Healthcare utilization during transition to adult care in patients with spina bifida: A population-based longitudinal study in Ontario, Canada

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ABSTRACT

Introduction: Individuals with spina bifida (SB) may experience negative health outcomes because of an informal transition from pediatric to adult care that results in using the emergency room (ER) for non-acute health problems.

Methods: We conducted a retrospective population-based cohort study of all people with SB in Ontario, Canada turning 18 years old between 2002 and 2011. These patients were followed for five years before and after age 18. Primary outcome was the annual rate of ER visits. Secondary outcomes included rates of hospitalization, surgery, primary care, and specialist outpatient care. We estimated the association between

KEY MESSAGES

- Among patients with spina bifida in Ontario, Canada, there was a 14% increase in the relative rate of ER visits from age 18–22 years old compared to age 13–17 years old.
- Concurrently, there was a decrease in the relative rate of hospital admissions.
- There was no change in the rate of primary care visits during this period; however, there was a reduction in the visit rate to specialists (neurology, neurosurgery, physiatry and rehabilitation medicine, orthopedic surgery, and urology)
- Pediatric-adult transition of care for patients with spina bifida is associated with preventable emergency room visits.

age with primary and secondary outcomes using negative binomial growth curve models, adjusting for patient-level baseline covariates.

Results: Among the 1215 individuals with SB, there was no trend of ER visits seen with increasing age (relative risk [RR] 0.99, 95% confidence interval [CI] 0.98–1.02); however, there was a significant increase in the rate of ER visits associated with turning 18 years (RR 1.14, 95% CI 1.03–1.27). Turning 18 years old was also associated with a decreased rate of hospital admissions (RR 0.79, 95% CI 0.66–0.95) and no change in surgeries (RR 0.80, 95% CI 0.64–1.02). Visits to primary care physicians remained stable over the same period (RR 0.96, 95% CI 0.90–1.01), while visits to SB-focused specialists decreased after age 18 (RR 0.81, 95% CI 0.75–0.87).

Conclusions: In patients with SB, the rate of ER visits increased significantly at 18 years old, while hospital admissions and specialist physician visits decreased at the same time. Models of transitional care can aim to reduce non-urgent ER visits and facilitate regular specialist care.

INTRODUCTION

Patients with spina bifida (SB) have multisystem issues that are degenerative with age,[1] and they can have difficulty with self-care and independence as they age. These patients are typically initially treated by pediatric specialists and eventually move into adult care. Transition of care is a difficult process that aims at transferring ownership of medical care to the patient while securing access to providers and facilities equipped to deal with adult patients with these problems.[2] The goal of transitional care is to provide uninterrupted, developmentally appropriate transfer of medical care from a pediatric setting to an adult-care model.[3] The reality is often more haphazard,[4] driven by administrative rather than patient factors. In Ontario, Canada patients lose access to pediatric institutions at 18 years of age.

The impression of many physicians, families and patients is that an arbitrary and abrupt transition age adversely impacts care,[5] however, generalizable data is lacking to support this statement.[6]

We hypothesize that in the setting of informal transition from pediatric to adult care in Ontario, Canada, patients with SB will increasingly seek care in the emergency room after age 18 years for issues that do not require hospital admission. Therefore, we evaluated emergency room (ER) care, hospital admissions, and other healthcare utilization before and after the age of 18 years in children with SB in Ontario, Canada.

METHODS

We conducted a population-based, retrospective cohort study of all patients turning 18 years old in Ontario, Canada with a diagnosis of SB using linked health administrative databases. Patients

had ten years of longitudinal follow up from age 13 to age 22. We evaluated the rates of healthcare utilization over this transitional period.

The Sunnybrook Health Sciences Center Research Ethics Board approved this study protocol (project identification number 293-2017). All analyses were performed between June 2018 and May 2019.

