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ORIGINAL ARTICLE

Identifying predictive factors for bowel control in patients with spina bifida and spinal cord injuries

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Abstract

Purpose This study aimed to assess our bowel management program (BMP) and identify predictive factors for bowel control in patients with Spina Bifida (SB) and Spinal Cord Injuries (SCI). Additionally, in patients with SB, we examined the impact of fetal repair (FRG) on bowel control.

Methods We included all patients with SB and SCI seen in the Multidisciplinary Spinal Defects Clinic at Children's Hospital Colorado from 2020 to 2023.

Results 336 patients included. Fecal incontinence was present in 70% and bowel control in 30%. All patients with urinary control also had bowel control. Fecal incontinence prevalence was higher in patients with ventriculoperitoneal (VP) shunt (84%), urinary incontinence (82%), and wheelchair users (79%) compared to those who did not need a VP shunt (56%), had urinary continence (0%) and non-wheelchair users (52%), respectively ($p = < 0.001$ in all three scenarios). After completing BMP, 90% remained clean for stool. There was no statistical significance when comparing bowel control in FRG with non-fetal repair group.

Conclusions Urinary continence predicts bowel control in patients with SB and SCI. Risk factors for fecal incontinence were the need for a VP shunt, urinary incontinence, and wheelchair usage. We did not find any positive impact of fetal repair on bowel and urinary control.

Keywords Fecal continence · Fecal incontinence · Bowel management program · Spina bifida · Fetal · Spinal cord injury

Abbreviations

ACE	Antegrade continence enema
CI	Confidence interval
CIC	Clean intermittent catheterization
FRG	Fetal repair group
NFRG	Non-fetal repair group
MOMS	Management of Myelomeningocele Study
MSDC	Multidisciplinary spinal defects clinic
RR	Relative risk
SB	Spina bifida
SCI	Spinal cord injury
VP	Ventriculoperitoneal

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Introduction

Spina bifida (SB) represents the most common congenital anomalies of the central nervous system compatible with life. Liveborn infants with SB have a death rate of 10%, and long-term survivors have significant disabilities [1–4]. While 70% of SB patients have an IQ above 80, only half can live independently as adults [5].

SB is a progressive condition beginning in early pregnancy, which has been explained with the "two-hit" hypothesis: a failed closure of the neural tube by the sixth week of gestation, followed by injury to the exposed spinal cord and nerves due to direct trauma and neurotoxic agents in the amniotic fluid [4, 6]. Clinically, SB leads to hydrocephalus and difficulties with mobility and ambulation. In addition,

most patients experience neurogenic sphincter dysfunction, impairing bladder and bowel control [4].

Typically, an operation to close SB occurred in the first hours of life; however, the first human prenatal repair was reported in 1998 [7]. Since then, several studies have shown a decrease in the risk of death, need for shunting, and degree of hindbrain herniation, and also indicated an improvement in motor function and walking independence compared to postnatal surgery [8–10]. However, fetal surgery poses risks to the mother, and it has been proven that those risks are highest when the fetal repair is done before 23 weeks of gestation [4, 8].

Spinal cord injury (SCI) is a common event, with the incidence of traumatic SCI in the USA being approximately 54 per million people and about 10,000 new cases reported yearly [11]. The most significant frequency occurs at the age of 15 to 25 years. The prevalence of non-traumatic SCI is unknown because of heterogeneous causes. SCI produces various changes in systemic physiology, leading to several complications (gastrointestinal, urinary, ambulation, etc.) affecting the quality of life [12].

Neurogenic bowel is present in 60–75% of patients with SB, manifesting as constipation or fecal incontinence [13, 14]. Achieving and maintaining bowel continence is one of the most difficult challenges for individuals with SB [15]. In a survey conducted by the Spina Bifida Association in 2019, 50% of parents of children with SB rated fecal incontinence as their biggest issue [16]. Neurogenic bladder affects more than 70% of SB patients and can progress to renal failure and death [13, 17]. There is a lack of data on patients with SCI; however, it is well-known that these complications are present [18–20].

