

Success of Malone's Antegrade Continence Enema (MACE) from the Patients' Perspective

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Abstract

Purpose: Fecal incontinence (FI) is a devastating problem for children. The failure of optimal medical treatment may require further interventions such as appendicocutaneostomy. We report on a patients' perspective of the success of a Malone procedure for FI.

Patients and Methods: The records of 32 patients who had undergone ACE procedure in the past 9 years were reviewed. Patients and families were contacted, and telephone inquiries were conducted to assess the overall success of the operation. The questionnaire covered the concerns of patients/families about the stoma, functional results and changes in the patients' quality of life (QOL).

Results: The indications for ACE stomas were meningomyelocele in 17 patients, anorectal malformation in 8, Hirschsprung/NID in 3, spinal tumor in 3 and traumatic spinal injury in one. 7 laparoscopic and 25 conventional operations were performed. The vermiform appendix was used in 27 of the patients and a cecal flap was used in 5. The most frequent complication was stenosis of the stoma orifice observed in 14 patients. 8 patients responded to dilatations

while 6 patients required minor surgical revision. There were 2 perforations during catheterization, and they required surgical repair of the conduit. 5 patients had mild leakage from the stoma; all 5 were open ACE procedures, and required revision. 25 patients could be reached by phone. 5 of these children stopped using the stoma due to previous perforation in 2 patients and stricture in 1. The remaining 2 stopped using their stomas because "they did not like the idea of it". 16 patients are completely clean. 3 patients have occasional soiling. Only one patient was not satisfied with using the ACE stoma and stated that it did not sufficiently improve her condition. 8 patients complained about the duration of the enema (longer than 1 h); however, 5 of them refuse to use the stoma every day. All patients but one perceived a significant improvement in their QOL. Mean QOL scores before and after the procedure were 5.8 (2–9) and 11.5 (5–14), respectively.

Conclusions: ACE stomas provide a satisfactory improvement in patients' quality of life. Stoma-related complications are not uncommon. The most common problems are strictures, followed by stoma leakage.

Introduction

Fecal incontinence is a socially devastating problem that affects some patients with spina bifida [1], anorectal malformations [2], Hirschsprung's disease [3], pelvic tumors [4,5], sacral agenesis [6,7] and severe pelvic-perineal trauma. Fecal incontinence needs to be resolved before the child starts school since it may constitute a problem for the child's social and interpersonal relationships. Failure despite optimal medical treatment including oral medications, dietary adjustments and rectal washouts may require further interventions such as appendicocutaneo-

stomy to achieve socially acceptable anorectal continence. We report here on a patients' perspective of the success of Malone's antegrade continence enema (MACE) procedure for fecal incontinence.

Material and Methods

The hospital records of 32 patients who had undergone MACE procedure for various indications between the years 2000 and 2009 were reviewed. Information on the type of operation (laparoscopic vs. conventional), duration of the

Table 1 QOLA scoring as described by Bai et al. [8].

Soiling never 4 accidental 3 constant 2	Food restriction no 2 somewhat 1 much 0
Incontinence none 2 accidental 1 constant 0	Peer rejection never 2 accidental 1 frequent 0
School/work absence none 2 accidental 1 constant 0	Unhappy/anxious none 2 accidental 1 constant 0

procedure, postoperative complications, and the need for additional interventions was recorded. After reviewing the medical records, patients and families were contacted, and telephone inquiries were conducted to assess the overall success of the procedure. The questionnaire also covered the concerns of patients/families about the stoma, functional results and change in quality of life (QOL). The questionnaire described by Bai et al. [8] was used for QOL assessment (● **Table 1**) and Student's *t*-test was used for statistical analyses.

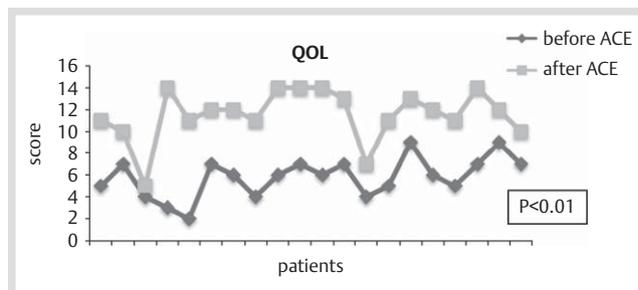
Results

The indications for MACE stomas included meningocele in 17 patients, anorectal malformations (high anomalies including cloaca) in 8, Hirschsprung's disease/intestinal neuronal dysplasia in 3, spinal tumor in 3 and traumatic spinal injury in 1.

