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Outcomes of a telemedicine bowel management program during COVID-19



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ABSTRACT

Purpose: Due to the COVID-19 pandemic, we transitioned from an in-person bowel management program (BMP) to a telemedicine BMP. The telemedicine BMP consisted of video and/or phone call visits (remote) or a single initial in-person visit followed by remote visits (hybrid). We hypothesized that patient/family satisfaction of a telemedicine BMP would be comparable to an in-person BMP and that there would be improvement in quality of life and functional outcomes after the telemedicine BMP.

Methods: After IRB approval, demographic and outcomes data were obtained for patients who underwent the telemedicine BMP from May–October 2020. Outcomes included a parent/patient satisfaction survey, Pediatric Quality of Life Inventory (PedsQL), and parent/patient-reported outcome measures (Vancouver, Baylor, and Cleveland scores) at baseline, 1 and 3 month follow-up. Variables were compared using Chi-square or Wilcoxon–Mann–Whitney tests and a generalized mixed model was used to evaluate outcomes scores at follow-up compared to baseline.

Results: Sixty-seven patients were included in our analysis with an average age of 8.6 years (SD: 3.9). Patients had the following diagnoses anorectal malformation (52.2%), Hirschsprung's disease (20.9%), functional constipation (19.4%), myelomeningocele (6.0%), and spinal injury (1.5%). Forty-eight patients (72%) underwent the remote BMP and 19 (28%) underwent the hybrid BMP. Sixty-two percent of parents completed the satisfaction survey, with a median score of 5 (very satisfied) for all questions. Over 75% of parents said they would prefer a telemedicine program over an in-person program. There was significant improvement in the Baylor and Vancouver scores after the BMP ($p < 0.01$), but no difference in the PedsQL or Cleveland scores ($p > 0.05$). There was a significant improvement in stool continence after the BMP ($p < 0.01$).

Conclusion: A telemedicine BMP can be an acceptable alternative to a traditional in-person program. There was high parental/patient satisfaction and significant improvement in outcomes. Further research is needed to assess long-term outcomes.

Level of evidence: III

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1. Introduction

Bowel management programs (BMPs) are a well-established clinical strategy used to remedy life-altering fecal incontinence

Abbreviations: BMP, bowel management program; ARM, anorectal malformation; PedsQL, Pediatric Quality of Life Index; PROMs, parent/patient-reported outcomes measures; BCS, Baylor Continence Scale; VSS, vancouver symptom score for dys-functional elimination; CCCS, Cleveland clinic constipation score; SD, standard deviation.

Type of Study: Retrospective cohort review

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and severe constipation in children with anorectal malformations (ARMs), Hirschsprung's disease, myelomeningoceles, spina bifida, other neurogenic bowel disorders, and functional constipation [1–11]. During BMPs, patients are treated with tailored bowel regimens including laxative medications and antegrade or retrograde enemas and assessed with abdominal X-rays and patient-reported information to achieve improvements in constipation or incontinence. While the efficacy of BMPs has been shown, the complexity and coordination of care during the bowel management week makes it so that only specialized centers can provide them. There are large geographic gaps in access to BMPs, and thus, families in need often have to travel hundreds of miles, devote substantial

time away from home, work, and other children, in conjunction with the additional burden of cost. Once the appropriate enema, medication, or diet regimen is found, patients continue their care at home and return for follow-up to assess continued success or the need for regimen modification.

Traditionally, our center offered in-person BMPs routinely before the COVID-19 global pandemic, as a 7 day-long program with multiple clinic visits and daily X-rays obtained in the hospital. Patients would typically stay at the hospital-provided housing while they were undergoing the BMP unless they lived close to the hospital. With the arrival of the COVID-19 pandemic, the healthcare sector was forced to rely heavily on telemedicine in order to provide adequate care to patients, while complying with social distancing and stay-at-home laws mandated by each state. Both out of necessity and with evidence showing that telemedicine in healthcare and surgery improves cost-effectiveness, patient satisfaction, and overall outcomes, we began offering telemedicine BMPs to patients soon after the pandemic began [12–16].

The goal of this study was to evaluate the outcomes of our telemedicine BMP to ensure the care provided was adequate and impactful and to establish whether the telemedicine BMP was an acceptable alternative to the standard, in-person BMP that was offered prior to COVID-19. We hypothesized that patient/family satisfaction of a telemedicine BMP would be comparable to an in-person BMP and that there would be an improvement in the quality of life and functional outcomes in patients who completed a telemedicine BMP.

