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Patient driven change: Is collaborative care the future of medicine? Lessons learned from the care of children with colorectal problems

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ABSTRACT

A basic premise in the care of complex patients is that experience, increased volume of cases, and an integrated, multi-disciplinary approach yields improved outcomes. Is this true using the example of the care of children with colorectal and pelvic reconstructive needs? This review gives a brief historical context on how care for this patient group evolved, delineates the key elements to create a collaborative care model, and describes multiple advances that have been developed, based on the model, which have improved patient care and quality of life.

Level of evidence: Review.

1. Introduction

It is clear when one considers pelvic anatomy that the concerns involving the patients' colorectal, urologic, gynecologic, and GI/motility systems are intimately connected, as they relate both anatomically and physiologically. Clearly specialists in each field are needed, and ideally, they should coordinate their efforts, because what happens in one system can affect the other anatomically contiguous systems.

Such an approach parallels many non-medical fields, for which collaboration is an absolute requirement. Consider for a moment the building of a new house. How would such a project start? I doubt that the electricians showed up one day, without considering when the cement for the foundation needed to be poured. The project began most assuredly with all parties sitting in a room (physical or virtual) and developing a comprehensive plan. For the building of a house this strategy makes perfect sense. Why then do we not have a similar process in the medical care of complex patients? How often does a urologist consider doing a bladder augmentation and/or ureteral reimplantation without considering the effect of an impacted colon on the patient's bladder function?

The often-read children's book *Everyone Poops*, by Taro Gomi [1] makes it clear to the children and their caregivers reading it that the physiology of stooling is one that needs to be thought about, and is an important part of a child's early development. It should be required reading because most of the parents with newborns diagnosed with a colorectal problem that I have seen never seem to have thought that their child could have a problem with stooling; it is a physiologic function that is taken for granted. Once discussing that their child will need surgery to correct their colorectal anatomy, all parents quickly focus on whether whatever surgery is needed, will ultimately create a reconstructed anatomy that will work and will allow their child to stool without difficulty or embarrassing accidents. As surgeons we must remember what it is that the family and patient wish for us to deliver to them, and we need to strive to achieve those goals. As proud of our surgical skills as we are, it is the functional outcome that matters most.

References to pediatric colorectal problems go back many thousands of years. In fact, the Babylonian Talmud written in 200 C.E., recommends that "an infant whose anus is not visible should be rubbed with oil and stood in the sun…and where it shows transparent the area should be torn crosswise with a barley grain." [2] Surgical techniques to manage such a patient have certainly evolved since that time, but the basic principles of care remain unchanged.

A recent experience I had in clinic illustrates what we are up against but also what we can achieve in this field. A six-year-old girl who had undergone a newborn repair of an anorectal malformation came in with the complaint of soiling. She was being teased at school and was miserable. We told her that, after the bowel management week we planned for her, she would be clean and able to wear normal underwear. She gave the team that quizzical doubtful look children often give to adults. One week later after implementing a successful enema program, the child entered the clinic again, now with a big smile and said, "You guys make good promises!" It is that moment, the culmination of complex care into a desired clinical result, that makes all the effort worth it.

My path in this field began as an eager medical student when, in 1992 I signed up for an elective in pediatric surgery with Alberto Peña, one of the pioneers in the field of colorectal care. (Fig. 1). I

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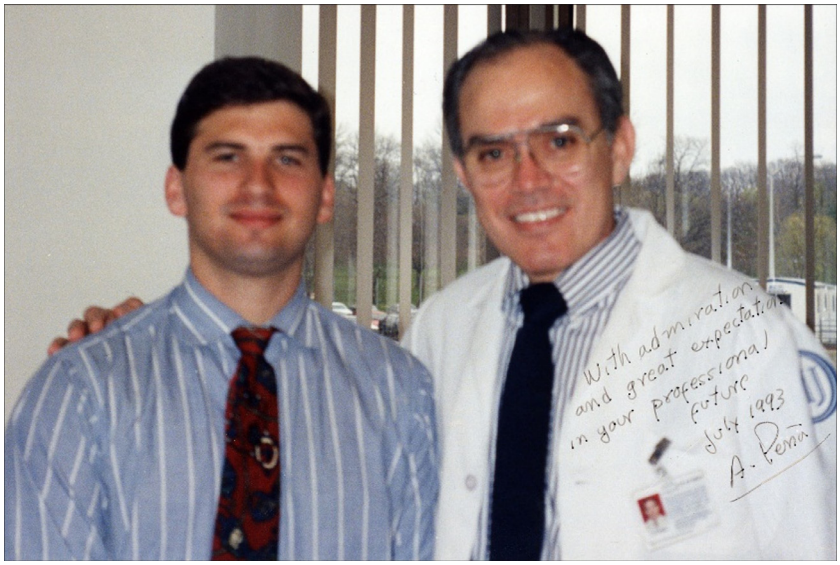

