Achieving Continence with a Neurogenic Bowel

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KEYWORDS

• Neurogenic bowel • Spina bifida • Continence
• Suppository • Enema

This article reviews the developmental considerations involved in helping the family of a child with spina bifida who needs to achieve bowel continence. Strategies for success based on an algorithm are interwoven throughout the discussion. The current medications and techniques used at the developmentally appropriate times designed for optimal success are presented.

OVERVIEW

A hallmark in every young family's life is toilet training and eliminating diapers. Parents of a newborn with spina bifida have no idea what to expect or how to parent an infant with a disability. Lack of knowledge can lead to anxiety and a crisis of confidence in the parent.

Toilet training is a watershed event in a young family's life. Bowel continence is a critically important aspect of adaptive function with enormous implications for the future. Bowel accidents are embarrassing and lead to social isolation, affecting peer relations and social success. They affect the work environment and may be a barrier to employment. Incontinence may have a lasting impact on friendships and intimacy.

Research has identified several issues related to incontinence in adults, including the decreased participation due to the time programs take, a sense of helplessness when the program did not work, the shame when asking others for assistance, and the social isolation if accidents occurred.[1] Adults with spina bifida have felt the loss of the pediatric clinic, with no identified resource for assistance in the adult health care community.

Quality-of-life (QOL) studies have attempted to evaluate the impact of achieving continence in a person's life.[2,3] Adults and teenagers with spina bifida have a lower health-related QOL score than matched controls. The effect of urinary versus fecal continence on QOL was difficult to separate. Surgical intervention, although effective

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in achieving continence, did not affect the health-related QOL. The developmental age when bowel continence was acquired has not been evaluated in relation to its impact on the QOL of the teenager/adult with spina bifida. Regardless, continence is clearly one important aspect of health-related QOL in those with spina bifida.

PATHOPHYSIOLOGY OF THE NEUROGENIC BOWEL

Bowel movements occur through the combined activity of colonic motility, rectal storage, and elimination. The neurologic innervations of the colon include the sympathetic nervous system from T10 through L2 (inhibitory impulses in the colon and rectum), the parasympathetic system from S2 through S4 (stimulatory innervation to the descending colon and rectum), and the enteric nervous system contained in the intestinal wall regulating colorectal motility.[4,5]

Liquid feces enter the ascending colon and move through the colon by contractions and mixing of the contents. This promotes absorption of water to form solid stool as it passes through the descending colon. The rectum's main function is to store feces, and it requires the ability to be relaxed until a certain amount of stool has filled the rectal vault. The internal sphincter remains closed through inhibitory impulses and has brief moments of relaxation, releasing gas. The internal sphincter relaxes (parasympathetic response) as the rectal vault reaches a certain volume and stool begins to move through it. The external sphincter's parasympathetic stimulation controls the stools' passage or containment. The neurogenic bowel has one or more of these components interrupted.[6]

In children with spina bifida, most lesions are above the S2 level, resulting in a neurogenic bowel. Colonic motility is not related to level of lesion or mobility and is prolonged as compared with controls.[7] Slow colonic transit is related to symptoms of constipation and fecal impaction. The inability to sense impending bowel movements or to "hold it" results in fecal incontinence.

DEVELOPMENTAL ASPECTS OF BOWEL CONTROL

Infants have several stools throughout a 24-hour period. Stools are seedy, loose, and soft until solid food is introduced. The frequency decreases to 1 to 2 stools per day as babies approach their first birthday. At about 18 months of age, the stool becomes more formed. At 2 years, the child becomes more aware of having had a stool. Toilet training ensues as the toddler becomes aware of impending stools and chooses to use the toilet or not. By age 4 years, most children are toilet trained and cleaning themselves.[8]

Infants with spina bifida tend to experience constipation as solid foods are introduced. Prevention of constipation is helpful in later development of a continence program.[9] Lack of rectal awareness and lack of sensation in the perineal/buttock area results in stool remaining in the diaper until odor brings attention to its presence. Cleaning and changing remain in the parental domain as the child enters school. Continence programs need to begin at the developmentally appropriate age, to assist children with spina bifida in reaching similar developmental milestones to their unaffected peers.

