Growing up with spina bifida: bridging the gaps in the transition of care from childhood to adulthood

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Spina bifida is the most common nonchromosomal birth defect, resulting in permanent disability of multiple organ systems, yet compatible with long-term survival. Important advances across various disciplines have now improved survival among the spina bifida population. Although the majority of individuals living with spina bifida are now adults, there are few publications in the neurosurgical literature regarding the care of adults with spina bifida, associated medical conditions, surgical interventions, and long-term complications. The major goals for transitioning adult patients with spina bifida are preservation of function and promotion of independence as well as general overall health. Nevertheless, many gaps exist in our knowledge and understanding of the complex needs of this aging patient population. The goal of this paper was to provide a comprehensive updated review of the literature regarding the challenges and considerations involved in the transitional care to adulthood for patients with spina bifida. Unique to this review, the authors provide a first-hand personal communication and interview with an adult patient with spina bifida that discusses many of these challenges with transition.

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SPINA bifida (SB) is the most common nonchromosomal birth defect compatible with long-term survival affecting multiple organ systems.⁸ Currently, most coordinated care efforts for SB remain within the pediatric specialties, and most clinics stop following patients after the ages of 18–21 years. Although awareness is increasing, few centers specialize in the transitional care of SB patients to adulthood.^{2,10,11,24} The survival rate for patients with SB has greatly increased from 10% in the 1950s. Age impacts health in this patient population due to the changes in medical management of infants and children over the last several decades.⁸ Today, the majority of individuals living with SB are adults, yet there is a paucity of neurosurgical literature regarding adults with SB and associated medical conditions, interventions, and long-term complications. In light of the recently published SB guidelines,⁶ this paper provides a comprehensive review

regarding the care of the aging SB population related to associated conditions and the challenges involved in transitional care of these patients.

Mortality and Survival in SB

Prior to the 1970s, the mortality rate for SB patients was nearly 38%. Today, due to advances in healthcare, the survival rate for patients with SB is upward of 75%.^{24,34} Patients born before the mid-1970s have health problems that are significantly different from patients born after due to aggressive neonatal care, preventative bladder/catheterization programs, supportive home care devices, and advancements in neuroimaging that allow for improved radiographic evaluation, among others.^{2,10,11,19} In the 1990s, latex allergies were identified in nearly 70%–100% of all SB patients, with latex exposure placing these patients at a

ABBREVIATIONS CM-II = Chiari malformation type II; CPC = choroid plexus cauterization; ETV = endoscopic third ventriculostomy; NSBPR = National Spina Bifida Patient Registry; QOL = quality of life; SB = spina bifida; TCS = tethered cord syndrome; TRAQ = Transition Readiness Assessment Questionnaire.

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500-fold higher rate of anaphylaxis during anesthesia induction. Enforcement of latex precautions and availability of nitrile-based gloves in the healthcare setting have made these life-threatening events less likely.²⁶

A longitudinal cohort study of 117 SB patients treated between 1963 and 1971 in the United Kingdom showed that 39% of patients survived to age 40 years, with a median survival of 28.5 years.³⁰ This study showed that the sensory level at birth correlated to long-term outcome; patients with sensory function at the level of the knees had 61% survival, while those with no sensation below the umbilicus had only 17% survival. Patients who did not require CSF diversion with shunting and/or did not have a shunt revision tended to live independently, drive a car, and were community ambulators. When this cohort was followed to age 50 years, there were a total of 37 survivors (31% survival); patients born with a sensory level below L3 had a higher survival rate than those with higher sensory levels (54% vs 22%). Fifty-four percent of patients who survived at age 50 years were living independently, and those without a history of hydrocephalus or shunt revisions were more likely to live independently.³¹

A study of 153 patients between 1995 and 2015 showed promising results for SB patients receiving aggressive care from the time of birth.²⁵ Only 3% of patients who underwent myelomeningocele closure within 24 hours of birth died by age 1 year. Factors associated with early mortality included low Apgar scores, hydrocephalus, and Chiari malformation type II (CM-II) with central respiratory abnormalities present at birth. Despite improved mortality, the overall morbidity remained high. Hydrocephalus was very common, with 90% of patients requiring shunting or endoscopic third ventriculostomy (ETV) at a median age of 5 days. It was found that patients with a higher myelomeningocele level were more likely to require a shunt; 93% of patients with a defect level at L5 or above required shunt placement, while only 56% with a defect level at S1–2 required a shunt. Many patients had symptoms of tethered cord syndrome (TCS), with 16% of patients requiring a detethering procedure. Eighteen percent of patients had symptomatic CM-II requiring decompression, with only 50% improvement; this subset demonstrated high morbidity (29% required tracheostomy and 34% required gastrostomy).²⁵ Considering these comorbid conditions, the remainder of this paper discusses the daily challenges that adult patients with SB encounter.

