The urologist’s role in bowel management of adult spina bifida: a narrative review

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Background and Objective: Urologists are central to the coordinated care of patients with spina bifida (SB), and efforts to optimize bladder management and protection of the upper tracts are well established. However, the urologist’s role in treating this population often extends to the management of bowel dysfunction which may be less defined. The methods available to the urologist for bowel management range from lifestyle modifications to medical and surgical therapy, with many patients requiring combinations of multiple strategies to combat conflicting symptoms of constipation and fecal incontinence (FI). This narrative review aims to compile a detailed algorithm of management options, for the practicing urologist to more confidently address this important facet of care.

Methods: A detailed review was conducted using PubMed and Google Scholar databases to assess the contemporary literature surrounding neurogenic bowel dysfunction in adult SB. Articles published in English between 1990 and 2023 were considered.

Key Content and Findings: This review presents and investigates a schema of increasingly definitive and invasive treatments for bowel dysfunction including lifestyle adaptations, pharmacological treatment, transanal irrigation (TAI), sacral neuromodulation (SNM), antegrade continence procedures, and bowel diversion. TAI and medical bowel care are beneficial in postponing or avoiding more invasive surgical interventions. Should conservative measures prove ineffective, surgical management provides the most definitive bowel control.

Conclusions: Symptoms of constipation and FI that result from neurogenic bowel are best managed with an individualized approach guided by the general treatment algorithm presented in this review. Educated on the numerous appropriate options, patients will often trial methods before proceeding with more invasive treatments. Additional work is required to further evaluate management options specific to the SB populations, especially in more contemporary and largely experimental treatment modalities such as SNM.

Keywords: Neurogenic bowel dysfunction (NBD); spina bifida (SB); fecal incontinence (FI); constipation; antegrade continence enema

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Introduction

Spina bifida (SB) represents the most common congenital malformation in the United States, affecting 1 in 2,758 live births (1). While the exact cause of SB is largely unknown and likely multivariable, the best-described mechanism centers around folic acid metabolism, supported by a 34% decrease in the incidence of SB following the widespread fortification of grain products (2,3). However, folic acid deficiency appears to be one of many potential contributing factors, and individuals with SB remain a considerable patient population requiring complex and coordinated, lifelong medical care (4).

While the urologist’s primary aims in SB have classically centered around the management of urinary tract emptying with the goal of preserving renal function, bowel regulation plays an important and complementary, yet underappreciated role. Bowel dysfunction is typically associated with gastroenterology or colorectal surgery. However, a recent survey of 75 SB clinics revealed that urology is the leading specialty primarily responsible for neurogenic bowel dysfunction (NBD) management (39%) in this unique population (5). Further, urologists perform 65% of their NBD-related surgeries. The physiology of a functioning bowel relies on peristalsis to propel the stool forward and a pair of anal sphincters to hold or pass stool at a voluntarily initiated time. In patients with SB, deficient innervation to the bowel leads to NBD, analogous to neurogenic bladder. Dysmotility of the bowel walls causes slow passage and accumulation of stool in the distended bowel. Sphincteric dysfunction alongside diminished sensation of the rectum filling with stool can contribute to constipation or provoke involuntary leakage (6). As a result, NBD tends to manifest as a constantly shifting spectrum from constipation to fecal incontinence (FI).

A continent bowel has been positively associated with employment for young adults with SB, demonstrating the importance of bowel management in this age group (7). At the time of transition from pediatric care, 34% of young adults with SB are fecally incontinent, and 77% view their FI as a major health issue (8). Constipation and FI can lead to social isolation and poor self-image while requiring a time-intensive bowel management. Therefore, NBD is a significant stressor on the patient’s quality of life (QOL), which may be assessed via a symptom questionnaire. Although not specific to the SB population, the NBD score has been associated with QOL impact and is commonly used to longitudinally trend bowel symptoms and satisfaction (9). Beyond QOL implications, complications relating to either FI or a distended bowel extend to hemorrhoids, anal fissures, skin breakdown, urinary issues, and the more serious autonomic dysreflexia or malfunction of an existing ventriculoperitoneal shunt (10,11). Specific to the urinary tract, a proper bowel program has been shown to mitigate some of these complications by improving overactive bladder and reducing the frequency of urinary infections. In a study by Radojicic et al., the treatment group of SB patients receiving standard bowel management experienced 50% longer dry intervals (12). A complementary study found a similar benefit to urinary infections, in that the bowel management group recorded a mean of 0.3 infections per year compared to 1.1 for the control (P<0.001) (13). For urologists managing adult patients with SB, addressing both urinary and bowel function is vital to optimize their care.