TYPES OF BOWEL CONTINENCE PROGRAMS

Dietary

Fluid and fiber remains the foundation for prevention of constipation and treatment of continence. The intake amount is determined by age and weight.[10] In infants, fluid and

baby fruits are key. In older children, fiber is added through cereals, fruits, vegetables, and breads/grains. Parents are taught to read labels to identify higher-fiber foods. Whole-grain products, introduced before low-fiber refined products, can be well-accepted by children as they grow. Fluid goals are determined by weight in children younger than 10 years. For those older than 10 years, 64 ounces a day is the basic goal. Fiber goals are based on the age plus 5 to 10 (3 years + 5 = 8 g of fiber a day).[11] Children with spina bifida have a Chiari II malformation and may exhibit dysphagia demonstrated by low fluid volumes and difficulty with food textures. Evaluation and intervention with dietary and oral motor therapy may be helpful.

Dietary triggers that cause an unexpected or loose stool need to be identified as the child is introduced to new foods. Chocolate and spicy and greasy foods can cause loose stools. Foods that contain corn or high-fructose corn syrup are especially implicated in causing loose or unexpected stools. Some children are more sensitive than others. Any child that has not had formed stools needs to have a diet history taken to identify possible food triggers.

Medications

Oral medications are used to promote a soft formed stool that is in the rectal vault at the time planned by the family/teenager for a bowel movement. Osmotic and bulk laxatives are effective in keeping the stool soft and formed when diet and liquids are not enough. A stimulant laxative, such as senna, strengthens colonic motility, enabling the stool to be in the rectal vault 6 hours (typically) after ingestion and providing predictability for elimination. When used with a suppository or enema program, individuals can be continent (**Table 1**).

Suppositories

Suppository programs are designed to produce a bowel movement within a few minutes of insertion. Liquid glycerin, liquid glycerin with docusate (mini-enema), and bisacodyl in a wax or water-soluble base are currently available (**Table 2**). The liquid suppositories require holding the external sphincter shut after the liquid is inserted for a few minutes to stimulate emptying. In the author's clinical experience, this is easier for a parent to do with a baby or toddler but difficult for an older child to do independently while sitting on the toilet.

The bisacodyl suppository needs to be inserted through the internal anal sphincter and not into stool. The wax-based suppository is difficult to time and may work in 15 or 45 minutes. The water-based suppository works in about 5 minutes and is easy for a school-aged child or teenager to insert on the toilet and have a bowel movement in 5 to 10 minutes.

Difficulties arise with either suppository if there is low rectal tone. The anal canal has loose tissue, making it challenging to insert the suppository (liquid or solid) through the loose tissue to the internal anal sphincter and rectal vault. A clue to the problem is a parent reporting that no suppository works, an indicator for use of the cone enema.

Enema Programs

Cone enemas (transanal) use a colostomy irrigation system, which administers 1 to 2 cups of tap water while sitting on the toilet. The cone acts as a plug to keep the water inside. It produces significant rectal distention and, once removed, results in a bowel movement being completed in 20 minutes. These enemas are very effective and can be used independently by teenagers with sacral level 1 to lumbar level 1 spina bifida (sitting balance is important).[12,13]