2. Methods

2.1. Study design and population

Following local Institutional Review Board approval, we performed a single-institution, retrospective review of patients who underwent a telemedicine BMP at our center from May to October 2020. Patients were categorized in two telemedicine BMP types: remote and hybrid. The remote BMP consisted of patients who underwent video and/or phone calls only during the bowel management week, with no in-person visits. X-rays were obtained by the families locally several times during the week and were uploaded from a disc or submitted as a screenshot of the image via e-mail or through the electronic medical record patient application (MyChart™). We also obtained the radiologist interpretation via fax from the local radiology office. The hybrid BMP consisted of patients who were seen at a single in-person clinic visit at the beginning of the BMP week, followed by video and/or phone calls the remainder of the program, similar to the remote BMP. X-rays were also obtained locally during the hybrid BMP as described above.

2.2. Measures

Demographic information was recorded for each patient. Outcomes data, including continence of stool and urine, Pediatric Quality of Life Inventory (PedsQL), and parent/patient-reported outcomes measures (PROMs) were collected for each patient at the first clinic visit prior to the program (intake), at 1 month follow up, and at 3 month follow up after the BMP. Patient urinary and stool continence was defined as the presence of ≤ 1 accident per week (“clean” to stool or “dry” to urine) [17,18]. Since potty training is variable in patients less than 4 years old, only patients 4 years or older were assessed for urinary and stool continence.

The PROMs recorded were the Baylor Continence Score (BCS) [19], Cleveland Clinic Constipation Score (CCCS) [20], and the Vancouver Symptom Score for Dysfunctional Elimination Syndrome (VSS) [21]. A 16-item parent/patient survey was created by the nursing and physician team members at our center (Appendix A).

Table 1
Cohort demographics.

	Overall Cohort	
	n	%
Total patients	67	
Age in years, mean (SD)	8.6 (3.9)	
Sex		
Males	37	55.2
Females	30	44.8
Diagnosis		
Anorectal Malformation	35	52.2
Hirschsprung's Disease	14	20.9
Functional Constipation	13	19.4
Myelomeningocele	4	6.0
Spinal Cord Injury	1	1.5
Race		
White/Caucasian	49	73.1
Asian	10	14.9
Black	5	7.5
Bi-racial/Multi-racial	3	4.5

Items included evaluation of general parental satisfaction of the program, thoughts on in-person versus telemedicine BMPs and appointments, and general comments about the week. This survey was administered to parents at the end of the BMP week and the results were collected. All data was recorded in a secure, HIPAA-compliant database.

2.3. Statistical analysis

Patient characteristics were reported using counts and frequencies (%) for categorical variables and mean with standard deviation (SD) for continuous variables. A generalized linear model accounting for repeated assessment of patient scores at intake, 1 and 3 month follow-up that predicted PedsQL and PROMs was fitted using negative binomial distribution and logit link (to fit distribution) to estimate the causal effect of BMP at 1 month and 3 month follow-up compared to baseline measurements. Similarly, logistic regression models were used to estimate percentages of continence outcomes (“clean” for stool or “dry” for urine) to estimate the percent change at 1 month and 3 month follow-up compared to their baseline. Model assumptions and residual diagnostics were then evaluated to assess model fit and to explore the presence of outliers or influential observations. Mean values from the SAS reports and P values ≤ 0.05 were considered statistically significant. The satisfaction survey contained 10 questions rated on a Likert scale (1 = very dissatisfied, 5 = very satisfied) in addition to several multiple choice questions and a free text comment; median responses (with range) and percentage of the respondents were summarized.

3. Results

3.1. Patient characteristics

Sixty-seven patients were included in the analysis, with an average age of 8.6 years (range 3–18 years, SD 3.9). Fifty-five percent (37/67) were male. The rest of the demographic information is detailed in Table 1. Most patients were white (73%), followed by Asian (15%) and black (7%). Patients had the following diagnoses: ARM (52.2%), Hirschsprung's disease (20.9%), functional constipation (19.4%), myelomeningocele (6.0%), and spinal injury (1.5%). Of the cohort, 48 (71.6%) patients underwent the remote BMP and 19 (28.4%) patients underwent the hybrid BMP.

