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Neurogenic bowel and continence programs for the individual with spina bifida

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Abstract. The neurogenic bowel in the person with spina bifida has been difficult to manage. Current literature reveals very little research conducted on the outcome of continence programs in the person with spina bifida. It has different characteristics than the neurogenic bowel seen with spinal cord injury because it occurs during fetal development. Management of the neurogenic bowel to achieve continence is based upon thirteen assessment items that include stool form, individual physiologic parameters, family patterns, diet and medications. Programs are developmentally related to appropriately support the child's involvement. Continence strategies include the use of oral medication early in the day and timed sitting, suppositories or enemas later in the day at a time convenient to the family. The timing of the medications and evacuation is very important to the success.
An interdisciplinary team is important in supporting the family as the child with spina bifida grows into an independent adult. The dietician and occupational therapist have invaluable insight into diet, fluids, adaptive aids and techniques that contribute to positive outcomes of the continence program.

Keywords: Neurogenic bowel, spina bifida, bowel continence programs

1. Introduction

A hallmark of family life is the "potty training" of their child and elimination of diapers. For families with a child with spina bifida, the hallmark is more incredible because of the neurogenic bowel.

The neurogenic bowel results from the interruption of the spinal cord above the Sacral level 2, 3, and 4. This causes lack of sensory feedback of impending bowel movements resulting in incontinence. Constipation may also be a factor as stool is incompletely eliminated and the remaining stool becomes harder. Constipation has also been associated with possible ventriculoperitoneal shunt malfunction [12].

2. Pathophysiology of bowel movements

The components of bowel movements consist of colonic motility, rectal storage and elimination (sensory awareness of defecation, and coordinated control of the internal and external sphincters). Incontinence occurs with interruption of one or more of these components.

2.1. Colonic motility

Neurologically the colon is innervated by the autonomic nervous system (sympathetic arising from T10-L2 and parasympathetic arising from S2-4), the voluntary or somatic nervous system, and the enteric nervous system (nerves contained only in the intestinal wall) [9].

The large intestine or colon receives the liquid waste in the ascending colon. It moves through the large intestine through two types of rhythmic contractions: intermittent and regular [9]. The intermittent contractions are slower and allow the fecal contents more exposure to the mucosa for water re-absorption and eventual formation of formed stool.

The enteric nervous system assists the intermittent contractions by mixing the fecal contents, allowing greater exposure to the mucosal wall and absorption of

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water. It is stimulated by distention of the colon which triggers regular contractions assisting with movement of the stool to the rectum [9].

2.2. Rectal storage

As the formed stool enters the rectum, storage occurs. The rectum must be compliant and relaxed to store the feces. There is no rhythmic movement in the rectum. It is responsive only to distention that triggers a contraction for emptying [3,9]. The internal anal sphincter consists of smooth muscle and has involuntary control allowing periodic relaxation to release flatus. Reflexive opening of the internal sphincter occurs with even weak distention of the rectum. The anal canal is a muscular tube 2–4 cms in length. It is normally empty, relaxed and closed. It forms an angle with the rectum to support the closure of the internal sphincter [9,25].

The external anal sphincter is comprised of skeletal muscle and is under voluntary and reflexive control. It can be voluntarily squeezed to further reinforce the retention of rectal contents [25].

2.3. Elimination

When distention of the rectum reaches a certain capacity the defecation reflex is stimulated. This reflex triggers the parasympathetic nerves at Sacral 2, 3, and 4. Relaxation of the internal anal sphincter begins. At the same time the brain receives the message that an impending bowel movement is about to occur, and if it is not convenient, the puborectalis muscle is stimulated to contract the external anal sphincter and stop the bowel movement until it is convenient.

2.4. The neurogenic bowel

The neurogenic bowel causes incontinence due to the interruption of the spinal cord in Spina Bifida. Spina Bifida levels occurring at T10 or below tends to have a large compliant rectum with weak ability to push the stool into the anal canal, flaccid internal and external anal sphincters, and impaired sensory awareness or motor control. The closer to the sacral region on the spinal cord the spina bifida lesion is the longer the colon transit time is [9,14]. One study on colonic transit time in children with myelomenigocele found that there was no relationship between level of lesion or patient mobility and colonic transit time. All study patients had prolonged transit time averaging 103 ± 49 hours vs. 23 ± 13 hours [24].

Bowel programs for people with spina bifida are based upon this physiology.

