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Inpatient and Emergency Room Visits for Adolescents and Young Adults With Spina Bifida Living in South Carolina

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Abstract

Objective—To compare emergency room (ER) and inpatient hospital (IP) use rates for persons with spina bifida (SB) to peers without SB, when transition from pediatric to adult health care is

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likely to occur; and to analyze those ER and IP rates by age, race, socioeconomic status, gender, and type of residential area.

Design—A retrospective cohort study.

Setting—Secondary data analysis in South Carolina.

Participants—We studied individuals who were between 15 and 24 years old and enrolled in the State Health Plan (SHP) or state Medicaid during the 2000–2010 study period.

Methods—Individuals with SB were identified using ICD-9 billing codes (741.0, 741.9) in SHP, Medicaid, and hospital uniform billing (UB) data. ER and IP encounters were identified using UB data. Multivariable Generalized Estimating Equation (GEE) Poisson models were estimated to compare rates of ER and IP use among the SB group to the comparison group.

Main Outcome Measures—Total ER rate and IP rate, in addition to cause-specific rates for ambulatory care sensitive conditions (ACSC) and other condition categories.

Results—We found higher rates of ER and IP use in persons with SB compared to the control group. Among individuals with SB, young adults (those 20–24 years old) had higher rates of ER use due to all ACSC (P = .023), other ACSC (P = .04), and urinary tract infections (UTI; P = .002) compared to adolescents (those 15–19 years old).

Conclusions—Young adulthood is associated with increased ER use overall, as well as in specific condition categories (most notably UTI) in individuals 15–24 years old with SB. This association may be indicative of changing healthcare access as people with SB move from adolescent to adult health care, and/or physiologic changes during the age range studied.

Introduction

Spina bifida (SB) is among the most common congenital disorders in the United States. SB is characterized by the incomplete closing of the neural tube, which occurs in the first few weeks of embryonic development [1]. This article focuses on SB aperta and not spina bifida occulta. SB aperta frequently results in long-term disability and includes 2 subtypes, namely, meningocele and myelomeningocele [2]. Increase in public awareness of the need for women to take folic acid supplements before and during pregnancy, as well as the early identification of the defect for women who undergo routine ultrasonography during pregnancy, have decreased both the intrauterine and birth prevalence of SB. However, approximately 3 to 7 in 10,000 children and adolescents from birth to 19 years of age are affected by SB [3,4].

SB requires medical attention throughout the life of the affected person. Multiple body systems are usually involved, and most relate to central nervous system abnormalities. Spinal cord dysfunction, hydrocephalus, Chiari 2 malformation, and tethered cord syndrome can result in weakness and limited mobility, seizures, neurogenic bladder and bowel, cognitive impairments, and insensate skin. People with SB are also at risk for the same chronic health conditions that are leading causes of morbidity and mortality in the general population [5]. In addition to a primary health care provider, people with SB must see many health care specialists, such as nurses, physical and occupational therapists, orthopedists,

urologists, physiatrists, and neurosurgeons, and likely need specialized care over a lifetime [6].

The continuation of multidisciplinary health care is important for adults with SB to prevent adverse outcomes. Early death may be related to renal failure, urosepsis, or respiratory complications [7]. Some of these complications can be related to long-standing neurologic conditions that have become symptomatic over time. The most serious neurologic conditions as people with SB age are symptomatic hydrocephalus (with headaches, nausea and vomiting, and changes in gait, vision, or cognition) and tethered cord syndrome (with back and leg pain, weakness and change in mobility, urinary symptoms, and deformities) [6]. Although it has been recognized that cord tethering is likely present in virtually all people with a repaired open dysraphic abnormality, the symptomatic tethered cord syndrome (TCS) may be either a new adult diagnosis or a return of symptoms from re-tethering after previous de-tethering surgery [8,9]. It is postulated that although health care use for people with SB is higher, preventive approaches, early identification, and treatment of developing problems have the potential to reduce medical care expenditures [10].

Presently, at least 75%–85% of children born with SB are expected to reach their early adult years [6]. As adolescents with disability reach adulthood, they are often discharged from multidisciplinary pediatric clinics to adult medical practices, where specialists are not necessarily in the same institution [7]. SB clinics are common for pediatric care but largely nonexistent for adult care. As a result, people with SB are usually left to navigate the process of finding adult care specialists without outside assistance. A report based on the National Survey of Children with Special Health Care Needs revealed that only half of families surveyed had conversations about their child's changing health care needs as they reach adulthood. The same survey also revealed that only 1 in 5 physicians had discussed transitioning the child to an adult provider [11]. Transition planning should begin early in adolescence to make changes in health care easier and outcomes more successful [10,12].

The purpose of this study was to compare emergency room (ER) rates and inpatient (IP) hospital use rates for persons with SB by age, race, socioeconomic status, gender, and type of residential area. We postulated that individuals with SB would have higher ER rates and IP hospitalization rates than the matched controls without SB. We also hypothesized the patients 20–24 years old with SB would have higher rates of ER and IP hospitalizations than those 15–19 years old with SB. In addition to investigating overall rates of IP and ER use, we also assessed ambulatory care sensitive conditions (ACSC) that should be manageable or preventable with effective outpatient care. The Agency for Healthcare Research and Quality (AHRQ) developed a tool that monitors the health care safety net using administrative data by tracking ACSC (Appendix 1) [13]. The original tool was supplemented by adding codes from the AHRQ prevention quality indicator measures and by including incidence rate of ER and IP use according to different body systems using ICD-9-CM book chapters (Appendix 2) [14]. Finding these conditions in IP hospitalizations and ER discharges can indicate that patients are not receiving effective and timely primary care, and may indicate areas in which outpatient health care quality can improve. This is especially relevant in the SB population because an increase in ER and IP use for ACSC in adolescents and young adults could raise an index of suspicion for providers and could facilitate efforts to prevent,

diagnose, or treat earlier. Increases in ER and IP use for ACSC could also indicate difficulty in the transition from pediatric to adult health care.

