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Using a Decision Tree to Guide Bowel Management in Spina Bifida

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ABSTRACT

Background: When born with spina bifida, there are numerous neurologic disorders that accompany this birth defect, including neurogenic bowel. Proactive, systematic, and rational approaches can lead to continence and a more functional lifestyle [1].
Methods: Based on the evidence in the literature and expert experience, our approach to bowel management was developed as a step by step, individualized approach. This was converted to a decision tree for easy guidance of treatment decisions. The approach includes teaching patients and families normal bowel function, changes resulting from neurogenic bowel, common pitfalls in bowel management, and techniques that may improve outcomes. The decision tree, starting with dietary management, breaks into a two-fold attack, oral and rectal. Our data as part of the National Spina Bifida Patient Registry (NSBPR) database was compared to public data from the NSBPR.
Results: Preliminary data from the NSBPR in 2011 reported bowel continence in 42.1% ($n = 898$) compared to our clinical outcomes of 72.1% ($n = 43$). As the variable of bowel continence was further defined and more patients were enrolled, the clinic results were comparable to the national reports.
Conclusion: Consistency among providers and caregivers is critical to evaluating the management of continence in spina bifida. While this protocol warrants further evaluation, it is offered as an evidence-based, step by step, approach to bowel management in spina bifida with good outcomes for patient management.

Introduction

When born with spina bifida, there are numerous neurologic disorders that accompany this birth defect, including neurogenic bowel dysfunction. This results from loss of normal sensory and motor control, and may encompass both the upper and the lower gastrointestinal tract. The lack of normal nerve function and hence the lack of normal bowel motility, or peristalsis, leads to constipation. The absence of normal sphincter function leads to stool leakage and fecal incontinence. Impaired awareness of a full rectal cavity also contributes to fecal incontinence (Doolin, 2006).

The management of fecal incontinence in spina bifida varies considerably. In children with functional constipation, dietary management has been suggested with reasonable outcomes (Koppen, Lammers, Benninga, & Tabbers, 2015). This has not been studied in spina bifida but is the first step toward managing the related constipation. Laxatives or stool softeners have been used also for constipation in childhood with a Cochrane review reporting a wide variability in study outcomes (Gordon, MacDonald, Parker, Akobeng, & Thomas, 2016). The use of suppositories is not reported in spina bifida. Retrograde enemas are reported as a step toward continence with limited success compared to antegrade continence methods (Velde et al., 2007). These authors report a high failure rate of the antegrade continence device or cecostomy. Anal irrigation with a balloon catheter or device (such as the Coloplast Peristeen) has been reported as successful (Choi, Shin, Im, Kim, & Han, 2013), (Pacilli et al., 2014), but with limited support from health insurance plans. Outcomes for cecostomy and Malone have been favorable but not without complication (Mugie et al., 2012).

In spina bifida, the secondary complications from neurogenic bowel dysfunction extend beyond constipation and incontinence as these contribute directly or indirectly to urinary incontinence, urinary tract infections, shunt malfunction, potential for skin breakdown, hemorrhoids, anal fissures, loss of social and work opportunities, and decreased quality of life (Cushing et al., 2016). Children with fecal incontinence and their caregivers have a decreased quality of life due to the effects on socialization, travel, caregivers' emotions, family relationships, and finances (Choi, Im, & Han, 2017), (Nanigian et al., 2008). Young adults with spina bifida perceive the incontinence as a problem, regardless of their bowel management methods (Verhoef et al., 2005). Fecal

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incontinence has also been reported to affect self-confidence, family and sexual relations, lifestyle choices, employment, and finances (Wilson, 2007).

Proactive, systematic, and rational strategies can lead to continence and a more functional lifestyle (Doolin, 2006). Though many studies have described specific methods for managing constipation and incontinence, there are none that address the necessary steps taken to reach optimal outcome. Suggested outcomes include maintaining healthy bowel function, bowel continence, adequate bowel emptying, maximum participation in society, and independence according to individual abilities (Stiens, Bergman, & Goetz, 1997).

Given the need for a comprehensive approach to address these issues of bowel continence and bowel management, the authors researched and collaborated to produce a protocol that was instituted in our multidisciplinary spina bifida clinic. The purpose of this article is to present the decision tree (Fig. 1) that came out of our collaborative approach. This protocol has the potential to guide practitioners through a step by step protocol for bowel management that accounts for each individual's unique clinical presentation and abilities, and that further optimizes outcomes. This proposed protocol has wide-based clinical applicability to management of neurogenic bowel in this population and spinal cord injury.

Methods

Our approach encompasses tiers of decision making, conducted with the decision tree presented In Fig. 1.