3. Continence programs

There is a small amount of evidence of the effectiveness of continence programs but almost none in the myelomeningocele population. The Cochrane Collaboration has done several reviews of different types of continence programs evaluating medications, biofeedback, pelvic exercises, and sacral nerve stimulation. It is summarized in Table 1 [3,22,23]. None of the studies included in the evidence base review included spina bifida as a diagnosis. A few of the biofeedback studies did include children, but none of the sacral nerve stimulator included them.

Other types of bowel programs utilized include the use of suppositories and small and large volume enemas. Most of the research has been done in the spinal cord injured population. The anatomy of the spina bifida population does not follow the differentiation of upper and lower motor neuron function used in the spinal cord injury literature because the enteric neurons migrate to the small and large intestines from the neural crest [21]. There is no reason to believe that if the spinal cord is interrupted in formation that the nerves lying next to it may also be interrupted. As mentioned before, a study on motility and spina bifida lesion level, found different types of constipation occurring in different segments of the colon. The increased transit time in the rectosigmoid colon has important influence on the planning of an elimination program [24].

3.1. Suppositories

Review of the literature on the use of suppositories has identified 2 studies that compare types of suppositories. The first study [11] compared the effectiveness of bisacodyl suppositories in a vegetable oil base, bisacodyl suppositories in a polyethylene glycol-base and glycerin/docusate sodium mini-enemas. The second study [29] compared the time between the 2 types of bisacodyl suppositories. Both studies found statistical evidence that the bisacodyl suppository in the polyethylene glycol-base worked much faster stimulating a defecation reflex sooner and shortening the time for the complete bowel program. The first study also identified that the glycerin/docusate sodium mini-enema took less time than the bisacodyl suppository in a vegetable oil base.

Table 1
Cochrane collaboration of three types of continence programs

Intervention	No. studies	Design Method	Outcomes	Flaws
Drug Treatment (3)	11 studies – all evaluating medications for diarrhea and incontinence	9 were cross-over	Limited evidence that antidiarrheal drugs and drugs that enhance anal sphincter tone may reduce incontinence	Small number and short duration
Biofeedback and/or sphincter exercises (23)	11 studies for total of 564 participants	8 had poor or uncertain methodology;	No study reported a major difference in outcome between any method of biofeedback or exercise combination	Wide variation among use of outcome measures, duration of treatment and length of follow-up
Sacral Nerve Stimulation (22)	3 studies – 2 evaluating incontinence and one evaluating constipation	All 3 were crossover design	Limited evidence that SNS can improve continence and constipation	Small numbers;

3.2. Enemas

Enema use has been controversial for fear of changes in the mucosal lining of the colon. One study [26] compared tap water and soapsuds enema solutions. Soapsuds enemas produced more output, therefore must be a stronger defecation stimulant. It was tolerated equally as well as the tap water. Some tap water was retained within the colon and assumed to be reabsorbed by the colonic mucosa as opposed to total elimination.

A second study on enema solutions [27] compared isotonic solution (PEG-ES) with 2 hypotonic solutions (tap water and soapsuds) for net output, mucosal irritation and tolerance. Soapsuds had the greatest output, followed by tap water. PEG-ES had the lowest output of stool. Mucosal changes were most evident following the soapsuds solution and the PEG-ES had the least mucosal changes. Comfort was reported most frequently with the PEG-ES but one subject did report cramping even with the PEG-ES.

Tap water enemas are frequently used as the most common and inexpensive solution in enemas. Concern has been raised of hyponatremia and other electrolyte abnormalities [31]. A study evaluating 40 children using tap water enemas showed all plasma sodium values were within normal limits and no evidence of water intoxication [20].

Other types of enema solutions include milk and molasses and phosphate. Milk and molasses enemas were first described in an 83 year old nursing text book. It is felt that the mechanism for elimination begins with distention, increased pressure, peristalsis and elimination. It also does not alter electrolytes. Allergy to milk is a contraindication [30].

Phosphate enemas (not recommended for children below age 2 years) cause an osmotic effect to produce an evacuation [19].

Administering enemas in children with no sphincter control has been problematic. There have been two types of equipment developed for transanal or transrectal irrigation. The cone enema is a colostomy irrigation system instilling the pre-determined solution through the anus. It is done sitting on the toilet holding the cone in place. It can be done independently.

The enema continent catheter is a large catheter with a balloon holding 100–300 mm Hg of air. This tube is inserted through the anus and into the rectum where the balloon is inflated. The pre-determined solution is instilled and then the balloon is deflated and removed. This can be difficult if the anal canal has lax tone and the catheter tip bends and comes back out during insertion.

Both methods of administration have been evaluated in several different centers. The cone enema was used on 40 children, born with spina bifida, using a tap water solution. All experienced improvement in constipation and 88% became continent. Most felt it was time consuming and only one became independent in doing it [20].

