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Outcomes and satisfaction in pediatric patients with Chait cecostomy tubes

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Summary

Introduction—Patients with spina bifida and other spinal dysraphisms commonly suffer from fecal incontinence and constipation, which can be treated with antegrade continence enemas. Currently, information regarding outcomes and satisfaction in children who have Chait cecostomy tubes is lacking. The aim of our study was to evaluate the effectiveness of Chait cecostomy tubes in management of constipation in children with spinal dysraphisms.

Materials and methods—A questionnaire was completed by patients and/or their families during office visits at the University of Iowa or Nationwide Children's Hospital during follow-up pediatric urology office visits. Two study groups completed the questionnaires: 1) Patients with neurogenic bowels who had a cecostomy tube in place (CT) and 2) patients with neurogenic bowels with no cecostomy tube (NCT). The survey used Likert scaled and nonrated questions to assess demographics, bowel continence, and satisfaction.

Results—A total of 86 patients completed the questionnaire: 53 CT patients and 33 NCT patients. CT patients rated the effectiveness of their cecostomy tube in managing their constipation significantly higher than the NCT group rated the effectiveness of their conventional bowel management methods ($p < 0.001$). Within the CT group, 48% of patients had complete or near complete continence, 40% had partial fecal incontinence, while only 12% remained incontinent. Of the CT respondents, 88% were overall satisfied with the cecostomy tube (Figure) and 92% would have the cecostomy tube placed again. In addition, hygiene, independence, and social confidence were significantly improved compared with baseline. Complications associated with the Chait tube included granulation tissue that required treatment (60%) and pain with irrigation (24%).

Conclusions—CT patients reported significantly improved constipation management, fecal continence, and improved quality of life compared with NCT patients. Our pilot study demonstrates that the Chait cecostomy tube is a well-tolerated, effective means for treating

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Conflict of interest

None.

Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.jpuro.2017.04.008>.

constipation and achieving fecal continence with minimal side effects in patients with neurogenic bowels.

Keywords

Neurogenic bowel; Pediatrics; Cecostomy; Antegrade enema

Introduction

In 1990, Malone et al. first described their experience using the appendix as a conduit to perform antegrade enemas [1]. Children with neuropathic and structural abnormalities of the colon and rectum, secondary to disorders such as spinal dysraphisms, anorectal malformation, and cloacal malformations, have benefited immensely from this procedure by reducing and/or eliminating fecal soiling and constipation. Multiple studies have reported successful outcomes and an improved quality of life for children who have undergone the MACE procedure [2–4]. In addition, there has been a similar improvement in quality of life for the families of these children. However, the MACE is not without drawbacks, as complications associated with this procedure include stomal stenosis, stomal bleeding, stool leakage, wound infection, prolapse of the stoma, and appendiceal necrosis [5–8] (Fig. 1).

In 1996 Shandling introduced the Chait cecostomy tube [9]. While the MACE principle of antegrade enema administration remained the same, the Chait tube uses a silastic pigtail tube with an extracorporeal trapdoor as the conduit to perform colonic irrigation [10]. To date, there are limited data on the success rates, quality of life, and complications in patients who have been managed with Chait cecostomy tube placement.

Our institutions primarily use Chait cecostomy tubes in patients with neurogenic bowels who are interested in performing antegrade enemas for the treatment of constipation and fecal incontinence. We believe that this approach is successful in treating these patients and that it results in an improved quality of life for these patients and their families. Our primary study aims were to evaluate the effectiveness of Chait cecostomy tubes in management of neurogenic constipation and to determine the effect that this procedure had on quality of life. Additionally, we sought to establish the complications that occur secondary to Chait cecostomy tube placement. We hypothesized that, compared with before cecostomy placement and with other patients with neurogenic bowels who have not had cecostomy tube placement, patients with Chait tubes have improved constipation, fecal continence, and quality of life, with a low complication rate.

Materials and methods

An IRB approved questionnaire (see Appendix) was completed by patients and/or their families during office visits at the University of Iowa or Nationwide Children's Hospital during follow-up pediatric urology office visits. Two study groups completed the questionnaires: 1) patients with neurogenic bowels who had a cecostomy tube in place (CT) and 2) patients with neurogenic bowels with no cecostomy tube (NCT). The survey used Likert scaled and nonrated questions to assess bowel continence and satisfaction. Questions on the survey queried overall satisfaction, social confidence, personal hygiene,

independence, esthetic of button, irrigation characteristics, level of fecal continence, and pain associated with the tube. Demographic data on the patient and the family were also collected and nonrated questions were used to assess procedure specifics, ambulatory status, and prior medical treatment of fecal incontinence. A retrospective chart review was also performed to evaluate complications related to the Chait cecostomy tube. Likert responses were dichotomized into either positive or neutral/negative responses. Data were analyzed using logistic regression and bivariate analysis using Statistical Analysis System (SAS) 9.4.