Methods

Study Background

This study is part of a larger endeavor investigating the transition from adolescent to adult services for persons with rare health conditions in South Carolina. The study protocol was approved by the South Carolina Department of Health and Human Services, the South Carolina Employee Benefit Administration, and the South Carolina Data Oversight Council. The study was granted exempt status by the institutional review board at the University of South Carolina.

Study Design

To describe the use of IP hospitalizations and ER use, and to investigate the association between age and use, we conducted a historic cohort study using South Carolina administrative data. To do this, patients from the control and SB groups were assigned propensity scores for likelihood of group membership based on age, gender, and years of insurance coverage. Control group individuals were then matched with a member of the SB group with the most similar propensity score.

Data Sources

The data used in this study came from 3 sources: South Carolina State Health Plan (SHP), South Carolina Medicaid, and all-payer hospital discharge uniform billing (UB) data. SHP is a self-insured plan managed by South Carolina Blue Cross/Blue Shield. SHP participants are government workers and their families are a diverse group ranging from agency directors to manual laborers. South Carolina Medicaid is a health insurance program run by the state of South Carolina. Medicaid is intended for people with low income in relation to family size, and individuals with significant disability. South Carolina Medicaid has a generous policy for children with significant disability; however, persons with disability from 21 to 64 years old generally qualify only for South Carolina Medicaid if they have substantial disability and also have a low family income. UB data are dischargebilling data for IP hospitalizations and ER use from all general, short-term acute care hospitals throughout South Carolina.

All 3 data sources are stored and managed by the South Carolina Budget and Control Board Department of Research and Statistics (DRS). DRS replaces personal identifiers, such as name and social security number, with a global unique identifier that can be used to locate data across multiple sources without compromising confidentiality. This identifier merges data across provider systems to prevent duplication.

By using the unique identifiers of both cohorts, DRS was able to link both to vital records for the years 2000–2011 to determine whether anyone had died, and to the South Carolina Department of Social Services (DSS) to determine Supplemental Nutrition Assistance (SNAP) use during the study period.

Age, gender, and type of residential area were also analyzed in this study from the health data; type of residential area was classified as either urban or rural using 2010 Rural Urban Commuting Area (RUCA) codes (http://www.ers.usda.gov/data-products/rural-urban-commuting-area-codes/documentation.aspx).

Participants

Date of service and primary ICD-9-CM diagnostic codes for ER and IP hospitalizations were acquired through UB data. For records to be considered in the study, patients had to be 15–24 years old during the 2000–2010 study period. Patient records were not considered until the patient was 15 years old; or, if the patient was enrolled between 15 and 24 years of age during the study period, the patient records were considered at the year in which the participant was enrolled. Patient records were not considered after the patient reached 25 years of age or, in case of premature death, the date of death.

SB cases were identified based on ICD-9-CM code diagnosis of SB (741). Between 2000 and 2010, a total of 695 unique cases of SB were identified. We created a comparison group matched on age, gender, and years of insurance coverage, of persons from the SHP. We excluded from the comparison group those individuals who had muscular dystrophy (359.0, 359.1, 359.21), cerebral palsy (343), spinal cord injury (344.0, 344.1, 767.4, 806, 952, 907.2), intellectual disability (317–319), fragile X syndrome (759.93), autism spectrum disorders (299) and multiple sclerosis (340). The exclusions were made to create a comparison group that was not experiencing the same medical challenges as the case group.

We compared SB group rates of IP and ER to comparison group rates. In addition to overall IP and ER use rates, we looked specifically at IP hospitalizations and ER visits due to ACSC overall, and specific ACSC categories of epilepsy, severe ear/nose/throat (ENT) conditions, UTI, and “other ACSC” (all other categories not included in the 3 specific categories). We expanded beyond ACSC, and analyzed IP and ER use according to categories consistent with the chapters of the ICD-9-CM codebook. (A more detailed description of the conditions in each category is provided in the appendices.) We also looked at the potential impact of age on ER and IP rates, by 2 age groups, 15–19 years old and 20–24 years old, under the assumption that transition from pediatric to adult care occurs in the late teen years.

Persons with SB were categorized as having or not having hydrocephalus, on the basis of the specific ICD-9 code for SB with hydrocephalus (741.0) or the code for SB without hydrocephalus (741.9) plus use of an additional code that indicated the presence of hydrocephalus (331.3 or 331.4). We also used a group of ICD-9 and Current Procedural Technology codes to identify individuals with shunt malfunction or shunt-related procedures (these codes are available on request). Any individual with SB who ever received any of these codes was categorized as having hydrocephalus. Persons with TCS were identified using ICD-9 code 742.59, which can include a range of spinal cord conditions including amyelia, atelomyelia, congenital anomaly of the spinal meninges, defective development of the cauda equine, hypoplasia of the spinal cord, myelatelia, and myelodysplasia; in the context of SB, our experience is that this code most often reflects the presence of TCS.

Statistical Analyses

All analyses were performed within DRS with only summary data released to the rest of the research team, as some of the outcomes had very small cell sizes. Multivariable generalized estimating equation (GEE) Poisson models were estimated to compare rates of ER and IP use among the SB group to the comparison group [12,15]. The GEE models accounted for the presence of repeated observations (within-group correlation) in the same individuals over time. The GEE models were estimated by specifying REPEATED option in the GENMOD procedure of SAS 9.3 (SAS Institute, Cary, NC). Each regression model included SB versus comparison group as the key independent variable. Separate models were run for each category of condition diagnosed during ER or IP encounters, by selected specific body systems and ACSC. In each Poisson model, we controlled for age group, gender, race, whether the type of residential area was urban or rural based on census codes, and socioeconomic status (a dichotomous variable indicating whether the individual was enrolled in the SNAP during the study period). The State Health Plan does not include a race variable, but Medicaid does; thus we were unable to control for race in the initial models. However, when we limited the models to individuals with SB who were all insured by Medicaid, we were able to obtain racial information for every individual with SB and therefore able to control for race in these models. Statistical significance was assessed using Wald tests based on empirical standard errors so that inference is robust to misspecification of the within-person correlation structure, which was assumed to be exchangeable in our models.