In September 2020, our pediatric colorectal team joined the Multidisciplinary Spinal Defects Clinic (MSDC) at Children's Hospital Colorado, implementing a standardized bowel management program (BMP) that has notably improved the quality of life of these patients [21]. The purpose of this study was to assess our bowel management program and to identify factors predicting bowel control in SB and SCI patients. In addition, we examined the impact of fetal repair on bowel control in patients with SB.

Materials and methods

Study design

A single-center, retrospective, cross-sectional, and descriptive study was conducted. We included all patients seen in the MSCD at Children's Hospital Colorado from September 2020 to January 2023. We reviewed electronic medical records for those patients and the mother's records for patients who underwent fetal repair. Demographics and clinical data were obtained for all patients included. Subsequently, we divided the population into the fetal repair group (FRG) and the non-fetal repair group (NFRG). This study was approved by the Colorado Multiple Institutional Review Board (COMIRB 20-2275).

The management protocol for patients with SB or SCI in the MSDC at Children's Hospital Colorado is as follows: patients are seen at 3, 6, 9, and 12 months of age, and then they are evaluated every six months until they reach age five. After age five, patients are seen yearly. In the MSDC clinic, patients are seen by the Colorectal, Urology, Orthopedics, Neurosurgery, Physical Medicine/Rehabilitation, Nutrition, Social Work, and Psychology teams on the same day. The Colorectal team does the bowel evaluation, which consists of the following:

1. An abdominal radiograph is obtained on each clinic visit to assess the amount of stool in the colon and adjust the current treatment or propose a new one as needed.
2. From age three months to three years, constipation is treated with Polyethylene Glycol. A liquid glycerin suppository is used when constipation and diaper rash are present. When severe constipation is present and not responding to the proposed management, or there is no improvement of the diaper rash, enemas are used.
3. At age three, we begin formal bowel management with laxatives for continent patients or enemas for incontinent patients.
4. When the patient reaches the age of five, the need for combined antegrade continence enemas (ACE) ± Monti/Mitrofanoff procedures, with or without bladder augmentation/bladder neck reconstruction, is discussed with the urology team and the family.
5. A yearly follow-up is done to determine if bowel regimen adjustments are needed.

The goal of the BMP is to keep the patient clean in the underwear for stool.

Evaluation of outcomes

This study aimed to evaluate our BMP and identify factors that predict bowel control in patients with SB and SCI. Additionally, we examined the impact of fetal repair on bowel control. Secondarily, we measured bowel and urinary continence and determined walking rates in patients with SB and SCI. In SB patients, we compared outcomes such as ambulatory independence, shunting rate, and bowel and urinary control between FRG and NFRG.

Walking independence analysis was done only in patients older than one year. Similarly, only patients over three years of age were included in the bowel and urinary continence analysis.

Bowel control was considered when the patient was on dietary modification or laxative treatments and was clean in the underwear, had no involuntary bowel movements, had at least one bowel movement on the toilet in 24 h, and had a clean abdominal radiograph. When the patient was dry in the underwear for at least 3 h, and there was no need for a clean intermittent catheterization (CIC), we considered the patient to be continent for urine.

The BMP was considered to be successful if a follow-up was documented (at least two visits at the MSCD) and when, regardless of the type of treatment, the patient was clean in underwear, had no involuntary bowel movements, had at least one bowel movement on the toilet in 24 h, and a clean abdominal radiograph. Our analysis also correlated the lesion level with walking independence, the need for a VP shunt, and bowel and urinary continence. The lesion level was grouped according to the Management of Myelomeningocele Study (MOMS) [3]

In the FRG and the NFTG, we compared outcomes such as walking independence, the need for a VP shunt, and bowel and urinary continence. When fetal repair occurred, we analyzed obstetrical risks, such as gestational age at birth, choriamniotic membrane separation, preterm premature rupture of the membranes (PPROM), oligohydramnios, and spontaneous onset of labor.