Mean patient age at the time of operation was 11 years (range 6–17). Most of the patients were adolescents. 7 laparoscopic and 25 conventional operations were performed. Open surgery was preferred for those patients who had had previous extensive abdominal and/or pelvic surgery, a previous appendectomy or needed concomitant open urologic reconstructive surgery including bladder augmentation. The most frequent primary disease was meningocele; thus, most of these patients required an appendicovesicostomy for urinary incontinence as well. In these cases, the appendix was divided, preserving the mesoappendix and the vascular supply to both conduits, and used for both the Mitrofanoff and the MACE stoma.

Mean operating time for laparoscopic procedures was 17 min. However, the operative time for open procedures varied between 45–90 min, depending on the type of the conduit. The vermiform appendix was used in 27 patients (7 laparoscopic) and a cecal flap was used in 5. 24 stomas were placed in the right lower quadrant (RLQ) and 8 were placed in the umbilicus. An umbilical stoma was preferred for laparoscopic approaches. The VQZ skin-flap technique is used in RLQ stomas and V-flap was used for umbilical stomas.

There were no early postoperative complications; however late complications were not uncommon. The most frequent complication was stenosis of the stomal orifice in 14 patients. 11 occurred after open surgery (44%) and 3 were after laparoscopic procedure (27%). 8 patients responded to dilatations while 6 patients required minor surgical revision. With regard to the site of the stomas, there were 12 stenoses in the 24 right lower quadrant stomas (50%) as opposed to 2 stenoses in the 8 umbilical stomas (25%). There were 2 perforations during catheterization and they required surgical repair of the conduit. 5 patients had mild leakage from the stoma; all 5 were open MACE procedures, all had imbrication of the appendix, and required revision. As a corrective procedure, the plication was extended during revision. One patient did not benefit from the revision and her problems were resolved with a stoma button.

**Fig. 1** Results of QOLA scoring.

After collecting the data from patient records, patients were contacted by telephone for an assessment of the patients' perspective of the success of the operation. The period with a MACE stoma ranged from 6 months to 9 years. 25 (78%) patients could be reached by telephone. 5 of these children stopped using the stoma due to previous perforation in 2 patients and stricture in 1. The remaining 2 patients stopped using their stomas because "they did not like the idea of it".

The procedure was mostly perceived "effective" in terms of anal continence. 16 patients were completely clean. 3 patients had occasional soiling; 2 only in situations such as diarrhea and the third only in the next hour after performing an antegrade enema. Only one patient was not satisfied with the MACE stoma and stated that it did not sufficiently improve her condition.

3 patients reported an occasional difficulty in catheterization but they did not consider it a constant problem and defined it as "negligible".

Another concern was the feasibility of the antegrade enema. The main problem patients complained of was the duration. 8 patients stated that it took longer than 1 h; however, 5 of them refused to perform daily enemas. One patient insists on using the stoma only once a week and is still continent. Maximum enema duration was 90 min and the mean time spent on the toilet was 46 min. However, the patients stated that the duration of the enema became shorter over time as they gained experience in its management and made personal adjustments. Only one patient required an additional use of oral laxatives. One patient stated nonspecific pain in the right lower quadrant during enema administration.

For an objective assessment, patients were also questioned about the change in their QOL following the procedure, using the QOL scoring system defined by Bai et al. [8]. All patients but one noted a significant improvement in their QOL. Mean QOL scores before and after the procedure were 5.8 (2–9) and 11.5 (5–14) respectively ($p < 0.01$) (● **Fig. 1**).

The patient with no change is a patient with meningocele who has many concomitant problems and shows a low compliance and is discontented with every issue regarding her condition.