We re-estimated the models, limiting them to persons with SB, and we used the dichotomy of adolescent age group versus young adult age group as the primary independent variable, controlling for the same covariates. To ensure adequate sample sizes, we estimated only those models for which there were at least 50 observations available. We also tested the effect of limiting analyses only to those individuals found to have data during both age ranges (15–19 years and 20–24 years), to ensure that analyses of the association between age and ER and IP use were as unbiased as possible, as the likelihood of continued enrollment could be affected by unmeasured variables that could not otherwise be accounted for.

We were also interested in the associations of ER and IP use related to a number of coded conditions, especially the high incidence of UTI and the 2 common neurological conditions of SB, hydrocephalus, and TCS, as these conditions can be symptomatic in the adult years. We investigated these by re-estimating the models described immediately above, adding a dichotomous variable indicating that an individual was ever diagnosed with hydrocephalus and tethered cord syndrome, at any time during the study period.

Results

There were 695 individuals with SB included in the analyses, and 1390 in the comparison group. Demographics for the 2 groups are shown in Table 1. There were 4166 ER and 1423 IP encounters for individuals with SB, for a rate of 0.83 ER and 0.28 IP visits per person-year. Among those without SB, there were 1787 ER and 310 IP encounters, for a rate of 0.18 ER and 0.03 IP visits per person-year. In the multivariable models, the adjusted ER and IP use rates were significantly higher for those with SB than for the comparison group. The

incidence rate ratios demonstrated markedly greater use for persons with SB for IP hospitalizations because of skin conditions, musculoskeletal conditions, nervous system conditions, respiratory conditions, and genitourinary conditions. Table 2 provides details of the ICD-9-CM conditions with the numbers of combined IP/ER encounters and the most common Clinical Classification System categories for each with numbers of encounters in individuals with SB.

ER and IP Use Among Persons With SB

As shown in Table 3, when analyses were limited to those with SB, the adjusted rate of ER use was significantly increased for the 20- to 24-year age group, but there was not a significant difference in the rate of IP use. There was also an increase in the rate of ER use for ambulatory care sensitive conditions (ACSC). The only categories for ACSC in which there was a significant difference in rate of use by age group were ER visits for UTI and other ACSC. Moving beyond ACSC to all reasons for ER and IP use, there were significant differences for the group 20–24-years of age compared to the group 15–19 years of age for the following categories of use: ER use for (in order of descending IRR) endocrine, nervous system, skin, musculoskeletal, genitourinary, digestive, and ill-defined conditions, and IP use for skin conditions.

ER and IP Use Among Persons with SB, Present in Those 15–19 and 20–24 Years of Age

When we limited the analyses to individuals with SB who were represented in the data during both the 15- to 19-year age range and the 20- to 24-year age range (presented in Table 4), we found that there was a significantly higher rate of both ER and IP use for those in the 20- to 24-year age range. Older individuals had significantly higher rates of ER use because of ACSC and ER use for the specific ACSC of other ACSC and UTI. Looking at all types of ER and IP use, persons with SB in the older age group exhibited higher rates of ER use because of endocrine, nervous system, skin, musculoskeletal, genitourinary, and digestive conditions and a higher rate of IP use for skin conditions.

Addition of Hydrocephalus and TCS to the Multivariable Models

Table 5 shows the results of repeating the models from Table 4, but adds dichotomous variables for hydrocephalus and TCS. Including hydrocephalus and TCS in the models had almost no effect on the findings of increased IP and ER use for persons in the older age group. Hydrocephalus was not significantly associated with ER or IP use overall, but the rate of ER use due to epilepsy was markedly greater in persons with hydrocephalus. TCS was not associated with IP use overall, but persons with TCS were found to have lower rates of ER use. The strongest associations were with a reduction in ER use because of epilepsy and nervous system conditions. Meanwhile, individuals with TCS had substantially more IP encounters because of UTI and genitourinary conditions, as well as ER use for endocrine conditions and IP use for skin conditions.

We compared the most common specific diagnoses in each category for persons with hydrocephalus versus those without, and for persons with TCS versus those without, combining the IP and ER categories. We were particularly interested in neurologic and genitourinary conditions because these relate directly to the effects of spina bifida and are

likely to differ for individuals with versus without hydrocephalus and for those with versus without TCS. We found that for nervous system conditions in persons with hydrocephalus, the top 3 diagnoses were convulsions, migraine, and epilepsy, whereas the top 3 nervous system conditions in persons without hydrocephalus were “other ear and sense organ disorders,” suppurative and unspecified otitis media, and inflammation or infection of the eye. For individuals with TCS, the top 3 diagnoses for genitourinary conditions were UTI, infections of kidney, and “other and unspecified diseases of bladder and urethra”; for persons without TCS, UTI, female genital pain, and menstrual disorders were the top 3 conditions.

Discussion

As expected, we found higher rates of ER and IP use in persons with SB compared to those without. We found that young adults (20–24 years old) with SB had higher rates of ER use than adolescents (15–19 years old). On the other hand, IP use was not significantly higher in the young adult group with SB.

There has been a significant amount of discussion in the literature about the effects of health care transfer from adolescence to adulthood in young persons with disabilities such as those associated with SB. The increased rate of ER use among young adults with SB may be taken as evidence that transition to adulthood does have an impact on the health and care of people with SB. However, there are many elements of a care transition plan that might be implicated, and at present there is no single, specific element that has been found to improve outcomes [16]. It is not clear from these data whether the increased ER use observed is related to problems accessing primary care and thereby promoting care seeking in the ER, lack of additional resources or training for advocacy related to symptom reporting previously provided by parents or family, or a general lack of experience or knowledge/skills on the part of accepting adult health care providers [17].

Other factors may also contribute to the higher rates of ER use among persons with SB in the young adult group. For example, the increase may be attributable to changes in the health status of persons with SB as they age. There is recent information reporting declining health with age in SB, but there is a paucity of information available about risks for additional or increasing problems with certain health conditions related to age and/or severity, or the effectiveness of specific interventions or prevention strategies for young adults and adults [18]. Specifically, there is no information about physiologic changes within the urinary system over time, especially with chronic bacteriuria or changes in urinary function because of TCS or Chiari 2 malformation progression. In fact there is no consensus for the recognition, evaluation, and management of bacteriuria in specialized clinics for persons with SB [19]. This administrative data analysis provides some insights into health areas that may be of medical concern in adolescents and young adults. These increasing health needs may be related to physiologic changes, as well as to the change in health care delivery from pediatric to adult systems.