Prior to undergoing cecostomy tube placement, all patients and their families had an extensive pre-operative discussion regarding peri-operative and post-operative expectations. Each patient and their families were given educational materials explaining the procedure and demonstrating the usage of the cecostomy tube from the American Pediatric Surgical Nurses Association website [11].

Ethical approval

The study was granted internal review board approval: IRB ID# 201405745.

Results

As seen in Table 1, a total of 86 patients completed the questionnaire. This included 53 CT patients and 33 NCT patients. The CT group included 25 males, with a mean age of 11 years (5–33). The NCT group included 13 males with a mean age of 13.6 years (3–42). When evaluating the entire study cohort, 80% had spinal bifida, 62% required mobility assistance devices, and 87% were Caucasian. As depicted in Table 2, the majority of patients (71%) had their cecostomy tube placed by 5 years of age and 81% had their tube in place for more than 1 year at the time of questionnaire completion. In addition, it seemed to take more than a month in 47% of patients to perfect the irrigation technique, finding the volume of irrigant, irrigant solution, and frequency of irrigation that worked. Within our CT cohort, 92% of patients irrigate at least once every other day. The primary caretaker, as defined by who performs bladder catheterization and bowel management, was most often a parent (64%) followed by the patient (21%), a professional caretaker (10%), a grandmother (3%), and school nurse (2%).

Table 3 demonstrates that all CT patients had tried previous management methods for fecal incontinence and constipation, including laxatives, enemas, suppositories, and timed toileting. There was a significant difference between the CT and NCT patients regarding which non-surgical management methods were most effective. The CT cohort favored enemas, whereas the NCT cohort favored timed toileting ($p < 0.01$). However, laxatives were still cited as being most helpful among both groups. Within the CT group, 48% of patients had complete or near complete continence as defined by less than three stool accidents per year, 40% had partial fecal incontinence as defined by one to three accidents per month, while only 12% remained incontinent defined as more than three accidents per month. This is in comparison with the NCT group, which reported 48% of patients had complete or near complete continence, 15% had partial fecal incontinence, and 37% was incontinent of stool. Of the stool incontinence episodes suffered by the CT group, 47% reported a smear of stool

less than 1 day after irrigating, 40% suffered a loose bowel movement on the day after irrigation, and 13% suffered full bowel movements. Protective garments were still worn by 85% of CT patients, although 25% wore them because of urinary incontinence; 62% of these patients wore protective garments daily, while the remainder wore them less often.

Of the CT respondents, 90% said their expectations were met, 88% were satisfied with their results after cecostomy tube placement, 88% would recommend tube placement to a friend, and 92% would have the procedure performed again. In evaluating quality of life measures, as compared with pre-procedure, 87% reported improved hygiene ($p = 0.01$), 79% reported increased independence ($p = 0.02$), and 79% had improved social confidence ($p = 0.02$). The appearance of the cecostomy tube did not bother 71% of respondents and 73% stated that the tube did not significantly affect their activities. In addition, preprocedure counseling adequately prepared 80% of respondents. The most common unanticipated issues were granulation tissue (60%), fine tuning the irrigation (42%), and pain (26%). On a 10-point pain scale, the average pain with irrigation was a 2.4 (1–8), pain with tube changes was a 3.7 (1–10), and pain with initial placement was a 4.0 (1–10). CT patients rated the effectiveness of their cecostomy tube in managing their constipation significantly higher than the NCT group rated the effectiveness of their conventional bowel management methods ($p < 0.001$). In addition, compared with the NCT group, CT patients also had increased satisfaction with their current bowel management ($p < 0.01$) and were more likely to recommend their current bowel management to a friend ($p < 0.01$).

When looking at the complications associated with cecostomy tube placement, one patient developed a wound infection around the tube, which occurred 7 days after placement. Other complications included granulation tissue requiring silver nitrate application (62.5%), accidental removal of the tube (15.8%), and persistent leakage from around the cecostomy tube requiring revision (10.5%).

Discussion

Children with spina bifida and spinal dysraphisms commonly suffer from fecal incontinence [1]. Such encopresis has been shown to have a negative impact of on a child's self-confidence, socialization with peers, and overall quality of life [6]. For most patients with fecal incontinence secondary to neurologic issues, non-surgical options are typically first explored, which may include dietary modifications, stool softeners, the establishment of regular defecation habits, bulking agents, and laxatives [1,6].