Fig. 1. Marc Levitt with Alberto Peña during his medical school elective, 1992.

had no idea that the month I was about to spend with him would be the start of a 30-year journey. That experience changed my career trajectory in a very dramatic and positive way. I observed Peña providing all aspects of care for a complex group of patients, and was in awe, and inspired. He would joke that if he answered a phone call from a patient who asked for the colorectal surgeon, or the urologist, gynecologist, psychologist, or social worker, he would reply "That's me!" As I advanced in my training, I became more and more nervous that, particularly with my lack of formal urologic training, there was no way that I alone could provide a similar comprehensive level of service. In addition, as medicine was becoming increasingly complex, and other fields such as neonatal care, transplantation, and cardiology were benefitting from a collaborative approach, I recognized that I would need help from key collaborators.

A little bit of history of this field is instructive. The modern story of the care of patients with anorectal malformations began in the 1940s in Melbourne, Australia when Frank Douglas Stephens, following his training at Great Ormond Street Hospital, London, worked on defining the anatomy of children with anorectal malformations by diligently performing autopsies on twelve patients with these conditions. His-focus on this field led to major contributions on the subject [3] Prior to his ground-breaking work, the anatomy of such patients was only a concept that existed in surgeons' minds, without anatomic precision, because no one had seen the anatomy with their own eyes. The anatomy was believed to look like the images shown in Fig. 2, in the bible of pediatric surgery in North America, the textbook by Robert Gross [4], which was, in retrospect, both oversimplified and inaccurate.

Stephens, during his autopsy dissections came to several anatomic conclusions. First, that when no anorectum had developed, the puborectalis muscle coalesced behind the urethra, and second, that posterior to that area, there was no muscular anatomy of surgical significance. The operation Stephens devised, involved identifying the urethra using a sound, then dissecting a space behind it to allow the rectosigmoid to pass anterior to the puborectalis sling. A small incision in the perineum was made for the pulled-through bowel to exit and to create the anus. The dissection in front of the puborectalis to find the distal rectum was a blind maneuver (Fig. 3). A little later, William Kiesewetter in Pittsburgh proposed his version of the sacral abdominoperineal pull-through using similar anatomic principles [5]. These ideas involving a sacral approach to the pelvis, had been promoted previously by several authors operating on adults [6].

Justin Kelly, one of Stephen's trainees in Australia learned how to do this operation, and then travelled to Boston, USA for further training. At Boston Children's Hospital in the late 1960′s, he taught what he had learned from Stephens to the surgeons there, including another trainee, Alberto Peña. In addition to his exposure to Kelly and the faculty at Boston Children's, Peña, along with other surgical residents, were greatly influenced by a master surgeon, Hardy Hendren, who they travelled across town to the Massachusetts General Hospital to watch. Hendren was the pioneer in the care of children with cloacal anomalies.

After completing his training in Boston, Peña went to Mexico City in 1972 to become the head of surgery at the National Institute of Pediatrics, at the age of 34. He tells the story that when he asked his new pediatric surgery faculty to choose an area of specialization, no one choose colorectal, so he decided to take on that group of patients, and thus embarked on his revolutionary career. Peña at first applied the technique he had learned from Kelly to repair anorectal malformations, but he became increasingly frustrated by the procedure because the maneuvers were blind, and they offered very poor exposure. Over time Peña's incision grew longer and longer. This culminated in 1980, thanks to a collaboration with Peter Devries, who had come to Mexico City to work on these cases with Peña, with the first posterior sagittal anorectoplasty (Fig. 4) [7]. Peña presented his findings at a meeting of the Pacific Association of Pediatric Surgeons in 1980.

This posterior sagittal approach opened a gift in surgery that kept on giving. It allowed for a true understanding of the pelvic anatomy and led to the care of many conditions which were previously, to use Peña's words, "too difficult to reach from above (via laparotomy) and too difficult to reach from below (perineally)." This new approach influenced the repair of cloacal malformations [8], urogenital sinus [9], pelvic tumors [10], urethral problems [11], reoperations for imperforate anus [12] and for Hirschsprung disease (HD) [13], a transpubic approach (splitting the pubis for complex genitourinary problems inaccessible any other way) [14], and a comprehensive strategy for the management of cloacal exstrophy [15]. In addition to surgical innovations, and perhaps the one which has had the most quality-of-life impact was Peña's concept to create a focused approach to the bowel management to treat fecal incontinence [16]. Because of such programs, now available