Urological Function

There is variable impact of SB on parasympathetic and sympathetic innervation of the bladder. Poor bladder dynamics can often lead to chronic kidney disease.⁴⁵ Urological function plays a significant role in the quality of life (QOL) of patients because it promotes both independence and social participation.^{18,20,27,48} Achieving bladder continence is a lifetime goal for SB patients, and the goals of treatment evolve as the patient ages. In the newborn phase, preservation of renal function is the primary goal. At school age, urine and fecal continence are paramount in promoting social participation. As puberty approaches for the adolescent/young adult, independence, self-care, and

sexual function become more relevant. The onset of adulthood poses an extremely difficult time for SB patients, and care transition becomes yet an even more important concept.

Reports have suggested that patients with myelomeningocele, shunted hydrocephalus, and higher lesions are at increased risk for neurogenic bladder and incontinence.⁴⁵ Liu et al.²⁷ conducted a longitudinal study of bladder continence in SB patients using the National Spina Bifida Patient Registry (NSBPR) and showed that both aggressive bladder management and surgical treatment are key interventions for achieving bladder continence (Table 1). Furthermore, a strong relationship exists between bladder management and continence in patients with myelomeningocele.^{27,57} While this correlation was present, approximately 43% of patients had a steady continence status, while the remaining patients had changes in their continence status with either improvement or regression.²⁷

Bowel Function

Up to 70% of SB patients face challenges with bowel control as a result of the variable loss of sensory and motor nerve function affecting the gastrointestinal tract. Loss of intestinal peristalsis, rectal sensation, and anal sphincter function often result in a mixed clinical presentation of constipation and bowel incontinence.⁵² As with urinary incontinence, loss of bowel control affects QOL, interfering with social relations and self-esteem. A study by Rocque et al.³⁶ found that children older than 5 years with SB and bowel incontinence had a significantly decreased health-related QOL than those with bowel control. As patients with SB age, the methods used to address bowel incontinence change. A study by Wiener et al.⁵⁶ utilizing the NSBPR found multiple examples of management algorithms varying with age. In school-aged children (ages 5–11 years), bowel management consists of timed evacuation, suppositories, and cone/mini enemas significantly more frequently than in adult patients (age 20 years and older). Adult bowel regimens, in contrast, were more likely to include standard/antegrade enemas, digital stimulation, or disimpaction. Adult patients were also more likely to have an antegrade colonic enema channel (Malone) creation or colostomy performed than school-aged children. These procedures are performed only after conservative efforts have failed to produce continence or when frequent fecal leakage leads to formation of severe sacral ulcers requiring intervention.

Data from the NSBPR also revealed a significant increase in continence levels between school-aged and adult patients, with only 45.2% of school-aged patients achieving continence while 58.3% of adult patients had achieved continence. The group of SB patients with the highest levels of continence are those who underwent Malone creation with full or partial continence levels upward of 63% and 21%, respectively.¹² However, this procedure should be reserved for patients in whom conservative medical management has failed, as it is associated with many complications, including stomal stenosis, stomal infection, and other stomal failures requiring revision.^{44,52} Because a higher proportion of adult SB patients have undergone

Malone creation, it is important for providers to recognize and treat these complications at an early stage to maintain continence.

Sexual and Reproductive Health

In a survey of young patients (ages 14–23 years),⁴⁰ 95% of patients and 59% of parents reported that they had inadequate education about reproductive health relating to SB. Healthcare providers frequently feel unprepared to discuss issues of sexuality with SB patients and cite the lack of formal training and knowledge gaps on the topics of sexuality, fertility, and pregnancy.⁴⁶ This presents quite a gap in a provider's ability to meet patient's needs, as 93% of young people and 100% of parents report that they would definitely talk about these issues if initiated by a physician.⁴⁰