Study subjects

We identified all individuals 18 years old with a previous diagnosis of SB (International Classification of Disease, 9th Revision [ICD-9] 741.00-3, 741.90-3, 756.17; ICD-10 Q051-9, Q76.49) from January 1, 2002 to December 31, 2011. We excluded patients who were not eligible for healthcare in the province between age 13 and age 22 to allow for 10 years of longitudinal evaluation. We also excluded those who were out of province during this period, and those who were missing location data.

Exposure

The primary independent variables were age as a continuous variable and the pediatric-adult transition (occurring at age 18 years) as a binary variable. The pediatric-adult transition occurs at 18 years since patients lose access to pediatric institutions and care from most pediatric providers in Ontario, Canada.

Covariates

We collected important patient demographics, comorbidity, and healthcare utilization baseline characteristics that may confound the association between age and ER visit rates. Demographic characteristics included sex, location (based on local health integration network), rural residence, distance to tertiary care and pediatric care hospital. Comorbidity characteristics included neuropathic bladder and bowel/constipation, hydrocephalus, presence of ventriculo-peritoneal (VP) shunt, developmental delay, mobility restraints, pressure ulcers, and a history of urologic surgery (*continent and incontinent urinary diversion including vesicostomy, neobladder, intestinal pouch with continent stoma, ileal conduit, and creation of continent stoma such as Mitrofanoff), augmentation cystoplasty, sphincterotomy/urethrotomy and intravesical botulinum toxin injection.* See Supplementary table 1 for diagnostic and procedure codes). The only healthcare utilization characteristic included as a covariate was the total number of hospitalizations before age 18.

Outcomes

The primary outcome was the rate of ER visits. ER visits were counted if the patient was seen by a physician and the visit did not result in hospital admission. Visits were not counted if the patient was transferred from another hospital, or they were seen in a scheduled visit.

Secondary outcomes included the overall hospital admission rate, surgery rate, and ambulatory care visit rate (primary care and specialist care). Hospital admission episodes were considered unique episodes if they occurred > 48 hours from a previous discharge and they were not a transfer from another acute care facility. We considered all surgical procedures performed in hospitals and captured in the Discharge Abstract Database. Ambulatory care episodes were counted when a physician billed an encounter, limited to one encounter per day per provider. Physicians categorized as primary care were family physicians and general practitioners. SB specialists were those specialties primarily responsible for the care of patients with SB: neurology, neurosurgery, physiatry and rehabilitation medicine, orthopedic surgery, and urology. We also captured the primary diagnoses recorded for ER visits and hospital admissions, up to the third digit in the ICD10 code.

Data sources

In Ontario, all necessary healthcare services, physician services and prescription medication information are recorded and held at ICES (http://www.ices.on.ca). All datasets were linked using unique, encoded identifiers, and were analyzed at ICES. We linked the following databases: the Ontario Health Insurance Plan (OHIP) database, which tracks claims paid for physician billings, laboratories, and out-of-province providers;[7] the Ontario Drug Benefits Program database (ODB), which consists of claims submitted by pharmacists for prescribed drugs at the time of medication dispensing from community pharmacies;[8] the Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD),[9] which contains records for hospital admissions; the CIHI National Ambulatory Care Reporting System, which contains diagnosis and procedure information during emergency department visits; and the Registered Persons Database (RPDB) which captures vital statistics for all individuals alive and eligible for OHIP during the accrual period.[10]

Analysis

Descriptive statistics of the baseline characteristics were evaluated. We determined crude rates of primary and secondary outcomes per year and stratified these according to patient age. We also identified the most common primary diagnoses for each ER visit and hospital admission, ranked by descending frequency in the pediatric period (13-17 years).