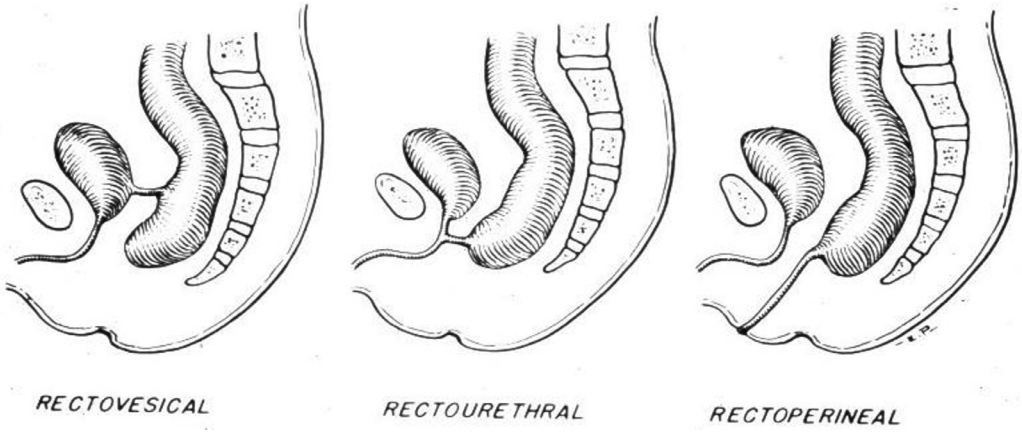

Fig. 2. Images of anorectal malformations from the Gross and Ladd textbook 1942.

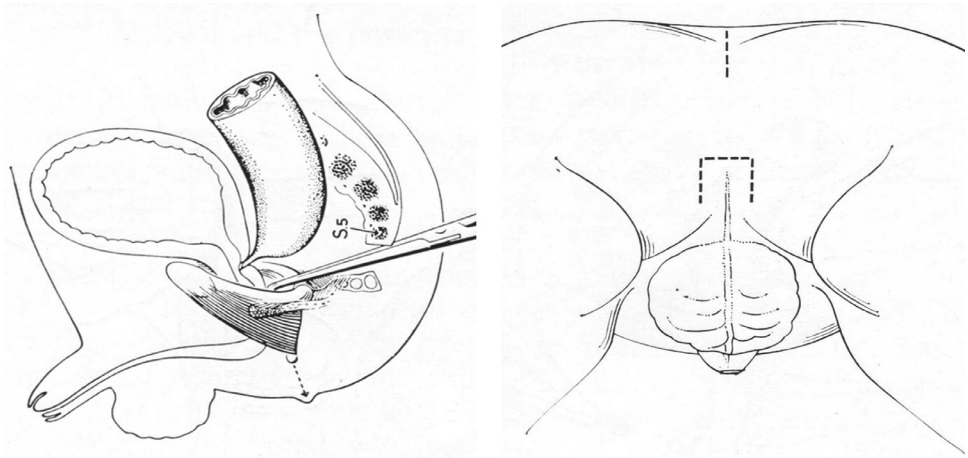

Fig. 3. Images from the Stephens sacroperineal technique, 1953.

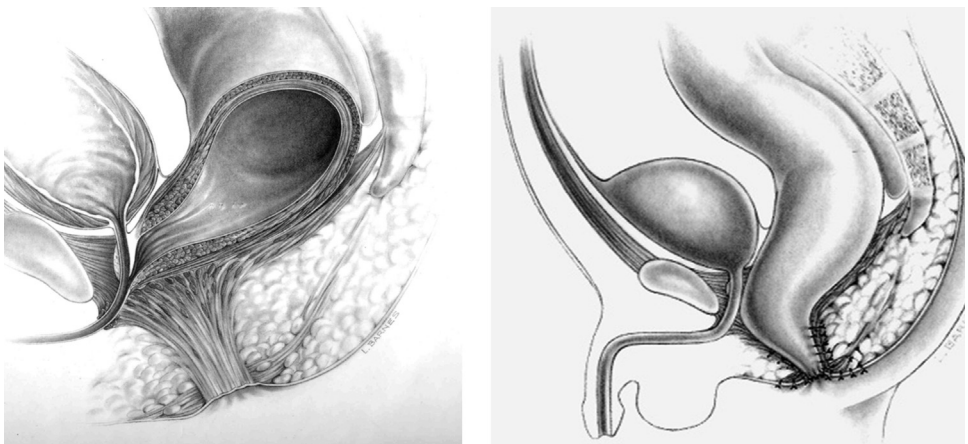

Fig. 4. Diagrams of the posterior sagittal anorectoplasty (PSARP).

at many centers across the world, thousands of children are no longer in diapers and no longer have their stomas, an impact perhaps comparable to the way intermittent catheterization has made so many patients dry for urine [17].