There were increased rates of all digestive, musculoskeletal, endocrine, and nervous system ICD-9-CM codes for ER use and skin conditions for both ER and IP use in the young adult

group compared to the adolescents. This was also true of the ill-defined ICD-9-CM conditions in the ER. These increased rates correlate with recent literature reporting a decline in general health, perceived health, and health-related quality of life found in young adults with SB [20–22]. These studies report an association with age and level of lesion, with some discussion regarding acute health changes imposed on chronic conditions and limited social participation as possible reasons for these perceptions of health. In this study, we were able to support the age association, but did not have the data regarding level of lesion.

The significantly high rate of UTIs and all GU ICD-9-CM codes for young adults compared to adolescents, noted in Tables 4 and 5, is particularly interesting, and has been noted in other studies of ER and IP use for persons with SB [4,23]. There are no guidelines for recognition or treatment of bacteriuria in individuals with SB, particularly acute on chronic; therefore the coding of “UTI” may represent both chronic bacteriuria and acute UTIs [17,24]. The rate of UTIs by age is not known, and physiologic changes to the urinary system with age are not reported. There is anecdotal acknowledgement that increasing rates of UTIs occur with age in SB, because renal failure is the most common cause of death and UTI is the most common cause for admission in adults with SB [4,25,26]. Reasons offered for higher UTI frequencies in adolescents and young adults include the inability to manage urinary procedures as well as resistance to maintaining lifelong urinary or bowel care regimens [26]. Poor self-management skills and lower education level have been associated with higher frequency of UTIs, but there have been no large cohort studies to prove or disprove the assumption of resistance to selfcare as a cause for increasing UTIs. Young adults with higher cognitive skills have also reported more frequent recurrent UTIs, which may indicate better recognition of symptoms and also possibly better recall and accuracy in reporting within the interview or survey [27]. This may suggest that there indeed is an increasing frequency of UTIs with age in SB. Smaller cross-sectional studies have identified a number of specific health issues noted in adults with SB, and our analyses support these. The common skin conditions of ulcers and cellulitis in the young adult group in our analyses reinforces an earlier study noting a higher number of hospitalizations associated with pressure ulcers for adults with SB [27]. For digestive conditions, disorders of the teeth and jaws likely represents the expected poor access to dental care noted for a variety of adults with disability [28]. Constipation is an ongoing management problem for individuals with SB, and strategies and procedures used at an earlier age may become ineffective over time [29]. Diabetes was the most common endocrine visit category seen within this cohort. Although diabetes mellitus is not commonly reported in adults with SB, Nelson et al demonstrated the high prevalence of metabolic syndrome especially in obese persons with SB, which includes abnormal glucose tolerance and type 2 diabetes [30].

Of interest is that some of the common conditions in people with SB may be related to the more progressive neurologic problems that can be seen in SB over time. The most common ill-defined conditions were headache, abdominal pain, and nausea/vomitingd–each of which could be an indication of progression of hydrocephalus (and Chiari 2 malformations) or tethered cord. The common musculoskeletal codes noted in these analyses focused on back pain (eg, lumbago and backache/back pain disorders). Pain complaints do increase with age in SB, and in particular back pain may be an indicator of TCS [6,21,31,32]. These

administrative data do not allow follow-up to determine whether a definitive diagnosis was eventually made for the ill-defined conditions.

We chose to look more closely at TCS and hydrocephalus, 2 of the common neurologic conditions that are seen with SB, and the manifestations of which can continue into adulthood. As noted earlier, these 2 conditions can present with many symptoms or health conditions noted in our ICD-9-CM code analyses. These additional models further identified the association of TCS to high rates of GU conditions/UTIs and skin conditions for both ER and IP usage. This could indicate 2 possibilities: 1) a diagnosis of ever having had TCS might heighten suspicion of or promote preventive strategies for UTIs and skin problems; and 2) adults with SB having increasing UTIs, pressure ulcers/cellulitis, or other increasing health problems might benefit from TCS evaluation (new or recurrent). The association of hydrocephalus with epilepsy is not surprising, and may suggest closer monitoring with age.

A major limitation of this study is the reliance on billing data to identify persons with SB and to describe their ER and IP use. We do not have access to clinical records, and therefore we cannot describe in detail the clinical status of persons with SB or specifics about why they may have accessed the ER or IP hospitalization in any given circumstance. Furthermore, we used uniform billing hospital discharge data to obtain information on ER and IP use. This provides complete ascertainment of nonmilitary institutions within the state of South Carolina, regardless of insurance status. However, it does not include military and Veterans Affairs hospitals, and it does not include hospitals outside the state of South Carolina, so episodes of ER or IP care in neighboring states would not be captured. The code used to identify individuals with TCS (742.59) can be used to diagnose a range of spinal cord conditions; although we believe that most people with spina bifida and this code do have TCS, some may have another of these conditions, and we have no way to identify these individuals.

The greatest strengths of this study are its large sample size and statewide scope. We did not rely on direct recruitment of patients from health care providers, which can result in a nonrepresentative sample based on the practices or institutions chosen for recruitment, as well as characteristics related to individuals' decisions to participate in research. The availability of linked data from the South Carolina Division of Research and Statistics is another strength of the study, because it permitted access to information on socioeconomic status (eg, SNAP enrollment) that would not be available in most data sets. Our adjusted incidence rate ratios are adjusted for race, type of residential area (urban or rural), and gender, in addition to socioeconomic status. The results of this study should be widely generalizable to individuals with SB living in South Carolina, and most likely to those in other states in the southeastern United States.

Conclusions

In summary, we found that young adulthood compared to adolescence is associated with increased ER use overall and for a number of specific condition categories in adolescents and young adults with SB. In particular, UTIs are noted more commonly in young adults. This association may be indicative of health care access limitations related to transition from

adolescent to adult health care, the vulnerability of young adults to certain health conditions, or relationships or increased risks with specific health conditions. Additional research is needed to further explore or rule out these or other potential explanations.

