ORIGINAL ARTICLE

Antegrade continence enema procedure: impact on quality of life in patients with spinal cord injury

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Study design: This is a prospective cohort study.

Objectives: Patients with spinal cord injury (SCI) often suffer from severe constipation/fecal incontinence. The antegrade continence enema (ACE) procedure is often used to control these distressing symptoms when medical management fails. Improvement in the quality of life (QOL) following the ACE procedure has been demonstrated in patients with fecal incontinence of various etiologies. We assess the impact of the ACE procedure on QOL in patients with fecal incontinence due to SCI.

Setting: This study was conducted in the United States.

Methods: We measured the impact of fecal incontinence on QOL in patients with SCI undergoing ACE using the validated fecal incontinence quality of life (FIQL) QOL instrument. The FIQL scores QOL in four domains: lifestyle, coping/behavior, depression/self-perception and embarrassment. Surveys were prospectively administered before and after surgery. Preoperative and postoperative survey scores were compared using two-sample *T*-test.

Results: Between 2003 and 2010, the ACE procedure was performed on 17 patients with SCI, including 10 paraplegic and seven quadriplegic patients with an average age of 33 years at the time of surgery. Scores in all four QOL realms assessed by the FIQL instrument improved significantly following the ACE procedure. Stomal stenosis requiring channel revision occurred in three patients and was the most common complication.

Conclusions: This is the first study to our knowledge that assesses the impact of the ACE procedure on the QOL in patients with SCI. Using a validated questionnaire, we demonstrated significant improvement in QOL related to fecal incontinence following the ACE procedure in these patients who are severely affected by their bowel dysfunction.

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INTRODUCTION

Neurogenic bowel dysfunction resulting in severe constipation and fecal incontinence is a very common sequela of spinal cord injury (SCI), with up to 85% of patients with SCI experiencing some degree of fecal incontinence.^{1–3} Severe constipation secondary to neurogenic bowel dysfunction and associated fecal incontinence has a marked impact on social and psychological well-being, and it is a source of significant distress for patients with SCI.^{2,3}

Regular and complete colonic evacuation forms the cornerstone in the treatment of fecal incontinence due to neurogenic bowel dysfunction. The initial treatment of constipation related to neurogenic bowel dysfunction generally includes combinations of oral therapies, suppositories and enemas. Such treatments have the benefit of being noninvasive, but they may be ineffective in adequately managing the severe constipation afflicting individuals with SCI and often require the patient to rely upon the assistance of a caretaker to administer the bowel regimen.

Malone *et al.*⁴ described in 1990 the creation of an antegrade continence enema (ACE) procedure for the treatment of severe constipation. The ACE procedure allows a patient to administer an enema directly into the cecum via an easily accessible abdominal wall stoma, and it is an effective method for controlling refractory fecal incontinence due to a variety of etiologies in both adult and pediatric

populations.^{5–9} The ACE procedure has been shown to provide significant improvement in patient and caregiver quality of life (QOL) when used in patients with neurogenic bowel dysfunction due to a variety of etiologies; however, no study has assessed the impact of the ACE procedure on QOL in patients with neurogenic bowel dysfunction due to SCI.^{10–12} We use a validated QOL instrument, which specifically assesses QOL related to fecal incontinence, to objectively measure changes in QOL related to fecal incontinence before and after the ACE procedure in patients with SCI.

MATERIALS AND METHODS

By recognizing the multifactorial disability of SCI, we use the disease-specific fecal incontinence quality of life (FIQL) instrument developed by Rockwood *et al.*¹³ to specifically assess the impact of the ACE procedure on QOL related to fecal incontinence. The FIQL instrument consists of a 29-question survey that generates scores in four QOL domains: lifestyle, coping/behavior, depression/self-perception and embarrassment. Scores for each domain are reported on a continuous scale of 1–4, in which a higher score indicates a more favorable QOL. Rockwood *et al.*¹³ have shown the FIQL scale to be a reliable and valid instrument to measure the QOL related to fecal incontinence. Furthermore, analysis for convergent validity demonstrates correlation of the FIQL scales with appropriately matched subscales from the SF-36 global QOL instrument, a validated and widely used instrument in studies of QOL in the SCI population.¹⁴

Between 2003 and 2010, FIQL surveys were administered to all patients with SCI undergoing the ACE procedure at our institution. Patients completed surveys preoperatively and postoperatively. The preoperative survey was administered during the preoperative clinic appointment, which occurred 1 to 2 weeks before the surgery date. The postoperative assessment was performed during a clinic appointment at a minimum of four months after surgery. All surveys were administered by the nurse coordinator of our neurogenic bladder/bowel clinic. In several patients in whom a preoperative FIQL could not be obtained, the preoperative survey was retrospectively completed during the postoperative period.