Challenges faced by male SB patients may include erectile dysfunction, anorgasmia, retrograde ejaculation, and azoospermia.⁵⁵ Forty percent of men with SB reported that they had normal erections, with two-thirds of ambulators and one-sixth of nonambulators able to achieve erections.³⁷ Sildenafil is able to improve erectile function in 80% of male SB patients.⁴⁵ Females with SB may enter puberty and menarche earlier than their non-SB peers.⁵⁵ While society has frequently viewed women with SB as “asexual,” 92% are interested in becoming sexually active and 76% are interested in having children and a family.⁴⁶

In a survey of 60 adolescents with SB, only 68% and 70% recognized that women with SB can have menstrual periods and get pregnant, respectively.³⁹ Seventy percent of women with SB who conceive are able to have successful pregnancies;⁵⁵ however, providers and patients alike must be aware that the gravid uterus may affect shunt drainage, neurogenic bladder/bowel function, stomal patency, pulmonary function (especially in patients with kyphoscoliosis), as well as balance and ambulation. According to Shepard et al.,⁴³ women with SB have a higher rate of cesarean delivery than women without SB (53% vs 32%). Women with SB undergoing cesarean delivery had a higher rate of complications, including preterm delivery, urinary tract infection, and need for blood transfusion than those without SB. In the 46.7% of women in this study with SB who underwent vaginal delivery, no increased rate of complications was appreciated when compared with women without SB.⁴³

Mobility and Independence

The degree of disability in patients with SB is influenced by the spinal level of the defect. The level of the defect can be classified into 3 primary groups (thoracic/high lumbar, low lumbar, sacral), with subgroups within the lower-lumbar and sacral groups based on gluteal, quadriceps, and gastrocnemius-soleus muscle function.⁴⁷ A study evaluating factors associated with mobility outcomes in the NSBPR showed that shunted hydrocephalus, higher motor level, and history of hip and knee contractures were inversely associated with ambulatory status.¹⁵ The results of the MOMS (Management of Myelomeningocele Study) trial, in which prenatal fetal closure of myelomeningocele is offered in select cases, have significantly altered the

TABLE 1. List of various bladder management strategies and surgical procedures considered for patients with SB depending on indication

Bladder Management
Spontaneous voiding
Medication use (alpha-adrenergic agonist, alpha-adrenergic blocker, antimuscarinic)
Clean intermittent catheterization
Crede maneuver (application of manual pressure on the lower abdominal wall to eliminate urine)
Condom catheter use
Urostomy bag
Indwelling catheter
Vesicostomy
Bladder Surgery
Bladder augmentation
Appendicovesicostomy
Construction of cutaneous stoma of the urinary bladder
Bladder outlet operations
Closure of cystostomy
Bladder reconstruction
Surgical closure of bladder neck &/or other bladder neck operations

trajectory of outcomes for SB patients. In particular, the rate of shunting for hydrocephalus is decreased, there is reversal of hindbrain herniation, and improvement in motor function when compared with postnatal repairs thus contributing to overall improved mobility.^{1,23,29}

The lesion level plays a significant role in the ambulatory capacity of SB patients and the need for assistive devices. In a study by Bartonek and Saraste,⁵ the lesion level predicted the type of assistive device required, but not the successful use of the aid. Orthopedic problems also influence the mobility of patients with SB. Scoliosis is present in 47.7% of adult patients and osteoporosis affects approximately 50% of patients, with increased risk in females, those with a history of renal failure, prior ileal diversion, sedentary lifestyle, and use of steroids or certain antiepileptic medications. Most fractures were found to occur in the femur and tibia.¹⁶ Because wheelchair users rely on their arms for mobility, transfers, and activities of daily living, injury to the upper extremities can have significant impact on mobility and independence. The ergonomics of wheelchair use can contribute to upper-extremity strain and further susceptibility to injury.¹⁶

CSF Diversion

As mentioned earlier, SB is associated with a high incidence of hydrocephalus. Multiple long-term cohort studies examining patients born in the 1970s who underwent myelomeningocele repair found that 61%–86% of patients required intervention for progressive hydrocephalus.⁸ As a result of this history of frequent intervention, the majority of adult patients with SB remain shunt dependent and require care related to the maintenance of shunt patency and avoidance of complications. In recent years, the per-

centage of patients requiring CSF shunting has markedly decreased, largely due to the development and success of fetal myelomeningocele repair.

