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Original Research

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 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

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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,