The medical care of children with colorectal problems is very difficult and to achieve success, patients with anorectal malformations (ARM), Hirschsprung disease, fecal incontinence (related to a variety of conditions), and colonic motility disorders, require care from a variety of specialists throughout their lives. These include providers in the fields of colorectal surgery, urology, gynecology, gastroenterology, motility, orthopedics, neurosurgery, anesthesia, pathology, radiology, psychology, social work, nutrition, and many others. Vital to their achievement of a good functional result is a patient's connection to superb nursing care. I often say that a complex colorectal operation takes about four hours to perform, but to get a good result, it takes an additional 96 hours of work – the vast majority of which involves nursing care. From the very beginning of my time in the field of pediatric colorectal surgery, the value of good nursing partners was clear to me. Their skills in identifying problems, solving them, being willing to get down

in the weeds, and always striving to fill the gaps, are unique. I am so convinced, and often shout from the rooftops, that without my nursing partners, I would have achieved very little as a surgeon.

The collaborative care model is certainly not unique. It has been shown to be successful in many areas of pediatric surgery, including bariatric surgery, ECMO, fetal surgery, transplant surgery, trauma, and vascular anomalies to name a few. Recently attempts to quantify the value of the collaborative model have been described. Some of these include the care at specified centers for patients with biliary atresia [18] and bladder exstrophy in the United Kingdom [19], that country's recent GIRFT report about specialization in pediatric surgery [20], pediatric oncology care in the Netherlands [21], an initiative through the American College of Surgeons for adults with rectal cancer [22], and the effort in the European Union to create rare disease Reference Networks [23].

Consider the time of your pediatric surgery training. During those years you may have performed on average 10 esophageal atresia repairs. You now embark on your career as a surgical attending and can expect to perform one esophageal atresia repair per year. So, in a career spanning 30 years, that is approximately 30 cases. Now imagine this scenario; 30 esophageal atresia repairs are lined up for you to perform over the next two months. You get help from many experts throughout the experience, making small changes in your technique. At that 30th case in both situations will the repair be the same? Likely the concentrated experience would lead to small improvements in technique leading to a final case that is much better. It is this level of experience for complex surgical problems that is essential to develop new ideas and to improve outcomes.

How does an institution go about creating such a multidisciplinary program? The first step is to obtain unique skills – create the team that will surround the patient to solve whatever problem needs to be solved. It is vitally important then to define hospital impact. Will the hospital benefit from new surgical cases, out-patient visits, radiology studies, etc. Will providing unique care for a complex patient population bring additional revenue to the hospital? Will such an approach enhance the hospital's reputation? Will the effort save costs by improving outcomes? The program should establish metrics to show progress, i.e. new cases attracted, downstream revenue, cost savings (by reducing emergency room visits, admissions, re-admissions, and/or reoperations), clinical outcomes, quality improvement, patient satisfaction, and staff satisfaction. The personnel needed to create the center should be defined – doctors, nurses, coordinators, etc. The marketing team needs to engage to get the word out that a new clinic has been established. This process for a colorectal center has recently been reviewed [24].

In the field of colorectal and pelvic reconstruction the multidisciplinary approach has led to numerous advances. These include new techniques and ideas that over time have made a dramatic and positive impact on the care and quality of life of children, who suffer from colorectal problems.

2. Prenatal diagnosis

Prenatal diagnosis of anorectal and cloacal malformations has been progressively improving. Perinatologists have learned to look for specific findings such as a pelvic mass, in a female, with a single kidney and think about a cloaca. Assessment of perineal anatomy, pubic bone integrity, sacral development, abnormalities of the radius bone, as well as cardiac, spinal, and renal anomalies all may clue in the clinician to considering that a fetus may have an anorectal malformation [25].

3. Newborn management

Care of the complex newborn has dramatically improved as neonatal techniques have advanced [26]. Specific to the colorectal patient have been advances in radiology – e.g. assessments of hydronephrosis, 3D reconstruction of cloacal anomalies [27], ultrasound guided distal colostography [28], as well as improved techniques in the management of hydrocolpos and stoma care.

4. Urologic anomalies

The importance of recognizing urologic anomalies cannot be overstated. With excellent urologic care chronic renal disease is diminishing, and proactive bladder management is reducing the need for bladder augmentations and renal transplantation [29,30].

5. Gynecologic concerns

Understanding the importance of a gynecologic collaboration has helped clinicians define the Mullerian anatomy and better plan for menstruation, sexual function, and future obstetric potential. [31,32]

6. Informing the conversation with families on future continence

To allay parent concerns relative to the future continence of their child, understanding associated problems with the sacrum and spine has allowed clinicians to have a more robust conversation with families, even in the newborn period, about their child's future [33].