An evaluation of the enema continent catheter using markers to determine the degree of rectal content emptying in spinal cord injury patients compared with idiopathic constipation indicated that the transanal colonic irrigation effects almost complete emptying of the rectosigmoid and descending colon. It was more effective than normal defecation [5].

Comparison of the enema continent catheter and conservative bowel management was evaluated in the spinal cord injured population. Conservative bowel management was defined to include food and liquids, activity and a daily schedule to develop a habitual emptying response. Laxatives or constipating medicines were included. The enema continent catheter used a tap water solution and laxatives or constipating medicines were also included if needed. The enema continent catheter took less time, had less discomfort and im-

proved bowel continence [5]. Some problems experienced with the enema continent catheter included expulsion of catheter, leakage and busting of balloon, but is less with a newer version by Coloplast that has not yet been approved by the FDA in the US [8].

3.3. Surgical options

Another method of enema administration is the Malone appendicocecostomy (MACE) a surgical procedure. This technique involves access to the colon via a stoma in the cecum. A small catheter is inserted into the stoma and a varying amount and type of solution is instilled. The average time to complete the procedure is 1 hour. This impacts compliance over time and may lead to skin breakdown or shearing injuries. Another complication is stomal stenosis. Some patients have placed a tube to maintain patency. Headaches, emesis and cramping occur with one third of the patients [10, 28]. Constipation may still be an issue requiring oral medications to promote stool consistency and aid in motility.

One review of outcomes from the MACE and the enema continent catheter in people with various forms of neurogenic function including spina bifida found that 12 out of 21 using the enema continent catheter over 16 months were continent. 3 out 5 of those successful had spina bifida. Problems encountered included the expulsion of the catheter, leaking and requiring assistance. The continent outcome over 38 months for the MACE was 7 out of 8. 2 out of 2 with spina bifida were in that continent category. Problems with the MACE were fewer but included abdominal pain, general discomfort, nausea and leaking of fluid through stoma site [6].

A variation of the MACE is the insertion of the Chait tube into the cecum or the descending colon. This is done in interventional radiology and has a faster recovery.

The use of colostomies is typically seen in the newborn with a variation of spina bifida with an associated cloacal abnormalities or imperforate anus. Once it is taken down typically a cone enema is an effective continence program.

4. Assessment tools

Three assessment tools for evaluation of constipation or fecal incontinence have been validated. Only one of the three has been designed for people having a neurogenic bowel. One other tool has been validated to evaluate intestinal transit time.

The Cleveland Clinic has developed an assessment tool for constipation in people with colonic inertia and pelvic outlet dysfunction. It has eight variables that provide an objective definition of constipation useful in diagnosis. The tool has been validated with patients diagnosed with the above problems. It does not aid in treatment decisions or predict effectiveness of intervention [1].

The St Mark's incontinence assessment tool is a modification of the Cleveland Clinic tool shifting from diagnosing constipation to assessing incontinence. It consists of three items about the type and frequency of incontinence with additional questions about alterations in lifestyle, use of incontinence barrier devices, use of medications for diarrhea, and ability to defer defecation. It does have good correlation with patients' subjective perception and with all types of incontinence. It has been found to have limitations in not representing the amount of leakage with accidents. It also does not reflect improvement from treatment to the degree that patients report improvement [17].