Hydrocephalus in SB patients has very high morbidity, resulting in a constellation of findings ranging from developmental delay to sudden death. As a result, these patients require early CSF diversion. Despite early intervention, the morbidity of shunted hydrocephalus remains high, as patients are at risk of shunt infections, shunt failure, and other complications. Multiple studies have shown that the etiology of hydrocephalus is not associated with shunt survival, and, consequently, patients with SB are not at higher risk of shunt failure than other shunt-dependent patients.³⁴ Nevertheless, the majority of shunt-dependent SB patients do face complications at some point in life. Bowman et al. found that 95% of shunt-dependent patients experienced at least 1 shunt failure requiring intervention. Many patients experienced multiple episodes of shunt failure, with 41% of the cohort having 2–3 shunt failures. Infection is also a common source of increased morbidity in SB patients, seen in 36% of shunt-dependent patients.⁸

The mortality rate in shunt-dependent SB patients also remains high. Davis et al.¹³ found that shunt-dependent patients who were alive at age 16 years are at increased risk of death before the age of 34 years. Only 75% of shunt-dependent patients survived to the age of 34 years, compared with 94% of patients without CSF diversion. This increased risk of mortality between ages 16 and 34 years once again demonstrates the importance of continued follow-up for SB patients into adulthood. Despite this crucial need, however, a study by Tomlinson and Sugarman found that adult follow-up is often lacking.⁴⁹ While 100% of patients younger than 16 years underwent an annual review of shunt function, this was only performed in 40% of adult patients. More recently, growing data support the role of ETV in the treatment of SB-related hydrocephalus.¹⁴ It has been reported that ETV can be successful in up to 50% of patients after failure of shunting.^{14,35} In addition to ETV, choroid plexus cauterization (CPC) appears to be more effective in the treatment of SB patients younger than 1 year; however, it is unclear if the same benefit persists in older age groups.⁵³ Further follow-up data and discussion regarding the role of ETV/CPC in the treatment of SB-related hydrocephalus is warranted.

Chiari Malformation Type II

CM-II is present in nearly all SB patients, with an incidence of approximately 0.5–1.0 per 1000 births in the US.^{7,42} CM-II is defined by inferiorly displaced cerebellar vermis, tonsils, and medulla, as well as hydrocephalus due to obstructed CSF outflow. Despite its near-complete association with myelomeningocele, CM-II is symptomatic in only 33% of patients.¹⁶ Patients with symptomatic CM-II may suffer from profound airway-related symptoms, including swallowing difficulties, stridor, aspiration, and apnea.⁵¹ These added issues may require multiple surgical interventions, including decompression surgery. Patients with CM-II were found to die at a significantly younger age than other SB patients, with mean ages at death of 40.5 and 56.3 years, respectively.¹⁶

In neonates and young children with symptomatic CM-II, the major goal is symptom management, particularly with CSF diversion and early surgical decompression. The primary goal of shunting is to achieve physiological intracranial pressure. Early shunting can often fully alleviate the patient's symptoms; in a study by Caldarelli et al.,⁹ 45% of CM-II patients had resolution of symptoms following the placement of a ventriculoperitoneal shunt. In patients who remain symptomatic despite this, early CM-II decompression may be more beneficial if performed before the onset of more severe symptoms, such as bilateral vocal cord dysfunction.⁵⁰ Young patients with CM-II may also require nonneurosurgical procedures for the management of neurogenic bowel/bladder, respiratory failure/central apnea, and feeding/swallowing difficulties.

As children with CM-II age, they may face several difficulties even after decompression. Sacco and Scott found that reoperation was frequently necessary after suboccipital decompression, required in 18% of their cohort of 33 patients, and most frequently due to the discovery of a syrinx or persisting neurological deficits.³⁸ In a study of 50 patients with CM-II, the most common complications requiring surgical intervention were shunt failure, syringomyelia, and scoliosis. Shunt revision procedures were required in 76% of patients. During routine imaging, 48% of patients had syringomyelia, 48% had scoliosis, and 24% had both.²⁸

Aging patients with CM-II are also at increased risk for central sleep apnea due to disruption of the central respiratory drive and compression of the medullary respiratory center.^{17,33} In a report by Waters et al.⁵⁴ investigating a cohort of CM-II patients with a mean age of 9.4 years, 42% of patients had a slightly abnormal breathing pattern on polysomnography, while 20% had moderately to severely abnormal breathing function. Risk factors associated with more severe breathing dysfunction included patients who used a wheelchair for ambulation, sensory/motor level above L3, and history of surgical decompression. The threshold for polysomnography in these patients should be low. A survey of SB clinics found that 11% of deaths in CM-II patients were related to respiratory failure, yet only 8% of these patients had undergone evaluation for sleep-disordered breathing.³ It is recommended that patients with risk factors for sleep-disordered breathing undergo nocturnal pulse oximetry screening; those with abnormal values should undergo polysomnography for definitive diagnosis.⁵⁴

