

Ambulatory Care Use among Patients with Spina Bifida: Change in Care from Childhood to Adulthood



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Abbreviations and Acronyms

DNT = patients 18 years old or older still followed in at least 1 pediatric clinic

PM&R = Physical Medicine and Rehabilitation

SB = spina bifida

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Purpose: We examined the ambulatory health care visit use of children with spina bifida, adults who transitioned to adult care and adults who continued to seek care in a pediatric setting.

Materials and Methods: We evaluated use during a 1-year period of patients with spina bifida who visited any outpatient medical clinic within an integrated health care system. Patients were categorized as pediatric (younger than 18 years) or adult (age 18 or older). Adults were divided into those who did not fully transition to adult care and patients who fully transitioned (adult). Frequency and type of health care use were compared. Subanalysis was performed for patients 18 to 25 years old to examine variables associated with successful complete transition to adult care.

Results: During 1 year 382 children, 88 patients who did not transition and 293 adult patients with spina bifida had 4,931 clinic visits. Children had greater ambulatory care use (7.25 visits per year) compared to fully transitioned adults (5.33 visits per year, $p=0.046$). Children more commonly visited surgical clinics (52.3% of visits) and adults more commonly visited medical clinics (48.9%) ($p < 0.005$). Adult transitioned patients were more likely to be female ($p=0.004$). Of the patients 18 to 25 years old, those who did not transition to adult care had similar outpatient visit types but greater use of inpatient and emergency care than those who transitioned.

Conclusions: Children with spina bifida used more ambulatory care than adults and were more likely to visit a surgical specialist. Adult patients with spina bifida who successfully transitioned to adult care were more likely to be female, and patients who failed to transition were more likely to receive more inpatient and emergency care.

Key Words: transitional care, spinal dysraphism, meningomyelocele, ambulatory care

WITH improved medical and surgical care 85% of patients with spina bifida are now living well into adulthood.¹ For the first time there are now more adults living with SB than children.¹⁻⁴ These patients have complex health care needs requiring

multi-subspecialty care coordination throughout their lives. Consistent care in the outpatient setting is thought to help these patients stay healthy and avoid potentially preventable adverse outcomes that require hospitalizations, surgeries or emergency department

visits.²⁻⁵ Age appropriate care can also help patients achieve their fullest potential as adults.⁶ However, it is well-known that transitioning patients from the pediatric to the adult setting can be problematic, with many patients never transitioning and others becoming lost to followup altogether.^{7,8} As such, there has been great effort from many major medical organizations to improve transitional care.^{6,9,10}

A major limiting factor in implementing effective transitional care is our poor understanding of exactly what care these patients need. Their health care needs undoubtedly evolve and change over their lifetime. Since the aging patient with SB is a relatively new phenomenon, these changes remain poorly defined. While there are reports on how patterns of inpatient admissions, emergency department visits and surgical use of these patients change as they age,^{2,4,5,11,12} an understanding of their outpatient care use is lacking. Additionally, use by patients who do not transition may be different from that of those who do transition, but these differences remain unclear. An improved understanding of the ambulatory care use of patients with SB across a life course and the use unique to the patients who do not transition can help providers better structure and facilitate patient centered transitional care.

We sought to gain a better understanding of the ambulatory health care used by various populations of patients with SB, including children, adults who fully transitioned to adult care and adults who have not transitioned. The primary aim of the study was to compare the type and frequency of nonemergent outpatient health care use among those 3 groups, namely what providers do they see and how often. We hypothesized that use remains consistent over time, with adults seeing the same types of providers with the same frequency as children. For the second aim of the study we performed a subset analysis on all young adult patients (18 to 25 years old) to examine use differences between patients who did and did not transition at a center that currently lacks a formal transition process. We hypothesized that those young adult patients who do not transition have significantly greater use of all types of care than those who have successfully transitioned. This knowledge will help determine the transitional care model that may be most effective for patients with SB, both at our institution and beyond.

MATERIALS AND METHODS

After approval from the institutional review board at the University of Michigan we used an ICD coding algorithm to identify all ambulatory care visits made by a patient with SB to any department within a single integrated health system during a 1-year period between 2012 and

2013. This process identified all visits made by a patient with SB, regardless of whether the chief complaint or diagnosis code for the encounter was directly related to their SB status. A chart review was performed to confirm the diagnosis for all patients. The pediatric and adult hospitals are part of the same institution and use the same electronic medical record, allowing us to track all visits across both hospitals.

An ambulatory care visit was defined as any visit in which the patient was cared for by a therapist, advanced practitioner or physician. Visits for ancillary diagnostic studies such as lab draws, imaging studies and other clinic procedures were excluded from analysis. Similarly, emergency room visits, surgical procedures and inpatient admissions were excluded from the ambulatory care visit definition and were recorded separately. The visits were categorized into surgical, medical and therapy visits based on the type of provider seen. A child was defined as a patient younger than 18 years, a patient who did not transition was defined as a patient 18 years old or older (no upper age limit) who was still seen in at least 1 pediatric clinic, and an adult was defined as a patient 18 years old or older seen exclusively in adult clinics. The age of 18 was chosen due to an institutional policy that all patients 18 years old or older must be seen in the adult emergency department. Currently there is no formal process or target age for transition of our patients with SB. Instead, each physician determines the timing of transition for each patient.

For our primary analysis we compared the number of visits and type of clinics visited among the pediatric patients, DNT and adult patients. For our secondary analysis we looked at all patients 18 to 25 years old, which is the time when transition often occurs. We excluded DNT and adult patients older than 25 years. After identifying within this cohort those patients who had transitioned and those who had not, we compared the number of nonemergent ambulatory care visits during the 1-year period. We then evaluated for ongoing issues that could impact transition readiness in this group of 18 to 25-year-olds. Specifically, we determined the number of hospital admissions, emergency department visits and surgeries these patients underwent during a 2-year period between 2011 and 2013. We compared the results between those who had and those who had not yet transitioned. We also evaluated possible sociodemographic factors that could impact transition readiness such as proximity to the hospital and insurance status.

Analysis was performed using parametric and nonparametric bivariate analysis, including the chi-square, t-test, Wilcoxon rank sum and Kruskal-Wallis test. All analysis was performed using STATA® version 14.

RESULTS

There were 4,931 ambulatory care visits to 76 clinics among 763 patients with SB during a 1-year period. Patient demographics for the entire cohort are detailed in table 1. Adult, fully transitioned patients were more likely to be female compared to DNT and the pediatric patients (69% vs 55% vs 57%,

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