Keep a bowel tracking record for 3 weeks

Though not pictured in the decision tree, this is a key step in managing neurogenic bowel dysfunction. The importance of this record is undertaken in the development of a Neurogenic Bowel Dysfunction Score (Kelly et al., 2016). Though this score will track symptoms, it does not reveal the specific information needed for guidance that a tracking sheet would provide. This tracking record should include the time of day, whether it was on the toilet or not, what the consistency was, whether there was urgency or straining, and what triggers may have

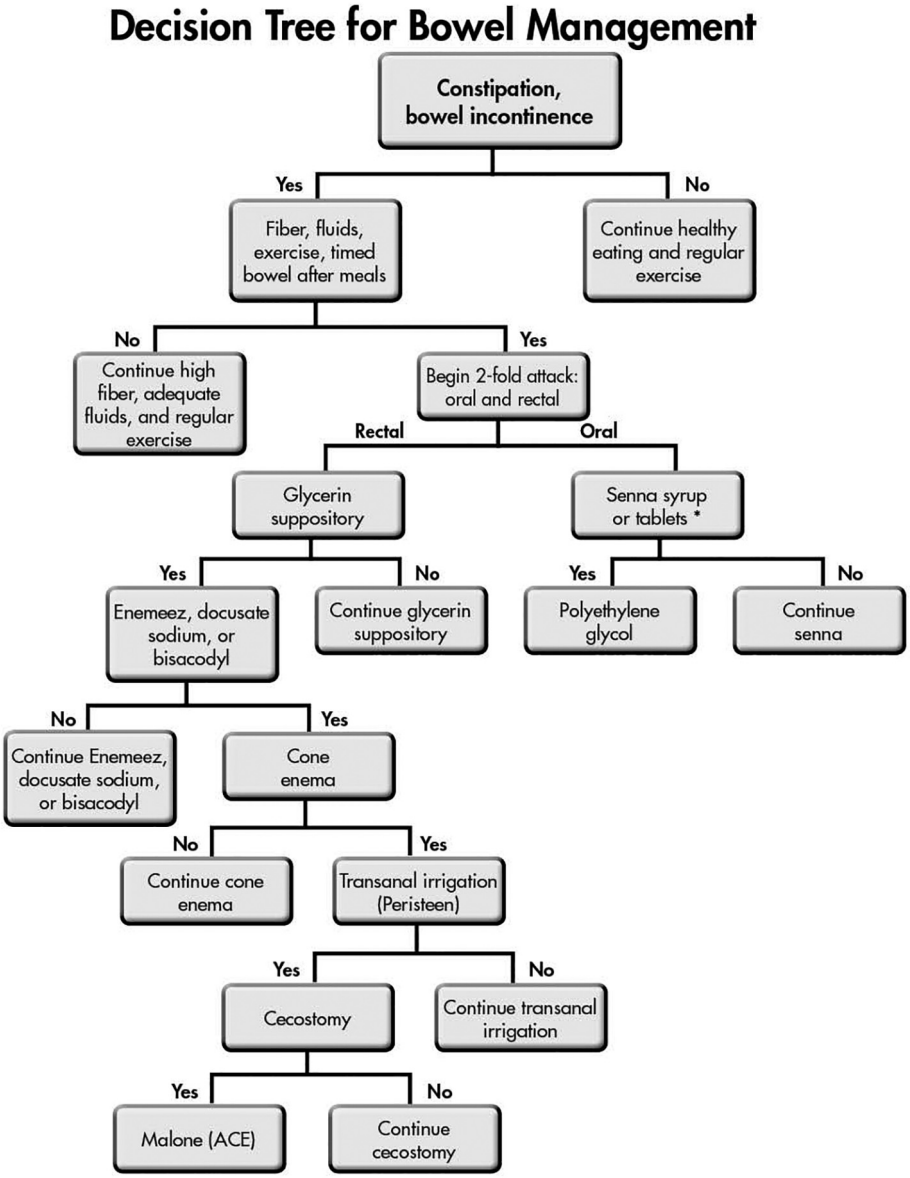

Fig. 1. Decision tree for managing neurogenic bowel with chronic constipation and fecal incontinence. "Yes" implies constipation and/or incontinence continue. *Polyethylene glycol may be given as a first step to medical management. Senna is a good option for children who are inconsistent with drinking the larger volume necessary to dissolve polyethylene glycol or who need the stimulant laxative effect.