Table 2

Changes in continence, quality of life, and parent/patient-reported outcomes measures prior to starting the BMP and at 1 month and 3 month follow-up.

	Intake	1 month	3 month	P-value Baseline vs. 1 month	P-value Baseline vs. 3 month
BCS*	28.2	17.2	12.7	< 0.01	< 0.01
CCCS [^]	9.2	7.9	9.9	0.16	0.5
VSS**	14.2	9.3	8.7	< 0.01	< 0.01
PedsQL ^{^^}	80.9	78.9	82.4	0.59	0.7
Dry (urine), %	55.3	63.6	73.8	0.42	0.09
Clean (stool), %	28.5	45.1	68.9	0.1	< 0.01

* Baylor Continence Score

[^] Cleveland Clinic Constipation Score

** Vancouver Symptom Score for Dysfunctional Elimination Syndrome

^{^^} Pediatric Quality of Life Inventory**Table 3**

Parent satisfaction rating with a telemedicine BMP.

Satisfaction Question	1 = Very Dissatisfied	2 = Somewhat Dissatisfied	3 = Neutral	4 = Somewhat Satisfied	5 = Very Satisfied	Median Rating (Range)
The courtesy and respect given by the providers	4	0	0	1	38	5 (1–5)
How well the staff responded to your child's needs	4	0	1	3	35	5 (1–5)
Efforts to keep your child comfortable and as stress-free as possible	4	0	3	1	35	5 (1–5)
The providers' ability to diagnose your child's condition	4	0	1	0	35	5 (1–5)
The providers' ability to treat your child's condition	4	0	1	2	36	5 (1–5)
The education you received about your child's condition	4	0	0	3	33	5 (1–5)
The education you received about your child's treatment	4	0	0	5	32	5 (1–5)
The expectations set for the bowel management program	4	1	0	6	32	5 (1–5)
The ability of the bowel management program to meet your expectations	4	1	0	9	29	5 (1–5)
The overall success of the bowel management program for your child	1	2	2	12	25	5 (1–5)

3.2. Functional outcomes

Changes in continence, PedsQL, and PROMs from intake to 1 month follow-up and 3 month follow-up are shown in Table 2. There was significant improvement in the BCS and VSS scores after undergoing the telemedicine BMP ($P < 0.01$ for 1 month and 3 month follow-up compared to baseline). There was not a significant change in the CCCS score after undergoing the telemedicine BMP ($P = 0.5$ at 3 month follow-up). We did not find a clinically or statistically significant change in the PedsQL score after the telemedicine BMP (maximum difference between scores 3.5, $P = 0.7$ at 3 month follow-up).

Prior to the BMP, stool continence data was available for 42 patients aged 4 or older. Of these patients, 28.6% (12/42) were continent of stool at intake. At 1 month follow-up, 45.1% (23/51) were continent of stool and, at 3 month follow-up, 68.9% (31/45) were continent of stool ($P = 0.1$ and $P < 0.01$, respectively). Prior to the BMP, urine continence data was available for 47 patients, and 55.3% (26/47) were continent of urine at intake. Urinary continence improved to 63.6% (28/44) at 1 month follow-up, with further improvement to 73.7% (28/38) at 3 month follow-up, though these differences were not statistically significant ($P = 0.42$ and $P = 0.09$, respectively).

3.3. Parental satisfaction

Sixty-nine percent (46/67) of families completed the parent/patient satisfaction survey. For the 10 questions graded on a Likert scale (see Appendix A), the median response was 5 (1 = very dissatisfied, 5 = very satisfied) for all questions (Table 3). Ninety-one percent (39/43) of parents said the telemedicine appointments were less stressful for their child compared to in-person visits and none reported that the telemedicine visits were more stress-

ful for their child. Eighty-four percent (36/43) of parents said the telemedicine appointments were less stressful for themselves and their family, with only 7.0% (3/43) parents saying the telemedicine appointments were more stressful for themselves and their family (Table 4). Eighty-four percent (36/43) of parents said the level of care received in the telemedicine appointments was equal to or better than the care they received at in-person appointments. Over 75% (33/43) of parents said they would choose a telemedicine program over an in-person program.

