Importance of the Development of a Bowel Management Unit: Evaluation After 5 Years of Experience

Ortolá P¹, García E², Fonseca R¹, Gutiérrez C¹, Barrios JE³, Mangas L¹, LLuna J¹ and Vila JJ⁴

¹Staff of Pediatric Surgery, Hospital Universitari y Politècnic de La Fe, Spain
²Nurse and Psychologist, Hospital Universitari y Politècnic de La Fe, Spain
³Clinical Chief of Colorectal Pediatric Surgery, Hospital Universitari y de Politècnic La Fe, Spain
⁴Head of Department of Pediatric Surgery, Hospital Universitari y Politècnic de La Fe, Spain

Abstract

Background: Fecal incontinence and constipation in children are frequently associated with diseases such as Spina Bifida (SB), Hirschsprung’s Disease (HD) and Anorectal Malformations (ARM). Bowel management programs aim to improve the continence and quality of life of these patients. We show the experience of our bowel management unit since its creation, five years ago, where Transanal Irrigation (TI) is used as one of the treatment options.

Results: We conducted a retrospective study from May 2014 to April 2019 in a tertiary hospital specialized in pediatric population. All patients with fecal incontinence and/or constipation initially received conventional medical treatment and, in case of no improvement, TI was initiated.

A total of 52 patients have been treated, mostly with SB, ARM or HD. 71.5% of the children required treatment with TI. After a mean follow-up of 2.5 years, complete absence of stool soiling was achieved in 50% of cases and a significant reduction in incontinence in 28.8% of them. 9.6% discontinued follow-up due to low adherence to treatment. No complications secondary to the use of the TI device were registered.

Conclusion: We consider that bowel management units are essential in the follow-up of this type of patients, being the approach of a specialized nurse essential to reach the therapeutic goals. TI is a safe and effective therapeutic modality that should be used in the treatment of these patients.

Keywords: Constipation; Fecal incontinence; Nurses; Pediatrics; Therapeutic irrigation

Abbreviations
SB: Spina Bifida; HD: Hirschprung’s Disease; ARM: Anorectal Malformations (ARM); TI: Transanal Irrigation; P-TI: Peristeen® device Transanal Irrigation; SD: Standard Deviation; MACE: Malone Antegrade Colonic Enema; ESPGHAN: European Society for Pediatric Gastroenterology Hepatology and Nutrition; NASPGHAN: North American Society for Pediatric Gastroenterology Hepatology and Nutrition

Background
Fecal incontinence and constipation are frequently associated problems in pediatric patients with Spina Bifida (SB), Hirschprung’s Disease (HD) and Anorectal Malformations (ARM), due to the disease itself or the reparative surgery. There can be other causes, of functional or idiopathic origin [1-6].

The spectrum of these entities ranges from mild defects of good prognosis, with response to initial medical treatment, to severe defects of poor prognosis, with other associated pathologies and no response to conventional treatment [7]. In any of the cases, the self-esteem and quality of life of both the patient and their caregivers are significantly affected [1,2,4,8,9].

Bowel management is a medical term used to refer to the treatment of fecal incontinence and constipation. These programs have the purpose of eliminating or reducing these episodes, achieving the autonomy of the patient and their psychosocial well-being. They must be individualized and directed in each case to achieve specific objectives. This is a slow process, which requires involvement of the patient, the caregivers and the entire medical team in which the specialized nurse plays an essential role [2,3,5,6,10].

Since the introduction of Transanal Irrigation (TI) in pediatric patients [11], different studies have shown good results in the treatment of cases that had not satisfying response to initial medical treatment, thus reducing the use of other more aggressive methods [1-3,6,7,9,10].

The application of TI with the Peristeen® device (P-TI) has shown good response in patients with fecal incontinence of neurogenic origin and, more recently, in these cases of functional origin and secondary to HD and ARM [4,8,10,12].

Our bowel management unit was created 5 years ago and offers treatment with P-TI as a therapeutic option. The present study shows the type of patients attended in this period, their evolution and results, as well as the protocol followed in our center.
Methods

We conducted a retrospective study of children with fecal incontinence and/or constipation attended in our bowel management unit from May 2014 to April 2019, in a tertiary hospital specialized in pediatric population.

Patients were selected and assigned to the program when, in the periodic medical consultations, the pediatric surgeon detected an inadequate defecatory control. All patients received a first visit with the nurse and psychologist, specialized in bowel management, and also with one of the unit’s pediatric surgeons. During this visit, the type of incontinence and the causal pathology were identified. After reviewing the medical history and performing the physical examination, an incontinence calendar was requested, for at least one month, detailing: number of stools, consistency, soiling episodes, use of oral and/or rectal medication, relationship with diet or physical activity [3,4] In selected cases, additional tests were requested, such as abdominal X-ray or contrast enema to complete the diagnosis [1,2].

