



Urologic provider experiences in transitioning spina bifida patients from pediatric to adult care

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Abstract

Purpose The lack of precedent in transitioning from pediatric to adult care poses a challenge to providers for patients with spina bifida (SB). The purpose of this study was to summarize perceptions about best practices for the care of adult spina bifida patients.

Materials and methods A national survey was electronically distributed to 174 urologists who are current members of the Spina Bifida Association Network and AUA Working Group on Urologic Congenitalism. De-identified voluntary responses were assessed for implementation of and barriers to interdisciplinary adult SB clinics, continuity of care, and practices for transitioning from pediatric to adult care.

Results The response rate was 40% with urologists practicing pediatrics, genitourinary reconstruction, female pelvic medicine and general urology. Patients undergoing transition or who have transitioned were seen in a multidisciplinary clinic (14%), regular adult clinic (34%), combined adult–pediatric multidisciplinary care (20%), or pediatric multidisciplinary clinic (28%). A majority believed transitioning to adult care should occur at 18 (24%) or 21 years (22%). In the absence of acute changes, providers followed adult SB patients annually with upper tract imaging (typically renal ultrasound) and serum creatinine. Acute urologic changes were preferentially managed with urodynamic testing and cystoscopy. Providers identified a need for multidisciplinary care in adult life, with neurosurgery/neurology (87%), social work (84%), and orthopedics (73%).

Conclusions Potential solutions to improve the urologic care of this population suggest additional national provider resources, standardized guidelines, multidisciplinary collaboration, access to care, and an advanced-training pathway to improve care of adult patients with spina bifida.

Keywords Spina bifida · Transitional care · Neurogenic bladder

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Introduction

Spina bifida (SB) is the most common congenital neural tube defect, accounting for 1500 births in the United States each year [1]. Improvements in the multidisciplinary care of pediatric patients with SB have resulted in a large population

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of adults with SB [2, 3]. The quality of life and common health problems encountered for SB patients in adulthood are incompletely characterized, but practical experience suggests that many do encounter ongoing health problems in adult life. Common neurologic concerns include possible shunt malfunction, progressive functional changes from tethered cord or secondary spine problems [4]. Orthopedic injuries can occur in lower and upper extremities, especially degeneration complications associated with wheelchair or ambulatory assist devices [5]. These injuries can include pressure ulcers, joint problems, and progression of skeletal deformities [6]. Neurogenic bowel problems, similar to neurogenic bladder symptoms, can be progressive into adulthood and also require changes in medical management or surgical intervention [7]. Urologic complications stem from neurogenic bladder, and may progress to upper urinary tract deterioration [8–10]. Many adults with SB are lost to routine follow-up; in one series 44% of patients required a surgical urological procedure in adulthood [11–13]. One potential barrier to routine follow-up in adulthood has been a lack of transitional care.

As pediatric patients transition care to adult specialists, there is a lack of precedent for coordinated multidisciplinary care as is common in pediatric life, posing as a unique challenge to patients and caregivers. The purpose of this study was to summarize perceptions and best practices of adult urologic providers for adult SB patients in North America.

Methods and materials

Following institutional review board approval, a survey was developed and electronically distributed to 174 current urologic provider members in the Spina Bifida Association (SBA) Network and members of the American Urological Association (AUA) Working Group on Urologic Congenitalism. Participants were required to treat patients with spina bifida in their urologic practice. The purpose of this survey was to evaluate urologic trends in care in the absence of published guidelines for optimal urologic and multidisciplinary management of patients with spina bifida. Survey questions were, therefore, based on published literature highlighting primary urologic and overall care goals [13, 14]. Participants were initially sent the survey in March and closed in April of 2016. Seventy-nine voluntary de-identified responses were assessed. Participants were given the option to answer all or some of the survey per their preference. Participants also identified current specialties involved in their multidisciplinary experiences and selected specialties they considered to be essential to the care of adult patients. The major urologic themes surveyed were: (1) perception and integration of multidisciplinary approaches, (2) protocols and tools used for urological surveillance, and (3) transition strategies and

perceptions. Responses were summarized with descriptive statistics to illustrate current practices in the United States and Canada.