To determine the association between turning 18 years old and the annual ER visit rate we used unadjusted and adjusted negative binomial growth curve models. These are multi-level models (level 1: patient age, level 2: individual patient). Repeated observations are clustered within patients. The growth curve models incorporated age as a random effect (continuous variable from age 13 to 22 years, allowing each patient to have their own growth curve) and turning 18 years old and other covariates as fixed effects. We checked the linearity assumption of the growth curve models using a multilevel model with random intercepts and age in years

treated as a categorical fixed effect, with age 17 years as the reference category (see Supplementary Figure 1).

All analyses were performed using SAS® version 9.4 (SAS Institute, Inc., Cary, NC, USA) and results with a p <0.05 were considered statistically significant.

RESULTS

We identified 1,219 eligible patients with SB who turned 18 years old between January 1, 2002 to December 31, 2011 (see Figure 1 for study flow diagram). Baseline characteristics are summarized in Table 1. More than half of these patients (n=662, 54%) were female. Most of these patients lived in a non-rural setting (n=999, 82%), and within 50 km of a tertiary care center (n=771, 63%). Nearly 25% of these patients had been hospitalized more than 10 times before age 18 (n=316). Many of these patients had VP shunts (n=521, 43%), developmental delay (n=331, 27%), and major urological surgery prior to age 18 (n=169, 13.9%).

   We evaluated the crude annual rates of acute care (ER, hospital admission, surgery) (Figure 2) and ambulatory care (primary care and specialist visits) (Figure 2) by age. There was a marked increase in the ER visit rates between 13 years old (68.3 visits per 100-person years [py]) and 22 years old (104.6 visits/100 py) with a notable rise after 17 years old (Figure 2). Seventeen percent of ER visits were preceded by an ER visit within 7 days. The most common diagnosis recorded at emergency room visits not leading to hospitalization was urinary tract infection, followed by abdominal pain and headaches (

). While the overall number of emergency room visits increased over this period (3590 visits for 13-17y vs 6000 visits for 18-22y), the percentage of those visits represented by the 10 most common diagnoses decreased. Over the same period there was a decreased hospital admission rate (28.6 to 19.6 admission/100 py) and a stable surgery rate (10.5 to 9.4 surgeries/100 py). Five percent of hospital admissions were preceded by a previous hospital discharge within 48 hours to seven days. The most common diagnosis recorded during hospitalization was VP shunt infection, followed by UTI and neurogenic bladder (

). The overall number of hospital admissions (1503 admission for 13-17y vs. 1312 admissions for 18-22y), and the percentage of these admissions represented by the most common diagnoses decreased over this period. The rate of primary care visits was stable over this time (**Error! Reference source not found.**), while the rate of visits to SB specialists (neurology, neurosurgery, physiatry and rehabilitation medicine, orthopedic surgery, and urology) decreased between age 13 and age 22 years (1.9 visits/year vs. 1.2 visits/year, respectively).

   To understand the effect of age on ER visit rates, we used adjusted negative binomial growth curve models, with continuous age and age = 18 years as random intercepts, and baseline characteristics as fixed effects (**Error! Reference source not found.**). In the adjusted model, we found that there was no effect for linear age between 13-22 (Relative rate [RR] 1.00; 95% Confidence Interval [CI] 0.98-1.02), however there was a discontinuity observed at age 18 years with a 14% increase in the relative rate of ER visits (RR 1.14; 95% CI 1.03-1.27). The patient's distance from a tertiary care center > 50 km (RR 1.34; 95% CI 1.09-1.63) and rural residence (RR 1.22; 95%CI1.00-1.47) were also associated with an increased rate of ER visits. Patient disease and disability related factors associated with increased ER visit rates included having

mobility restraints, a previous diagnosis of neuropathic bladder, developmental delay, or pressure ulcers (**Error! Reference source not found.**).