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Appendix 1: Ambulatory Care Sensitive Conditions (ACSC) and ICD-9-CM Codes

Ambulatory care sensitive conditions such as asthma, diabetes, or dehydration are potential conditions for hospitalization for which timely and effective ambulatory care can decrease hospitalizations by preventing the onset of an illness or condition, controlling an acute episode of an illness, or managing a chronic disease or condition.

Ambulatory Care Sensitive Conditions [and ICD-9-CM Codes] (by primary diagnosis unless otherwise noted)	Comments
Avoidable Conditions	
Congenital syphilis [090]	Secondary diagnosis for newborns only
Failure to thrive [783.41]	Age <1 y
Dental conditions [521–523, 525, 528]	
Vaccine preventable conditions [032, 033, 037, 041.5, 045, 052.1, 052.9, 055–056, 070.0–070.3, 072, 320.3, 390, 391, 771.0]	Hemophilus meningitis [320.0] for ages 1–5 y only
Iron deficiency anemia [280.1, 280.8, 280.9]	Primary and secondary diagnoses
Nutritional deficiencies [260–262, 268.0, 268.1]	Primary and secondary diagnoses
Acute Conditions	
Bacterial pneumonia [481,482.2,482.3,482.41,482.42,482.9, 483,485,486]*	Excludes cases with secondary diagnosis of sickle cell anemia [282.6] and patients <2 mo of age
Cellulitis [681,682,683,686]	Excludes cases with a surgical procedure (01–86.99), except incision of skin and

	subcutaneous tissue (86.0) for which it is the only listed surgical procedure
Convulsions [780.3]	
Dehydration—volume depletion [276.5]	Principal and secondary diagnoses examined separately
Gastroenteritis [558.9]	
Hypoglycemia [251.2]	
Kidney/urinary infection [590.0, 599.0, 599.9, 595.0, 595.9][†]	
Pelvic inflammatory disease [614]	
Severe ear, nose, and throat infections [382, 462, 463, 465, 472.1]	Excludes otitis media [382] cases with myringotomy with insertion of tube [20.01]
Skin grafts with cellulitis (DRGs 263 and 264)	Excludes admissions from SNF/ICF
Chronic Conditions	
Angina [411.1, 411.8, 413]	Excludes cases with a surgical procedure (01-86.99)
Asthma [493]	
Chronic obstructive pulmonary disease [466.0, 491, 492, 494, 496]	Includes acute bronchitis (466.0) only with secondary diagnosis of 491, 492, 494, 496
Congestive heart failure [402.01, 402.11, 402.91, 428, 518.4]	Excludes cases with the following surgical procedures: 36.01, 36.02, 36.05, 36.1, 37.5, or 37.7
Diabetes [250.0–250.3, 250.8–250.9]	Excludes diabetes with renal manifestations [250.4], diabetes with ophthalmic manifestations [250.5], diabetes with neurological manifestations [250.6], and diabetes with peripheral circulatory disorders [250.7]
Grand mal and other epileptic conditions [345]	
Hypertension [401.0, 401.9, 402.00, 402.10, 402.90]	Excludes cases with the following procedures: 36.01, 36.02, 36.05, 36.1, 37.5, or 37.7
Tuberculosis (nonpulmonary) [012–018]	
Tuberculosis (pulmonary) [011]	

SNF/ICF = skilled nursing facility/intermediate care facility; DRG = diagnosis related group; AHRQ = Agency for Healthcare Research and Quality.

[*] In addition to the above, we added bacterial pneumonia due to methicillin-resistant *Staphyloccocus aureus* (MRSA) bacteremia compared with methicillin-sensitive *Staphyloccocus aureus* (MSSA) bacteremia as included in AHRQ Prevention Quality Indicators #11 Technical Specifications Bacterial Pneumonia Numerator definition and acute cystitis and cystitis as included in AHRQ Prevention Quality Indicators # 12 Technical Specifications Urinary Tract Infection Numerator definition.

[†] In addition to this list, we added acute cystitis and cystitis as included in AHRQ Prevention Quality Indicators #12 Technical Specifications Urinary Tract Infection Numerator definition.

Source: Institute of Medicine, Millman M, ed. Access to Health Care in America. Washington, DC: National Academy Press; 1993.

Appendix 2: Categories of Ambulatory Care Sensitive Conditions (ASCS) and ICD-9-CM Book Chapters

Ambulatory Care Sensitive Conditions	Definition
All ACSC	All avoidable, acute and chronic conditions listed in table

Ambulatory Care Sensitive Conditions	Definition
Bacterial pneumonia	Bacterial pneumonia [481, 482.2, 482.3, 482.41, 482.42, 482.9, 483, 485, 486]
Epilepsy/convulsions	Grand mal/other epileptic conditions [345] and convulsions [780.3]
Severe ear, nose, and throat infections	Severe ear, nose, and throat infections [382, 462, 463, 465, 472.1]
Urinary tract infections	Kidney/urinary infection [590.0, 599.0, 599.9, 595.0, 595.9]
Other ACSC topics	All ACSC conditions not listed in second to fifth ACSC conditions in left-hand column
ICD-9-CM Book Chapters	
All circulatory	390–459
All digestive	520–579
All endocrine	240–279
All genitourinary	580–629
All ill-defined	780–799
All infections	001–139
All mental health	290–319
All musculoskeletal	710–739
All nervous system	320–389
All respiratory	460–519
All skin	680–709

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Table 1

Distribution of the number of adolescents and young adults from South Carolina according to condition and demographic and socioeconomic characteristics (2000–2010)

	Spina Bifida	Comparison Group*
Total n†	695	1390
Gender		
Male	285 (41.0%)	570 (41.0%)
Female	410 (59.0%)	820 (59.0%)
Age group, y‡		
15–19	664 (55.4%)	1307 (54.6%)
20–24	534 (44.6%)	1086 (45.4%)
Race		
White	351 (50.5%)	
African American	219 (31.5%)	
Other	110 (15.8%)	
Missing	15 (2.2%)	1390 (100%)
Residential area		
Urban	493 (70.9%)	1014 (73.0%)
Rural	202 (29.1%)	376 (27.1%)
Food stamps		
Yes	126 (18.1%)	66 (4.7%)
No	569 (81.9%)	1324 (95.3%)
Eligibility		
Average ± SD of years§	5.5 ± 3.0	5.5 ± 3.0

SD = standard deviation.