Previously, surgical procedures to strengthen the anal sphincter were attempted; however, these procedures were not effective in patients with neuropathic fecal incontinence [1]. Retrograde colonic enemas have been shown to be effective, but may be impractical or extremely uncomfortable for some patients because of their immobility and lax perineal muscles [2]. In addition, retrograde enemas rarely reach the transverse or ascending colon so the entire colon is not cleansed with this approach and fecal accidents may continue [12]. In 1990, Malone first described the antegrade colonic enema (ACE) [1]. Since this original description, MACE procedures have grown drastically in popularity because of its effectiveness and high patient satisfaction. Despite the success of the MACE procedure,

there are reported complications including stomal stenosis, prolapse of the stoma, and inability to catheterize. These complications occur in upwards of 40% of MACE patients. In addition, a 2009 study by Yardley et al. identified that 18% of patients had stopped using their MACE after 5 years and 40% stopped using their MACE after 11 years. The most common reason for cessation of MACE usage was ineffectiveness of the procedure, followed by complications such as stomal stenosis [5]. As an alternative to the MACE, Shandling introduced the Chait cecostomy tube in 1996. To date there are few data evaluating the effectiveness of the Chait tube in treating neurogenic constipation and encopresis, quality of life, and its associated complications.

Our study indicated that Chait cecostomy tubes were effective at treating neuropathic constipation and fecal incontinence. Placement of the cecostomy tube resulted in infrequent stool accidents in 87% of our CT cohort and was rated superior to previously attempted treatments. Despite some continued stool leakage after cecostomy tube management, overall satisfaction after the procedure was quite high. These results were also superior compared with the NCT cohort. Quality of life also appeared to improve in these patients as indicated by an improvement in personal hygiene, independence, and confidence.

Careful patient selection is crucial for the cecostomy procedure and largely relies on patient/family motivation and dedication [6]. The severity of disease as determined by success with other methods could also help inform this decision. Timed toileting was significantly more effective in the NCT cohort, whereas the CT cohort found enemas more effective. Children who can be managed with timed toileting likely have intact sphincters and therefore may not benefit the most from antegrade enemas. This distinction could be useful when selecting candidates for cecostomy tube placement.

There have been several studies evaluating quality of life and patient satisfaction for MACE patients [3,4,7]. Overall patients have had positive experiences with this procedure. One MACE questionnaire-based study found that 77% of patients achieved complete fecal continence and all others experienced improved continence. Of these patients, 89% experienced the highest level of satisfaction, and 88% cited significantly better social confidence and personal hygiene [4]. Our study found a similar level of satisfaction in quality of life measures such as social confidence, hygiene, and independence. Our study did find lower levels of total fecal continence, but this may be by definition, as our study included smears of stool following irrigation as incontinence. Unfortunately, there are no universally accepted definitions of pediatric stool incontinence, making it difficult to compare success rates between different publications.

Between the MACE and Chait tube, one would expect similar improvements in fecal continence and subsequent quality of life measures given that they work by a similar mechanism. Conversely, the complication rate between the two procedures is very different. MACE patients can develop stool leakage or stomal stenosis causing difficulty catheterizing for irrigation. As described by Saikaly et al., they identified that leakage from and stenosis with the MACE occurred in 24% and 27%, respectively, within their study cohort [13]. These complications necessitate surgical revision, requiring repeated general anesthetics, and the complications may be recurrent in 30% of patients [14]. In our population, leakage

around the tube occurred in 10.5% of cases. These cases required surgical revision to revise tube placement. In addition, the tube was accidentally removed in 16% of patients, requiring an unplanned procedure and all patients require planned replacement of the cecostomy tube once a year. However, these replacement procedures are typically performed in our clinic under sedation and do not generally require general anesthesia. Others worry about the appearance of the cecostomy tube and the inability to conceal its trapdoor; whereas the ACE can be hidden in the umbilicus of the right lower quadrant, which may give an improved esthetic appearance. However, 71% of our CT cohort reported that they were not bothered by the appearance of the tube. This occurred despite the high rate of associated granulation tissue (62.5%) often requiring application of silver nitrate treatment multiple times in the clinic setting. In addition, of our patients managed with a cecostomy tube, 88% of patients would recommend tube placement to a friend and 92% would have the procedure performed again. This demonstrates the importance of improved constipation/fecal incontinence and quality of life in these patients and how these measures take precedence over appearance.

