

ORIGINAL ARTICLE

Youth and Young Adults With Spina Bifida: Their Utilization of Physician and Hospital Services



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Abstract

Objective: To describe current patterns of health care utilization of youth and young adults who have spina bifida (SB) and provide evidence to guide the development of health care for this growing population.

Design: We conducted a secondary analysis of health services utilization data from the Canadian Institute for Health Information to determine the rates and patterns of health care utilization, because comprehensive health care has been recognized as critical to positive health outcomes.

Setting: Participants were identified from 6 publicly funded children's treatment centers.

Participants: Health records from youth (n=164; age range, 13.0–17.9y) and adults (n=120; age range, 23.0–32.9y) with SB contributed to this study.

Interventions: Not applicable.

Main Outcome Measures: The rates of outpatient physician visits and hospital admissions for the youth and adult groups were calculated. The proportion with a "medical home" was also calculated.

Results: The annual rates of outpatient physician visits per 1000 persons were 8031 for youth and 8524 for adults with SB. These rates were approximately 2.9 and 2.2 times higher, respectively, than for their age-matched peers. On average, 12% of youth and 24% of adults with SB had a medical home. The annual rates of hospital admissions per 1000 persons were 329 for youth and 285 for adults with SB. Rates of admissions were 19.4 and 12.4 times higher, respectively, for these groups than for the general population.

Conclusions: It appears that persons with SB are accessing health services more often than their age-matched peers, and few have a medical home. We recommend that seamless medical care be provided to all adults with SB, coordinated by a primary care provider, to facilitate comprehensive care.

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Spina bifida (SB) is the second most common complex disability of childhood, after cerebral palsy (CP). Children with SB require extensive medical attention and are supported by well-developed pediatric health services. However, 90% of children with SB are now living into adulthood¹ as a result of advances in health care^{1,2} and must transition to adult health care services. Unfortunately,

there is a discontinuity of care during the transition to adult care³; specialized adult care centers are rare, and most primary care clinicians have limited experience or evidence to guide their practice. Previous research¹ indicates that adults with childhood-onset physical disabilities are admitted to hospitals 9 times more often than the general population.

Prospective observational studies have provided valuable information on the types of comorbidity experienced by adults with SB, such as problems associated with cerebrospinal fluid diversion (shunts), tethered cord syndrome, scoliosis, allergies, seizures, and bladder incontinence.⁵ More recent research⁶ showed that the number of shunt revisions adversely affected

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long-term independence for adults with SB. These findings are supported by a literature review by Webb,² who identified comorbid conditions associated with SB in adulthood and underscored the importance of access to multidisciplinary clinics for ongoing monitoring.

Moreover, the evidence points to many barriers affecting quality of care for persons with SB.⁷ Kinsman and Doehring,¹ in 1996, estimated that 47% of hospital admissions among adults with SB were for preventable conditions (eg, serious urologic infections, renal calculi, pressure ulcers, osteomyelitis).¹ Dicianno and Wilson⁸ reported that approximately one third of hospital admissions for adults with SB were for preventable conditions (primarily infections and skin wounds). A seamless transition to high-quality outpatient care services for adults may prevent these hospitalizations. A medical home approach is suggested as an important characteristic of high-quality care.⁹⁻¹³ At present, there is little information on the patterns of health care utilization among adults with SB.³

We have previously published estimates of health care services utilization for youth and adults with CP from a Canadian sample. On average, outpatient physician visit (OPPV) rates were twice those of age-matched peers, and hospitalization rates were 7 times those of age-matched peers.¹⁴ However, no comparable information is available for adults with SB.

The purpose of this article is to report the rates of utilization of inpatient and outpatient health care services among youth and young adults with SB in Ontario, Canada, an environment with universal health insurance. This article explores the types of outpatient health services utilization and the reasons for hospital admissions. Within each analysis we examine differences related to sex and age group.

Methods

This article reports on a cross-sectional analysis of health services utilization data for youth and adults with SB. They are a population-based sample, and all had similar access to services funded by a universal health insurance program. The data were drawn from the database of a larger study that included health and quality-of-life surveys¹⁵ and a qualitative analysis of health care transition experiences of youth and adults with CP, SB, and childhood-acquired brain injuries.¹⁶ The health services analysis methods used in this article have previously been reported for the subgroup with CP.¹⁴

Sampling frame

Youth (age range, 13y to 17y11mo) and adults (age range, 23y to 32y11mo) with SB were identified through a manual review of

health records at 6 children's treatment centers in Ontario.¹⁶ Participants were limited to those living in Ontario during the 4-year study period. Health card numbers (HCNs) were collected from health records at recruitment sites under institutional consent and with ethics approvals. These HCNs were securely transferred to the Institute for Clinical Evaluative Sciences (ICES), where all analysis was performed. Once at ICES these numbers were translated to ICES key numbers to ensure anonymity and enable linkage to the Registered Persons Database to confirm eligibility. General population data were estimated using age-matched youth and adults from the province of Ontario.

Datasets

Two different datasets provided the health care utilization information. The Ontario Health Insurance Plan (OHIP) dataset contained claims submitted for services funded by the provincial health care system. These services were largely physician services. The Canadian Institute for Health Information (CIHI) dataset contained information on acute hospitalizations, based on information provided by physicians in the discharge abstract of the hospital chart. The CIHI data contained information on number of admissions and length of stay (LOS), and were coded for the reasons for each admission.

Generation of operational definitions

The term *outpatient physician visit* is used to denote all outpatient physician claims submitted for services rendered on the same day by the same physician. The OHIP dataset also provided information on the type of visit, the type of site where the service was provided (eg, emergency department), and the specialty of the physician who provided the service.

The term *medical home* has been used in the literature to indicate the presence of a primary care provider who coordinates complex care for a specific patient.^{11-13,17-21} Young et al¹⁴ specified 3 definitions of a medical home based on OHIP data: *primary care provider* (2 annual physicals plus 1 other visit to the same physician); *dominant care provider* (minimum of 50% of care received from 1 physician); and *annual physical* (1 annual physical over 4y). Note that all 3 definitions were limited to general practitioners (GPs), specialists in family medicine (FM), and pediatricians, and the definition of annual physical represented a minimum standard for persons with SB because of their significant health care needs.

Hospital admissions were identified in the CIHI data and represent a stay of at least 1 night as a hospital inpatient. Examination of the reasons for the admissions used the *International Classification of Diseases, Ninth Revision* codes assigned to the admission record. Only the primary reason for each admission was considered. In the event that the primary reason was recorded as SB, the second reason for the admission was used as the main reason for the admission.

Analysis

The analysis focused on 2 different sites of care: outpatient physician services and hospital care. We used the OHIP data to answer the following questions regarding outpatient care:

List of abbreviations:

CIHI	Canadian Institute of Health Information
CP	cerebral palsy
FM	family medicine
GP	general practitioner
HCN	health card number
ICES	Institute for Clinical Evaluative Sciences
LOS	length of stay
OHIP	Ontario Health Insurance Plan
OPPV	outpatient physician visit
SB	spina bifida

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