7. Newborn surgical interventions

In patients with anorectal malformations the desire to perform a primary newborn operation must be balanced with the need to know exactly where the rectum is located. At this point the distal rectal anatomy in males, unless a perineal fistula is visible, cannot be known without a distal colostogram, which obviously needs a colostomy present to perform. In most females except for a cloaca, a primary newborn operation is possible. The decision of whether to do a newborn repair vs. a colostomy, must be guided by the surgeon's experience and the clinical circumstances in which they find themselves [34], and often a colostomy is the safest initial operation. In the case of Hirschsprung disease, to do a primary newborn repair, surgeons are dependent on good quality pathology (to avoid a poor outcome and the need for a reoperation), which is a skill not available in many parts of the world [35].

8. Defining the anatomy

Surgeons should describe the anatomy of an anorectal malformation in an understandable and protocolized way, as this will influence the operative approach chosen and the clinical outcomes expected (Fig. 5) [36].

9. Minimally invasive approaches

Laparoscopy has dramatically advanced pediatric surgery, but it is vital to understand in which cases it is best used [37]. If one draws a line from the pubic bone to the coccyx, the PC line, this anatomic guide helps decide on the operative approach – if the rectum lies below this line, it is reachable from a posterior sagittal incision and laparoscopy is not needed. If the rectum lies above this line, laparoscopy is the ideal approach (Fig. 6). If a rectum that is too low is approached from above, complications such as leaving

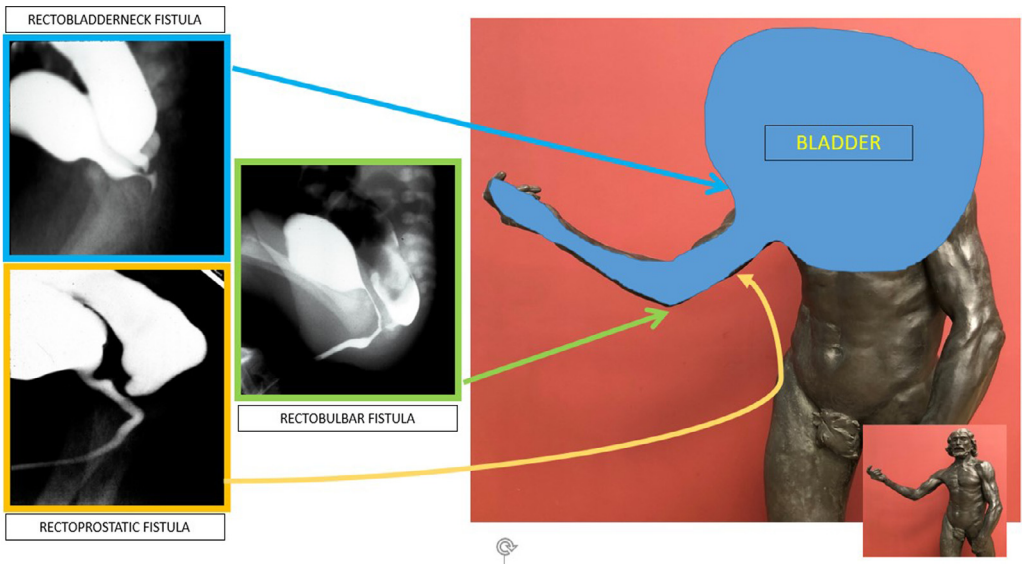

Fig. 5. Defining the anatomy for rectourethral fistulae.

