain, while

not life-threatening, are costly and affect the quality of life for individuals with SB. These diagnoses should be a priority for further investigations to identify risk factors, treatment, and prevention strategies.

Acknowledgements

We would like to thank Dr. Owen Devine, Dr. Melissa Adams, Dr. Brian Armour, Ms. Melissa Danielson, and three anonymous reviewers for their helpful comments.

Conflicts of Interest

None reported.

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