Table 1
Oral maintenance medications

Common Use	Medications	Actions	Dose	Comments
Maintenance Oral	Lactulose	Poorly absorbed sugar with osmotic effect	Infant: 2.5–10 mL/d Child: 7.5 mL/d	Gas and bloating can be common side effects
	Senna (8.6 mg/5 ml = 1 tab) Pedia-Lax senna (1 strip = 8.6 mg senna)	Stimulant laxative Grape-flavored quick-dissolving strips	Infant: 1.25–2.5 mL/d 1–5 y: 2.5–10 mL/d >6 y: 5–15 mL/d	Produces peristalsis; works usually in 6 h from ingestion
	Psyllium- (Perdiem, Fiberall)	Bulk laxative	Titrate	May cause bloating; must take with plenty of water to avoid intestinal obstruction
	Polycarbophil (Fibercon, Equalactin, Konsyl)	Bulk laxative	Titrate	Synthetic fiber resistant to bacterial degradation = less bloating; helpful in regulating fluid excess in bowel
	Guar gum (Benefiber)	Bulk laxative	1 scoop = 3 g fiber; increase as needed every 3 days	Taste-free, grit-free; does not thicken or alter taste or texture of food
	Polyethylene glycol 3350 (MiraLax)	Osmotic laxative	0.8 g/kg once/d	Not as effective in neurogenic bowel; difficult to time; can cause gas bloating and nausea
	Metoclopramide (Reglan)	Motility agent-gastro/colonic	0.1–0.2 mg/kg 2–3 times/d	Decreases time stool sits in colon and prevents constipation
	Erythromycin	Motility agent-gastro/colonic	2–3 mg/kg/dose 3 times/d	Decreases time stool sits in colon

Table 2
Maintenance medications

Common Use	Medications	Actions	Dose	Comments
Maintenance Rectal	Docusate (Enemeez [4 mL of docusate, glycerin, polyethylene glycol])	Stimulant	Contents of 1 mini enema; If added to transanal or MACE irrigation solution may add 1–2	Difficult to hold in with incompetent external sphincter—does not support independence Assist in speed of emptying; administration technique supports independence
	Bisacodyl-rectal suppository (Magic Bullet [bisacodyl in water base])	Stimulant	1 suppository inserted on toilet	Can be done independently; works in 5–10 min

Abbreviation: MACE, Malone antegrade continence enema.

The antegrade continence enema (ACE) or Malone antegrade continence enema (MACE) is a surgical intervention that creates a continent channel at the ascending colon near the cecum. Tap water with or without other stimulants is run through, flushing out the entire colon. The MACE can be used independently by older school-aged children and teenagers.[14] The time can be problematic, taking an average of 53 minutes. There can be "wash out" failure allowing for the water to move around the stool and not push the stool with it. Long-term follow-up indicates a 40% dropout rate in adulthood, which may be related to the lack of support in maintaining a bowel management program in the transition to adult care. Stomal stenosis may occur, requiring surgical revision.[15] Despite many of these concerns, there remains a high degree of contentment.

A variation on this is the placement of a tube such as the Chait Trapdoor (Cook, Bloomington, IN, USA),[16] which is similar to a gastrostomy (g-) tube (has a balloon on the tube end that is inserted into the stomach) but has a coil on the end inserted into the ascending colon to anchor it. The Chait Trapdoor is opened to insert a catheter and run the solution through the colon. The Chait Trapdoor can be done through interventional radiology as opposed to a surgery needed to create the continent stoma.

The left antegrade continent enema[17] is a continent channel created in the left abdomen into the descending colon and acts like antegrade cone, eliminating the stool in the descending colon. The average transit time is 31 minutes and requires less solution to be instilled. The occurrence of stomal stenosis is 50% less than with the ACE.

Colostomies are not currently used unless there is a malformation of the rectum. They can be effective for some families, providing a measure of control and eventual independence.

There are no published reports on the use of the sacral nerve stimulator in the spina bifida or pediatric population, but it may have some future possibilities. The sacral nerve stimulator has electrodes implanted into the S2-4 anterior nerve roots, which are controlled by an external transmitter to stimulate the anal-rectal area so that evacuation occurs. The sacral nerve stimulator has been used and evaluated in adults with

spinal cord injury. The results in this population indicate an improvement in constipation, increased defecation frequency, reduced defecation time, reduction in the number of medications required previously, and high degree of patient satisfaction.[18]

GOALS OF A BOWEL CONTINENCE PROGRAM

The goals of a bowel program need to be developmentally based and adjusted for independence as the child grows. This may necessitate interventions with adaptive toileting equipment or enlargement of the bathroom and entrance for a wheelchair. Flexibility is also important. Family routines differ from the working week to the weekend, and by adjusting the time that oral medications are given, the time of elimination is adjusted.