Plan of analysis

We used Student's t-test and chi-square or Fischer's exact test to compare proportions. Statistical significance was considered when a *p*-value was < 0.05, and in those circumstances, a relative risk (RR) and its 95% confidence interval (CI) were estimated. The statistical analysis was done through the Statistical Package for the social sciences (SPSS®) 26.0 version.

Results

Of the 365 patients reviewed, 29 were excluded. Our colorectal team has not yet seen twenty-six patients, from which two have died (cerebellar herniation and complicated pneumonia), and one has been diagnosed with cerebral palsy but did not have a spinal cord lesion (Fig. 1).

The final study population included 336 patients; 170 (50.6%) were female, and 166 (49.4%) were male. Overall, the most common diagnosis was SB at 79%, and SCI accounted for 21%. Among the most frequent conditions in SCI was trauma in 24%, transverse myelitis in 18%, and ischemia event in 17%.

Bowel control

Out of the 288 patients older than three years of age, 203 (70%) were found to have fecal incontinence and 85 (30%) bowel control. When analyzed by groups, we found that patients with SCI had a higher rate of bowel control than SB (48% and 24%, respectively. $p = < 0.001$).

Forty-four (47%) non-wheelchair users had bowel control, and 41 (21%) wheelchair users (RR, 3.73; 95% CI, 1.97 to 5.74; $p = < 0.001$). Patients who did not require a VP shunt had a higher rate of bowel control (43%) than those who needed a VP shunt (15%) [RR, 4.31; 95% CI, 2.46 to 7.55; $p = < 0.001$]. Additionally, all patients with urinary control

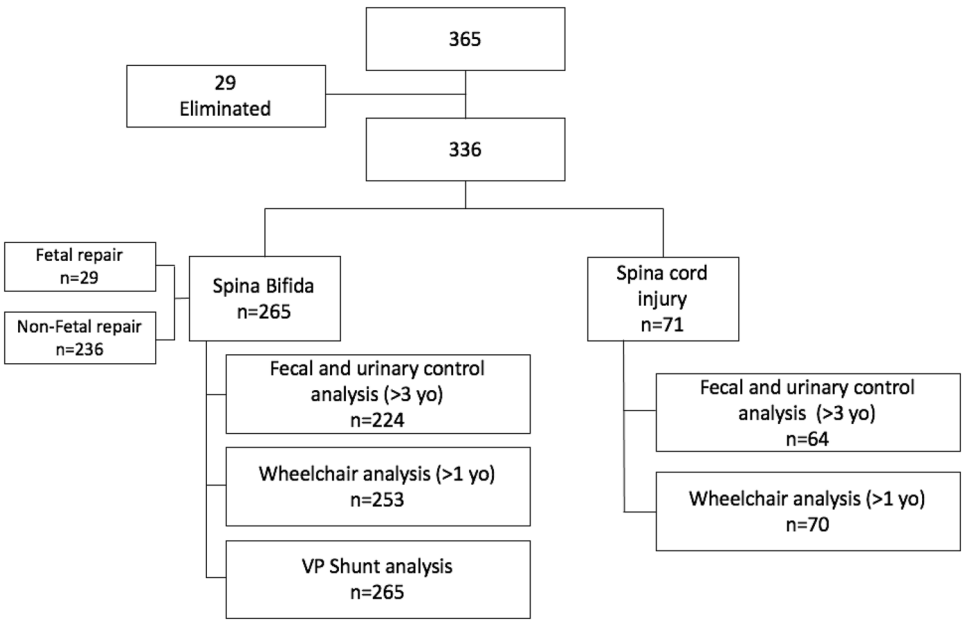

Fig. 1 Study flow diagram

Table 1 Factors that affect bowel control

	Bowel control[1] n (%)	Fecal incontinence[1] n (%)	p value
Non-Wheelchair users[2]	44 (47%)	49 (52%)	< 0.001
Wheelchair users[2]	41 (21%)	154 (79%)	
No VP Shunt needed[3]	63 (43%)	81 (56%)	< 0.001
VP Shunt needed[3]	22 (15%)	122 (84%)	
Urinary continence[1]	41 (100%)	0 (0%)	< 0.001
Urinary incontinence[1]	44 (18%)	203 (82%)	