contributed to this bowel movement. An example of a tracking sheet is provided in Fig. 2. Until continence without constipation is obtained, the tracking sheet may be needed to continue to individualize management. The Bristol Stool Scale is a useful supplement to the tracking record and can be used to monitor the consistency of stools in both children and adults (Lane et al., 2016). Although there is no direct correlation to colon transit time and the Bristol Stool Scale, using this in combination with the tracking record allows consideration of management when colon transit time is used as a discriminator of treatment options (Vande Velde et al., 2013). There are several options for medically measuring colon transit time. However, these are not easily conducted and require radiologic support. Given the need to constantly re-evaluate in this population, an alternative technique to consider is eating corn as a dietary marker and noting when it comes through in the feces. A transit time of 24–48 h is considered normal. Transit time may be important in understanding the relationship of bowel management to diet and to constipation when considering treatment with a stimulant laxative versus a stool softener (Gordon et al., 2016).

Dietary management

Dietary management should include consideration of amounts of fiber, fluids, and recognition of food triggers. The effects of dietary fiber are well explored in adults but less so in children. There are recommendations for dietary fiber but how the insoluble versus soluble fibers affect children at different ages has not been explored (Kranz, Brauchia, Slavin, & Miller, 2012). Understanding what fiber and what types of fiber the typical diet of the individual with spina bifida includes is important in treating the constipation. Fiber recommendations vary with age and gender. The American Heart Association recommends 38 g for adolescent and adult males and 26 g for females, 31 g for males and 26 g for females ages 9–13, 25 g for children 4–8 years, and 19 g for children 1–3 years (Whole grains and fiber, 2017). Fiber supplements may be used when intake of dietary fiber does not meet these goals, however, the clinically meaningful effects, such as water holding capacity (Robertson & Eastwood, 1981), should be considered in choosing a fiber supplement (Lambeau & McRorie, 2017). These effects should also be considered for soluble fiber versus insoluble fiber as insoluble does not absorb or dissolve in water so will have a bulking effect different than soluble.

Though minimum fluid requirements (8 cups per day for females and 11 for males), are listed in the literature, there is no evidence that increasing fluids beyond this will improve constipation (Tabbers, Boluty, Berger, & Benninga, 2011). Consideration should be given to caffeine intake as this will pull more fluids out of the gastrointestinal tract. Popular pediatric beverages, such as those containing dairy products, also contribute to constipation.

One other dietary consideration is food that may act as a trigger. Foods high in fat, red meats, cheeses, and bananas may contribute to constipation. Alternatively, foods high in fiber, fermentable sugars, or water content may provide constipation relief. Recognition of triggers that may cause diarrhea or leaking of stool will help manage incontinence. Typical triggers include chocolate, chocolate milk, foods with high fructose corn syrup, greasy foods, and spicy foods (Bohn, Storsrud, Tornblom, Bengtsson, & Simren, 2013). The duration of the three week bowel tracking record is justified in its ability to identify constipating and triggering foods.

Medication management and positioning

A two-fold approach is undertaken that includes oral and rectal medications. In infants, this protocol starts with stimulant laxatives such as senna. Polyethylene glycol (PEG) could also be considered as first line management: however, the need for a stimulant and being able to drink the higher volume PEG were considered. Consideration of the results of the bowel tracking record should evaluate the need for a stimulant based on frequency of bowel movements. Osmotic laxatives such as lactulose are used less often due to the bloating and cramping. Because of the necessity for rectal evacuation, daily glycerin suppository is recommended along with positioning that includes flexion of the hips and knees. The same steps are taken for toddlers and preschoolers. If they fail to have good evacuation with the glycerin suppositories, then a trial of a mini enema (docusate sodium with glycerin and PEG such as Enemeez) is recommended. In addition to positioning the feet so hips and knees are flexed, scheduling 15–20 min of "toilet-time" after the evening meal is recommended. Consideration should be given to the insensate buttock when timing. Padded toilet seats or inflated cushions for the toilet seat are available. For older children and adults, the same recommendations are made. If these interventions fail, consider other osmotic laxatives, stimulant laxatives, stool softeners, or combinations of stool softeners with stimulant laxatives. Novel therapies (Lubiprostone, linaclotide, and prucalopride) have not been studied in this population (Koppen et al., 2015) and were excluded from our protocol though specific cases showed efficacy.

Cone enema or transanal irrigation

Oral medications are continued but a cone enema replaces the suppositories. As this population cannot retain an enema, either a cone or rectal balloon is used. Potential additives may be used to enhance the transanal administration of the enema solution. Typical additives include glycerin, baby shampoo, salt, bisacodyl, PEG, or mineral oil (Bani-Hani, Cain, King, & Rink, 2008). As independence with a cone enema for transanal irrigation is difficult, the Peristeen anal irrigation system is next considered. The Peristeen anal irrigation system is as effective as other systems, is easy to learn, safe, and increases the patient's independence (Lopez Pereira et al., 2010), (Pacilli et al., 2014).