Bowel programs taking only 20 to 30 minutes can be fit into a daily routine and have a greater compliance as children enter their teenage years (**Table 3**).

PLANNING A BOWEL PROGRAM

Assessment is the cornerstone of determining a bowel program because each child is different, and for a program to be successful, it needs to be individualized. At Texas Scottish Rite Hospital for Children, a 13-point assessment has been developed that assists with planning a bowel program for achieving continence. The program still requires initial adjustment of medications or timing and troubleshooting with changes of routine. Parents can be reassured that their first actions are not in vain, and minor adjustments continue to help them move toward their goal (**Table 4**).[19]

Assessment frequently identifies constipation. "Clean-out" is needed before starting a continence program. The use of oral and rectal medications can prevent cramping and discomfort. The rectal vault has the hardest stool, and use of an enema is the first step. Oral medications move the stool around to the rectal vault. If there are balls of stool throughout, starting with mineral oil for lubrication is helpful. The clean-out is successful when the stool is liquid (**Table 5**).

DEVELOPMENTAL CONSIDERATIONS IN BOWEL CONTINENCE PROGRAMS

In 1998, Texas Scottish Rite Hospital developed an algorithm to assist with planning a bowel continence program that provides a family with the greatest success in achieving continence (**Fig. 1**).

Infancy

The transactional model of development[20] is a useful construct for pediatricians to use when considering how to support parents and their infants with spina bifida. Briefly, this approach suggests that the infant, the caregiver, and the environmental context surrounding them are all active players in the child's developmental and behavioral

Table 3
Goals of a bowel continence program

Goal	Factors
Time	20–30 minutes is easily incorporated into a daily routine
Flexibility	It can be done at camp, on vacation, in college, or adjusted from school days to weekends
Independence	Program is adjusted as the child grows, transferring the program from the parent to the school-aged child/teenager

Table 4
Assessment of neurogenic bowel

Assessment	Rationale	Treatment Options
Stool Form	Balls indicate slow motility and too much water being absorbed. Oatmeal consistency indicates increased motility and the need for bulking.	Clean out old hard stool; assess fiber and fluid intake and adjust them. Assess foods that may increase motility.
Stool Consistency	Hard or formed or soft	Fluid and/or fiber goals Fiber supplements, motility aids
Stool Amount	4–6 in for 3–6-year-olds 6–8 in for 6–8-year-olds 8–10 in for 9–11-year-olds 12–18 in for 12 years and older	Emptying typical amount for age ensures descending colon is empty and prevents constipation
Tone of Anal Canal	If there is good tone to the internal anal sphincter, it responds to a suppository.	If it does not respond to a suppository or fleet enema, check rectal tone.
Level of Paraplegia	Ease of transfer to toilet; ability to balance on toilet	Ability to balance works with a suppository or enema; ability to transfer, ability to follow an enema program (cone or ACE)
Age	<5 years >6 years	Parent-dependent Work toward independent program
Mobility	Wheelchair fits into bathroom	If not, work on a program using a bedside commode
Fluid	Provides the liquid to keep stool soft.	If cannot meet fluid goals, may indicate dysphagia
Fiber	Adequate intake bulks stool and form is easier to eliminate	Introduce supplements if cannot eat target goals
Medications	Anticholinergics slow smooth muscle and contribute to constipation. Anesthetics slow motility.	Plan to counteract when beginning anticholinergics or anticipating surgery
Family Routines	Can schedule activities and have flexibility to adjust	Assist parents with more support when they require exact plans to follow.
Programs Attempted in the Past	Families may be resistant to trying again when *nothing has worked*.	Families need to know that a bowel management program is inclusive and includes fluid, fiber, medications, and timing of elimination.
Learning Issues	Executive function can pose problems to adjusting bowel program for changes in routine or weather.	Work with early teenagers to start assessing their output and what adjustments need to occur in situations that they encounter.