To explain the effect of age on ER visit rates, we analysed the effects of turning 18 years old on secondary outcomes including acute and outpatient care, and surgery, using unadjusted and adjusted negative binomial growth curve models (Table 4). Turning 18 years old was associated with a decreased rate of hospital admissions (RR 0.79; 95% CI 0.66-0.95) and no change in the rate of surgery (RR 0.80; 95% CI 0.64-1.02). While there was no change in the rate of primary care visits between age 13 and 22, turning 18 was significantly associated with a decreased rate of SB specialist visits (neurology, neurosurgery, orthopedic surgery, urology, physiatry).

DISCUSSION

Among a population-based cohort of 1,219 patients with SB in Ontario, Canada, there was a marked increase in the annual ER visit rate between 13 years old and 22 years old, with a 14% increase in the relative rate of ER visits between 18-22 years old. Concurrently, there was a decrease in the rate of hospital admissions. The rate of primary care visits was stable over this time while the rate of visits to specialists who manage SB decreased significantly.

To our knowledge this is the largest longitudinal population-based cohort of patients with SB that reports on outcomes following transition from pediatric to adult care. Previous cohorts have attempted to identify healthcare utilization and outcomes associated with it, however these included smaller sample size, single institutions, or shorter follow-up. Mann et al. analyzed a population-based cohort of 695 patients with SB in South Carolina from 2000-2010.[11] They found higher rates of emergency room visits attributed to urinary tract infections and other ambulatory care sensitive conditions. Young et al. tracked a cohort of 345 graduates from a single physical rehabilitation clinic managing children with cerebral palsy, SB, and acquired brain injuries.[12] They found that these patients had increased healthcare utilization after age 18, with an average of 11.5 physician visits per year and a hospital admission every 6.8 years (9 times the general population rate). In a separate study, Young et al. found that significantly fewer adults in their cohort reported good health (5%) while far more adolescents reported good health (38.5%) suggesting that their health had deteriorated over that period.[13]

We found that the rate of emergency department visits not leading to admission increased over the transition period among patients with SB, while the rate of hospitalization did not change. This is consistent with findings by Mann et al., showing that rates of emergency room visits for ambulatory care sensitive conditions (ACSC) and urinary tract infections were higher in 20-24 year olds compared to 15-19 year olds with SB (relative rate (RR)=1.61, p<.0001).[11] At the same time, hospital admission did not increase between these two age groups (RR=1.15, p=.268). Although they did not provide any information regarding admissions prior to age 18, Dicianno et al. found that 38% of admissions in the National Inpatient Sample (United States) among patients with SB were due to preventable causes among 18-35 year olds.[1] Preventable use

of the emergency department for ambulatory conditions points to a need for more comprehensive outpatient care for these patients as they transition from adolescence to adulthood.

There are several factors that are associated with preventable emergency room visits by patients with SB. Patients with SB generally have deteriorating health and quality of life as they age. A cohort from the National SB Registry (2009-2013; n=4,644) found that the rates of fecal and urinary continence and skin breakdown increased with age and the ability to ambulate declined.[14] This deterioration would predispose patients to needing more frequent care. Our study identified that characteristics representing increased disability (mobility restraints, a previous diagnosis of neuropathic bladder, developmental delay, or pressure ulcers) were significantly associated with an increased ER visit rate. There are also social and access challenges that these patients face during transition which may result in a discontinuity of regular care. In our study, patients who lived more than 50 km from a tertiary center had higher rates of ER visits. Young et al. reported several challenges voiced by patients with SB that affect this transition including lack of access to primary care, lack of information regarding transition of care, and lack of support during the process.[15] Our data indicates that primary care access is not affected during the transition period. However, the rate of visits with specialists who typically manage the complex care of patients with SB decreased after transition and this may explain the increased use of the emergency department. Binks et al. identified that there was a real or perceived lack of interest by adult providers to provide care for young adults with SB.[16] Even with a well-established referral system from children's hospitals to a dedicated SB clinic, like those evaluated in a study by Summers et al., many patients with SB may delay establishing care with adult providers.[17] The potential for a discontinuity of specialist care during transition of patients with SB was recently highlighted in Canada, where 13 of 28 pediatric urologists do not provide ongoing urological care to their SB patients after referral has been made to adult centered care.[18] This emphasizes the potential value of a focused transition program with centralized oversight of the process. A survey of 142 SB transition clinics from 2017 in the United States found that 50% of these clinics have a transition program while 25% of these started in the last year.[19] Discussion about transition begins at mean age of 15 (10-25 years) while the mean age of transition is 21 years (18-30). Nurse coordinators or social workers manage transition in more than half of clinics (n=33).