Results

The response rate was 40% comprised of urologists practicing pediatrics (55%), female pelvic medicine and reconstructive surgery (FPMRS) (17%), genitourinary reconstruction (10%) and other (18%). A majority of providers (84%) reported that they treat adults with SB. When asked to describe the clinical model that most closely approximates their practice environment for adult SB care, over half stated that they treat patients in “regular clinic” (34%) or in a pediatric multidisciplinary clinic (28%). A minority reported treating these patients in an adult–pediatric multidisciplinary (20%) and adult-only multidisciplinary (14%) clinics (Fig. 1). Most clinicians believed transitioning should occur between 18 (24%) and 21 (22%) years of age. Among pediatric urology responders, average age for transitioning to adult care was 19 years, FPMRS average age was 19 years, GURS average age was 17 years, and urologic providers who did not identify a subspecialty average age was 19 years. Only 1% of providers endorsed waiting to transition patients from pediatric to adult care upon an inciting event or acute change in a patient’s condition.

Urologic surveillance for routine (non-acute) follow-up demonstrated a 78% preference for seeing patients annually. Upper urinary tract imaging was recommended annually by over half the respondents (55%). Other respondents recommended upper tract imaging at 1.5 years (10%), 2 years (23%), or were unsure (11%). The preferred imaging modality for upper tract surveillance was renal ultrasound (91%). Similarly, renal functional assessment was recommended annually (53%) or biennially (23%). Both baseline assessment and surveillance of renal function with serum

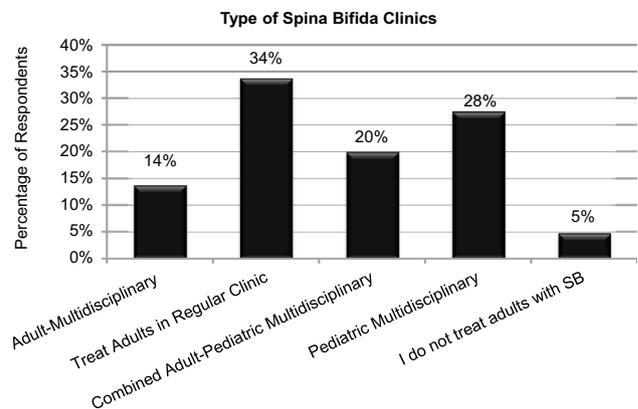


Fig. 1 Types of SB clinics per survey participant responses

creatinine and/or calculated estimates (93%) were favored by a majority of survey participants, 17% of whom also included Cystatin C, and 5% who performed surveillance with Cystatin C exclusively. In the management of any bladder complications, cystoscopy was performed dependent on contact between the urinary and bowel system (50%) or when there is an acute change in the patient’s urological condition (32%). Most respondents (80%) utilized urodynamic testing only when there was a reported change in the patient’s urological condition.

Even though the respondents represent a select group of providers specialized in the care of patients with SB, most of the clinics had a relatively small population of adult patients, with 59% reporting annual populations ≤ 50. Survey respondents were asked to describe the specialties involved in their own adult SB multidisciplinary clinics and compare it to the services they believe essential for optimal care. The most common specialties (in addition to urology) were neurosurgery/neurology (85%), orthopedics (74%), medicine/pediatrics (52%), physical therapy (72%), occupational therapy (59%), and social work (74%). The distribution of specialties described as “essential” or necessary for adult patients in a multidisciplinary clinic were: neurosurgery/neurology (87%), orthopedics (73%), physical therapy (66%), occupational therapy (52%), and social work (84%) (Fig. 2).

When respondents were asked to describe obstacles to establishing an adult-only multidisciplinary clinic and creating a successful transition experience from pediatric clinics, lack of resources to organize and execute a specialized clinic was most common, followed by inability to identify adult providers to staff the clinic, a belief that multidisciplinary

care is unnecessary, lack of administrative support from the department and/or hospital, the provider did not feel he/she had the skillset, or there are not enough patients to justify a multidisciplinary clinic (Fig. 3). For urologic practitioners who do not have a dedicated adult SB clinic, the most common barriers to implementing adult multidisciplinary clinics are inability to identify adult providers to the staff the clinic (42%) and belief that it is not necessary (19%).

Looking to the future, less than 5% of the extracted responder comments for areas of improvement revolved around improved patient education; whereas the greatest support revolved around development of care guidelines (22%), improved provider collaboration (18%), improved access and advocacy for this population (15%) and development of an advanced-training pathway for providers (15%) (Fig. 4).