This narrative review discusses the urologist’s role in managing adult SB patients and explores a range of options for bowel dysfunction including lifestyle adaptations, pharmacological treatment, transanal irrigation (TAI), sacral neuromodulation (SNM), antegrade continence procedures, and bowel diversion. The goal is to present an algorithm of increasingly definitive and invasive treatments for the practicing urologist to more confidently address this important facet of care. We present this article in accordance with the Narrative Review reporting checklist (available at https://tau.amegroups.com/article/view/10.21037/tau-23-389/rc).

Transition to adult care

From birth (or even prenatally), SB is managed by a multidisciplinary team of pediatric neurosurgeons, orthopedists, urologists, and physician-extenders. However, SB patients in contemporary series are living considerably longer lifespans compared to historical cohorts. For children born with myelomeningocele, the most prevalent and severe form of SB, an estimated 46–75% now reach adulthood compared to merely 10% of those born before the 1960s (14). While pediatric multidisciplinary clinics are common at major medical centers, adult SB care is generally disparate and less coordinated. Of the clinics in the United States reported by the Spina Bifida Association, 97 serve children with SB while only 24 are available to adult patients (15). Furthermore, successful management strategies for pediatric patients could lose efficacy as their NBD progresses and anatomy changes with age. For the adult urologist, understanding each individual’s congenital anatomy, baseline function, prior surgeries, and previous effective and ineffective non-surgical management is
Clinicians may assess the likelihood of certain symptoms as well as treatment effectiveness in their SB patients by a number of predictors including the level of spinal cord lesion, subtype of SB (aperta vs. occulta), and presence of hydrocephalus. The resulting NBD from a spinal cord disruption, such as in SB or spinal cord injury (SCI), is further classified as reflexic or areflexic based on the lesion level. A dysfunctional bowel from a lesion at or above vertebra T12 is termed reflexic, due to the preserved reflex arc between bowel and spinal cord (10). Although these patients may not have conscious awareness of their filling bowel, clinicians can take advantage of their intact reflex for mechanical or chemical stimulation of peristalsis. However, more typical to SB is areflexic bowel, in which a lesion at L1 or below interrupts this reflex (16). Rectal stimulation may not be effective for this group, who instead rely on physical removal of stool by methods such as manual evacuation or enemas (10,16). Further, patients with a lesion at or above L5 have been found more likely to suffer from FI compared to patients with a sacral lesion (39.7% vs. 13.2%) (8). Instances of the more severe SB aperta (open SB) are associated with a higher prevalence of incontinence than those with SB occulta (40.8% vs. 8.1%) (8). Finally, patients with concurrent hydrocephalus have a significantly higher likelihood of developing FI than those without (46.2% vs. 10.0%) (8). Fortunately, upon transitioning to adult care, SB patients often present with a well-documented medical history from their extensive pediatric management.

Previous surgeries like appendicovesicostomy or antegrade continence enema alter the urologist’s surgical options as they consider future procedures. Across a lifetime of care, SB patients could require revisions or elect conversions of prior procedures (17). Specific considerations exist for patients following urological reconstruction (generally bladder augmentation or urinary diversion) using sections of terminal ileum, which is responsible for absorption of bile acids and vitamin B12. Stein et al. followed 157 patients post-augmentation or diversion and recorded chologenic diarrhea experienced by 30% (18). Fortunately, over time the liver is presumed to accommodate the lost bile, however, 5% of their patients required long-term management for diarrhea (18). Further, adult patients in this study demonstrated significantly diminished serum vitamin B12 by their fourth postoperative year (18). Accordingly, these operations necessitate close metabolic monitoring with potential supplementation for B12 specifically. Overall, the SB patient’s past medical and surgical history helps contextualize their current complaints and plan the next steps for bowel and bladder management.

