ORIGINAL ARTICLE

The effects of transanal irrigation as a stepwise bowel management program on the quality of life of children with spina bifida and their caregivers

EK Choi¹, SH Shin¹, YJ Im², MJ Kim¹ and SW Han²**Study design:** Experimental, prospective study.**Objectives:** Fecal incontinence and constipation affect the quality of life (QOL) of children with spina bifida and their caregivers. We evaluated the clinical efficacy of a stepwise bowel management program on QOL for children with spina bifida and their caregivers.**Setting:** Republic of Korea.**Methods:** Between December 2010 and April 2011, 53 children with constipation, fecal incontinence or both underwent a stepwise bowel management program at our spina bifida clinic. The children and their caregivers were evaluated before and after this program using a self-administered questionnaire.**Results:** Among the children, 11.3% received only oral laxatives and controlled well, 88.7% received transanal irrigation. After this program, the mean number of episodes of fecal incontinence per week, number of diaper changes and total time for bowel care decreased from 6.9 to 0.5 ($P=0.004$), from 1.6 to 0.2 ($P=0.001$) and from 27 to 15.9 min ($P=0.003$), respectively. Caregivers and children were able to leave their houses more often ($P=0.006$), and caregivers' bothersomeness, anxiety and depression due to bowel care decreased ($P<0.001$). Factors related to family relationships ($P=0.265$) and financial impact ($P=0.071$) improved, but not significantly.**Conclusions:** We observed significant improvement in defecation symptoms and QOL scores of spina bifida patients who underwent this program. We recommend that this simple therapeutic method be considered as a safe and valid choice for the treatment of chronic constipation and fecal incontinence.*Spinal Cord* (2013) **51**, 384–388; doi:10.1038/sc.2013.8; published online 26 February 2013**Keywords:** spinal dysraphism; neurogenic bowel; quality of life

INTRODUCTION

Spina bifida is the second most common congenital birth defect worldwide. It is caused by failure of the neural tube to close during the early weeks of gestation.¹ Almost all children with spina bifida have impairments in bowel and bladder function from infancy.² Of the myriad clinical features of spina bifida, neuropathic bowel and bladder dysfunction arguably have the greatest impact on social integration.³ As appropriate management of the neurogenic bladder has made it possible to achieve urinary continence, bowel control is a major concern in patients with spina bifida.⁴ In fact, more than 50% of children and adolescents do not achieve full bowel continence.²

Fecal incontinence is reported to be significantly more stressful than impaired motor function.⁵ Fecal incontinence is the most important factor in the deterioration of the mental and emotional aspects of quality of life (QOL).⁶ A wide range of medical problems, such as chronic constipation, megacolon, inadequate bladder emptying, urinary tract infection and shunt malfunction, and psychological problems such as psychosocial trauma, damage to self-esteem, negative impact on social interaction and delayed psychosocial development are associated with unsuccessful bowel

programs.² Today, many children with spina bifida are cared for in interdisciplinary spina bifida programs, where bowel continence is addressed. However, not all families have access to such programs. Families universally report a difficult and long journey, finding an effective bowel program for their children with spina bifida, encountering major barriers to achieving continence.²

This study focused on the management of constipation and fecal incontinence, and evaluated whether a stepwise approach was successful in achieving bowel continence in the spina bifida population followed at our children's hospital. We evaluated the clinical efficacy of a stratified bowel management program on the improvement of defecation symptoms, and QOL in children with spina bifida and their caregivers.

MATERIALS AND METHODS

The prospective research proposal was approved by the Institutional Review Board of Yonsei University Healthcare System.

Between December 2010 and April 2011, we enrolled 53 children with spina bifida who were referred to the pediatric urology department of the spina

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bifida clinic at Severance Children's Hospital in Korea to undergo a stepwise bowel management program.

Inclusion criteria were as follows: patients with spina bifida, aged 3–18 years, with the presence of chronic constipation or unsatisfactory bowel management defined as fecal incontinence, constipation or both. Fecal incontinence was defined as involuntary stool loss more than once a week. Constipation was defined as the presence of one or more of the following: a stool frequency of less than three times a week; hard, large stools that were difficult and painful to pass; or the use of laxatives.⁶ Exclusion criteria were as follows: evidence of bowel obstruction or inflammatory bowel disease or a history of operation owing to a congenital colorectal disorder.

Children and their caregivers were evaluated prospectively before and after the bowel management program. The primary caregiver or children who could read and understand the survey questionnaire completed the survey. The majority of the surveys were administered in the clinic, but some were completed at home and mailed back.