*Data retrieved from State Health Plan records, which did not record race.

†Total denotes unduplicated number of persons with muscular dystrophy in Medicaid, State Health Plan, and hospital discharge uniformbilling data and met study definition criteria.

‡Age groups sum to a number greater than overall total. Age category numbers are based on number of persons in each age group; therefore some individuals could be in both age categories.

§During 2000–2010 study period.

Table 2

Condition categories of inpatient and emergency room encounters and the most common Clinical Classification System (CCS) categories for individuals with spina bifida in South Carolina

ICD-9-CM Condition Code (n)	Most Common CCS Categories (n)
Ill-defined conditions (759)	Other headache (231)
	Abdominal pain (173)
	Nausea/vomiting (69)
	Nonspecific chest pain (53)
Genitourinary conditions (652)	Urinary tract infection (345)
	Infections of the kidney (76)
	Menstrual disorders (27)
	Female genital pain and other symptoms (26)
	Other diseases of bladder and urethra (26)
Nervous system conditions (298)	Convulsions (84)
	Migraine (59)
	Otitis media (29)
	Other central nervous system disorder (22)
	Other ear and sense organ disorder (22)
	Epilepsy (21)
Musculoskeletal conditions (264)	Other connective tissue diseases (68)
	Lumbago (57)
	Other nontraumatic joint disorders (34)
	Backache unspecified (27)
	Other back pain and disorders (26)
Skin conditions (253)	Decubitus ulcer (71)
	Chronic ulcer of the leg or foot (32)
	Allergic reaction (31)
	Cellulitis and abscess of leg (23)
Digestive conditions (217)	Disorders of teeth and jaws (36)
	Constipation (32)
	Noninfectious gastroenteritis (31)
Mental health (143)	Anxiety disorder (48)
	Depressive disorder (40)
	Schizophrenia and other psychotic disorders (13)
Infections (106)	Other and unspecified viral disorders (30)
	Unspecified septicemia (20)
	Intestinal infection (12)
Endocrine conditions (84)	Diabetes with other manifestations (30)
	Hypovolemia (22)
	Gout and other crystal arthropathies (14)

Table 3

Rates and incidence rate ratios of inpatient (IP) and emergency room (ER) hospital discharge encounters for individuals with spina bifida

	Spina Bifida Patients				Age Group		Residential Area		Race		SNAP		Gender	
	15–19 y		20–24 y		(20–24 y vs 15–19 y)		(Urban vs Rural)		(Black/Other vs White)		(Yes vs No)		(Female vs Male)	
	n	Rate	n	Rate	IRR	*P* Value	IRR	*P* Value	IRR	*P* Value	IRR	*P* Value	IRR	*P* Value
Total visits														
All visits	2744	0.96	2845	1.33	1.33	<.0001	1.15	.230	1.07	.523	1.55	<.0001	1.31	.013
ER	1978	0.69	2188	1.02	1.61	<.0001	1.07	.647	1.08	.578	2.04	<.0001	1.49	.009
IP	766	0.27	657	0.31	1.15	.268	1.36	.030	1.06	.645	1.05	.762	1.04	.789
Ambulatory care sensitive conditions														
All ACSC (ER)	490	0.17	451	0.21	1.36	.023	1.09	.609	1.48	.013	1.89	.003	1.14	.449
All ACSC (IP)	139	0.05	105	0.05	1.13	.507	1.13	.638	1.63	.029	1.58	.224	0.65	.096
Epilepsy (ER)	103	0.0	38	0.02	0.55	.084	0.41	.019	1.90	.059	1.20	.783	0.37	.006
Other ACSC (ER)	64	0.02	91	0.04	2.20	.017	2.22	.047	1.27	.562	2.60	.004	1.03	.947
Other ACSC (IP)	44	0.02	44	0.02	1.57	.090	1.65	.137	1.89	.025	1.82	.145	0.45	.010
Severe ENT (ER)	105	0.04	82	0.04	1.08	.696	0.95	.843	1.29	.273	1.80	.014	2.37	.001
UTI (ER)	204	0.07	235	0.11	1.74	.002	1.37	.168	1.67	.016	2.14	.016	1.38	.183
UTI (IP)	64	0.02	47	0.02	1.09	.713	1.00	.993	1.57	.150	1.84	.191	1.03	.924
ICD-9-CM book chapters														
All digestive (ER)	101	0.04	108	0.05	1.52	.019	1.17	.541	1.07	.742	1.74	.033	1.37	.193
All digestive (IP)	31	0.01	35	0.02	1.49	.355	2.62	.031	1.46	.422	0.61	.257	2.35	.029
All endocrine (ER)	14	0.01	47	0.02	5.82	.007	4.94	.062	1.94	.509	0.87	.843	0.14	.004
All genitourinary (ER)	279	0.10	313	0.15	1.64	.001	1.22	.306	1.29	.185	2.01	.009	1.65	.020
All genitourinary (IP)	117	0.04	85	0.04	1.02	.925	1.20	.509	1.15	.547	1.38	.39	0.99	.952
All ill-defined (ER)	478	0.17	465	0.22	1.40	.008	0.89	.571	1.18	.339	1.75	.003	1.57	.016
All ill-defined (IP)	49	0.02	26	0.01	0.69	.193	1.37	.331	0.98	.936	0.38	.038	0.60	.073
All infections (ER)	45	0.02	30	0.01	0.97	.921	1.62	.140	1.01	.978	2.71	.004	1.76	.059
All infections (IP)	23	0.01	29	0.01	1.256	.397	1.80	.127	0.81	.490	0.76	.606	0.65	.171
All mental health (ER)	75	0.03	57	0.03	1.12	.603	1.78	.227	1.02	.966	1.88	.17	0.81	.628
All musculoskeletal (ER)	127	0.04	144	0.07	1.84	<.0001	1.31	.290	0.79	.330	3.69	<.0001	1.28	.358
All musculoskeletal (IP)	35	0.01	29	0.01	1.20	.61	0.86	.696	1.69	.122	1.27	.565	0.72	.372