Table 5
Medications for bowel clean-out

Common Use	Medications	Action	Dose	Comments
Clean-out Oral	Polyethylene glycol	Osmotic laxative	2–11 y: 8.5 g (halfway to measuring line in 4 oz liquid) >12 y: 17 g in 8 oz of liquid	Disimpaction
	Mineral oil	Lubricant	5–11 y: 5–15 mL 1–3 times/d >12 y: 30–60 mL 1–3 times/d	Do not use if suspect aspiration; long-term use loses fat-soluble vitamins; may break down g-tube
	Milk of magnesia	Osmotic laxative	<2 y: 0.5 mL/kg/dose 2–5 y: 5–15 mL/d, once or in divided doses 6–11 y: 15–30 mL/d or in divided doses >12 y: 30–60 mL/d, once or in divided doses	Also in chewable form
	Magnesium citrate	Osmotic laxative	<6 yr: 2–4 mL/kg, once or divided 6–12 y: 100–150 mL >12 y: 150–300 mL	Do not use in patients with renal insufficiency
Clean-out Rectal	Phospho-soda enema	Osmotic effect in intestine by drawing water into lumen of the gut, producing distension, promoting peristalsis, and evacuation	2–11 y: contents of one 2.25-oz pediatric enema >12 y: contents of one 4.5-oz adult enema	Not for use in patients with renal insufficiency Do not exceed more than 1/d
	Fleet mineral oil enema	Ease elimination of stool, decreasing water absorption and lubricating rectum	2–11 y: 30–60 mL as single dose >12 y: 60–150 mL as a single dose	Used with significant hard stool in rectal vault; difficult to keep in with incompetent sphincter Safe for children with renal insufficiency
	Milk and molasses enema	Osmotic effect without a shift in electrolytes	<8 y: equal parts milk and molasses (1oz:1oz; 2oz:2oz) 8 y–teenaged: 4–8 oz milk and 4–8 oz molasses	Safe for patients with renal insufficiency