As part of the parent/patient satisfaction survey, parents were encouraged to provide free text comments regarding their experience with the telemedicine BMP. Positive parent comments centered around “not having to travel and stay away from home for the bowel management week,” which helped them save time and money. They “preferred being in a normal and comfortable home environment” and “felt it was easier on [their children] to implement the regimen changes and give enemas or rectal irrigations at home and not in a hotel room.” In addition, many parents stated they were “grateful to avoid public exposure during the COVID-19 pandemic.”

Critical comments centered mostly around “difficulty obtaining and submitting X-rays prior to the appointment that day,” especially for those who lived in different time zones or in rural places without nearby imaging facilities. Parents also said they missed the “hands-on, face-to-face interaction” that they would receive in-person and missed the “social connection with the medical team and other families.”

4. Discussion

The results of our study show that a telemedicine bowel management program is a feasible alternative to an in-person bowel management program in patients with fecal incontinence

Table 4
Parent rating for comparison of a telemedicine BMP to an in-person BMP.

Satisfaction Question	1 = More Stressful	3 = Equally as Stressful	5 = Less Stressful	Median Rating (Range)
Compared to in-person visits, the telemedicine appointments were... to my child	0	3	39	5 (3–5)
Compared to in-person visits, the telemedicine appointments were... to myself and my family	3	3	36	5 (1–5)

and severe constipation, with an improvement in continence, parent/patient-reported outcomes measures, and overall parent satisfaction. Both the BCS and VSS scores significantly improved after attending the telemedicine program. Urinary and bowel continence rates also improved. The telemedicine program was less stressful for patients and their families and the majority of parents said they would choose a telemedicine bowel management program over an in-person bowel management program.

Prior to the COVID-19 pandemic, telemedicine use within pediatric surgery had already begun to increase and showed established efficacy [12,15,16,22–25]. While there is no literature to our knowledge discussing the use of telemedicine for BMPs, our results show that it can be a useful alternative in the care of these patients. Continence rates improved after the telemedicine BMP, with over two-thirds of patients achieving one or less stool or urine accidents per week at 3 month follow-up. In the literature, BMP success rates are variable and are also based on varying, and often lax, definitions. Some of these definitions include “clean without soiling,” a clean underwear (no soiling or large, unexpected bowel movement) for 24 h between enemas, or an abdominal X-ray clear of stool in the descending colon and rectum and no soiling within a week of starting the BMP [1,2,9,26,27]. Reported success rates range from 84 to 97%, depending on the patient’s underlying diagnosis or type of incontinence. Two studies that share a similar, more stringent “success” criteria to ours (one or less accidents per week) have cited in-person BMP success rates of 70 to 87%, depending on the patient’s underlying pathology, type of incontinence, adherence to treatment, and time of follow-up (ranging from immediately after the BMP week to 2 years follow-up) [7,28]. Our institution has recently published our 1-year BMP outcomes for children with ARMs [29]. We found that, one year after undergoing the traditional, in-person BMP, 70.4% of patients were continent to stool (one or less accidents per week) compared to 0% of patients prior to the BMP. Given the variety of factors that affect these reported success rates, it is difficult to compare our telemedicine BMP outcomes directly to in-person BMPs; however, we achieved similar success compared to published data, including our own in-person BMP for ARM patients.

Of the 3 assessed PROMs, we noted significant improvement in 2 of them: BCS and VSS. The BCS is a 23 item survey that was developed and validated to assess social continence in children post-ARM repair [30]. In our cohort of patients who completed a telemedicine BMP (in whom over half had an ARM), we found significant improvement in the BCS at both 1 and 3 month follow-up. The VSS is a 14-item survey that has been validated in children aged 16 years and younger [31,32]. It aids in assessment of non-neurogenic urinary and stool elimination dysfunction. We also found significant improvement in the VSS at 1 month and 3 month follow-up. The CCCS is a scoring system developed to quantify the frequency and severity of constipation and incontinence and assess quality of life in adult patients [20,33]. Although there was an initial decrease in the CCCS score at 1 month follow-up, the trend was not seen at 3 month follow-up. In fact, CCCS was worse at 3 month follow-up than at the time of intake. We suspect this is

due in part to the fact that the CCCS has not been validated in children. We noticed a similar pattern with the PedsQL, which is a measurement system for health-related quality of life in pediatric patients [34]. There was not a clinically meaningful difference in PedsQL scores in our cohort, which can be identified by a change in the parent-proxy reported PedsQL score of 4.5 or more [35–37]. We suspect this is due in part to the increased burden of therapy implemented during the bowel management week.