Data pertaining to patient age, sex, age at the time of surgery, mechanism and level of injury, type of channel (appendix or other intestinal segment), complications and length of follow-up were obtained from the medical record.

All statistical analyses were carried out using SAS statistical software version 9.3 (SAS Institute, Cary, NC, USA). Categorical data pertaining to patient characteristics, operative data and complications were summarized according to percentage and frequency. Preoperative and postoperative survey responses were compared using a paired *T*-test for the cohort as a whole, as well as separately, for the groups of patients who retrospectively or prospectively completed the preoperative evaluation. A two-sample *T*-test was used to compare the change in the survey responses between preoperative and postoperative scores.

RESULTS

Seventeen SCI patients, five female and 12 male, underwent the ACE procedure between 2003 and 2010. This group consisted of 10 paraplegic and seven quadriplegic patients. The average patient age at the time of surgery was 33 years (range 6–49). The mean duration of follow up was 56 months (range 4–102).

Five patients, who had retrospectively completed the preoperative survey after surgery, were excluded from final analysis. In the remaining 12 patients, the QOL scores increased significantly in all categories of the FIQL survey after surgery (Figure 1). The lifestyle score increased from an average of 2.3 (s.d. = 0.9) preoperatively to 3.7 (s.d. = 0.5) postoperatively ($P < 0.001$). The mean preoperative coping/behavior score was 2.2 (s.d. = 0.9), versus 3.8 (s.d. = 0.3) postoperatively ($P < 0.001$). The mean depression/self-perception increased from 2.8 (s.d. = 0.9) to 3.8 (s.d. = 0.4) ($P < 0.001$), and the embarrassment score improved from 2.2 (s.d. = 1.1) to 3.8 (s.d. = 0.3) ($P < 0.001$). For all four QOL domains, the change in score from the preoperative to

postoperative assessment was not significantly affected by patient age, gender or level of injury.

The ACE channel was created using appendix in the vast majority of patients (Table 1). In three patients, the appendix was either of insufficient size to create an effective channel or was absent owing to prior appendectomy. In situations in which the appendix could not be used, the ACE channel was created using either ileum or sigmoid colon. Urinary tract reconstruction was performed concurrently with the ACE procedure in four patients. The types of urinary tract reconstructions performed in these patients included creation of a continent catheterizable urinary stoma (Mitrofanoff procedure), bladder augment and bladder neck sling. The timing of the procedure relative to the initial injury was variable among the cohort; however, approximately half of the patients underwent the ACE procedure 10 or more years after their injury.

Four patients developed complications during the follow-up period. Complications included stomal stenosis in three patients and delayed small-bowel obstruction in one patient. There was no association between the type of intestinal segment used for the ACE channel and the development of postoperative complications.

DISCUSSION

SCI is a devastating condition, which disproportionately affects younger patients with long life expectancy. Neurogenic bowel dysfunction resulting in severe constipation and fecal incontinence is a common consequence of SCI, and it is the source of some of the most bothersome symptoms in this patient population.^{2,3} To our knowledge, no previous study has specifically addressed the impact of the ACE procedure on QOL related to fecal incontinence in patients with neurogenic bowel dysfunction due to SCI. Using a disease-specific QOL instrument, the FIQL survey, we showed significant improvements in QOL following the ACE procedure in patients with neurogenic bowel dysfunction secondary to SCI. Significant improvements in QOL scores were identified in all four QOL domains assessed by the FIQL survey, with the most marked changes observed in the

Table 1 Clinical and demographic characteristics of patients undergoing the ACE procedure

Gender	Level of injury	Age at surgery	Years from SCI to ACE	Appendix used	Urinary reconstruction at the time of ACE
M	T9	48	19	Yes	Yes
M	T4	19	13	Yes	No
F	T4	44	1	Yes	Yes
M	C5	43	11	Yes	No
M	T4	6	3	Yes	No
F	C5	29	2	Yes	Yes
M	C6	37	17	Yes	No
F	T11	22	4	No	No
M	T11	36	6	Yes	No
M	C7	49	5	No	No
M	T1	13	10	Yes	No
M	C5	31	11	Yes	No
M	C5	34	6	Yes	No
M	T4	48	30	Yes	No
F	C6	39	12	Yes	Yes
F	C5	37	14	No	No
M	T10	22	6	Yes	No

Abbreviations: ACE, antegrade continence enema; F, female; M, male; SCI, spinal cord injury.