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	Spina Bifida Patients				Age Group		Residential Area		Race		SNAP		Gender	
	15–19 y		20–24 y		(20–24 y vs 15–19 y)		(Urban vs Rural)		(Black/Other vs White)		(Yes vs No)		(Female vs Male)	
	n	Rate	n	Rate	IRR	*P* Value	IRR	*P* Value	IRR	*P* Value	IRR	*P* Value	IRR	*P* Value
All nervous system (ER)	75	0.03	126	0.06	2.35	.002	0.43	.011	1.41	.300	1.68	.128	1.68	.130
All nervous system (IP)	41	0.01	26	0.01	0.78	.465	0.71	.323	0.77	.409	0.76	.540	1.18	.608
All respiratory (ER)	191	0.07	156	0.07	1.13	.366	1.35	.115	1.06	.767	1.93	<.0001	1.65	.018
All respiratory (IP)	34	0.01	28	0.01	1.14	.751	2.78	.082	0.97	.950	1.01	.992	0.28	.001
All skin (ER)	79	0.03	114	0.05	2.19	.003	2.45	.006	1.98	.020	2.09	.007	1.21	.618
All skin (IP)	47	0.02	63	0.03	1.98	.004	1.77	.118	1.63	.073	1.13	.786	0.28	<.0001

Note: Only results for outcomes with sufficient cell sizes are shown.

Data for ER and IP use for the ACSC of bacterial pneumonia, IP use for the ACSC of epilepsy, IP use for the ACSC of severe ENT, ER and IP use for all circulatory conditions, IP use for all endocrine conditions, IP use for all mental health conditions, and ER and IP use for all neoplasms are excluded from this table because of very small cell sizes.

ACSC = ambulatory care sensitive condition.

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Table 4

Incidence rates and adjusted incidence rate ratios of inpatient (IP) and emergency room (ER) encounters among individuals with spina bifida, with data for both age groups

	Spina Bifida Patients				Age Group		Residential Area		Race		SNAP		Gender	
	15–19 y		20–24 y		(20–24 y vs 15–19 y)		(Urban vs Rural)		(Black/Other vs White)		(Yes vs No)		(Female vs Male)	
	n	Rate	n	Rate	IRR	*P* Value	IRR	*P* Value	IRR	*P* Value	IRR	*P* Value	IRR	*P* Value
Total visits														
All visits	1954	0.85	2646	1.31	1.49	<.0001	1.19	.202	1.06	.642	1.53	<.0001	1.36	.017
ER	1458	0.64	2043	1.01	1.68	<.0001	1.09	.622	1.08	.600	1.90	<.0001	1.55	.014
IP	496	0.22	603	0.30	1.39	.003	1.52	.009	1.08	.608	1.13	.506	0.98	.917
Ambulatory care sensitive conditions														
All ACSC (ER)	305	0.13	435	0.22	1.66	<.0001	1.12	.542	1.41	.043	1.64	.028	1.23	.323
All ACSC (IP)	84	0.04	102	0.05	1.41	.068	1.14	.646	1.37	.178	1.19	.664	0.57	.024
Epilepsy (ER)	54	0.02	35	0.01	0.81	.583	0.38	.026	1.89	.120	2.00	.356	0.44	.079
Other ACSC (ER)	41	0.02	88	0.04	2.59	.005	2.01	.129	1.36	.503	1.94	.089	1.06	.920
Other ACSC (IP)	34	0.02	42	0.02	1.50	.16	1.64	.181	1.96	.027	1.45	.447	0.34	.001
Severe ENT (ER)	77	0.03	78	0.04	1.18	.401	1.08	.770	1.52	.101	1.74	.045	2.38	.005
UTI (ER)	123	0.05	229	0.11	2.18	<.0001	1.33	.228	1.39	.125	1.48	.232	1.37	.219
UTI (IP)	38	0.02	46	0.02	1.39	.189	0.95	.897	1.16	.655	1.10	.838	0.84	.595
ICD-9-CM book chapters														
All digestive (ER)	66	0.03	97	0.05	1.76	.002	1.32	.349	1.12	.6601	1.73	.075	1.87	.034
All digestive (IP)	20	0.01	34	0.02	1.99	.126	2.13	.118	1.51	.443	0.73	.519	2.15	.084
All endocrine (ER)	11	0.01	47	0.02	6.01	.005	4.67	.081	1.76	.585	0.64	.576	0.12	.003
All genitourinary (ER)	187	0.08	306	0.15	1.90	<.0001	1.18	.406	1.08	.667	1.47	.161	1.64	.028
All genitourinary (IP)	76	0.03	83	0.04	1.23	.266	1.25	.488	0.95	.841	0.91	.793	0.87	.596
All ill-defined (ER)	360	0.16	430	0.21	1.44	.006	0.95	.826	1.18	.385	1.89	.003	1.72	.011
All ill-defined (IP)	29	0.01	25	0.01	0.99	.982	1.72	.167	1.08	.799	0.67	.386	0.65	.190
All infections (ER)	27	0.01	29	0.01	1.27	.404	1.38	.373	1.05	.865	2.52	.006	1.56	.183
All mental health (ER)	65	0.03	52	0.03	0.97	.902	1.85	.250	1.10	.841	1.76	.304	0.75	.543
All musculoskeletal (ER)	89	0.04	131	0.07	1.91	<.0001	1.21	.489	0.94	.822	3.10	<.0001	1.39	.236
All nervous system (ER)	51	0.02	117	0.06	2.67	.001	0.37	.006	1.4	.373	2.00	.075	1.89	.108

	Spina Bifida Patients				Age Group		Residential Area		Race		SNAP		Gender	
	15–19 y		20–24 y		(20–24 y vs 15–19 y)		(Urban vs Rural)		(Black/Other vs White)		(Yes vs No)		(Female vs Male)	
	n	Rate	n	Rate	IRR	*P* Value	IRR	*P* Value	IRR	*P* Value	IRR	*P* Value	IRR	*P* Value
All respiratory (ER)	143	0.06	146	0.07	1.20	.199	1.42	.099	1.10	.633	1.79	.005	1.70	.031
All skin (ER)	51	0.02	107	0.05	2.48	.001	2.49	.015	2.12	.019	1.52	.192	1.03	.951
All skin (IP)	35	0.02	60	0.03	2.05	.008	1.73	.173	1.74	.068	1.18	.755	0.19	<.0001

Note: Only results for outcomes with sufficient cell sizes are shown.