Tethered Cord Syndrome

Secondary TCS is another complication faced by patients following surgical repair of spinal dysraphism. TCS usually presents in childhood at an average age of 6 years;²² however, late presentations are common and should be monitored for by providers. While often asymptomatic and incidentally found on MRI, postoperative secondary adhesion of the spinal cord can lead to late-onset pain and progressive neurological deterioration.³² Adult patients with TCS often face delayed diagnosis and onset of treatment due to late age of onset and vague presenting signs. Aufschneider et al.⁴ found a mean age at diagnosis of 36.5 years for adult-onset TCS. The most common presentation

was low-back pain. Due to the vague symptomatology, the pain was often initially attributed to more common etiologies such as trauma, excessive exercise, or spinal stenosis, delaying true diagnosis of TCS.⁴

In an evidence-based outcome study reviewing adult-onset TCS in patients postrepair, the authors showed that patients who had lower myelomeningocele levels were more likely to experience TCS and orthopedic and urological complications.²¹ It was suggested that surgery should be considered for patients with symptomatic TCS

confirmed by MRI, urodynamic studies, or somatosensory evoked potentials. While mortality secondary to TCS is low, the morbidity remains high. The complication rate following corrective surgery has been found to be 11%–36%, with the most common being wound infection, wound dehiscence, and pseudomeningocele.²¹ While rare, these patients should be monitored for intradural cauda equina abscess, a devastating surgical complication associated with paralysis and urinary incontinence. In addition, patients should be followed for recurrence, as

TABLE 2. Interview with a 33-year-old man with SB who transitioned to wheelchair at age 13 years with a past surgical history of a ventricular shunt with 5 revisions, tethered cord release, and baclofen pump placement

Q1	What challenges have you faced transitioning from care in a pediatric setting to an adult setting?	<p>“Not knowing where to go for questions and having a lack of contacts.”</p> <p>The patient explained that he had a period of time from approximately age 16–25 years where he had very few health issues related to his SB. He was seen by his pediatric neurosurgeon during that time and told that he would be no longer needing the physician's services. When his mother asked where they should go if they had issues with the shunt in the future, she was told to “Go to the nearest ER; any neurosurgeon can handle shunt issues.” When he did develop issues but was out of the age range of a pediatric neurosurgeon, he had a very difficult time determining where to turn.</p>
Q2	What advice would you give a current pediatric patient with spina bifida in transitioning from pediatric to adult care?	<p>“It's like planning for college. You don't start the day you graduate high school. You have to start preparing for it well before then.”</p> <p>The patient and his mother both reported that having resources and contacts identified before they are needed is important. Additionally, having a point person who would help coordinate care for an adult patient with SB would be very helpful.</p>
Q3	What resources do you find most helpful in contributing to your mobility inside and/or outside your home?	<p>“I think where there's a will, there's a way. I've adapted to the world I live in, because it can't always be adapted to me.” —patient</p> <p>“I think he got up there by sheer determination.” —patient's mother</p> <p>Mother: “[The] patient has ramps that he keeps in his trunk, so if he ever needs to get somewhere without a ramp, he can use those. He also has reachers.” She then described that the patient has always found a way to do something he wants to do, such as when visiting his sister in college who lived on the 3rd floor in a building with no elevator.</p> <p>Both mother and patient also stated that physical therapists were very helpful in generating ideas for ways to improve mobility, either in ways to modify activities to allow patients to participate or in different assistive devices that could improve mobility.</p>
Q4	What resources do you wish were available for young adult patients transitioning to adult care?	<p>Mother: “I think a way to transfer patient history. Maybe a log for patients to write down their history that tells us what information we need to know to transfer when we change physicians. Also, having a stable care coordinator. Someone who knows spina bifida patients and is able to provide contacts and guidance as issues arise.”</p> <p>They also mentioned that having a resource book for PCPs who care for SB patients would be helpful. “Our PCP is great but seemed a little lost on who to call for certain issues.” Resources to include in the book would be signs/symptoms associated with SB complications, contacts for specialty physicians for SB, community resources for SB.</p>
Q5	How frequently did you see a urologist/PCP/neurosurgeon as a child to evaluate your health and mobility? How often do you see them as an adult compared to how often would you like to see them?	<p>Growing up, the patient said he would see the multidisciplinary clinic every 4–6 months, more frequently if he was having issues. As an older teen/adult, he had a span of several years where he did not need to be seen by a specialist, from ages 16 to 25 years. When he did run into difficulty with spasms, it ended up taking 3 years to find the appropriate physician to diagnose and treat his spasms. During that time, he had loss of mobility and strength due to his spasms that he is working to regain.</p> <p>The patient and his mother estimated that once a year seemed to be an appropriate frequency to be seen in a multidisciplinary clinic, and that they would include assessment of strength/mobility as well as urodynamic evaluation to ensure that patients were not having a slow decline that they may not notice on a day-to-day basis.</p>
Q6	What advice would you give a neurosurgeon in caring for an adult patient with spina bifida?	<p>“Keep a broad differential; patients with spina bifida are complex.”</p> <p>The patient continued to state, “A single chief complaint may be related to any of a multitude of medical problems such as tethered cord, Chiari, shunt malfunctions, or orthopedic issues. Tell family ahead of time if you need history documents or other information.”</p>