Figure 1 Comparison of preoperative and postoperative FIQL scores.

domains pertaining to patient embarrassment, lifestyle and coping related to fecal incontinence.

In addition to noting significant improvement in FIQL scores following the ACE procedure, we also demonstrated postoperative FIQL scores in our population that approach scores that would be expected among individuals without fecal incontinence. On the continuous scale of 1–4, where a score of 4 implies no impact of fecal incontinence on QOL, we recognized postoperative FIQL scores ranging from 3.7 to 3.8 among the four QOL domains. Conversely, the low preoperative FIQL scores seen in our series highlight the profound impact of fecal incontinence on QOL in this patient population.

Previous series have shown that fecal incontinence, reliance on a caregiver to assist with toileting and the need for time-consuming bowel regimens are major components of the bowel function-related distress experienced by patients with SCI.¹⁵ The significant improvements in QOL seen in the present study are likely multifactorial and may be related to improved fecal continence, patient independence with bowel management and a less time-consuming bowel regimen following the ACE procedure.

The ACE procedure has become a mainstay in the treatment of refractory constipation and fecal incontinence in patients with neurogenic bowel dysfunction since its introduction in 1990. Previous series have highlighted a QOL benefit from the ACE procedure in patients with fecal incontinence due to neurogenic bowel dysfunction of various etiologies. Ok and Kurzrock¹² have developed and validated a QOL questionnaire to assess the impact of fecal incontinence and constipation on the families of children with spina bifida. In their prospective series of 18 families of patients with spina bifida, fecal incontinence and QOL scores improved significantly after the ACE procedure. Laurberg reported long-term outcomes in 69 adult patients who had undergone the ACE procedure, 33 of whom had neurogenic bowel dysfunction. Using an arbitrary scale, patient-reported bowel function, social function and QOL all significantly improved after the ACE procedure (mean follow-up 75 months).⁷

Because SCI is a multifactorial disability, we believe that a disease-specific QOL instrument, which specifically addresses QOL related to fecal incontinence, is the most appropriate means to measure the QOL impact of the ACE procedure as a procedural outcome in SCI patients. The FIQL instrument not only meets this criterion, but it also correlates with comparable scales of the SF-36 global QOL instrument, which is a widely used measure of QOL in the SCI population.¹⁴ Although we demonstrated significant improvements in QOL specifically related to fecal incontinence, the impact of the ACE procedure on global QOL in the SCI population remains undefined. As the impact of fecal incontinence is weighed with other global QOL factors, the benefit to global QOL may be less significant. This phenomenon is highlighted by the work of MacNeily *et al.*¹⁶ (2009) that showed no global QOL benefit to lower urinary tract reconstruction in the spina bifida population.

Stomal stenosis is one of the most common complications of the ACE procedure. Stomal stenosis requiring revision occurred in 18% (3/17) of our patients, which is comparable to that reported in other series.^{5–7,17} One patient (6%) in our series developed a delayed small-bowel obstruction, which required surgical exploration. The risk of major complications following the ACE procedure, although low, underscores the role of proper preoperative counseling.

Our series is limited by a relatively small cohort size, which we attribute to the infrequency with which the ACE procedure is performed in patients with SCI. Larger prospective studies will be

needed to fully define the positive QOL impact of the ACE procedure in patients with SCI demonstrated in this pilot study. In addition, the present series selects for patients with more severe symptoms related to bowel dysfunction that have been refractory to conservative measures and may not reflect the impact of fecal incontinence on QOL in the SCI population at large. We believe that the QOL benefit seen in our study objectively highlights the value of the ACE procedure in patients with refractory fecal incontinence due to SCI, and it may aid in proper patient selection and preoperative counseling.

CONCLUSIONS

The ACE procedure is a highly effective method of treating severe constipation and fecal incontinence in patients with neurogenic bowel dysfunction due to SCI. In our series of 17 SCI patients with neurogenic bowel dysfunction, the ACE resulted in marked improvements in QOL related to fecal incontinence.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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