



Antegrade continence enemas improve quality of life in patients with medically-refractory encopresis[☆]



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ABSTRACT

Purpose: Fecal incontinence is a socially debilitating problem for many children. We hypothesized that in selected patients with medically-refractory encopresis, placement of an appendicostomy or cecostomy tube for administration of antegrade continence enemas (ACE) would improve quality of life (QOL).

Methods: We reviewed all patients with encopresis who underwent appendicostomy or cecostomy placement from 2003 to 2014 at our institution. We contacted subjects' parents by phone and administered 3 surveys: a survey reflecting current stooling habits, a disease-specific QOL survey, and the PedsQL™ QOL survey. QOL surveys were completed twice by parents, once reflecting pre-operative QOL, then again reflecting current QOL. Pre-procedure and post-procedure scores were compared by paired *t*-test.

Results: Ten patients underwent appendicostomy/cecostomy for encopresis. Eight completed phone surveys. All procedures were performed laparoscopically. All patients experienced fecal soiling pre-operatively, whereas 5/8 surveyed patients (63%) noted complete resolution of soiling post-procedure ($p < 0.01$). General and disease-specific QOL improved from pre-procedure to post-procedure in the following domains: social habits, physical activity, ability to spend the night elsewhere, feeling, and overall QOL ($p < 0.05$). PedsQL™ scores improved significantly in physical functioning, social functioning, and overall functioning ($p < 0.05$).

Conclusions: Antegrade continence enemas significantly improve quality of life in patients with medically-refractory encopresis, likely related to resolution of soiling.

Level of evidence: 4

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Fecal incontinence is an embarrassing, psychologically debilitating issue faced by many children, with well-documented detriment to quality of life (QOL) and physical and mental well-being [1,2]. Many patients who suffer from fecal incontinence have no organic cause. Encopresis is defined as repeated involuntary passage of stool by a child older than four years without an anatomic or organic cause [3]. Prevalence decreases with age, with 2.8% of 4-year-olds affected, compared to 1.6% of 10-year-olds. Up to 90% of childhood encopresis is associated with functional constipation [4]. The mainstay of therapy for encopresis is a combination of behavioral therapy with laxatives; dietary modifications and suppositories are sometimes employed to supplement these interventions [5]. However, in randomized trials, rates of remission or improvement in incontinence range from 63% to 78%, leaving a large proportion of patients requiring more aggressive therapy [6,7].

Abbreviations: ACE, Antegrade continence enema; ARM, Anorectal malformation; HD, Hirschsprung Disease; QOL, Quality of life.

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Surgical intervention for fecal incontinence includes the antegrade continence enema (ACE), introduced by Malone in 1990 [8]. This procedure allows for administration of an antegrade enema into the cecum either by appendicostomy or tube cecostomy, which can be carried out in the privacy of one's home by the child or his/her family [9,10]. This is often preferable to retrograde enemas, which may be difficult for patients to tolerate and for parents to administer [11]. Most of the data surrounding ACE comes from patients with anatomic or neurologic etiologies of their fecal incontinence, such as anorectal malformations (ARMs), Hirschsprung Disease (HD), or spina bifida [12–15]. We recently demonstrated that ACE procedures can result in significant improvement in QOL in patients with HD or ARMs [16]. However, the benefit of ACE in patients with no organic etiology of their constipation and incontinence is less clear, and therefore, selection of patients with encopresis for this procedure remains controversial.

To address this, we investigated the success of ACE in patients with encopresis in improving stooling habits and QOL. We hypothesized that, despite the lack of an anatomic or organic etiology of incontinence, antegrade continence enemas would be successful in improving QOL in selected patients with medically-refractory encopresis due to their ease of use and ability to establish a more regimented stooling schedule. Our goal was not only to elucidate the efficacy of ACE in this patient

population but to identify characteristics that will guide selection of future encopretics for ACE procedures.

1. Materials and methods

After Institutional Review Board approval at C.S. Mott Children's Hospital in Ann Arbor, MI (#HUM00071527), a retrospective chart review was done on pediatric surgery patients who had undergone placement of an appendicostomy or cecostomy tube between 2003 and 2014 and had antegrade continence enemas initiated with guidance by our pediatric colorectal program. Patients with a diagnosis of encopresis were included in the study. Diagnosis was confirmed by pre-operative chart review, which also characterized pre-operative bowel function and stooling habits. Variables of interest included demographic information, indication for operation, and age at procedure. We also gathered data on type of operation, comorbidities, length of stay, readmissions, and short and long-term complications.