**Literature search methodology**

A detailed literature review was conducted using PubMed and Google Scholar databases, including articles containing keywords and phrases, such as “neurogenic bowel dysfunction”, “spina bifida”, and “fecal incontinence” (Table 1). The search was initiated in September 2022 and continued into June 2023. Articles included in the review were published in peer-reviewed journals no earlier than
1990. References for included articles were also reviewed to include those studies that were also relevant to this review. In particular, the literature search was assisted by a recent publication from the Spina Bifida Association, the Lifespan Bowel Management Protocol, which details a protocol for adult NBD (16). The search was limited by the small number of existing studies specific to adult SB bowel management. Notably in the literature, studies of adult NBD management tend to focus on those patient populations with acquired dysfunction such as SCI, while pediatric studies are more likely to discuss SB or other congenital causes. As such, adult NBD due to SB presents a unique intersection between the two, with less representation among available studies. While primary consideration was given to studies of adult SB, articles regarding the general NBD population (SCI, multiple sclerosis) were included to supplement where evidence for the adult SB population was lacking.

Non-surgical management

The goal of all bowel management in SB is to increase the predictability of bowel movements, avoiding both constipation and FI. Conservative treatment of NBD is flexible, with a wide variety of lifestyle modifications and available pharmacological agents. Specific treatment choices depend on patient preference, independence, and dexterity. Finding homeostasis between FI and constipation can be challenging as medications targeting one tend to worsen the other.

Lifestyle adaptations

Management of NBD in SB is oriented by initial conversations about current bowel habits, goals for treatment, and realistic expectations of results. Patients may benefit from a bowel movement journal tracking time of day, frequency of incontinence, potential diet triggers, and stool consistency using the Bristol scale. A template bowel diary is referenced and available in the SBA’s Lifespan Bowel Management Protocol (16). Following this assessment, dietary changes should be directed toward correcting the patient’s current issues.

For patients with predominant FI, diet options include fiber and fluids to optimize stool bulk and consistency. Target consistency aims for moderate firmness to relieve FI, as loose or liquid stools are difficult for a dysfunctional sphincter to retain (19). Good sources of dietary fiber include whole-grain products, vegetables, beans, and fruits. Fiber supplements (also known as bulk-forming laxatives), such as psyllium and polycarbophil, are readily accessible without a prescription. The general consensus for fiber intake is that a moderate amount (15 up to 30 g/day as tolerated) is appropriate for adults with NBD, with excessive amounts having diminishing or adverse effects (20,21). In one study, adults with NBD placed on a high-fiber diet (>30 g/day) experienced increases in colonic transit time from 28 to 42 hours, a measure of worsened constipation (22). Adequate fluid facilitates the effects of other agents such as fiber supplements and osmotic laxatives, both of which function by pulling water into the colon. Individuals with NBD are recommended at least 1.5 L of daily fluids, though a large amount of fluid without corresponding amounts of fiber is thought to result in poorly formed stool (20,23). Additionally, SB patients may consider limiting alcohol, caffeine, prunes, and other foods that can lead to watery stools or trigger FI by a variety of mechanisms (21). The bowel diary becomes a more invaluable tool in determining each patient’s specific diet triggers.