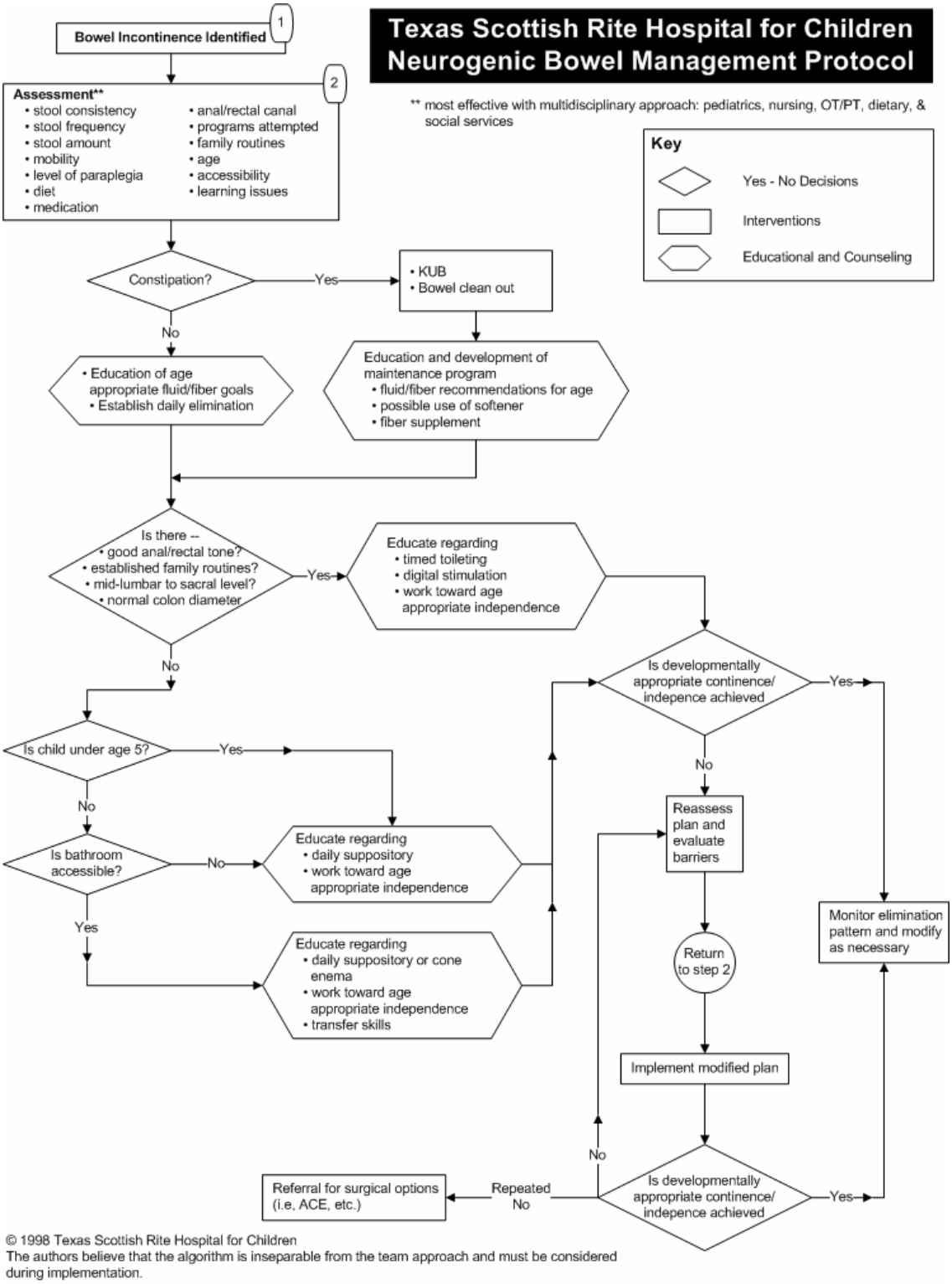
The neurogenic bowel dysfunction score was developed for people with a combination of constipation and fecal incontinence. It is a 10 item tool that has weighted answers that relate to quality of life issues. It has been validated in the spinal cord injured population. It does reflect the patient satisfaction of the type of continence program in use. It is constructed for comparison of groups rather than for clinical decision making in individual groups. Validation in other patient groups is recommended [13].

The Bristol Stool Form Scale [16] is the only validated tool that evaluates intestinal transit time. It is a scale that evaluates eliminated stool form in the toilet and assigns a ranking number. Based upon that rating, the intestinal transit time of defecation is estimated and decisions for treatment can be made. It is validated to reflect the colonic transit time and the rating of the stool form.

None of the tools asked the amount of stool when eliminated. Constipation may be under reported when a bowel movement occurs and is only a small amount [24].

5. Determining a bowel continence program

A developmental approach to bowel management in the spina bifida population is in place at Texas Scottish


Texas Scottish Rite Hospital for Children
Neurogenic Bowel Management Protocol
** most effective with multidisciplinary approach: pediatrics, nursing, OT/PT, dietary, & social services
Key
Yes - No Decisions
Interventions
Educational and Counseling
1
Bowel Incontinence Identified
2
Assessment**
• stool consistency
• stool frequency
• stool amount
• mobility
• level of paraplegia
• diet
• medication
• anal/rectal canal
• programs attempted
• family routines
• age
• accessibility
• learning issues
Constipation?
Yes
• KUB
• Bowel clean out
No
• Education of age appropriate fluid/fiber goals
• Establish daily elimination
Education and development of maintenance program
• fluid/fiber recommendations for age
• possible use of softener
• fiber supplement
Is there --
• good anal/rectal tone?
• established family routines?
• mid-lumbar to sacral level?
• normal colon diameter
Yes
Educate regarding
• timed toileting
• digital stimulation
• work toward age appropriate independence
No
Is child under age 5?
Yes
No
Is bathroom accessible?
No
Educate regarding
• daily suppository
• work toward age appropriate independence
Yes
Educate regarding
• daily suppository or cone enema
• work toward age appropriate independence
• transfer skills
Is developmentally appropriate continence/ indepence achieved
Yes
No
Reassess plan and evaluate barriers
Return to step 2
Implement modified plan
Monitor elimination pattern and modify as necessary
No
Is developmentally appropriate continence/ indepence achieved
Yes
Repeated No
Referral for surgical options (i.e, ACE, etc.)
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The authors believe that the algorithm is inseparable from the team approach and must be considered during implementation.