[1]Only patients older than three years of age

[2]Only patients older than one year of age

[3]Only patients with SB

also had bowel control, while only 18% with urinary incontinence had bowel control (RR, 188.22; 95% CI, 25.21 to 1405.28; p = < 0.001). In contrast, fecal incontinence prevalence was higher in patients with VP shunt (84%), urinary incontinence (82%), and wheelchair users (79%) (Table 1).

Bowel management

The average age for patients to begin formal bowel management with the goal of staying clean in the underwear for stool was 8.6 years (2 months to 21 years). Of the 233 patients over three years of age who were followed up (at least two visits at the MSCD), 210 (90%) remained clean for stool after completing the bowel management. Enemas were the most common treatment method in 154 (66%). Among these patients, 47% used ACE, 36% used balloon catheter, 12% used Cone, 4% used Peristeen system, and only 0.6% had an ostomy. Laxatives were used in 63 (27%) patients and dietary modifications in 16 (6%).

Urological management

Out of the 288 patients older than three years of age, 247 (85%) had urinary incontinence. CIC was needed in 217 (88%), and among those, 85 (25%) had a Monti/Mitrofanoff procedure, while only 3 (0.9%) had a vesicostomy. Bladder reconstruction was performed on 55 (16%) patients, with 36 (65%) receiving bladder augmentation, 5 (9%) bladder neck reconstruction, and 19 (35%) both procedures.

Lesion level

The distribution of lesion levels in SB and SCI patients is shown in Table 2. Patients with L3-L4 lesions had the highest rate of fecal incontinence (80%), while those with L1-L2 lesions had the highest rate of urinary incontinence (93%) (Table 3). Cervical lesions had the lowest rate of fecal and urinary incontinence (Table 3); however, only 11% of those patients had SB (Table 2).

Among the 323 patients over one year, 64% needed a wheelchair, with the highest rate being those with thoracic lesions (86%) and the lowest for L5-S1 lesions (29%). VP shunt placement was needed for 154 (58%) SB patients. It was most prevalent in lesions at the L3-L4 level (65%),

Table 2 Lesion level in SB and SCL

	Cervical n = 26 (7%)	Thoracic n = 31 (9%)	L1-L2 n = 39 (11%)	L3-L4 n = 155 (46%)	L5-S1 n = 85 (25%)
SB[1]	3 (11%)	11 (35%)	34 (87%)	150 (97%)	67 (79%)
SCI[2]	23 (89%)	20 (65%)	5 (13%)	5 (3%)	18 (21%)

[1]Spina bifida

[2]Spinal cord injury

Table 3 Correlation between level of spinal cord injury, VP shunt, walking independence, and bowel and urinary control

		Fecal incontinence[1] n = 203	Urinary incontinence[1] n = 247	Wheelchair users[2] n = 207	VP shunt[3] n = 154
Lesion level	Cervical	7 (28%)	14 (56%)	19 (73%)	3 (11%)
	Thoracic	19 (63%)	25 (83%)	26 (86%)	6 (19%)
	L1-L2	23 (69%)	31 (93%)	30 (81%)	18 (46%)
	L3-L4	110 (80%)	125 (91%)	109 (72%)	101 (65%)
	L5-S1	44 (69%)	52 (82%)	23 (29%)	26 (30%)

[1]Only patients older than three years of age

[2]Only patients older than one year of age

[3]Only patients with SB

while cervical lesions had the lowest occurrence rate (11%) (Table 2).