Instruments

The survey questionnaire for clinical efficacy of bowel management was developed by the researchers based on literature related to bowel program for children with spina bifida and their caregivers.^{1,2,4–10} Most of items in the questionnaire for QOL were based on the study by Nanigian *et al.*⁷ with author's permission, which reported fecal incontinence and constipation quality of life for children with spina bifida. To assess content validity and cultural approval of the questionnaire, six experts (two pediatric urologists, one pediatrician, one specialized nurse practitioner and two parents who have a child with spina bifida) were consulted and the items were revised accordingly. The questionnaire focuses on the aspects of daily life, in which bowel incontinence and bowel care have a significant impact. It had a total of 40 items in three parts: part (1) nine items on defecation symptoms and bowel management status; part (2) 21 items on QOL related to bowel management (eight items on travel and socialization; six items on caregiver support and emotional impact; four items on family relationships; three items on financial impact); and part (3) 10 items on general characteristics of the child and parent. A high score indicated a poor QOL. Internal consistency of 21 items (excluding the defecation symptoms and bowel management status and the general characteristics) showed a Cronbach's Alpha coefficient of .763.

Bowel management program

The stepwise bowel management program is described in Figure 1. If children who had constipation or fecal incontinence had no history of laxative medication to manage their bowel problem, they initially received enema or manual extraction to clean bowel. And then we used polyethylene glycol 3350

at a dose of 0.5 g/kg/day of isosmotic polyethylene glycol electrolyte balanced solution as a laxative, which was devoid of significant side effects, and was well tolerated.⁹

If medication failed or if patients had previously experienced failure using medication, we initiated transanal irrigation. Children and their caregivers were instructed regarding how to run lukewarm tap water from a plastic bag into the bowel through an irrigation cone or catheter (Cone or Peristeen anal irrigation system, Coloplast, Denmark) depending on the child's age. Using Peristeen transanal irrigation with its rectal balloon catheter is difficult in younger children, who are less cooperative, because the procedure requires more cooperation from the child than that required for Cone anal irrigation. Therefore, we usually recommend cone enema for children younger than 6 years. Transanal irrigation has been shown to empty the colon to the splenic flexure using a volume of 750 ml water, in adults.¹¹ Initially, transanal irrigation was given on a daily basis. If successful, frequency was reduced to once every 2–3 days.⁴ Transanal irrigation volume was initially 300–500 ml, but was increased to 500–700 ml, according to the child's age, if necessary. To ensure sufficient knowledge about transanal irrigation, a specialized nurse practitioner taught the patients and parents its use. During the trial, the nurse practitioner phoned parents at least once to consult about their bowel management status. Fundamentally, a normal healthy diet is recommended for all children regardless of the treatment method. The diet should consist of small portions of fiber foods and sufficient water intake to maintain good fluid balance for a successful outcome in the bowel management program. Over at least 3 months of treatment, we reevaluated the effects of the stepwise bowel management program. Success was defined as fecal continence or pseudo-continence. Fecal continence was defined as no involuntary stool loss in the absence of treatment, and pseudo-continence was defined as involuntary stool loss no more than once a week with the use of a treatment modality.⁶ Statistical analysis was performed on the survey items before and after the program with paired *t*-test. Data were analyzed using SPSS version 19.0 (SPSS, Seoul, Republic of Korea).

We certify that all applicable institutional regulations concerning the ethical use of human volunteers were followed during the course of this research.

RESULTS

The 53 patients included 27 boys and 26 girls. Of these, 28 (52.8%) were born with meningomyelocele, and 25 (47.2%) with lipomeningomyelocele. Their median age was 5.4 (range 3–13.8) years, and the median treatment duration for the stepwise bowel management program was 4 (range 3–7.3) months. About two-thirds of the children had used digital stimulation or manual extraction for defecation at the start of the bowel program (Table 1).

Figure 1 Results of the stepwise bowel management program in 53 children with spina bifida.

Table 1 Patient characteristics (N=53)

	N(%)
Gender	
Male	27 (50.9)
Female	26 (49.1)
Diagnosis	
Meningomyelocele	28 (52.8)
Lipomeningomyelocele	25 (47.2)
Age	5.4 (3.0,13.8) years
Program duration	4.0 (3.0,7.3) months
Method for defecation	
Self	22 (41.5)
Digital stimulation or manual extraction	34 (64.2)
Suppositories or enemas	19 (35.9)
Laxatives	8 (15.1)

Age and duration were presented with median (minimum, maximum).

Figure 1 summarizes the results of the stepwise bowel management program. Success with laxatives only was seen in six children (11.3%). Of the remaining 47 children, transanal irrigation treatment was successful in 43 (81.1%), while four (7.5%) remained constipated, had fecal incontinence or both.