Fig. 1.

Table 2
Assessment points

Category	Assessment
Stool Form	Stool Consistency
	Stool Frequency
	Stool Amount
Individual Physiologic Parameters	Tone of the anal canal
	Level of paraplegia
	Age
	Mobility
Diet Factors	Fluid
	Fiber
	Trigger foods
Medications	Anticholinergics
	Anesthesia/pain medicine
Family Patterns	Accessibility
	Family routines
	Programs attempted in the past
	Learning issues

Rite Hospital for Children (Fig. 1, Table 5). It is based upon a thirteen item assessment (Table 2) and is adjusted as the child develops. Inclusion of the 13 items in the assessment will help design a program with the greatest potential for success. The short term goal is to prevent/treat constipation and the long term goals are continence and independence.

5.1. Assessment points

5.1.1. Stool form

Evaluating the elimination pattern is important to know if a clean out is needed prior to beginning a continence program and the amount of assistance the rectum may need to empty. The use of the Bristol stool form may be helpful here. The **stool consistency** can vary from balls that are hard or soft, unformed that is oatmeal, paste or watery or a formed log. The **stool frequency** reveals the degree of reflex working in the rectum to eliminate the entire contents or only a small portion of the contents frequently through-out the day or week. If elimination occurs only once a week, it indicates the degree of over-compliance the rectum has to store a large amount of stool without eliminating. **Stool amount** again indicates the degree of emptying of the rectum. If a ten year old child is only emptying 2 inches, quite a few inches are remaining that can become harder and more difficult to eliminate.

An "Inches Table" has been designed to assist parents with evaluating stool amount (Table 3). This is based on the estimated length of the recto-sigmoid colon, with individual variation depending on the diameter of the colon.

Table 3
Estimated daily stool output for parents

Age	Output in inches
2–4 years	2–4 inch log
4–8 years	4–6 inch log
8–11 years	6–12 inch log
12 years to adult	12–18 inch log

5.1.2. Individual physiologic parameters

The **tone of the anal canal** can be very low and "collapses" on itself. This makes finding the internal anal sphincter difficult as the canal is like a maze. Suppositories are not successful in this patient population as the parent/young person will not insert it through the internal anal sphincter. It will remain in the anal canal and not help evacuate the rectum. Also some anal canals have tone but not external sphincter tone to hold the suppository in and it falls out as soon as it is inserted.

Level of paraplegia indicates how much support the child will need for donning and doffing clothing, strength of pushing and balance on a toilet.

The **age** of the child impacts the design of the continence program also. An infant/toddler is dependent in their elimination skills and a program is designed for the parents to do. A school-age child is assuming more of their self-skills and needs to have a program they can eventually do themselves.

Mobility of the child plays an important part in colon motility. Children that ambulate may have more frequent accidents due to the level of activity or when activity is increased. Ambulators also have less bathroom accessibility issues.

5.1.3. Dietary Factors

The diet plays an exceptional role in the stool consistency. **Fluid** intake impacts the hardness or softness of the stool. Dietary **fiber** works with the fluid to bulk up the stool and hold water in it. Children who have fiber in their diet as toddlers tend to continue to have adequate amounts of fiber as they grow older.

Dieticians have an important role in providing goals for both fluid and fiber for children as they grow. They also have great strategies for incorporating fluid and fiber into a child's day. The daily recommended fiber amount is determined by taking the child's age and adding 5–10. For example, if the child is 3 years old his fiber needs would be 8–13 gms per day. One study found that constipation was alleviated in neurologically intact children simply by increasing their intake of fiber to 10 grams for a child 5 years and younger and 15 gms for children 6–10 years old [2].