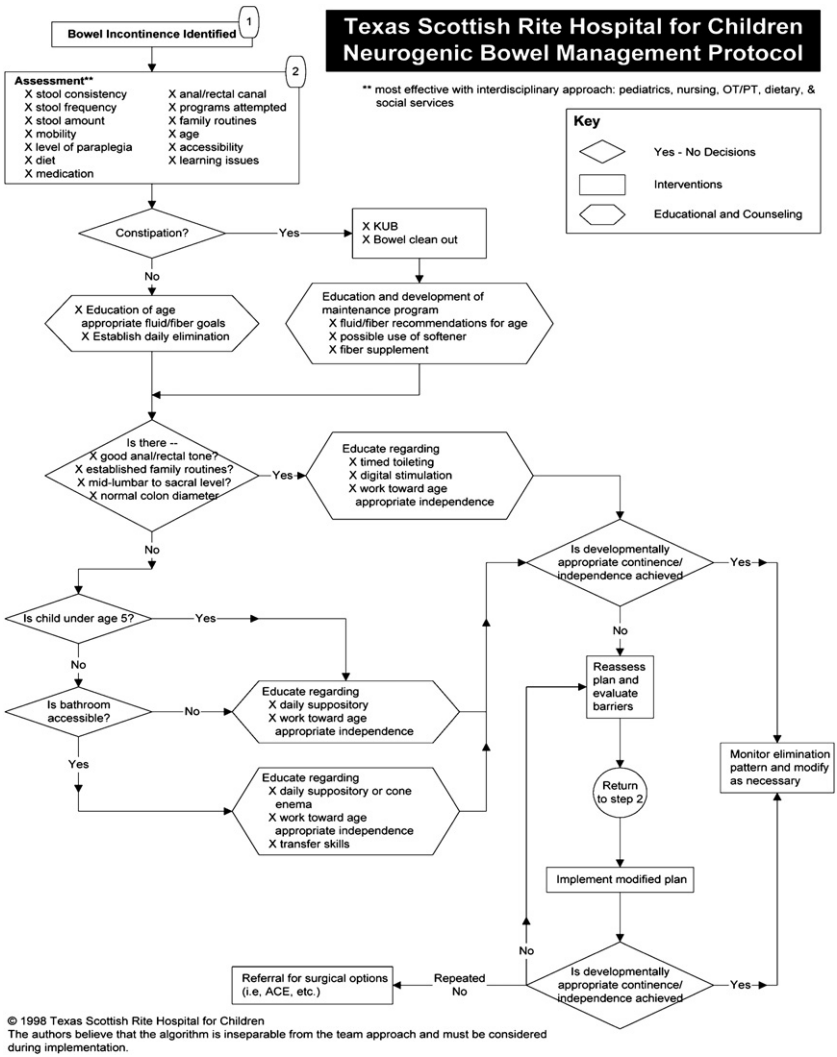

Fig. 1. Neurogenic bowel management protocol. (*From* Texas Scottish Rite Hospital for Children; with permission.)

growth. The interaction is a dynamic, organic process that alters each of the aforementioned players.

This is especially true in a situation as complex as the delivery, neonatal surgery, rehabilitation, and ultimate normalization of activities that occur in these infants and their families. Attachment issues on the part of the infant and the caregiver are potential risk factors, especially as they affect feeding and elimination in the infant with Chiari II malformations. Underlying neurodevelopmental differences in the infant can create real or perceived feeding issues and a sense of concern regarding self-competency in the parents.

What would otherwise seem to be the *simple acts of feeding and defecating* can create questions of health, well-being, competency, and emotional well-being for

the infant-parent dyad. Even the ability to adequately handle a diaper rash can be a challenge, because the acidic stool *burns* the skin in an insensate area without infants *communicating* their needs to the parent.

Thus, what would otherwise be considered typical infant care can create barriers to the natural attachment of infant to parent, because caution, worry, and competence remain daily issues. The child-health profession (eg, physician, nurse) must have awareness and understanding of these dynamics to avoid contributing to the tension experienced in families of infants with spina bifida. Supporting the family with suggestions of adding juice or lactulose enhance parent competence if stools become pasty (like peanut butter) or ball-shaped and difficult to push out, whereas polyethylene glycol can cause diarrhea and adding fiber may cause increased gas and bloating, resulting in infant discomfort and parent stress. Understanding and patience in this pivotal developmental period can reap rewards for years to come for the family and the professionals supporting them.

Toddler/Preschooler

The goal at this age is to learn independence, and toilet training is one of the tasks needed to achieve this goal. Children with spina bifida lack the sensation to know when they have had a bowel movement in their diaper. Creating the opportunity for choosing to sit on the potty-chair provides experience in asserting independence. Toilet training may be facilitated by the following:

- Clean out hard stool if necessary, and maintain soft stools with fluids, fiber, and polyelthylene glycol or lactulose if necessary.
- Identify when/if the toddler has a daily bowel movement.
- If no regular emptying time exists, begin giving senna syrup, a natural vegetable laxative that can be timed to predict when a bowel movement would occur. It works in 6 hours. Using a liquid suppository at the 6-hour mark triggers an emptying, assisting with toilet training because the child has predictable stool. Fluid and fiber need to be included in the daily routine. Lactulose can be added if fiber intake is low.
- All changing of diapers should be in the bathroom by this age to teach that all bladder/bowel emptying occurs there. The potty-chair should be available and offered to the toddler after the suppository is administered. Making the choice of where to have the bowel movement becomes the child's.
- As children grow, including them in making choices with foods and fluids begins to lay the ground work for decision-making in the future.

School Age

The challenges for school-aged children are to expand their world outside the family home. Making friends and exploring interests in the community are important for future independent life. Participation may be threatened if a child has bowel accidents. Parental anxiety can undermine the child's emerging sense of autonomy and competence. Guidance needs to be provided to transition the bowel program to one that can eventually be followed by the older child.