Fetal repair

Of the 265 patients with SB, 29 (10%) underwent prenatal repair. The procedure was performed at an average gestational age of 23.9 weeks, with a range of 22 to 27 weeks. The majority of repaired cases (34%) had L3-L4 lesions, followed by L5-S1 lesions (31%), L1-L2 lesions (17%), thoracic lesions (10%), and cervical lesions (6%). In SB patients older than three years, there was no statistical significance in terms of bowel and urinary control when comparing FRG with NFRG. The need for a VP shunt was lower in the FRG than in the NFRG (p = < 0.001). Finally, patients from the FRG were more likely to walk than those in the NFRG (p = 0.005) (Table 4).

Preterm delivery was observed in 27 (93.1%) patients who underwent fetal repair; 17 (58%) occurred at ≤ 34 weeks, and four (13%) at < 30 weeks, with an average age of delivery of 33 weeks (25–36 weeks). Pregnancy complications were reported in 23 (79%) cases; preterm labor was the most common in ten (43%), followed by preterm premature rupture of the membranes (PPROM) in nine (39%), choriamniotic membrane separation in two (8%), and oligohydramnios and preterm labor in one (4%). Cervical cerclage was required for three cases (10%) within the first ten days after the fetal repair procedure.

Discussion

SB and SCI are disabling conditions for life. Fecal incontinence has been ranked among the most significant issues these patients and their families deal with, consuming a considerable part of their day [16, 20]. The prevalence of bowel control among SB patients varies greatly in published literature, ranging from 48% [22]. In this study, we found the prevalence of bowel control to be 30% among patients with SB and SCI and 24% when only SB patients were analyzed. L3-L4 level lesions were the most commonly associated with fecal incontinence (80%). Cervical lesions had the lowest prevalence of fecal incontinence, which can be attributed to the fact that 89% of these lesions were secondary to varying degrees of SCI, and most of the SCI was at the cervical level. In addition, SCI presented a lower rate of fecal incontinence than SB (75% vs. 46%. p = < 0.001).

As we previously published [21], the participation of a dedicated colorectal team in the management of SB and SCI patients plays a crucial role. Although we cannot determine if a patient under the age of three will have bowel control, it is essential to identify risk factors for fecal incontinence in order to initiate an appropriate BMP by the age of 3 years. By doing so, we can improve their quality of life and self-esteem, and avoid difficult situations such as social rejection. In the present study, we found that all patients with urinary control also had bowel control. Therefore we can assume that urinary continence predicts bowel control in patients with SB and SCI. In contrast, the need for a VP shunt, wheelchair users, and urinary incontinence were risk factors for fecal incontinence.

BMP is essential in managing this population [21, 23]. In this cohort, 90% of the patients were clean for stool after completing our BMP, enemas being the most common method to keep them artificially clean. Abdominal radiographs and continued follow-up were the keys to the success of our BMP. An abdominal radiograph allowed us to assess the treatment response objectively and decide, based on the findings, whether to continue with the same enema recipe or make adjustments.

Beyond fecal incontinence, patients with SB and SCI face many other concerns, including impaired mobility and, potentially, the development of renal damage. Early treatment of neurogenic bladder after birth is necessary to prevent such complications [17, 18]. We found that 85% of the study population suffered from urinary incontinence. Most patients (73%) were on CIC, and 25% underwent a Monti/Mitrofanoff procedure. Bladder reconstruction surgeries were performed in 16% of patients, providing the opportunity to convert a high-pressure bladder into a low-reservoir that is safe for the upper urinary tract. The inability to walk or the use of a wheelchair is common in SB and SCI, and it is mainly dependent on the lesion level. This study found that 64% of patients needed a wheelchair. However, it was noteworthy that only 29% of the patients with L5-S1 lesions required a wheelchair. This finding is supported by Bowman et al. and Hunt et al. [5, 24].