ER = Emergency Room; IP = Inpatient; ACSC = ambulatory care sensitive condition.

Table 5

Adjusted incidence rate ratios of inpatient (IP) and emergency room (ER) encounters among individuals with spina bifida, with data for both age groups, including persons with hydrocephalus and tethered cord syndrome

	Patient Age		Residential Area		Race		SNAP		Gender		Hydrocephalus		Tethered Cord	
	15–19 y		20–24 y		(20–24 y vs 15–19 y)		(Urban vs Rural)		(Black/Other vs White)		(Yes vs No)		(Female vs Male)	
Condition	**IRR**	***P* Value**	**IRR**	***P* Value**	**IRR**	**P**	**IRR**	***P* Value**	**IRR**	***P* Value**	**IRR**	***P* Value**	**IRR**	***P* Value**
Total visits														
All visits	1.49	<.0001	1.20	.168	1.06	.665	1.50	.001	1.34	.022	1.03	.771	0.87	.269
ER	1.67	<.0001	1.14	.430	1.07	.680	1.77	<.0001	1.45	.027	1.00	.982	0.62	.007
IP	1.41	.002	1.49	.017	1.09	.566	1.18	.380	1.02	.927	1.10	.538	1.16	.290
ACSC														
All ACSC (ER)	1.65	<.0001	1.13	.504	1.41	.049	1.61	.030	1.21	.328	0.98	.918	0.93	.721
All ACSC (IP)	1.47	.051	1.04	.881	1.41	.130	1.44	.318	0.67	.145	1.37	.278	2.40	.001
Epilepsy (ER)	0.88	.739	0.35	.021	1.57	.24	2.37	.231	0.41	.054	13.78	.000	0.19	.0127
Other ACSC (ER)	2.64	.007	2.04	.096	1.36	.519	1.93	.050	1.06	.908	1.45	.224	0.73	.5072
Other ACSC (IP)	1.52	.156	1.52	.279	2.01	.019	1.65	.275	0.39	.008	0.96	.902	2.46	.019
Severe ENT (ER)	1.13	.552	1.21	.484	1.45	.129	1.43	.171	1.97	.022	0.65	.079	0.39	.002
UTI (ER)	2.16	<.0001	1.23	.376	1.40	.114	1.62	.147	1.47	.116	0.70	.141	2.02	.004
UTI (IP)	1.44	.153	0.84	.654	1.21	.543	1.41	.429	1.03	.929	1.27	.517	3.53	.001
ICD-9-CM book chapters														
All digestive (ER)	1.70	.005	1.43	.226	1.08	.756	1.50	.171	1.65	.099	0.75	.266	0.53	.021
All digestive (IP)	1.98	.108	2.08	.157	1.50	.419	0.74	.587	2.18	.057	0.88	.790	1.22	.662
All endocrine (ER)	6.60	.004	4.62	.114	1.89	.548	0.79	.788	0.15	.005	4.46	.040	4.52	.032
All genitourinary (ER)	1.87	<.0001	1.14	.495	1.08	.683	1.49	.149	1.67	.018	0.71	.102	1.41	.115
All genitourinary (IP)	1.25	.234	1.11	.76	0.98	.950	1.11	.762	1.03	.906	1.00	.990	3.23	<.0001
All ill-defined (ER)	1.55	.003	1.09	.723	1.13	.566	1.84	.007	1.94	.003	1.35	.153	0.56	.015
All ill-defined (IP)	1.37	.363	2.62	.052	1.03	.937	0.81	.692	0.80	.525	4.21	.004	1.02	.953
All infections (ER)	1.22	.499	1.45	.301	1.03	.935	2.24	.015	1.41	.273	0.51	.033	0.86	.646
All mental health (ER)	0.96	.851	1.95	.203	1.09	.862	1.62	.354	0.69	.373	0.87	.707	0.63	.364
All musculoskeletal (ER)	1.87	<.0001	1.27	.382	0.93	.769	2.86	<.0001	1.29	.347	0.85	.480	0.69	.160
All nervous system (ER)	1.85	.035	0.41	.003	1.38	.268	1.85	.125	1.07	.853	2.73	.002	0.20	<.0001

	Patient Age 15–19 y		Residential Area 20–24 y		Race (20–24 y vs 15–19 y)		SNAP (Urban vs Rural)		Gender (Black/Other vs White)		Hydrocephalus (Yes vs No)		Tethered Cord (Female vs Male)	
Condition	**IRR**	***P* Value**	**IRR**	***P* Value**	**IRR**	**P**	**IRR**	***P* Value**	**IRR**	***P* Value**	**IRR**	***P* Value**	**IRR**	***P* Value**
All respiratory (ER)	1.18	.247	1.54	.041	1.07	.718	1.57	.020	1.51	.069	0.97	.848	0.41	.001
All skin (ER)	2.52	.001	2.36	.018	2.16	.020	1.67	.091	1.11	.780	1.08	.777	1.60	.078
All skin (IP)	2.04	.011	1.61	.249	1.81	.046	1.34	.553	0.22	<.0001	0.74	.362	3.20	.003
Miscellaneous														
Abdominal pain, nausea, and constipation (ER)	1.27	.237	1.61	.125	1.11	.698	2.72	.001	1.75	.105	0.72	.231	0.67	.299
Backache, lumbago, and other back pain (ER)	1.99	.001	1.05	.897	0.63	.138	4.31	<.0001	1.43	.313	0.75	.291	0.72	.307

ACSC = Ambulatory Care Sensitive Condition; SNAP = Supplemental Nutrition Assistance Program.

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