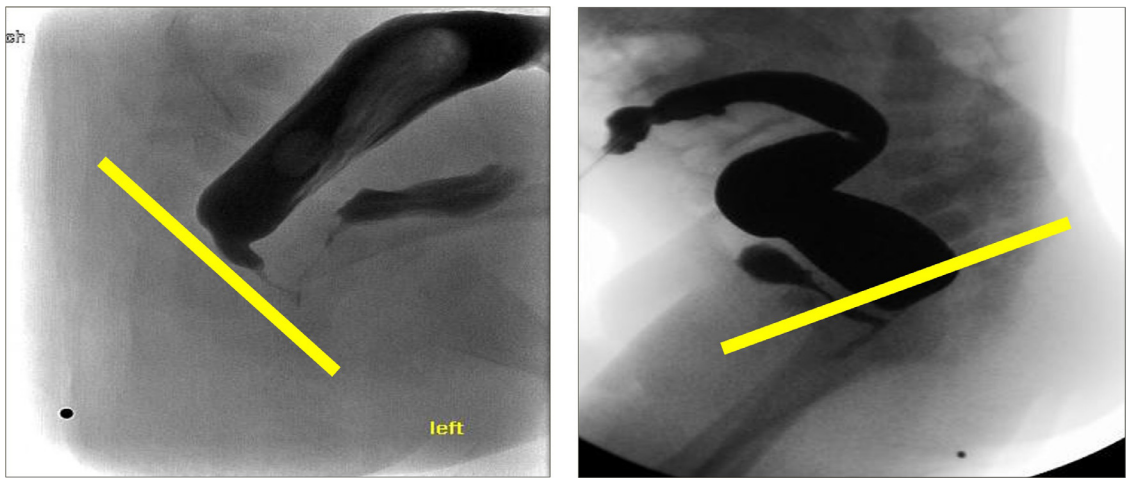

Fig. 6. The pubococcygeal (PC) line to determine if a rectum should be approached laparoscopically or via PSARP.

behind the distal rectum, a remnant of the residual fistula (ROOF) can occur [38]. In HD cases, laparoscopy can avoid an abdominal incision and also limit the stretching of the sphincters which can occur during the transanal rectal dissection [39].

10. Cloaca management

Before recent work in this field, the common channel length guided the decision on how to perform a repair of a cloacal malformation, with a total urogenital mobilization a major tool in this reconstructive effort. However, it became clear that a total urogenital mobilization done for a cloaca patient with a short urethra (less than 1.5 cm), would lead to an anatomic situation whereby the bladder neck is left at the perineum and below the urogenital diaphragm, leading to urinary leakage. Or, if a total urogenital mobilization were done for a high confluence cloaca which does not reach, then a urogenital separation is needed which can lead to urethral loss, since the anterior aspect of the common channel had already been dissected. If the surgeon defines both the common channel and the urethral length and plans accordingly – making sure the urethra remains at least 1.5 cm at the end of the cloacal repair - these complications can be avoided. A total urogenital mobilization for the appropriate case offers a reconstruction that provides an accessible urethra that is of adequate length, and if the urethra is short, a urogenital separation makes the new urethra a combination of the common channel and the native urethra – preserving an adequate length urethra and the bladder neck [40–42] (Fig. 7).

11. Complications after surgery for anorectal malformation and hirschsprung disease

The morbidity following operations for ARM are significant. To understand why this, consider the image of a sand timer. When one does a PSARP for example and completes the operation but inadvertently places the anus in the wrong place relative to the sphincters, when would the surgeon know this complication has occurred? Likely not until the anoplasty is put to the test – and the child cannot achieve bowel control. How is a surgeon supposed to modify their technique for the next operation, if they only realize their misadventure four years later?

Reoperations for anal mis-location, stricture, rectal prolapse, and a ROOF may be required. If the anatomy is restored, patients can achieve fecal continence [43] [Fig. 8]. *Re*-do surgery for HD

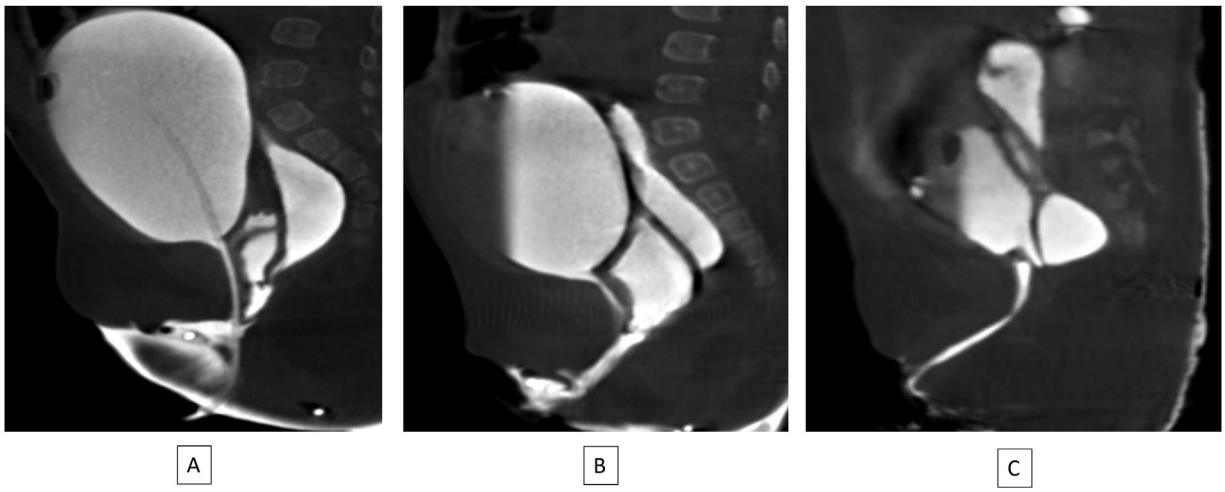

Fig. 7. If urethral Length is > 1.5 cm (A and B) a total urogenital mobilization can be done, if <1.5 cm (C), the cloacal repair will need a urogenital separation.