Patients with primary constipation issues have access to various techniques to assist with defection including digital stimulation and manual evacuation of stool. Although these methods have been implemented successfully by SB patients, they are guided primarily by anecdotal evidence or small cohort studies using other NBD populations. The stimulation technique involves insertion and rotation of a lubricated, gloved digit in the rectum to dilate the canal and relax the surrounding muscle (24). In a study measuring peristaltic activity of adults with SCI, Korsten et al. demonstrated that digital stimulation promotes colonic motility (24). Manual evacuation is distinct in that the patient or caretaker uses a finger to directly withdraw the stool. A study with 181 young adults with SB found that 15% of their participants utilized manual evacuation as an effective part or sole method of their bowel regimen (8). Notably, successful digital stimulation relying on an intact spinal reflex arc will favor patients with reflexic bowel, while manual evacuation may be more appropriate for areflexic bowel (10,16). However, lacking strong evidence for many of these lifestyle interventions, the individual SB patient and clinician are encouraged to develop a flexible treatment plan that weighs heavily on personal preference and results. Further, patients must be comprehensively educated on both constipation and FI so that they are prepared to self-titrate regimens in the shifting landscape of their NBD.
Pharmacological treatment

If bowel management remains difficult following lifestyle modifications, oral and/or rectal medications can be added to further aid in bowel management. Because evidence is scarce for the use of laxatives specific to the SB population, administration of these agents for SB relies on expert opinion, results from the general population, and experience with other NBD populations such as SCI and multiple sclerosis (25). It is recommended that SB patients trial various options and combinations to determine their optimal regimen.

Oral medications

Oral medications are often accessible over the counter, and patients may have already tried multiple options. Any concurrent bladder medication (anticholinergics) that can exacerbate constipation should be noted, and their risks vs. benefits considered on a patient-by-patient basis (26). Typical oral treatment starts with gentle stool softeners, such as docusate sodium, or osmotic laxatives, such as polyethylene glycol (PEG) and magnesium hydroxide, which are safe for long-term use without significant tolerance (27). Stool softeners reduce stool firmness to alleviate constipation while osmotic laxatives draw water into the intestines facilitating an easier passage of stool (28). Stimulant laxatives, such as bisacodyl and sennosides, act on the colonic mucosa to promote peristalsis and secretions (29). In the general population, long-term treatment with stimulant laxatives has been associated with tolerance and effects on the colonic peristaltic musculature (30). However, for SB patients who require lifelong care for neurogenic bowel, these recommendations are conflicting. Regardless, only a small percentage (5%) of adults with SB will settle on a treatment regimen of oral medications alone (31). More likely is that oral laxatives become an important part of a combination of treatment methods.

Rectal medications

While effective for constipation, the longer and more variable action times of oral medications could lead to less predictable bowel movements. Fortunately, many of the same oral agents (osmotic and stimulant laxatives) are available in the form of rectal suppositories or mini-enemas with significantly faster action times. For example, oral bisacodyl has an onset of action at 6 to 12 hours, while a rectal bisacodyl suppository acts within 15 to 60 minutes (32,33). Initiating a suppository within 30 minutes of the planned bowel movement helps to prevent unpredictable FI. Even so, different suppository medications and preparations can influence patients’ bowel program times. A base of PEG for bisacodyl suppositories, for instance, has been shown to reduce total bowel program times to 43–51 minutes in SCI patients, nearly half the 75–102 minutes needed when using generic vegetable oil-based bisacodyl (28,34). As with physical stimulation, pharmacologic stimulation of the bowel will also be less effective for areflexic NBD, the presentation of most SB patients (10,16). In this case, results from SCI populations are useful but must be approached with caution. A list of bowel medications commonly used for NBD is shown in Table 2.

TAI

TAI involves instilling large volumes of fluid directly into the rectum and colon. While this intervention generally requires more time, supplies, and caregiver assistance than other conservative measures, it is indicated for patients who do not respond to lifestyle adaptations or medical management. TAI is effective for relieving functional constipation, and the timely evacuation of the bowels is favorable in managing FI as well by removing stool before its burden overcomes the patient’s weakened sphincter tone. Brochard et al. conducted a multicenter study of adult patients with SB suggesting that TAI is more effective than standard bowel management (lifestyle adaptations and pharmacological treatment). The irrigation group experienced significantly fewer incontinence episodes per week at week 10 as well as a greater improvement in NBD scores (43). For these reasons, many physicians and patients have lauded TAI systems, which have also been shown to enhance independence for individuals with reduced dexterity (44).