Initially, a conventional medical treatment was prescribed, based on: oral and/or rectal medication (laxatives and/or antidiarrheals), recommendations or dietary modifications (in relation to water and fiber intake) and hygienic habits (sitting in the bathroom routinely taking advantage of the gastrocolic reflex, comfortable position, duration...) [2,3,9].

In case of lack of improvement, enemas were started. If these were effective, TI was introduced with Peristeen® system (Coloplast A/S, Kokkedal, Humlebaek, Denmark). This device was used daily on an initial basis and, depending on the adherence and response to the treatment, the number or frequency of the irrigations and the volume of liquid were adjusted in an individualized manner [3-5,8,9,12].

The nurse and psychologist met periodically with the patient and their caregivers, initially every 3 to 4 weeks and, later, adjusting the frequency of visits to the needs of each case. These visits were aimed at solving doubts, checking the correct performance of the P-TI and adjusting, if necessary, the amount or frequency of the irrigations or the dose of medication administered. Both the patient and the caregivers learned basic concepts of bowel anatomy and physiology, in order to facilitate understanding and adherence to treatment [2,5]. The aim and use of Peristeen® was explained both visually and verbally, according to the manufacturer’s instructions. Depending on the age of the patient, the caregivers or the child himself were instructed on how to insert the catheter, as well as its fixation with the balloon and the instillation of the liquid [10,12].

The psychological approach was also another objective of these visits, trying to eliminate feelings of guilt or shame and turning the process into something normal, a routine with clear, close messages and rewards after fulfilling goals [3].

Results

Since the creation of the bowel management unit in our center, in May 2014, we have followed a total of 52 patients. We show the demographic characteristics of our population in (Table 1).

The most frequent causes of fecal incontinence or constipation in our group were Hirschsprung’s Disease (HD), Anorectal Malformations (ARM) and Spina Bifida (SB), assuming a total of 86% of the cases. The functional cause (totally integrated by patients with encopresis) and other pathologies (myotonic dystrophy and a case of ARM+HD in the same patient) were less common (Table 1 and Figure 1).

Table 1: Demographic characteristics of the study population.

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>40 (76.9)</td>
</tr>
<tr>
<td>Female</td>
<td>12 (23.1)</td>
</tr>
<tr>
<td>Cause</td>
<td></td>
</tr>
<tr>
<td>Anorectal Malformation</td>
<td>18 (34.6)</td>
</tr>
<tr>
<td>Hirschsprung’s Disease</td>
<td>15 (28.8)</td>
</tr>
<tr>
<td>Spina Bifida</td>
<td>12 (23.1)</td>
</tr>
<tr>
<td>Functional</td>
<td>5 (9.6)</td>
</tr>
<tr>
<td>Others</td>
<td>2 (3.9)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>Median (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>8 years (3-14)</td>
</tr>
<tr>
<td>Number of medical visits</td>
<td>6.5 visits (1-14)</td>
</tr>
</tbody>
</table>

Figure 1: Causes of fecal incontinence or constipation.

In all patients, conventional medical treatment was started, being sufficient to improve their initial situation in 17.1% of cases. Eventually, 71.5% of the children required P-TI. 11.4% of the children needed, in addition to the P-TI, administration of laxatives and/or antidiarrheals (Figure 2).

At the time of the first visit, most patients had daily fecal soiling (92.3%) and only a small percentage did so occasionally (5.8%). At the present time, and after a mean follow-up of 2.5 years (SD 1.42), 50% of our patients have managed to stay clean permanently and 28.8% have occasional and mild soiling episodes. 11.5% still have daily soiling events or in a major way (Figure 3). Therefore, after the start of our bowel management program and the introduction of P-TI as a therapeutic tool, 78.8% of our patients have improved their initial situation significantly.

The adherence to treatment by our population was 90.4%, without registering any significant complication derived from the use of P-TI. The low adherence to the treatment in the remaining 9.6% was the reason for interrupting the follow-up.
Discussion

Fecal incontinence in children can be due to organic (SB, ARM, HD) or functional causes, with chronic constipation, encopresis and pseudocontinence [1-6]. This can affect up to 30% of the cases [1-3]. These problems have negative consequences in regard to social integration, quality of life and self-esteem in an important period for the development and maturity of these patients [9,10]. That is why the goals of bowel management programs are reducing or eliminating fecal incontinence and constipation and improving the patient’s quality of life, self-esteem and autonomy. However, it is a slow and complex process, which requires the involvement of the patient, their caregivers and the entire care team, mainly the specialized nurse [3,5,6,10]. This sometimes leads to limited therapeutic adherence [4,8,10].