We observed clinical efficacy of the bowel program for improvement in defecation symptoms. Comparing questionnaire scores before and at the end of the study, the frequency of bowel movements changed from 1.7 to 2.5 days ($P<0.001$), and the Bristol Stool Form Scale improved from type 2 to type 3 ($P=0.008$). Bowel care time significantly decreased from 27 to 15.9 min per day ($P=0.003$). The number of diaper changes and episodes of fecal incontinence were significantly improved (from 1.6 to 0.2, $P=0.001$; from 6.9 to 0.5, $P=0.004$; respectively) (Table 2). Additionally, the frequency of manual evacuation or digital rectal stimulation for defecation was reduced from 32 (60.4%) to 6 (11.3%) of 53 patients, who were treated our bowel management program.

Children and their caregivers reported improved QOL after the stepwise bowel management program (Table 2). We observed a significant reduction in impact on travel and socialization (from 23.5 to 9.3, $P=0.006$) and caregiver support and emotional impact (from 12.7 to 9.0, $P<0.001$) in QOL. On the other hand, there was a nonsignificant decrease in scores for family relationships (from 3.9 to 2.1, $P=0.265$) and financial impact (from 1.7 to 1.0, $P=0.071$). There was a trend toward parents and children being less likely to be prevented from leaving the house due to bowel care and decreased anxiety related to leaving home. The worries of children and parents regarding the smell from stool incontinence were also alleviated. There was a positive influence on socialization of children and parents (Table 3).

Moreover, there was a significant decrease in caregiver depression (from 1.7 to 1.0, $P=0.001$), anxiety (from 1.9 to 1.2, $P<0.001$) regarding constipation or fecal incontinence, and bothersomeness (from 2.2 to 1.0, $P<0.001$) related to bowel care problems (Figure 2).

DISCUSSION

Spina bifida has a significant impact on patient and family member QOL.^{8,12,13} The lack of social acceptance and the discomfort caused by fecal incontinence should not be underestimated.¹⁴ Fecal incontinence causes odor and skin irritation, increases dependence,

Table 2 Results of clinical efficacy and quality of life before and after a stepwise bowel management program (N=53)

	Before	After	P-value
Clinical efficacy			
Frequency of bowel movements, days	1.7 ± 1.7	2.5 ± 1.1	<0.001
Bristol stool form scale	2.0 ± 1.7	3.0 ± 1.5	0.008
Bowel care time per day, minutes	27.0 ± 24.1	15.9 ± 7.8	0.003
Frequency of diaper change per day	1.6 ± 1.7	0.2 ± 0.4	0.001
Frequency of fecal incontinence per week	6.9 ± 8.1	0.5 ± 0.7	0.004
Quality of life (the range of score)			
Travel and socialization (0–32)	23.5 ± 3.2	9.3 ± 1.4	0.006
Caregiver support and emotional impact (0–18)	12.7 ± 3.6	9.0 ± 3.3	<0.001
Family relationships (0–12)	3.9 ± 2.8	2.1 ± 2.1	0.265
Financial impact (0–6)	1.7 ± 1.2	1.0 ± 0.7	0.071

impacts social interaction, lowers self-esteem and results in psychosocial problems.^{13,15} Studies have shown that bowel dysfunction has a major impact on social activities or QOL in 48% of children with spina bifida, and a negative impact on QOL with advancing age.¹³ Our results support previous findings that bowel problems have a significant impact on physical and psychosocial status in QOL for not only children with spina bifida, but also their caregivers. Despite obvious psychological and physical consequences, colorectal symptoms in children with spina bifida have often been underestimated, resulting in neglected bowel management.¹⁰

Several methods are used to deal with constipation and fecal incontinence in children with spina bifida, including conservative, pharmacological and surgical approaches. Pharmacological treatments with different laxatives have been tried with varying success. Polyethylene glycol, used with success to treat neurogenic bowel disturbances, has been tried, and its effectiveness has been evaluated.⁹ However, when the internal sphincter relaxes, bowel accidents or soiling occurs.¹⁶ Therefore, a more active approach is needed for bowel continence. Since its introduction by Malone *et al.*,¹⁷ the Malone antegrade continence enema(MACE) procedure has been accepted as one of the most useful techniques for resolving fecal incontinence in children with spina bifida. However, the downside of this procedure is the necessity of surgery.¹⁸ Furthermore, about one-third of patients have stopped MACE because of complications, including stomal stenosis and catheterization difficulties.^{19,20} Given this drawback, the mainstay of conservative treatment remains the transanal irrigation. Several studies provide evidence that transanal irrigation improves bowel function in patients with spina bifida.^{10,16,18} In another study, transanal irrigation was not inferior to MACE with regard to fecal continence.¹⁸ None of these treatments has a 100% success rate. Furthermore, as patients with spina bifida are a heterogeneous population, a uniform policy for the treatment of fecal continence is impossible.⁴ Accordingly, conventional treatment should be tested first, and the efficacy of transanal irrigation may be a predictor of the efficacy of MACE for bowel management. Therefore, it is important to individualize treatment using a stepwise approach, as in this study.