As an intermediate-level treatment, TAI can be useful in delaying more invasive surgical interventions or avoiding them entirely. In fact, TAI is a safe long-term treatment for NBD and an alternative to surgery for some patients (45). A recent study of patients with NBD planning to undergo combined bladder augmentation and Malone antegrade continence enema (MACE) showed that after 3 months of TAI, 83% of participants elected to forego the MACE procedure, having found irrigations to be adequate for their bowel management (46). While there is the potential risk of irrigation-related bowel perforation, this is extremely
uncommon with an incidence of 2 per 1 million applications of one commercial TAI system (47).

**Surgical management**

Surgical management remains an option for SB patients with otherwise refractory NBD. While surgical intervention is more invasive, not all procedures require bowel surgery, nor are all options irreversible. For SB patients who continue to struggle with QOL-altering NBD, the following surgical procedures should be considered.

**SNM**

Historically indicated for neurogenic bladder, implementation of SNM for FI was first demonstrated to be feasible in 1994 (48). Since then, SNM has been used sparsely for NBD and almost exclusively alongside concurrent bladder dysfunction, which is thought to respond to a similar mechanism of action: depression of afferent nerve signaling and manipulation of neuronal plasticity (49). As described in detail elsewhere, patients undergo initial implantation of electrodes into the S3 sacral foramen with a temporary pulse generator to evaluate for an adequate response. The anatomy of SB with malformed sacral foramina complicates the procedure, in which case, surgeons may prefer to perform an open approach (50). With >50% improvement in their symptoms during a 1–2-week trial period, patients may proceed with placement of a permanent subcutaneous generator (51).

SNM acts through an implantable device, presenting possible complications but also great potential improvements with advances in the technology. Complications of SNM include pain, infection, and device malfunction with...
reoperation rates (revision, replacement, or explant) as high as 35% in NBD patients (52). Even when complications are avoided, current SNM devices have limited battery life and require a replacement procedure every 4.4 years on average for non-rechargeable devices (53). Both Medtronic and Axonics have produced rechargeable generators for SNM with approximate 15-year lifetimes, although the recharging process increases the burden of device maintenance (54). SNM was historically a contraindication for magnetic resonance imaging (MRI), however, the MRI-compatible InterStim sacral neuromodulator developed by Medtronic has been shown safe even for lumbosacral imaging (55).

For the general NBD population, durable results following initial improvement of FI have been reported almost 10 years postoperatively (48). Only limited evidence exists to support SNM for bowel management of SB patients, although this treatment maintains the benefit of a trial period. In a study by Lansen-Koch et al., only 1 of 10 SB patients proceeded with a permanent implant. However, this patient experienced an improvement from 12 episodes of FI across 3 weeks down to only two episodes and continued to report good results at 7 years follow-up (50). Due to the lack of robust evidence and concerning sample sizes, neuromodulation cannot be recommended without caution. SNM poses a potential minimally invasive option for SB, however, the treatment remains altogether experimental for this population and requires further investigation.

**MACE and cecostomy**

As opposed to retrograde irrigation administered transanally, antegrade irrigation delivers fluid directly into the proximal colon through a surgically created stoma or a cecostomy tube. Individuals with SB who require antegrade irrigation should be carefully counseled on the distinct benefits and challenges of the two different iterations of treatment. Initially described in 1990, the MACE is a catheterizable channel to the cecum made from reappropriated bowel, generally the appendix (56). In the absence of concurrent procedures, a MACE can be created via a laparoscopic approach in the outpatient setting (57). The continent stoma allows an irrigation catheter to be placed into the cecum intermittently, reducing potential skin breakdown from a permanent device in contact with the skin. The most common complications related to a MACE are leakage and stomal stenosis. Stenosis rates range from 14% to 38%, and differences in incidence have been attributed to surgical technique (58,59). While many instances of stenosis require revision, minor stenosis is managed or prevented by more frequent catheterization or a plug for the stoma that is also useful for patients with leakage issues (60).