Surgical options

If the preceding interventions have failed to achieve optimal outcomes for management of NBD, or were successful but the patient desired greater independence with management, then antegrade enema options were offered. At our institution, cecostomies were performed in the interventional radiology suite as a less invasive option than a surgically constructed conduit or Malone. If a family preferred no external device, then a Malone antegrade continence enema (MACE) was discussed, either alone or as a surgical procedure in conjunction with urinary continence surgeries. Studies have shown both to be effective in reaching outcomes for management (Arya, Gupta, Gupta, &

When Date	Time	Where Toilet	Diaper	Pant	What Hard	Soft	Loose	How Strain	Urgent	Why Exercise	Food, Fluids	Meds

Fig. 2. Bowel tracking record. This is the first step in understanding the specific neurogenic bowel dysfunction of each individual.

Procedure	Pros	Cons
Cecostomy	Two step insertion process usually done in interventional radiology	Potential for leakage around the site
	Can be done as an outpatient	Potential for device to be dislodged
	Less likelihood of stomal stenosis	May have cramping with peristalsis
	More likely to be independent than with retrograde (cone) enema	If Chait tube used, will need adapter
		Change button device every 3 months. Chait every 6-12 months
Malone	Provides benefits similar to cecostomy without external device	Surgical procedure
	Larger bore catheters – easier administration of volume	Potential for leakage around the site
	More likely to be independent than with retrograde (cone) enema	Requires daily catheterization
		Potential for stomal stenosis

Fig. 3. Pros and cons of cecostomy and Malone procedures.

Aggarwal, 2016; Vanderbrink et al., 2013). The pros and cons of each procedure are outlined in Fig. 3. Colostomies were usually done as a rescue effort for patients also suffering from chronic sacral wounds. A colostomy may also be resorted to if there is a bowel obstruction. Though reversible, patients may find it less difficult to manage than the effects of neurogenic bowel dysfunction. Additionally, sacral nerve stimulation was offered to one patient who did well until an infection necessitated removal of the stimulator. Sacral nerve stimulation has limited efficacy in management of neurogenic bowel dysfunction in spina bifida (Lansen-Koch et al., 2012).

Outcomes from one center

In 2011, shortly after joining the NSBPR, we examined our continence outcomes in children over age 5. When asked the question "are you usually continent or incontinent of bowel?", 72.1% ($n = 43$) stated they were usually continent. The data were preliminary and the registry question was later changed to a measure with more specific continence outcomes. However, these initial outcomes were favorable compared to the 42.1% ($n = 898$) in the NSBPR at that same date. As the variable of bowel continence was further defined and more patients were enrolled, the clinic results were comparable to the national reports. Eventual enrollment in the NSBPR rose to almost 200 at this center, however, the center is no longer part of the NSBPR and we have no further data on the outcomes in this specific population at this site.

Conclusion

We offer the above outcomes as an incentive for further evaluation of this bowel management protocol. Though further work is needed, it is clear that use of a decision tree in the management of neurogenic bowel offers an individualized approach to attain fecal continence. The relationship of this protocol to a larger population is recommended. The NSBPR has adjusted to measurement of fecal incontinence to capture more specific data related to fecal continence so that more than "mostly continent" is captured for review.

In addition to expanding the evaluation of this protocol, outcomes at each level of intervention should be measured. Understanding the levels of interventions and relating it to the level of spina bifida would be useful to providers managing these patients.

This protocol continues to be used and informally shared with other spina bifida clinics because of the experiential success with managing neurogenic bowel.

Limitations: This article presents limited evidence though we have more experiential support for this protocol. Though we believe as clinicians that this evidence based protocol is clinically sound and we have experiential evidence, we do not have the data to further evaluate. Though this paper discusses optimal treatments, it does not address the financial and insurance barriers of bowel management. Many of the suggestions require an out of pocket expense for over the counter medications. Insurances have yet to recognize instruments such as the anal irrigation devices as necessary medical supplies. The cost can be prohibitive for some, yet were they to attain continence, they would benefit in so many other aspects as is mentioned in the introduction. This decision tree empowers patients and families to understand the bowel management plan, and goal attainment is contingent on their acceptance. The decision tree allows customizing a bowel management program for each patient while following evidence-based practice guidelines for bowel management. While further research into the applicability of the decision tree with larger populations is warranted, it provides a clear and rational strategy for bowel management in spina bifida patients.

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