Individuals with SB are at risk for associated nervous system malformations [25]. The chances of developing hydrocephalus that requires a VP shunt placement are high, estimated to be between 80–85% [26]. The MOMS has proved that fetal surgery performed before 26 weeks of gestation reduces the need for a VP shunt and improves independent

Table 4 Fetal repair outcomes

Outcome	Fetal repair group n (%)	Non-fetal repair group n (%)	*p* value
Fecal incontinence[1]	10 (83%)	160 (75%)	0.41
Urinary incontinence[1]	11 (91%)	183 (87%)	0.56
VP Shunt placement	6 (20%)	147 (62%)	< 0.001
Wheelchair users[2]	8 (34%)	148 (64%)	0.005

[1]Only patients older than three years of age

[2]Only patients older than one year of age

walking [3, 7–9]. In this cohort, 10% of patients with SB underwent fetal repair surgery at an average gestational age of 23.9 weeks. Our results also demonstrated a decrease in the need for a VP shunt and for a wheelchair in the FRG compared with the NFRG.

We did not find any statistical significance in terms of bowel and urinary control when comparing FRG with NFRG. As has been mentioned, there is a variable range in the rate of bowel and urinary continence [22] which poses a challenge in evaluating the effects of fetal repair on the bowel and urinary continence. To our knowledge, besides the research conducted by Theodorou CM et al. on ovine fetuses [27], there is no data about the impact of fetal repair on bowel control. In this cohort, with a clear definition of bowel control, we found that 83% of patients from the FRG had fecal incontinence compared to 75% from the NFRG ($p = 0.41$). In 2009, the MOMS published a long-term assessment of bladder function [28]. In this analysis, Brock JW 3rd et al. reported that FRG resulted in less reported CIC at school age and, based on parental reports, showed that FRG may be more likely to void volitionally. However, most children were in diapers or on clean intermittent catheterization. We agree with the statement of Clayton DB et al. [29] that the current evidence for fetal repair on urologic outcomes is still insufficient, and we would add that it appears to have no positive impact on bowel control.

Despite the benefits that fetal repair has demonstrated, considerable maternal and fetal risks exist [3, 4, 8]. According to the MOMS [8], there is a high rate of preterm births, and 11% of those occurred at < 30 weeks of gestation. In this study, we identified a preterm birth rate of 93%, with 58% occurring at ≤ 34 weeks and 13% at < 30 weeks. In addition, the most common pregnancy complications were chorioamniotic membrane separation, PPROM, and preterm labor, as was also reported in the MOMS [8].

It is important to note that our study has limitations due to its retrospective nature and being conducted at a single center. As a result, the sample is small and heterogeneous when comparing FRG with NFRG.

Conclusion

Urinary continence predicts bowel control in patients with spina bifida and spinal cord injury. Risk factors for fecal incontinence were the need for a VP shunt, urinary incontinence, and wheelchair usage. This study corroborates that fetal repair in patients with spina bifida improves motor function and decreases the need for a VP shunt. However, we did not find any positive impact on bowel and urinary control.

Author contributions Study conception and design: Andrea Bischoff, Luis De la Torre, Alfredo Domínguez-MuñozData acquisition: Alfredo Domínguez-Muñoz, Jill Ketzer, Víctor Rodríguez, Lauren Schneider, Anne Merritt and Maura WickhamAnalysis and data interpretation: Andrea Bischoff, Alfredo Domínguez-Muñoz, Karla Santos-JassoDrafting of the manuscript: Andrea Bischoff, Alfredo Domínguez-MuñozCritical revision: Andrea Bischoff, Luis De la Torre, Alberto Peña, Alfredo Domínguez-MuñozAll authors reviewed the manuscript.

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Declarations

Conflict of interest The author declare that they have no conflict of interest.

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