We noted a higher number of ER visits with the primary diagnosis of UTI for adults compared to adolescents. This was the second most common primary diagnosis recorded at hospitalization, with VP shunt infection being more common. In contrast, Dicianno et al. identified among adults with SB that UTIs were the most common primary diagnosis during hospitalization (10.2%) in the National Inpatient Sample from 2004-2005, while complications from devices/grafts/implants were second most common (9.1%), with VP shunt problems representing the majority within this category of diagnoses (53%).[1] The high frequency of UTIs

is not surprising as the symptoms can be non-specific, and a diagnosis of UTI may represent both chronic asymptomatic bacteriuria, which is common in this population, and acute infection.

The strengths of this study include the use of a large population-based cohort with longitudinal follow up during the transition from pediatric to adult care. Identifying a large cohort of patients with SB has been limited in the past due to its low birth prevalence (0.2 per 1000 persons in Ontario[20]). Moreover, in Ontario, Canada all necessary inpatient and outpatient healthcare services and physician services are universally funded, theoretically ensuring equal access to care, irrespective of insurance status.

There are also limitations of this study. A general limitation of all studies using administrative databases is the potential for misclassification. Patients were identified with SB diagnosis codes; however, we are unable to confirm this diagnosis. Coding for this disorder is specific and has been used in previous reports.[20] In Ontario (population 13.1 million in 2010), there were 3,469 patients identified with SB, with 67.5% of them 18-64 years old.[20] We are confident that we have captured a large proportion of the entire population of patients with SB in this study. Another limitation is the lack of a healthy control group in this study. The effect of increased ER use after transition to adult care has been described in other chronic childhood illness, such as diabetes.[21] However, some of the effect we are capturing may be increased ER visits in young adults in general, as seen in the United States, where young adults receive a considerable portion of care in the ER, greater than any other age group.[22]We were also unable define the degree of disability, which can affect outcomes.[14] In this study, we could not ascertain the severity or rationale for the primary diagnoses at each patient encounter and we are unable to follow-up to determine whether a definitive diagnosis was eventually made for an ill-defined condition such as abdominal pain or headache. Although we are testing the effect of informal transitional care in Ontario, there is the possibility that some pediatric centers or providers in this population sample are using a formal transition program with some patients, although this would not be captured using administrative health data. As well, there is residual confounding with respect to education, family dynamics, and the level of caregiver support for these patients that we are unable to ascertain from administrative data.

CONCLUSIONS

Among a population-based cohort of children with SB, the rate of ER visits not leading to hospitalization increased significantly at 18 years old during the observation period from age 13 years to 22 years, with the most common diagnosis being UTI. Hospital admissions and specialist physician visits decreased over the same time. Factors significantly associated with this increased rate of ER visits were living further from a tertiary care center and disability. Future models of transitional care for these patients can focus on promote regular access to specialist care and reducing non-urgent emergency room visits.