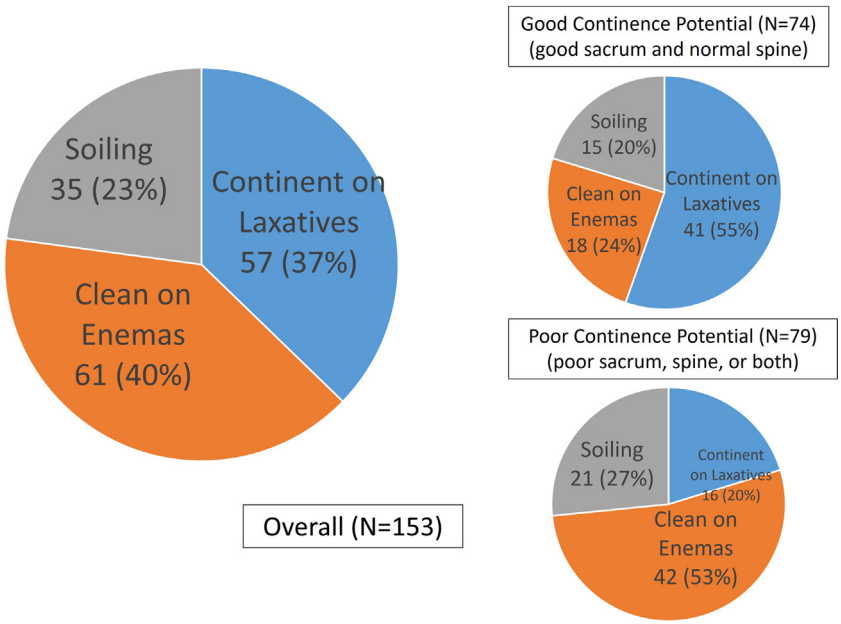

Fig. 8. Results following redo for ARM patients with anal mislocation, stricture, prolapse or remnant of the original fistula (ROOF).

re-do surgery for retained transition zone, stricture, retained cuff, dysfunctional Duhamel pouch or a twist can improve flow and resolve obstructive symptoms [44]. Of course, the main objective should always be to get the best initial operation possible and to that end, improve the training of surgeons with a focus on how to avoid key pitfalls in the surgical repairs. For patients with ARM, recent advances in the primary technique include a posterior rectal mobilization with avoidance of the anterior wall altogether for perineal fistula which avoids any periurethral or posterior vaginal dissection [45] and a modification of the traditional PSARP for rectovestibular fistula which avoids any perineal body incision, which can thus avoid the feared perineal body dehiscence [46]. For patients with HD, injury to the sphincters was previously a guarantee of fecal incontinence, but recently a technique of sphincter reconstruction is showing promise in restoring continence [47].

12. Management of constipation and fecal incontinence

Understanding what causes fecal incontinence, what amount of incontinence can be anticipated, and what are the surgical contributors to achieving continence, is vital in the management of this patient population [48]. The application of bowel management techniques has been a major advance in improving patients' quality of life which benefits from an institutional commitment particularly to providing a nursing team is a growing trend that will help many patients. Long term results, including patient reported outcomes, were recently published, are very positive but require a deep team and a labor-intensive effort [49,50].

A better understanding of motility disorders has developed because of the vital collaboration between surgery and GI/motility. The clinician must know when to use medical management with laxatives, when enemas (retrograde and antegrade) are appropriate, and the possible techniques for antegrade access. A key determinant of care is defining what "failure of medical management" means, and when to offer surgical interventions. These include botulinum toxin for internal sphincter achalasia, antegrade access for colonic flushes, and removal of dysmotile segments guided by an objective assessment of colonic function [51,52]. New data has shown that antegrade works in the vast majority of patients, and that segmental colonic resections are only rarely necessary [53].

13. Surgical collaboration between colorectal and urology

Developing a collaboration between colorectal surgery and urology is vital to plan for both systems' management in parallel. For example, an opportunity could arise to use a segment of colon for a bladder augmentation, simultaneously improving the ability to empty the colon and bladder capacity during the same operation. Similarly, the appendix can be shared and used for both the Malone ACE and Mitrofanoff procedures [54]. This proactive planning has improved the lives of many patients, has reduced the numbers of operations these patients need, as well as their hospital stays [55].

14. Sacral nerve stimulation

Sacral Nerve Stimulation (SNS) has shown great promise in the management of urinary incontinence and seems to also have a role in improving fecal continence and promoting motility as an adjunct to treatments for constipation [56].