Discussion

This study describes current practices and barriers to advances in the multidisciplinary care of adults with SB among a select population of urologic practitioners. These providers were identified through professional associations they have established within the urological and SB

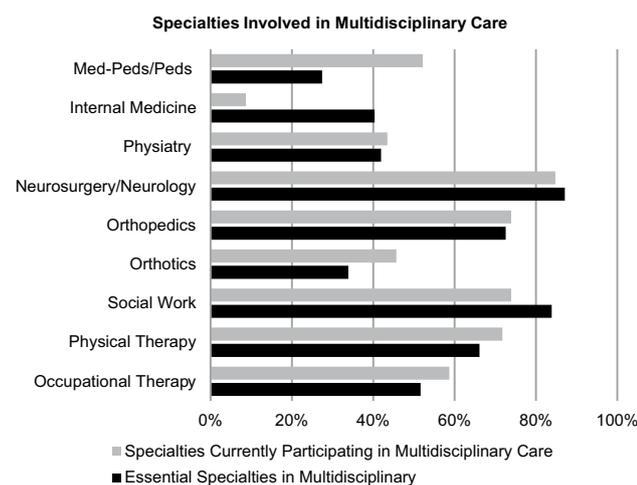


Fig. 2 Comparisons of current provider involvement in adult multidisciplinary clinics and ideal provider involvement in addition to urologists both in 2016 and 2006. Please note 2016 survey respondents identified additional specialty care not including urology

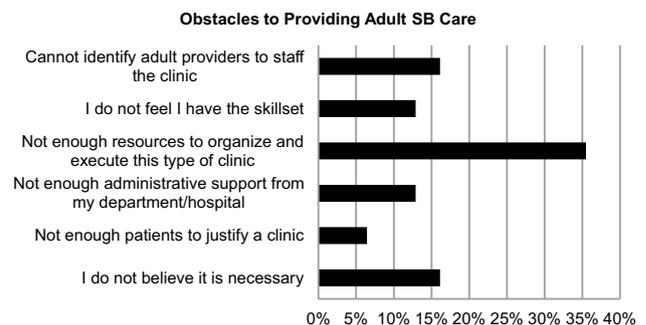


Fig. 3 Urologic provider obstacles to providing longitudinal care to adult patients with SB

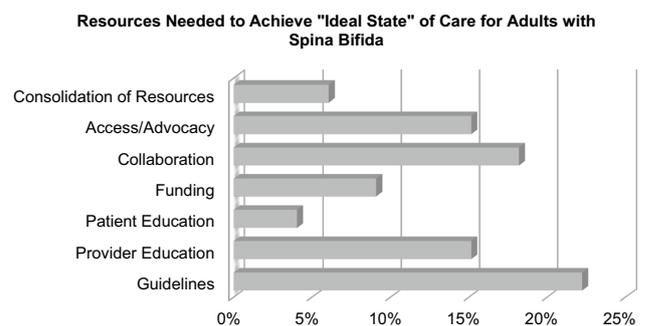


Fig. 4 Future resources identified by providers to facilitate pediatric to adult care pathways for patients with SB

communities and, therefore, represent a cohort of highly experienced urologic providers for SB care. Despite the expertise of this cohort, our data suggest there remains little consensus on how adults with SB should be monitored and a wide variety of suggestions about the barriers to multidisciplinary care. These results, while not particularly surprising, are alarming. If a group of experienced professionals are not unified in their approach to this population, then we remain quite far away from developing guidelines that can be utilized by the general urological population. However, these responses suggest contemporary changes in adult care of patients with spina bifida. A previous study subcontracted by the Agency for Healthcare Research and Quality (AHRQ) in 2006 evaluated practice patterns of SB care in 172 clinics (73 responded). The results of this study compared to our study a decade later show an increase in urologic and interdisciplinary care provided to adult patients. In contrast to our study, only 41% of the respondents in the 2006 survey stated that they served adult patients, and those adult patients are receiving more interdisciplinary services [neurosurgery/neurology (59% vs. 87%), social work (68% vs. 84%), and orthopedics (59% vs. 73%)] (Fig. 2) [15]. Though not emphasized by survey responders in this study or in the AHRQ 2006 study, gynecologic care for sexual/reproductive health and gastroenterology for neurogenic bowel management among adult patients should be incorporated into multidisciplinary care. There remain no data to determine whether the uptick of adults being served is a reflection of population growth or greater awareness of the importance of routine care for adults with SB.