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Figure 1. Study flow diagram of inclusion and exclusion criteria. OHIP Ontario Health Insurance Plan. *Exact numbers are suppressed when cell counts are ≤5 or can be back calculated, to protect patient confidentiality.
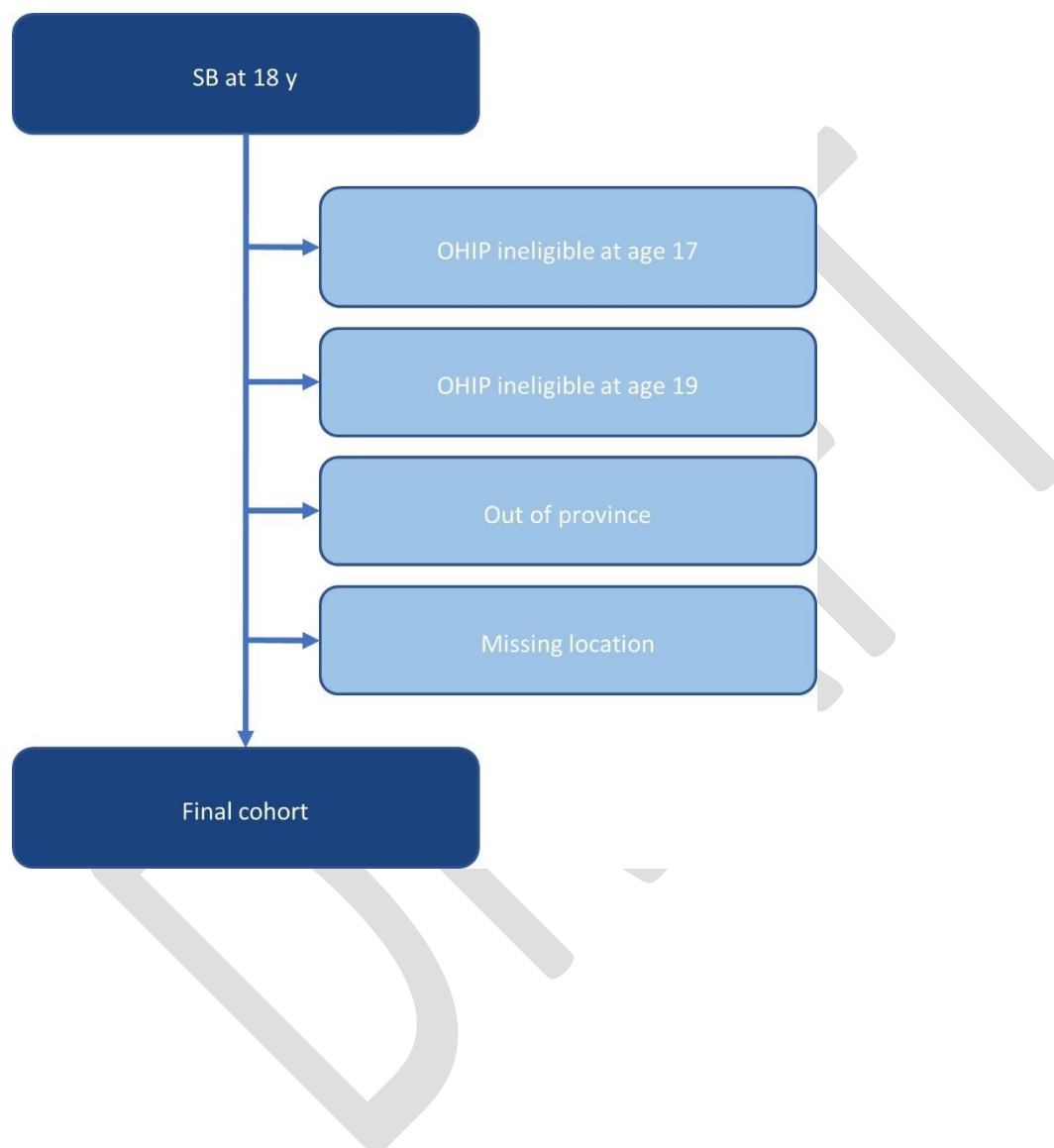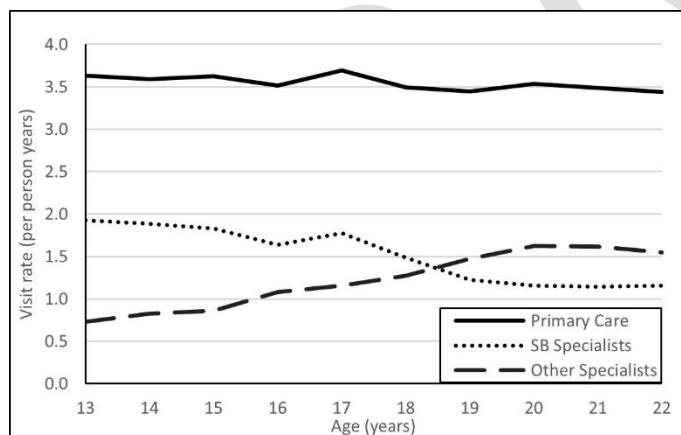
Figure 2. Annual rate of (A) inpatient service volumes and (B) outpatient service volumes for patients with SB between ages 13 years and 22 years old.