Table 4
Medications for bowel clean out

Common Use	Medications	Action	Dose	Comments
Clean-Out Oral [19,30]	Polyethylene glycol	Osmotic Laxative	2–11 yrs: 8.5 gm (1/2 to measuring line in 4 oz liquid) > 12 yr 17 gm in 8 oz of liquid	Disimpaction
	Mineral Oil	Lubricant	5–11 yr: 5–30 ml 2–3 times/day > 12 yr: 30–60 ml two-three times/day	Do not use if suspect aspiration; May break down g-tube;
	Milk of Magnesia	Osmotic Laxative	< 2yr: 0.5 ml/kg/dose 2–5yr: 5–15 ml/d once or in divided doses 6–11 yr: 15–30 ml/day or in divided doses > 12 yr: 30–60 ml/day once or in divided doses	Is in chewable form also;
	Magnesium Citrate	Osmotic Laxative	< 6yr: 2–4 ml/kg once or divided 6–12 yr 100–150 ml > 12 yr 150–300 ml	Do not use with patients in renal insufficiency.
Clean-Out Rectal [19,30]	Phosphosoda Enema	Osmotic effect in intestine by drawing water into lumen of the gut, producing distension, promoting peristalsis, and evacuation	2–11 yrs: contents of one 2.25 oz pediatric enema > 12 yrs: contents of one 4.5 oz adult enema	Not for use in patients with renal insufficiency; Do not exceed more than 1 per day;
	Fleet Mineral Oil Enema®	Ease elimination of stool decreasing water absorption and lubricating rectum	2–11 yrs: 30–60 ml as single dose > 12: 60–150 ml as a single dose	Used with significant hard stool in rectal vault; Difficult to retain in with incompetent sphincter; Safe for children with renal insufficiency
	Milk and Molasses Enema	Osmotic effect without a shift in electrolytes	< 8 yrs; equal parts milk and molasses; (1oz:1oz; 2oz:2oz) 8 yrs to teens: 8 oz milk and 8 oz molasses	Safe for patients with renal insufficiency;

There are also dietary **triggers** that cause diarrhea or accidents. Corn and high fructose corn syrup can cause diarrhea that is not associated with constipation. The high sugar content can cause many people with spina bifida to have accidents. Other food triggers include chocolate, greasy foods and spicy foods. Families are asked to eliminate the offending food found in the diet history for 2 weeks. If the stool consistency is better, they are asked to slowly add in the offending food over a three to four day period. That helps them to know what amount of the food can cause the accident and choices can be made as to how important it is to eat that food.

5.1.4. Medications

Many **medications** may contribute to a more constipated pattern of elimination. Antihistamines, anesthesia/pain medicines, anti-cholinergic and antispasmodic medicines can all cause constipation. Many antibiotics can cause diarrhea. Knowing which medicines a child takes and when is necessary for improving the stool consistency. If surgery is planned, medication adjustments will need to be made before and after surgery.

5.1.5. Family patterns

Accessibility of the child's home reveals the degree of difficulty a family will encounter getting a child on to the toilet as the child grows. Bathroom doors notoriously are small and as wheelchairs get bigger to accommodate a growing child access becomes more difficult. The degree of difficulty can impact the motivation to independently do a bowel program. Also, if there is only one bathroom in the home, the amount of time a bowel program may take will also impact the rest of the family. Occupational therapists can offer many solutions such as a bedside commode or a technique for lifting themselves up onto a 2-step stool and then on to the toilet.

The **family routines** can impact the ability of a family to implement a program. If the mother works evenings and the dad is home or she is single, leaving the child with a sitter, accommodations in the design of the program may be necessary.

Table 5
Developmental Goals for bowel continence

Age	Developmental Goals	Team Member	Intervention
Infant	Keep stool soft like oatmeal	Dietician	Fluid goals; How to introduce fiber foods like infant oatmeal or barley cereal;
Toddler/Preschooler	Support formation of soft/formed stool;	Dietary	Increase fluid goals; Offering variety of fruits and vegetables that prevent food battles with developing independence;
	Begin potty training	OT	Different types of cups for fluid intake; Donning/doffing clothes; Adaptive equipment for toilet to improve sitting balance;
School-age child	Achieving Continence; Learning components of achieving continence; Participating in bowel program	Dietary OT/Nursing	Increase fluid goals and teach strategies to the child for intake throughout the day; Teach child foods that contain fiber; Location of rectum; Bathroom accessibility and transfers; Timing of oral medications with elimination times;
Adolescence	Independence	Dietary Nursing	Strategies for ingesting fluids and fiber; Explanation of how spina bifida affects the bowel/bladder necessitating continence programs; trouble shoot handling continence programs in new situations;

The **programs attempted in the past** also indicate a family's frustration level and confidence in achieving a successful continence program. A mom who manually disimpacts her son on the floor of the family room in front of the TV may believe that she has tried everything and this is the only thing that works.