Using the contact information obtained from the medical record, after consent, we completed a detailed phone interview with the child's parent(s), legal guardian, or the child (with the parent's consent) to assess the long-term stooling habits and QOL. Information obtained from the phone interview was confirmed with chart review as documentation permitted.

1.1. Conduction of the interview

Each phone interview consisted of the following components:

- Consent obtained over the phone
- Stooling survey
- Recall disease-specific QOL prior to surgery
- Current disease-specific QOL post-surgery
- Recall PedsQL QOL prior to surgery
- Current PedsQL QOL post-surgery

1.2. Measures

Three surveys were used for this study – a stooling survey and two QOL surveys.

1.2.1. Stooling

This stooling survey has been previously used and specific questions were selected to best reflect the functional result of the operation [16,17]. This is a 12-item questionnaire to assess frequency, soiling, constipation, continence, previous medications, and toilet training (Table 1). A total stooling score was calculated as the summation of all 12 stooling question scores. Total scoring ranged from 0 to 28, and patients were secondarily classified into 3 groups: good (19–28), fair (10–18), and poor (0–9).

1.2.2. Quality of life

We used two quality of life measures for this study. The first was a 7-item disease-specific QOL measure which, like the stooling survey, had been previously used to assess QOL before and after the operation (Table 2) [16,18,19]. This 7-item questionnaire included evaluation of relationships of subjects with their peers, social habits, and emotions. Behavioral disorders such as autism spectrum disorder are frequently associated with a diagnosis of encopresis. We therefore also administered a validated QOL measure, the PedsQL™, which includes four scales: physical functioning, emotional functioning, social functioning, and school functioning. This survey had been studied in patients with autism spectrum disorder and deemed an appropriate measure of QOL [20]. Scores were converted into a 100-point scale, with higher numbers representing better QOL.

Table 1
Stooling survey questions.

Question	Answer	Score
1. How often does your child defecate?	Normal	3
	Often (2–4/day)	2
	Every 2 days or more but spontaneous	1
	Very often (> 6/day)	0
	Normal	2
2. What is the consistency of your child's stool?	Loose	1
	Liquid	0
3. What is the odor of your child's stool?	Normal	2
	Sometimes offensive	1
	Offensive	0
4. Does your child have trouble with soiling?	No	3
	Occasionally (1–2 times/day)	2
	Often (3–5 times/day)	1
	All the time (> 5 times/day)	0
	No	2
5. Is your child constipated?	Stools only with laxative	1
	Stools only with enema	0
	No	2
6. Does your child have fecal urgency?	Most of the time	1
	Always	0
7. How long does your child have between feeling the need to defecate and actually using the restroom during the day?	Normal (minutes)	2
	Short (seconds)	1
	Absence of a sense of urgency	0
8. Does your child have abdominal distention?	No	2
	Mild	1
	Moderate to severe	0
9. Has toilet training been tried?	Successful	3
	Occasional	2
	Tried and failed	1
10. Does your child need medical therapy to control stooling?	No impending awareness of stool	0
	No	2
	Occasionally	1
11. Does your child require any diet modifications (i.e. constipated or laxative diet)?	Always	0
	No	3
	At night only	2
12. Does your child require diapers?	Occasionally (night and activity)	1
	Always	0

1.3. Outcomes and statistical analysis

The primary outcome was QOL post-procedure as compared to pre-procedure. Values are expressed as mean ± standard deviation. Statistics were performed using paired t-tests or Chi-square analysis using Microsoft Excel (Microsoft Corporation, Redmond, WA). P values ≤0.05 were considered significant. Secondary outcome measures included comorbidities, stooling scores, complications, and readmissions.

2. Results

An 11-year retrospective review between 2003 and 2014 identified 10 patients who had received a new appendicostomy or cecostomy for the administration of antegrade enemas related to the diagnosis of encopresis. There were 6 males and 4 females. The mean age was 11.4 ± 4.9 years old at the time of the study. The mean age at operation was 8.9 ± 4.5 years, and patients had a tube in place for a mean 2.5 ± 2.5 years.

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