Our current findings should be interpreted in light of several limitations. Limitations to the study include those common to survey studies. As this questionnaire was completed during clinic visits, there was a lack of anonymity, which may have influenced responses and resulted in under-reporting of potentially embarrassing information. In addition, as this is not a prospective, randomly assigned study, recall bias may also possibly impact the validity of our data. Also, we were unable to determine whether the parent or the patient completed the questionnaire. We asked that children under the age of 10 years complete the questionnaire with the assistance of their parent and that children over the age of 10 years complete the questionnaire independently, but it is unknown whether these guidelines were followed. In addition, a child's cognitive abilities may limit their ability to complete the questionnaire independently and, again, we do not have data to gauge this variable. If the parent completed the questionnaire without the child's input, then this certainly could lead to some bias and, for instance, we may actually be measuring the parent's satisfaction, rather than the child's satisfaction. Although we included data from two institutions, the total number of patients in our study was low. Based upon our questionnaire, we are also unable to determine why some patients decided to have a cecostomy tube placed, while others decided to use their current measures for bowel management. This could lead to some selection bias, especially as this is not a randomized trial. Despite these limitations, we believe that our study provides valuable data regarding the effectiveness, quality of life, and complications associated with Chait cecostomy tube placement. These data could be useful in counseling future patients and their families prior to undergoing this procedure.

Conclusion

Fecal incontinence and constipation may be treated effectively with Chait cecostomy tube placement, resulting in improved quality of life. These improvements are comparable with previously reported results after MACE creation. In addition, these results may be obtained with minimal complications and high patient satisfaction. Based upon our study, the Chait cecostomy tube appears to be an effective treatment of neuropathic bowel issues.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure.
Overall satisfaction with current bowel management methods.

Figure 1.
Quality of life measures after cecostomy tube placement. All categories were significantly positive responses ($p < 0.05$).

Table 1

Patient characteristics.

	CT	NCT	p-value
Questionnaires completed	53	33	
Mean age, years	11 (5–33)	13.6 (3–42)	0.11
Sex			
Male	25 (47%)	13 (39%)	0.38
Female	28 (53%)	20 (61%)	
Ethnicity			
White	46 (92%)	29 (97%)	0.4
Black	2 (4%)	1 (3%)	
Asian	1 (2%)	0	
Hispanic	1 (2%)	0	
Primary diagnosis			
Spina bifida	40 (75%)	29 (88%)	0.25
Imperforate anus	10 (19%)	4 (12%)	
Sacral agenesis	3 (6%)	0	
Mobility			
No assistance	24 (45%)	7 (21%)	0.71
Crutches/braces	9 (17%)	12 (36%)	
Wheelchair + other	20 (38%)	14 (42%)	

Values are listed as patient number (% of patients) or as age in years (range).

Table 2

Cecostomy procedure and usage.

Age placed	0–4 years	15 (29%)
	5–8 years	22 (42%)
	9–12 years	9 (17%)
	13–18 years	5 (10%)
	>18 years	1 (2%)
Cecostomy duration	<6 months	2 (4%)
	6–12 months	7 (15%)
	1–5 years	22 (47%)
	>5 years	16 (34%)
Time to perfect irrigation	0–7 days	13 (27%)
	1–2 weeks	5 (10%)
	2–4 weeks	8 (16%)
	>1 month	23 (47%)
Frequency of irrigation	twice daily	2 (4%)
	daily	33 (63%)
	every other day	13 (25%)
	1–2 × per week	3 (6%)
	1–3 × per month	1 (2%)
Average volume irrigated		427 mL

Values are listed as patient number (% of patients).

Table 3

Non-surgical bowel management methods and current continence level.

	CT	NCT	p-value
Most effective treatment	Laxatives	20 (51%)	9 (38%)
	Enemas	17 (44%)	3 (13%)
	Timed toilet	1 (3%)	9 (38%)
	Other ^a	1 (3%)	3 (13%)
Least effective treatment	Laxatives	8 (16%)	4 (20%)
	Enemas	8 (16%)	3 (15%)
	Suppositories	6 (12%)	6 (30%)
	Timed toilet	23 (47%)	6 (30%)
Current incontinent episodes ^b	Other ^a	4 (8%)	1 (5%)
	0–3 per year	23 (48%)	13 (48%)
	1–3 per month	19 (40%)	4 (15%)
	>3 per month	6 (12%)	10 (37%)

^a Other bowel management methods included fiber supplementation, probiotics, rectal stimulation, and manual disimpaction.

^b Current continence level using antegrade enemas for CT patients or traditional bowel management methods for NCT patients.