- If the child is using a liquid suppository, change to a solid suppository, which can be inserted on the toilet.
- Accessibility to the toilet affects the degree of independence with a continence program. Bathroom doorways can be a huge barrier if a child is a full-time

wheelchair user, which may necessitate the parent carrying the child into the bathroom. Transfers from wheelchair to toilet are the next step for independence.
- If there is low rectal tone or continued bowel accidents on the suppository program, the cone enema can be very effective.

Surgical intervention with creation of a stoma in the right ascending or left descending colon is the next step if the cone enema is not effective. Accessibility to the bathroom and onto the toilet is important in this program as well. Most children are able to learn to do this independently.

Adolescence

Independence and identity are the important goals in the teenager. Teenagers may begin to question why they must do all the health routines asked of them in a day. Nonadherence to a continence program may be an expression of adolescent rebellion. Helping teenagers to develop a basic understanding of their spina bifida provides a basis for the self-care regimen suggested by the health care team. Developing social activities with other teenagers with spina bifida creates a normalizing environment in which continence programs are perceived as normal and acceptable. Bowel programs may go awry because teenagers decrease fluid intake to reduce the frequency of catheterization, refuse high-fiber foods, choose not to follow the bowel program, or forget to take their medicines, and so forth. A supportive and structured environment helps to reduce many of these behaviors.

Table 6
Troubleshooting

Problem	Suggestions
Stools without time to sit	Lower dose of oral medication. Response to oral medication may be quicker and the time needs to be moved closer to the elimination time. Evaluate diet for high-fructose corn syrup or other food triggers.
Stools after finishing	Consider adding fiber supplement to bulk up stool. Increase physical activity before timed evacuation. Change mechanism of eliminating (from suppository to transanal enema)
Stools begin hard and become loose	Evaluate water intake and increase if needed. Evaluate mechanism for emptying and change program if needed. Evaluate for high-fructose corn syrup.
Stools when walking	Use of transanal enema assists in emptying the descending colon and preventing ambulation stools.
Teenage girls with liquid stool once a month	Assess if associated with monthly period; if so, give quarter dose of medications used for diarrhea. If not associated with cycles, evaluate for impaction or constipation.
Cannot meet fluid goals	Evaluate for dysphagia related to the Chiari II malformation.
Cone enema leaks while water is instilling	Anal canal dilates reflexively with fluid; wiggle cone in for a tighter seal.

- Use of a weekly medication box showing multiple times of the day is helpful in remembering and checking on the medication use. This can be filled weekly together with the parent and eventually become the responsibility of the teenager.
- Place all of the bathroom equipment conveniently close to the toilet. Parents have placed gloves, lubricant, suppositories/enema, and personal wipes and disinfectant wipes for equipment in plastic drawers next to the toilet. A small covered disposal unit can mask odors from others using the bathroom.[21,22]
- Use fiber supplements so that teenagers eat similar food to their peers. Encouraging fluid intake at catheterization and mealtimes helps teenagers develop healthy habits that can be carried into adulthood.
- Design bowel programs for the teenager to do independently. Working with an occupational therapist may be helpful to identify adaptations and equipment.

TROUBLESHOOTING

After deciding on the initial program, all bowel programs require adjustment. More fiber may be needed for improved stool consistency. A range of possible senna or polyethylene glycol doses allows parents to adjust the dose based on daily diet and fluid intake. Surgery causes constipation from the anesthesia and/or pain medication. Adjustments before and after surgery minimize constipation. Helping parents identify progress is important when adjustments are needed (**Table 6**).

SUMMARY

Achieving an effective bowel continence program requires support for the family in areas of bowel management, medication adjustment, dietary triggers, fluid/fiber goals, and adaptive equipment use. The Spina Bifida Association has an excellent manual on bowel management,[12] with helpful guides for many of the continence techniques. Helping families understand that continence is an achievable goal is very important when facing the future and the transition of children into adulthood. The understanding and support provided by the primary care doctor to the family is invaluable in achieving lifelong success.

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