A
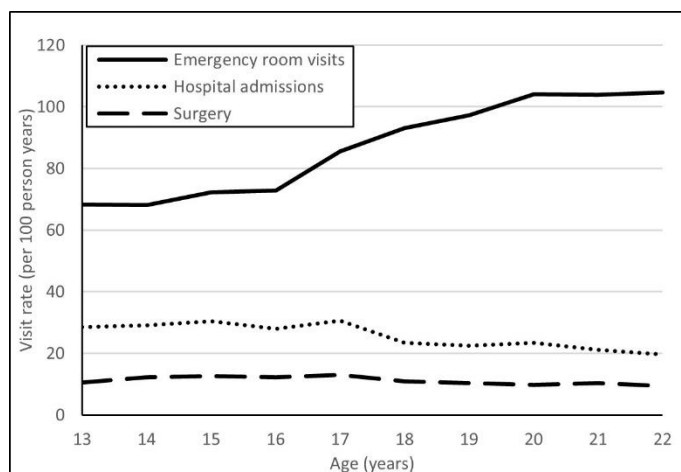
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Table 1. Baseline characteristics of patients with SB turning 18 years old from January 1, 2002 to December 31, 2011 in Ontario, Canada	
Characteristic	**Overall cohort, n (%) (N=1219)**
Gender (female)	662 (54.3%)
Age at first contact with Ontario healthcare system (years)	
0	845 (69.3%)
≥1	374 (30.7%)
Rural residence	220 (18.0%)
Household income quintile*	
1	257 (21.1%)
2	254 (20.8%)
3	254 (20.8%)
4	231 (18.9%)
5	223 (18.3%)
Distance to tertiary care center (km)	
0–19	376 (30.8%)
20–49	395 (32.4%)
50–199	398 (32.6%)
200+	50 (4.1%)
Distance to pediatric center (km)	
0–19	304 (24.9%)
20–49	366 (30.0%)
50–199	455 (37.3%)
200+	94 (7.7%)
≥10 hospitalizations before 18 y	316 (25.9%)
Neurological comorbidity	
Hydrocephalus	634 (52.0%)
Ventriculo-peritoneal (VP) shunt placement	521 (42.7%)
VP shunt complications	411 (33.7%)
Developmental delay	331 (27.2%)
Musculoskeletal comorbidity	
Mobility restraints	18 (1.5%)
Pressure ulcers	215 (17.6%)
Urological surgery**	169 (13.9%)

*Household income quintile is based on the nearest census-based neighborhood income quintile.

**Urological surgery includes continent and incontinent urinary diversion (includes vesicostomy, neobladder, intestinal pouch with continent stoma, ileal conduit, and creation of continent stoma

such as Mitrofanoff), augmentation cystoplasty, sphincterotomy/urethrotomy, and intravesical botulinum toxin injection. See Supplementary Table 1 for complete list of codes and procedures.