Our questionnaire based on the fecal incontinence and constipation quality of life¹⁴ instrument allowed the measurement of the impact of constipation and fecal incontinence on the QOL in the spina bifida population. In this study, the stepwise bowel management program resulted in significant improvement incontinence with a decrease in

Table 3 Results of travel and socialization scores in quality of life before and after a stepwise bowel management

	Before	After	P-value
Child's bowel care prevents him/her from going out of the house.	1.6 ± 1.3	1.1 ± 0.9	0.036
Child's bowel care prevents me from going out of the house.	1.5 ± 1.3	1.1 ± 0.9	0.043
I avoid traveling with my child.	1.2 ± 1.1	0.8 ± 0.8	0.113
My child is afraid to go out because of stool incontinence.	1.3 ± 1.0	0.5 ± 0.7	<0.001
I worry about the smell of my child's stool incontinence.	2.2 ± 1.1	1.3 ± 1.2	<0.001
My child's worries about the smell of stool incontinence.	1.5 ± 1.2	0.8 ± 0.8	0.004
My child's stool incontinence affects his/her ability to socialize and meet friends.	1.7 ± 1.1	0.9 ± 0.8	<0.001
My child's stool incontinence affects his/her physical activities (walking, sports, etc).	1.4 ± 0.8	0.7 ± 0.6	<0.001

Figure 2 Chart illustrating representative caregiver support and emotional impact QOL changes (a: bothersomeness, b: depressed, c: anxious). All questions were on a Likert scale (0: not at all, 1: slightly, 2: moderately, 3: very much) and all differences were statistically significant. QOL; quality of life.

the number of bowel movements, bowel care time, frequency of diaper changes and episodes of fecal incontinence. Regular and complete bowel movements have many social and psychological benefits, including parents and children being less likely to be prevented from leaving the house due to bowel care, decreased caregiver anxiety, strain and depression. However, improved bowel care did not significantly affect family relationships and financial status related to caregiver employment, although the average scores improved. We surmise that family relationships are influenced by many factors, and caregiver employment is not affected in the short period of several months. These results are similar to a previous study of outcomes after MACE surgery.¹²

In our stepwise bowel management program, motivation, compliance and education were major prerequisites for success in achieving fecal pseudo-continence. Regular follow-up by specialized nurse practitioners, and enhancing motivation in the parents and children were also influential factors.²¹

Despite good clinical effects, some children and parents using transanal irrigation found this method very time consuming and too complicated for self-management. To improve this discomfort, it may be important to start a bowel management program initially and provide sufficient time and support to help children with neurogenic bowel disturbance to be independent at the toilet.¹⁰ On the other hand, practical problems with the irrigation procedure are able to occur, including pain with insertion of the catheter, expulsion of the catheter and leakage of irrigation fluid beside the catheter.²² Interestingly, 3 of 47 patients using this transanal irrigation method experienced rapid bladder distention, although they had emptied their bladder by clean intermittent catheterization before the transanal irrigation. Therefore, if the patient performs this enema at night, they must learn that they may need to empty their bladder again. One nonlethal bowel perforation requiring emergency surgery occurred in one patient in ~50 000 irrigations, giving an estimated risk of

perforation of 0.002% per irrigation, in the previous study for adult patients.²²

The weakness of the study is the relatively short time perspective. Long-term use of transanal irrigation resulted in successful outcome in 46% of adult patients after a mean follow-up of 19 months.²² The time course of successful outcome showed an 80% rate of success after 3 months, which dropped to 35% after 3 years.^{23,24} It will be necessary to design future studies to investigate the long-term outcome and safety of our stepwise bowel management in a same cohort of children. There is another limitation in our present study, including the use of non validated questionnaires. Therefore, there is a need for a reliable and validated QOL measure specifically designed to assess the impact of fecal incontinence and constipation on the lives of children with spina bifida and their families.

CONCLUSION

Constipation and fecal incontinence should not be overlooked in spina bifida patients, as bowel problems have significant effects on the QOL of children with spina bifida and their caregivers. As patients with spina bifida are a heterogeneous population, it is necessary to apply an individualized stepwise bowel management approach. In most children in our study, regular transanal irrigation was needed to achieve this goal. Therefore, we recommend this simple therapeutic method as a safe and valid choice for the treatment of chronic neurogenic constipation and fecal incontinence, especially before attempting surgical treatment.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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