15. Transition of care to adulthood

As with congenital heart disease and cystic fibrosis, colorectal surgeons are obligated to develop a transition plan for their patients as they enter adulthood. This entails training and recruiting adult providers to collaborate with the pediatric team [57].

16. Basic science: tissue engineering and genetics

Much work is being done in the basic science aspects of colorectal surgery. Tissue engineering is poised to revolutionize the field. The day when a cloacal reconstruction could be based on a previously tissue engineered segment of vagina, produced by the patient's own stem cells, is now on the horizon [58]. In addition, the genetics of anorectal malformations as well as Hirschsprung disease are being vigorously pursued which will impact parental counseling and potential therapies [59,60].

17. Data and working within consortiums

Common in industry but rare in medicine, keeping track of complications as well as outcomes will allow for real-time adjustment of protocols which will improve results [61]. A great example in colorectal is to track wound infections as a routine audit, and with that data observe efforts to reduce surgical site infections such as adopting a GI bundle or changing preoperative antibiotics. Such data efforts can show trends and affect outcomes [62]. An initiative to track such data across institutions, the Pediatric Colorectal and Pelvic Learning Consortium (PCPLC), www.pcplc.org [63] has yielded very positive results, and can help patients in a way not achievable by a single institution. When a positive change is realized, the new idea can be spread quickly. The PCPLC also allows nursing and advance practice providers the opportunity to collaborate and share best practices in bowel management and inpatient care.

18. Care in under-resourced areas

There is a great deficiency in advanced colorectal care throughout the world, particularly in the developing world. The care of colorectal patients in a resource limited setting has unique challenges which must be understood, and creative solutions by innovative surgeons in those areas have a led to dramatic improvements in care. Some such examples include the management of Hirschsprung patients without the help of pediatric pathology by opening a colostomy in the dilated part of the colon and then pulling through that segment which has been demonstrated *in vivo* to work for the child. Also, operative techniques to make the anoplasty in a patient with an anorectal malformation larger anticipates avoiding a significant stricture if there is a lack of follow-up [64].

The complexity of care of such patients requires an organized approach to bring order to perceived chaos. A recent writing on this idea that is particularly applicable to the care of children with anorectal malformations comes from my daughter, Jess Levitt, and it is reproduced here:

> *"A" must come before "B," which must come before "C," everybody knows that. But what if the Millercamp's of this world did not have to sit next to the Millerchip's when it comes to seating arrangements? Can Pat Zawatsky be called before Jack Aaronson when the teacher is taking attendance? Do those 26 letters that make up all the dialog, signs, thoughts, books, and titles in the English-speaking department of the world need their specific spots in line? Everyone can sing you the well-known jingle from A to Z, but not many people can tell you why the alphabet is the way it is.*
>
> *For almost as long as humans have had the English language, they have had the alphabet. The good ole ABCs. However, the alphabet represents the human need for order and stability. I believe that the same thinking that went into the construct of time and even government went into the alphabet. Justifiably, lack of order leads to chaos. Knife-throwing, gun-shooting chaos, in the case of lack of governmental order. Listen to me when I tell you that there is absolutely no reason that the alphabet is arranged the way that it is. Moreover, the alphabet is simply a product of human nature and how it leads people to establish order for things that do not require it.*
>
> *Now I know this sounds crazy, but bear with me. Only if you really peel away the layers of the alphabet will you find the true weight it carries. People organized the letters of our speech into a specific order simply because there wasn't already one. Questioning this order will enlighten you on the true meaning of it. Really dig deep into the meaning behind the social construct that is the alphabet. Short and sweet as it may be, the order of the ABCs are much less than meets the eye. There is no reason that "J" should fall before "K!" Understand this. Very important as order is, it is only a result of human nature.*
>
> *What's next? X-rays become independent of Xylophones in children's books of ABC's?*
>
> *You know what the best part is? Zero chance you even noticed that each sentence in this essay is in alphabetical order [65].*

19. Conclusions

Presenting the Journal of Pediatric Surgery Lecture at the BAPS is particularly poignant to me as it was Sir Denis Browne (who is honored with the highest award BAPS bestows) and who said, "The aim of pediatric surgery is to set a standard, not to seek a monopoly." For caregivers who commit to helping children with colorectal and pelvic problems, seeking a high standard requires a deep understanding of the daily struggle it take to deliver on the goal of improving a patient's quality of life, which benefits from a collaborative care model. I firmly believe that if a multidisciplinary approach focused on collaboration and good outcomes can be applied more broadly to other parts of pediatric surgery and beyond, the lives of many more children will be improved. Patients deserve this level of care, and will drive this change once the benefits are realized.

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