ER = emergency room; PCP = primary care provider.
The patient was interviewed with his mother.

retethering is relatively common, affecting 25%–80% of patients.²¹ Close long-term follow-up is crucial in these patients to monitor for complications.

Transition of Care

Children's of Alabama was one of the first centers in the US to develop a successful transitional program for SB patients, termed the "Lifetime Care Model."²⁴ This program begins the transition process at age 13 years, when a patient's readiness to transition to adult care is assessed with the Transition Readiness Assessment Questionnaire (TRAQ), a validated, quantitative assessment of a patient's ability to manage his/her own care. From this point on, patients are gradually given more responsibility until they reach age 21 years, when they are fully transitioned from the pediatric to the adult clinic. This process is guided by an Individualized Transition Plan, a set of 5 measurable goals that are reassessed and updated each year during the transition. Two of the goals must be in the area of patient education and bowel continence, which have been found to be key limitations of independence in SB patients. The other goals are individualized and developed by the patient, primary caregiver, and provider. These goals should be designed to promote increased patient autonomy and responsibility for management of their own care.²⁴

A similar transition program has been developed at Gillette Children's Specialty Healthcare,⁴¹ in which outpatient resource nurses were asked to proactively assess SB patients and assist them in developing individualized transitional care plans between the ages of 11 and 17 years, with the goal of increasing independence before the transition from pediatric to adult care. The nurses met with patients monthly to develop, reassess, and modify realistic and individualized goals to increase independence and prepare them to manage their own care. While this program only assessed patients for 6 months, comparison of pre- and postintervention TRAQ scores showed an increase in both patient and caregiver comfort with the upcoming transition of care (20.2% and 18.6%, respectively).⁴¹

The importance of a standardized transition process is also emphasized in the 2018 Guidelines for the care of people with spina bifida.⁶ These guidelines encourage initial intervention at a young age, as patients with SB typically lag behind the general population in developing autonomy skills by 2 to 5 years. The guidelines recommend that between the ages of 12 and 14 years, patients should develop goals that will prepare them for self-management of their own care, and also for potential higher education, employment, or other long-term plans. As a supplement to our review and to emphasize the importance of transition of care in SB patients, we provide a first-hand interview with an adult SB patient and his mother discussing their personal experiences (Table 2). It is clear from the transitional systems established at various institutions that the patient must be at the center of this process, with their views and preferences taken highly into consideration for the overall transition to be successful.

Conclusions

Due to the medical advances over the past several de-

cades, the vast majority of children with SB now survive into adulthood. Despite these advances, patients with SB still suffer from significant functional sequelae that persist into adulthood. As clinicians, we must understand these complex conditions and implement a well-defined transition process from the pediatric to adult environment for patients with SB.

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Disclosures

Dr. Bierbrauer is a board member of the Spina Bifida Coalition of Cincinnati.

Author Contributions

Conception and design: Patel, Bierbrauer. Acquisition of data: Patel, Staarmann, Heilman, Mains, Bierbrauer. Analysis and interpretation of data: Patel, Staarmann, Heilman, Mains, Bierbrauer. Drafting the article: Patel, Staarmann, Heilman, Mains. Criti-

cally revising the article: Patel, Woodward, Bierbrauer. Reviewed submitted version of manuscript: all authors. Approved the final version of the manuscript on behalf of all authors: Patel. Administrative/technical/material support: Patel. Study supervision: Patel, Bierbrauer.

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