Since the introduction of TI in pediatric patients in the 1980s by Shandling and Gilmour [11] and the description of bowel management programs by Peña and cols [1,2]. Many studies have been published on the use of Peristeen®. This device consists of a catheter with balloon, a hand pump, a pressure gauge and an irrigation solution container [10]. Its use is based on the controlled introduction of water into the colon through the catheter with balloon, which allows it to be on the site and avoids leaks during the instillation. Subsequently the balloon is deflated and the catheter is removed, allowing the evacuation of water and bowel contents. This procedure lasts less than 30 minutes and allows a controlled evacuation of the colonic content, facilitating a period of continence between washes of up to 2-3 days, depending on the patient [4,8,10,12]. Although intestinal perforations have been described [3,6,10], adverse effects are infrequent and mild (discomfort during washing, nausea, self-limiting bleeding) [3,4,6,8,10,12]. Other alternatives to TI, whatever the device chosen, are sacral neurostimulation or the Malone Antegrade Colonic Enema (MACE), but they are more aggressive techniques, which require surgery and are not free of risks (infection, leakage, stenosis ...) [3,6,8,12]. The advantage offered by Peristeen® with respect to other TI models, is that it allows the autonomy and independence of the patient when it reaches enough age and maturity to perform the washes himself, as he does not need the help of a caregiver for its application as others mechanisms do [4,5,12]. Moreover, it is a latex-free instrument, which is an advantage in patients who undergo numerous interventions [9].

The indications of P-TI have been increasing in recent years, from the beginning with fecal incontinence of neurogenic origin [7,8,12] to idiopathic and non-neurogenic causes (HD, ARM) currently [3-8,10,13]. The promising results obtained may be due not only to the mechanical action produced by the irrigation, but also to the stimulation of secondary colonic peristalsis [7]. The average success rate with respect to reduction of fecal incontinence is around 80% and with regard to the perception of increase in the quality of life, it is around 90% [3]. Thanks to this, the use of other more aggressive techniques already mentioned has been reduced [3,6,7,9,10].

In our study, the results obtained (78.8% of success rate) are similar to others published to date, but it is difficult to establish an accurate comparison since the groups are not homogeneous and the results are not quantified in the same way. Alhazmi describes a 90.4% total absence of soiling, obtained after a follow-up period of 48 months in patients with myelomeningocele [12]. A close result is obtained by Costigan et al. [5] after treating patients with HD, ARM and SB, with improvement in 93.7% of them. Peña [1,2] publishes in his wide series a success rate of 95% with manual enemas and Märzheuser [4] obtains 80% in patients with ARM treated with Peristeen®. Midrio, in a multicenter study in patients with ARM and SB, obtained a reduction of incontinence from 50% to 18.6% in ARM and from 39% to 9.8% in SB [7]; and Paccilli describes absence of soiling in 70% of his group and 13% improvement after treatment in patients with ARM, HD and SB during 2 years [10].

With regard to adherence to treatment, we have also achieved similar results (90.4%) to those obtained by other groups. Other authors [4,8,10] describe low adherence to treatment in 5% to 17% of their cases.

Once the TI have begun, close clinical monitoring by the bowel management team is essential, in order to verify correct use, adjust amounts of irrigating liquid and medication dose and reinforce the patient and caregivers [3,5,6]. In fact, according to NICE and the clinical guidelines of ESPGHAN and NASPGHAN, education and demystification are the first steps to be taken in bowel management programs [3,5,13,14]. Results are not immediate and changes may take time to be perceived. They are usually very progressive, which is why long-term follow-up is important [3]. Likewise, the psychological approach is a priority in some cases, to leave feelings of guilt, shame or anger and to establish a treatment that offers rewards after fulfilling goals [3].

We know the limitations this study presents due to its retrospective nature. In addition, data from a single center is shown and has not been compared with other types of treatments. However, it is one of the 5 largest series published in pediatric patients [2,5,7,12] and we cover a long follow-up period, with good results.

Despite all the above mentioned, to date and unlike what occurs in adults, a clear treatment protocol for this type of patient has not been systematized or validated, so it is performed empirically [1-3,10,12]. Therefore, we believe it is necessary to carry out prospective, multicenter studies that allow the establishment of validated and equal bowel management programs in all centers.

Conclusion

We have obtained a significant improvement in our patients after the creation of a bowel management unit in our center. We believe that this kind of program and the help of a trained and specialized nurse are essential in the follow-up of these patients. We also want to highlight P-TI as a safe and effective treatment modality, which should be used once the initial medical treatment has failed.

Figure 3: Clinical status at the beginning of the study and nowadays.
Funding Source and Conflict of Interests

No financial or nonfinancial benefits have been received or will be received from any party related directly or indirectly to the subject of this article.

Ethical Approval

As this is a retrospective study, not a clinical trial, there has been no Ethical Committee assessment. However, all the patients and relatives have been informed and have given their consent to be part of this study.

Authors’ Contribution Statement

All authors have contributed intellectually, meet the conditions of authorship and have approved the final version of it. The present work is original, has not been previously published and is not being reviewed by any other journal.

References