Table 2. Most common diagnoses recorded during hospital admissions and visits to emergency room not leading to admission to hospital for patients with SB between age 13–17 years and 18–22 years in Ontario, Canada				
Diagnosis	**Encounters during 13–17 y**	**%**	**Encounters during 18–22 y**	**%**
Hospital admissions (total)	**1503**	–	**1312**	–
Ventriculo-peritoneal (VP) shunt complications and infections	173	11.5	122	4.3
Urinary tract infection	121	8.1	106	3.8
Neuromuscular dysfunction of bladder	53	3.5	19	0.7
Decubitus ulcer, stage 3–5	44	2.9	61	2.2
Acquired deformities of limbs	40	2.7	9	0.3
Scoliosis	44	2.9	6	0.2
Tubulo-interstitial nephritis, acute or chronic	25	1.7	34	1.2
Complications of procedures	24	1.6	31	1.1
Constipation	24	1.6	10	0.4
Congenital malformations of spinal cord	24	1.6	8	0.3
Emergency department visits (Total)	**3590**	–	**6000**	–
Urinary tract infection	425	11.8	659	6.9
Abdominal and pelvic pain	139	3.9	292	3.0
Headache	130	3.6	183	1.9
Cellulitis	116	3.2	218	2.3
Other medical care	83	2.3	139	1.4
Acute upper respiratory infections	79	2.2	92	1.0
Dorsalgia	63	1.8	137	1.4
Constipation	58	1.6	91	0.9
Convulsions	55	1.5	70	0.7
Limb pain	51	1.4	62	0.6

Table 3. Rates of emergency room visits for children with SB by age (unadjusted model) and baseline characteristics (adjusted models)			
Variable	**Adjusted**		
		95% CI	
	RR	**LCL**	**UCL**
Age (years)	1.00	0.98	1.02
Turning 18 years old	1.14	1.03	1.27
Rural residence	1.22	1.00	1.47
Gender (Female)	1.10	0.97	1.24
Distance to tertiary center (km)	1.00	–	–
<20	1.01	0.84	1.20
20–49	1.34	1.09	1.63
50–199	1.32	0.88	2.00
200+			
Income quintile			
1	1.11	0.90	1.35
2	1.17	0.96	1.44
3	0.99	0.81	1.22
4	0.92	0.75	1.14
5	1.00	–	–
Mobility restraints	1.74	1.07	2.83
Neuropathic bladder	1.20	1.03	1.40
Neuropathic bowel, constipation	1.04	0.90	1.20
Hydrocephalus	0.96	0.79	1.16
Developmental delay	1.20	1.06	1.37
Pressure ulcers	1.21	1.02	1.44
Urologic interventions	1.00	0.84	1.18
Ventriculo-peritoneal (VP) shunt	0.89	0.70	1.13
Complication to VP shunt	1.00	0.80	1.24

Unadjusted rates for age and turning 18 years old are available and similar to adjusted rates. CI: confidence interval; LCL: lower confidence limit; RR: relative rate; UCL upper confidence limit. Adjustment for local health integration network not shown.

Table 4. Rates of healthcare utilization (secondary outcomes) for patients with spina bifida (SB) turning 18 years old in adjusted models			
Outcome	**Adjusted***		
		95% CI	
	RR	**LCL**	**UCL**
Acute care			
Hospital admissions	0.79	0.66	0.95
Surgeries	0.80	0.64	1.02
Outpatient			
Primary care visits	1.00	0.88	1.13
Other specialist visits**	0.96	0.90	1.01
SB specialist visits***	0.81	0.75	0.87

*Adjusted for all baseline covariates, not shown in this table. Unadjusted rates are similar.

**Other specialists are all non-primary care physicians who are not SB specialists

***SB specialists include neurology, neurosurgery, physiatry and rehabilitation medicine, orthopedic surgery, and urology. CI: confidence interval; LCL: lower confidence limit; RR: relative rate; UCL upper confidence limit.