To address the deficiencies in available PROMs for studying pediatric patients with incontinence or severe constipation, we have created and validated a survey to assess the impact and difficulties of implemented therapies during BMPs [38]. The results of the survey are being collected and will be analyzed alongside the aforementioned PROMs and PedsQL in the future, in hopes of being able to accurately capture outcomes and quality of life measures.

Parents reported high satisfaction with the telemedicine BMP. Most parents felt the telemedicine appointments was less stressful for both their children and themselves. More than 75% of parents would choose a telemedicine BMP over an in-person BMP in the future. These results show that, from a patient/parent standpoint, telemedicine BMPs are a suitable and preferred option.

An obvious benefit of a telemedicine BMP during the COVID-19 pandemic is that both providers and patients minimize the risk of social exposure or transmission of the virus. This is particularly beneficial for the complex patients undergoing BMPs, as they are more likely to have additional co-morbidities and anomalies that put them at high-risk for complications from the virus [39]. Families also do not have to spend as much time, money, and resources throughout the week compared to in-person programs. They can stay in the comfort and familiarity of their own home. Children miss less school and parents can dedicate more time to work and their other children. Another benefit of a telemedicine BMP is that the bowel regimens are tested in the child’s regular environment and routine as opposed to the artificial environment of an in-person BMP. We suspect less changes to bowel regimens would need to be made after a telemedicine BMP since they were already being implemented in concurrence with the patient’s normal schedule.

There are several shortcomings of a telemedicine BMP. Perhaps the most apparent one is that there is a lack of “face-to-face, hands-on interaction” between providers and patients. Communication may be negatively affected, and parents may leave the bowel management week with more uncertainty and less reassurance than they would if they had several in-person visits and the opportunity to ask questions and state concerns more freely. Several parents stated they wished there was “more of a sense of community during the telemedicine BMP,” as these programs were previously a “source of comfort” for patients and parents to share in their hardships and experiences with other families. For in-person appointments and programs, families often stay at the temporary housing provided by the hospital. This gives them the opportunity to interact with one another and form shared bonds. Since patients were not at the hospital for their BMP, they potentially missed out on this.

From both a patient and provider standpoint, two of the most common difficulties faced during the telemedicine BMP were coordinating appointment times across various time zones and obtaining and uploading X-rays performed locally. Often, these two issues coincided; patients with early appointments who lived in a region with a larger time difference would have difficulty getting the X-ray and uploading the image prior to the appointment time. As we progressed through multiple telemedicine bowel management weeks, our team adapted to inquiring prior to the start of the week about time zones and scheduled those appointments later in the day, so as to provide adequate time for families to obtain and upload the imaging. Obtaining X-rays was often also difficult for families who lived in rural areas or who did not have an imaging facility near them. If cloud imaging was not available, some images would be sent in as a cellphone screenshot, which often led to poorer quality images that were difficult to interpret, perhaps leading to errors in judgment.

One limitation of this study is that we used two slightly different versions of the telemedicine BMP—one that was entirely remote and the hybrid option, which included an initial in-person visit followed by remote visits. Patients were allowed to choose which program they preferred, with over 70% preferring the completely remote option. Beyond the initial in-person visit for the hybrid BMP, there were no differences in how the BMPs were conducted. We did not design this study to examine the differences between these two options but rather to determine if the concept of a telemedicine BMP is feasible and able to lead to significant improvement in outcomes with high parental satisfaction.

Other limitations of the study include the small cohort size and short follow-up period. Additional studies with more patients and a longer follow-up are needed to assess the long-term efficacy of a telemedicine BMP. In addition, most of our outcomes and quality of life data are obtained by patient/parent questionnaires or surveys, so much of our data is dependent on the number of responses received by parents. Survey fatigue can often result in incomplete or inconsistent data.

The results of our study show that a telemedicine BMP is a feasible alternative to an in-person BMP, with high rates of parental satisfactions and improvement in continence and outcomes of children with severe incontinence or constipation secondary to a variety of conditions, including anorectal malformations, Hirschsprung's disease, and functional constipation. Telemedicine BMPs are acceptable and sustainable options both during the COVID-19 pandemic, and after its resolution. Additional studies with larger cohorts are needed to assess long-term outcomes.

Declarations of Competing Interest

None

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.jpedsurg.2021.09.012](https://doi.org/10.1016/j.jpedsurg.2021.09.012).

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