The literature is robust with evidence that the US medical system as it stands has not performed well in transitioning pediatric patients with chronic and congenital conditions to adult care [16]. Even in well-established urologic transition programs, rates of successful transition are less than 50% [17]. However, particularly in urology, transition is imperative, as the spectrum of “adult urology” extends to include sexual and reproductive health [18]. This necessitates a urologic care plan as patients transition to adulthood, requiring establishing care with a new urologic provider or continued care with the same urologist. Despite widespread acknowledgement that transition is important in urology, particularly for young people affected with SB, there remains a paucity of literature to guide providers in which model is most effective [19]. It is, therefore, not surprising that there remains heterogeneity in basic aspects of transition, including what age it should be initiated, and what types of providers will serve this population most effectively.

Even though most respondents recommended routine follow-up annually or biannually, many adults with SB demonstrate a low level of compliance with routine following. In fact, many only visit their health care providers when there is an active and/or acute urologic problem

[20–22]. The reasons for noncompliance with routine follow-up among adults with SB are poorly understood, but many speculate they are multifactorial [23]. Patient education has been widely cited as an important mechanism to overcome this challenge [24]; however, the respondents in our study curiously pointed to other opportunities to create an “ideal” state for these patients. The greatest support for areas of improvement revolved around development of care guidelines, improved provider collaboration, improved access and advocacy for this population and development of an advanced-training pathway for providers—with few responders commenting on further efforts in patient education. Additional research into the deficiencies of the present system and obstacles for both patients and providers in achieving routine, high-quality care is sorely needed to address the unique and challenging urologic problems experienced by patients with SB [25, 26].

There are limitations to this study, including the highly select group of providers who were invited to participate, with a survey response rate of 40%. We do not believe that these findings are generalizable across the whole spectrum of the population of urologic care providers, and may be skewed based on responder practice settings and expertise. In efforts to maintain anonymity, regional status, practice type, and years in practice were not collected from respondents, but could have further informed barriers to care between rural and urban areas, academic and private or community practice centers. Most importantly, this study is one sided, representing only provider views about barriers and needs. The patient’s voice is not represented herein to inform future longitudinal care protocols. Further barriers to patient participation such as insurance status, access, patients’ preferences, and adequate education about past medical and surgical history in the setting of adult multidisciplinary care cannot be assessed by this survey [27].

Conclusions

For urologic management of adult patients with SB, most respondents report a preference for annual office visits and upper tract surveillance, preferably with renal ultrasound and serum creatinine in the absence of any acute changes in condition. The major roles for cystoscopy and urodynamic testing in the adult SB population were in the setting of acute urologic complaints or changes, not routine surveillance. Survey respondents highlighted the contemporary necessity of longitudinal multidisciplinary care between medical providers, occupational therapists, and social services.

This national study highlights the present state of adult SB care and future needs as reported by expert providers in the field. Potential solutions to improve the urologic care of this population are suggested, and include creation of

advanced-training opportunities to better equip providers and establishment of standards and tools to permit general providers to partner with specialists in the ongoing surveillance and healthcare of this population. Our results show that urologic experts identify an important role for continued multidisciplinary care for adults with SB, including neurosurgery/neurology, orthopedics, physical therapy, occupational therapy, social work, physiatry, internal medicine, orthotics, and wound care, though outcome data to demonstrate this are currently lacking.

Author contributions SA, HW: project development, data collection/management, data analysis, manuscript writing/editing. KS: data analysis, manuscript writing/editing. TW: project development, manuscript writing/editing. SK: project development, manuscript writing/editing.

Compliance with ethical standards

Conflict of interest The authors have no conflicts of interest to report. There were no sources of funding for this study.

Human and animal rights This type of study did not involve patients, as it was a survey. For this type of study, formal consent was not required, but survey participants agreed to participating in this institutional review board (IRB)-approved study software prior to initiating the survey.

Informed consent Formal informed consent was not required for this type of study, but all participants were informed of the purpose of this IRB-approved study and understood no identifying details were collected in the process of this survey, and all responses were securely stored and remained confidential. Participants agreed to this statement prior to initiating the survey.

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