Discussion

Fecal incontinence is a devastating problem for children and their parents. Children with fecal incontinence or soiling often experience discrimination by other children in their social lives, leading to severe psychological and behavioral problems. Unresolved fecal continence problems beyond the school years, in adolescence and adulthood may have grave consequences,

affecting the level of education, interpersonal relationships, productivity and QOL [9]. Therefore, resolution of anal continence problems is of paramount importance and requires patience, commitment, adjustment, close follow-up, and monitoring of the patient. Family compliance is another important aspect of management. Interventions for bowel management including dietary adjustments, laxatives and rectal washouts are sometimes ineffective in patients with persistent symptoms of fecal incontinence. In that case, appendicocutaneostomy (Malone procedure) for antegrade colonic washouts, a simple but effective method, is considered a highly promising solution for the resolution of symptoms.

The Malone procedure is not a definitive treatment for anorectal incontinence; however, it offers a significant improvement in patients' continence problems. Therefore, the criteria to assess the feasibility of the procedure depend on the patients'/families' own subjective perception of their status. Thus, our study concentrated mainly on questions about patients' continence levels as well as their quality of life. After completing our initial survey which focused on objective criteria, patients were also inquired using open-ended questions to identify the changes in their lives.

Following the introduction of antegrade enemas, almost all our patients reported a considerable improvement in their quality of life which was also affirmed by a statistically significant change in QOL scores. This was largely credited to the improvement in their continence status. Similarly, a remarkable improvement was also noted with regard to "peer rejection and depression". Patients also stated that their "self-confidence" had improved and indicated that remaining continent made them "feel hygienic" and "respectable". Almost all our patients acknowledged that "getting rid of the horrible odor" was an important aspect for their contentment. Moreover, families defined their children as "more active in their social lives". Another aspect mentioned by families was the children's reluctance to go to school prior to the procedure. 12 children were unwilling to go to school because of fecal incontinence/soiling which improved after the initiation of antegrade enemas.

Cosmesis is another aspect of patient satisfaction. Umbilical stomas are probably more socially acceptable, therefore our clinic's current approach is to perform umbilical stomas if possible. On the other hand, RLQ stomas are created below the underwear line, and the VQZ skin-flap technique for burying the appendiceal mucosa is used, giving a cosmetically pleasing result. No specific questions on cosmesis were included in the questionnaire, however there was no statistically significant difference between the QOL scores of both groups ($p=0.29$).

Stoma-related complications are not rare after a MACE procedure [10]; however, even patients who experienced such problems affirmed a "big change" in their lives. Strictures are the most common problem; most of these are not serious and can be resolved by dilatations [11]. Stenosis following conventional procedures appeared to be higher in our series (44% vs. 27%). The difference was not statistically significant ($p=0.46$). Similarly, there appeared to be a 2-fold increase in the stenosis rate for lower quadrant stomas (25% vs. 50%). The difference was also not statistically significant ($p=0.18$). Possibly the tone of the abdominal muscle layers pressurizes the marginal arterial supply to the tip of the conduit, leading to an increased tendency to ischemia and fibrosis. The difference between the laparoscopic and conventional group was also probably due to the site of stoma with a higher rate of umbilical stomas in the laparoscopic

group. Difficulties in catheterization were also the possible reason for perforation of the conduit, also observed in right lower quadrant stomas in our series. Therefore, umbilical stomas should be encouraged when feasible because of the lower rate of complications and the improved cosmesis.

The MACE procedure is a relatively simple operation which may be done in an open or laparoscopic fashion. However, the complexity of concomitant reconstructive efforts, especially in patients with meningocele (i.e. the creation of a continent Mitrofanoff stoma, bladder augmentation, etc. [12]) or previous abdominal surgery, necessitated the performance of open surgery in the majority of cases in our series. There was a selected group of patients where the clinical history and anatomic circumstances allowed a laparoscopic appendicocutaneostomy to be performed. Laparoscopy provided a minimally invasive access, had a low morbidity and effective results. The mean operative time was also significantly shorter for laparoscopy procedures. As they may provide a comparable outcome with a better cosmesis and no additional risk of complications, laparoscopic procedures should be performed when open surgery is not otherwise required.

Conclusion



Fecal incontinence impacts the quality of life of children and adults, affecting almost every social aspect of their life. It influences school and peer relationships, leads to a deterioration in education, personality development, and self-confidence. The Malone procedure provides a significant improvement in the level of continence and thus a satisfactory quality of life both for patients and their families.

Conflict of Interest: None

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