The percutaneous cecostomy is considered a less invasive alternative to a MACE (61). Cecostomy tubes are an option for patients lacking usable appendix tissue for a MACE, due to a prior appendectomy or previous use in a Mitrofanoff. The cecostomy tubes are also more easily revisable (by simply removing the tube), which may be desirable for patients. Tubes are placed percutaneously into the cecum and remain indwelling. Exchanges are performed by urology or interventional radiology annually or earlier in cases of tube malfunction or blockage. Multiple options exist, including the Chait Trapdoor™ that coils within the cecum and the newer AMT MiniACE™ featuring an internal balloon catheter. Regardless, while the less invasive cecostomy tubes offer the advantage of less leaking and stenosis compared to a MACE, the visibility of the device and possible skin breakdown may dissuade patients.

As both procedures rely on a similar irrigation technique, it is perhaps unsurprising that MACE and cecostomy would have comparable outcomes. Hoy et al. demonstrated no significant differences in achieving fecal continence between MACE and cecostomy (85% vs. 91%) among their participating SB patients (mean age 18 years) (17). A small number of conversions were reported within 5 years: 11.5% of their patients with a MACE had switched to a cecostomy tube, and 8.7% of cecostomy patients converted to a MACE (17). Specific outcomes of antegrade irrigation among SB adults differ from those of pediatric patients. Velde et al. found the median time for stool evacuation following enema administration to be 40 minutes (ranging from 30 to 60 minutes) for children with SB (62). Conversely, adult patients required 60 minutes (ranging from 30 to 120 minutes) as well as significantly higher enema volume (1.75 vs. 1 L) (62). Another study reported that 41% discontinued use of their antegrade irrigation procedures after 11 years due to complications, decreased effectiveness, or poor compliance (63). These findings suggest that over time and as patients age, MACE and cecostomy may become less effective treatment methods. Thus, adequate follow-up with an individualized bowel program remains necessary to maintain patient compliance as well as the effectiveness of antegrade enemas.

**Bowel diversion**

Bowel diversion via an ileostomy or colostomy is a last resort treatment for NBD, implemented only after other failed
treatments. According to the National Spina Bifida Patient Registry, only 4% of adults with SB are managed by a bowel diversion compared to 17.7% using antegrade enemas (31). Although utilized by a small fraction of this population, a diversion affords predictable control to SB patients who may otherwise spend hours per day on irrigations and defecation. There is minimal evidence for the impact of bowel diversion in SB specifically, however, studies following SCI patients have consistently demonstrated good results. Branagan et al. showed a significant reduction in weekly bowel program time, from an average of 10.3 to 1.9 hours following stoma creation (64). In another study, 76% of patients felt their stoma had improved their health-related QOL, and 89% would have a stoma formed again (65).

Aside from the benefits to bowel function, a diversion is particularly beneficial for SB patients with challenging sacral pressure ulcers. Fecal diversion away from the perineal area significantly improves healing times and reduces ulcer recurrence (66). Bowel diversions demand serious lifestyle and psychological adjustments and are not without maintenance and care themselves. Further, changes in patient body image must be considered. Extensive counseling and education preoperatively are therefore essential. Ultimately, as the downsides of a stoma are weighed against a potentially burdensome and time-consuming bowel program, the decision to pursue a bowel diversion must be made on an individual basis by a well-informed patient. Figure 1 summarizes available treatment options for patient education.

Figure 1 General algorithm for bowel management in spina bifida. PRN, as needed.
Conclusions

While bladder management and protection of the upper tracts have long been the focus of urologic care for SB patients, the treatment of NBD is a crucial component of pelvic health for these patients. The overarching goal of treating NBD in SB is to establish predictable bowel function. An understanding of each patient’s baseline neurogenic dysfunction, congenital and acquired anatomy, and treatment history is necessary for intervening on NBD in SB. The treatment spectrum ranges from lifestyle modifications to medical and surgical therapy, and patients often require combinations of multiple strategies to combat both constipation and FI. Additional work is required to further evaluate management options specific to SB populations, especially in more contemporary and largely experimental treatment modalities such as SNM.

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