Learning issues need to be considered when teaching the young person new techniques for elimination. Breaking down the steps to accomplish one at a time is important. Begin with mastering the technique and timing of the medications. The next step is to recognize the "triggers" for constipation /accidents. Once identified, they learn to trouble shoot those events. This takes a lot of patience on the family's part as problem solving is one of the executive functioning skills people with spina bifida have difficulty with.

5.2. Implementing a bowel continence program

The design of the continence program is based on the assessment points and three guiding principles.

1. Any bowel program should be 20–30 minutes start to finish. This can be accommodated into a family routine and a young adult routine as the child grows.
2. A bowel program should be flexible and transportable so vacations, wheelchair basketball tournaments and college can be accommodated. It should also be able to be done at different times of the day based on activities during the day or evening. Weekends may be busy in the evening and bowel programs can be done earlier in the day.
3. A bowel program needs to be designed for the young person to be independent in performing it.

Texas Scottish Rite Hospital for Children has developed an algorithm (Fig. 1) to assist with determining the most effective bowel program for the age and current bowel pattern of the child. If it is determined that the child is constipated (i.e. having small, hard stool) an abdominal x-ray is obtained to verify the degree of constipation and determine the type of medications needed for a clean-out (Table 4) [19,30].

Following the clean-out the maintenance phase is begun. The age of the child determines one aspect of the program. An interdisciplinary team is involved to provide parents with enough information and support to be successful (Table 5). Oral medications are introduced based upon the age of the child and the goals the family is interested in (Tables 6, 7) [19,30]. Adjustments in bowel programs may be needed as vacations, illness or a change of routine occur (summer vacations vs. school). A trouble shooting guide is included to assist with success (Table 8).

– Infants: Lactulose® syrup may be started to assist with keeping the stools soft. If the infant continues to have difficulty in eliminating, a liquid glycerin

Table 6
Oral maintenance medications

Maintenance Oral [19,30]	Lactulose®	Poorly absorbed sugar with osmotic effect	Infants: 2.5–10 ml/day Children: 7.5 ml/day	Gas and bloating can be common side effects
	Senna (8.6 mg/5 cc=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 yr: 2.5–10 ml/day > 6 yr: 5–15 ml/day	Produces peristalsis; works usually in 6 hrs 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 gm fiber; increase as needed every 3 days;	Taste free, grit free; Will not thicken or alter taste or texture of food;
	Miralax®	Osmotic Laxative	0.8 g/kg one time/day	Not as effective in neurogenic bowel; difficult to time; Can cause gas bloating & nausea;
	Reglan®	Motility agent-gastro/colonic	0.1–0.2 mg/kg 2–3 times/day	Decreases time stool sits in colon and prevents constipation
	Erythromycin®	Motility agent-gastro/colonic	2–3 mg/kg/dose 3 times/day	Decreases time stool sits in colon;

Table 7
Maintenance medications – rectally

Maintenance Rectal [19,30]	Enemeez® (4 ml of docusate, glycerin, polyethylene glycol)	Stimulant	Contents of 1;	Difficult to hold in with incompetent external sphincter-does not support independence;
			If added to trans anal or MACE irrigation solution may add 1–2;	Assist in speed of emptying; Administration technique supports independence;
	Magic Bullet® (bisacodyl in water base)	Stimulant	1 inserted on toilet	Can be done independently; works in 5–10 minutes;

suppository or an Enemeez® suppository may be tried. These can be continued on a daily basis if the infant continues to struggle with elimination.

– Toddler/Preschooler: "Potty training" is only effective if there is some stool eliminated. Working toward one stool a day, senna may be started to time the bowel movement. Miralax® is commonly used in the general population and is very effective in treating constipation. In children with a neurogenic bowel, it can be difficulty to determine the appropriate dose that does not produce a liquid stool. The timing of it has been found to be difficult for many families and they stop using it as it is not predictable. Other families are successful with adjusting the dose, but the difference in the colonic tone and motility has not been evaluated [12]. Enemeez® suppository can be administered 6 hours after taking the senna so the child should have some results. At this age, a child should only sit for about 10 minutes.

Parents begin to involve the pre-schooler in the program by looking at the amount and shape eliminated in the toilet and talking about changes in medicine if the stool is too hard or soft. This begins to help the child with problem solving as they get older.

– School-age child: If the child has been continent on the enemeez, this is the time to change to the Magic Bullet® suppository for independence. A six year old's fingers will not be long enough to insert it completely, but they can begin to learn where it is inserted. One technique for teaching the location of the anal canal is to have the child run their finger down the gluteal medial fold and

Table 8
Trouble shooting

Problem	Suggestions
Stools before 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 prior to timed evacuation; Change mechanism of eliminating (from suppository to trans-anal 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 trans-anal enema assists in emptying descending colon and preventing ambulation stools;
Teenage girls with liquid stool once a month	Assess if associated with monthly period; if it is, give $^1/_4$ 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;
Cone enema leaks while water is instilling	Anal canal dilates reflexively with fluid, wiggle cone in for a tighter seal;

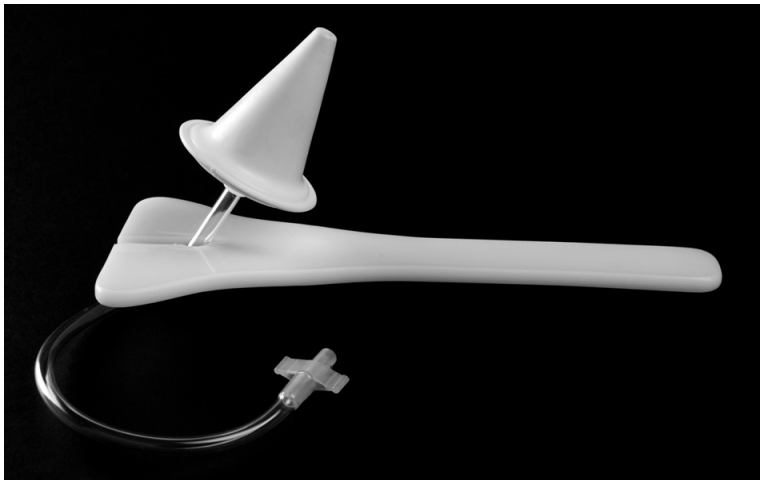

Fig. 2.

locating the first cavity they come to. They can practice their balance and location prior to the actual insertion.

The timing of the medications is very important to achieving continence. As children learn to tell time, working with them on the time senna is given is 6 hours before the elimination program is done. Also adjustments can be made to take the oral medication earlier and eliminate earlier if an activity is planned later in the evening. Introducing these concepts now, assists their transition into independence later.

Many children have low anal canal tone, redundant tissue in the anal canal or delayed emptying with a suppository and can be switched to a cone enema. This is hard to hold in for the younger children as it becomes heavy as the fluid is instilled. The occupational therapist has devised a "cone holder" (Fig. 2) which is a plastic handle that fits around the tubing at the base of the cone and extends to the toilet seat. The thigh can lay over it to help the holding of the enema during administration. The solution is held for 2–3 minutes and then released. If the stool is soft or formed into a soft log, the rectum should empty over the next 10–15 minutes. The solution of the cone enema is usually 500 ml of tap water or normal saline. If elimination is delayed, an enemeez® suppository can be added to either solution. Independence can be achieved in this technique by age 12 if appropriate adaptive equipment is provided [15].

Some children do not have the balance or upper extremity strength to insert a suppository or hold in a cone

enema. The parents feel that they have tried everything and nothing is working. The MACE may be a consideration. Some of the problems that have occurred with the MACE may be avoided through motility studies prior to the surgery. Motility studies may identify those children with delayed rectosigmoid transit time that may cause the delay or absent emptying. Ensuring the young person has a strategy for getting into the bathroom and onto the toilet is also an important consideration prior to the surgery.

– The adolescent: after many years of participating in a successful continence program, the teen developmentally may rebel and resist doing it. One important question to ask is "what is hard about this?" Several parents found many simple solutions that improve the continence program by having disinfectant wipes available, a small covered wastebasket next to the toilet and small plastic drawers or other containers to keep necessary supplies within reach.

6. Conclusions

Establishing a bowel continence program for the person with spina bifida is a complex intervention with 13 aspects affecting the outcome. Implementing programs as the child grows from stage to stage is important for ongoing success and for family integration of the continence concept. Assessment of constipation when problems arise must include the amount of stool eliminated as well as the shape and consistency to really establish a diagnosis of constipation. A team approach that includes dieticians, occupational and physical therapy as well as the nurse/physician team provides families with the support they need to be successful.

7. Future needs

Many questions surface while working with this population to achieve continence. Research that explores the colonic motility with larger numbers is very important for implementing an effective continence program. The use of tap water in enema solution needs further study when used in the MACE. Reimbursement of "over-the-counter medications" and the long term cost of those medications that support a successful continence program need to be compared to the cost of a surgical intervention and the ongoing support that is required. Many families and individuals may turn to a surgical option because of lack of funding to cover the "over-the-counter" medications. Acknowledgements: The author would like to thank the spina bifida team at Texas Scottish Rite Hospital for Children whose commitment and dedication assist families with spina bifida to achieve success.

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