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INVITED REVIEW

Gastroenterology

# A narrative review of the ileal pouch in pediatric inflammatory bowel disease and familial adenomatous polyposis

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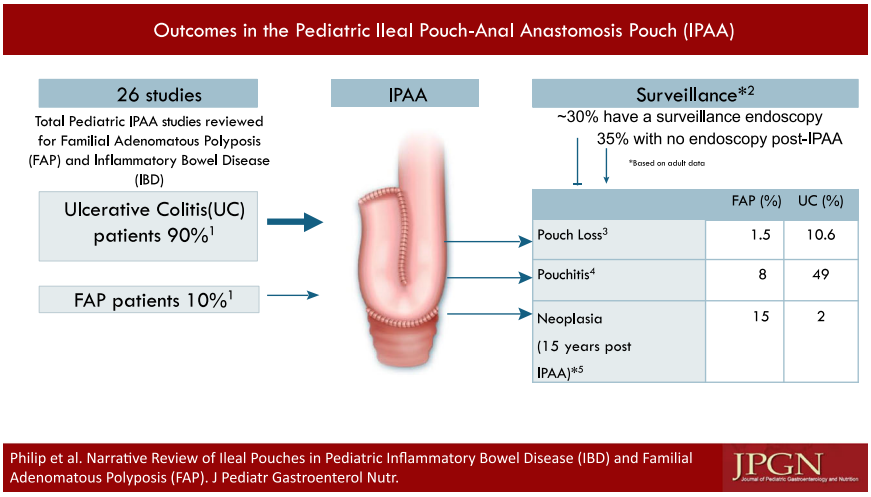
## Abstract

Ileal pouch-anal anastomosis is a surgical intervention in patients with medically refractory inflammatory bowel disease and familial adenomatous polyposis syndrome. Reported outcomes in children have been limited by both the retrospective nature and sample size of the investigations. In addition, there is a lack of consensus on surveillance guidelines in this patient population. Delay or lack of surveillance may increase the risk of complications (pouchitis, Crohn's disease-like inflammation, dysplasia, etc.). This narrative review aims to summarize the most recent literature (2013–2023) on short-term, long-term, and quality of life (QoL) outcomes in pediatric ileal pouch (J-pouch) patients. A proposed surveillance guidance is also provided.




**KEYWORDS**

colectomy, ileostomy, inflammation, outcomes

## 1 | INTRODUCTION

Total proctocolectomy with ileal pouch-anal anastomosis (IPAA) can be a life changing solution for a subset of pediatric inflammatory bowel disease (IBD) and familial adenomatous polyposis (FAP) patients. Surgery consists of total proctocolectomy (TPC) with creation of a J-pouch from the ileum that is connected to the anorectal ring, in a single or multistep fashion.[1] The procedure removes the majority of diseased portions of the bowel to improve outcomes (see Figures 1, 2 and Supporting Information S1: Figure S1).

IBD is a chronic autoimmune driven inflammation of the gastrointestinal tract manifesting as diverse phenotypes.[2] Genetic predisposition, and environmentally influenced epigenetic and microbiome changes are hypothesized to contribute to development of IBD.[2] IBD is broadly categorized into three disease processes, Crohn's disease (CD), ulcerative colitis (UC) or IBD-unclassified (IBDU). CD can affect any part of the gastrointestinal tract, and UC is largely limited to the colon. An increasing variety of immunosuppressive treatment regimens are available depending on the patient's clinical picture among other factors.[3] Beyond medical therapy, particularly for medication-refractory UC, TPC followed by IPAA is commonly performed,[4] which not only improves quality of life (QoL) but reduces the risk of colorectal cancer (CRC).[5]

FAP is the result of a mutation in the *APC* gene and is inherited in an autosomal dominant pattern, leading to colorectal polyposis with a near definite risk of transformation into CRC by the age of 40 years.[6] In patients with FAP, IPAA is performed for CRC prevention.[7] Surgical planning depends on patient age, polyp burden, and prior histology.[8]

While numerous studies and resources exist for adult patients with ileal pouch disorders, there is a paucity of pediatric literature.[9] These resources are challenged by their retrospective nature and relatively small cohort studies. We aim to review the recent pediatric literature and provide a comprehensive summary and recommendations.

### What is Known

- Long-term pouch outcomes and post-operative quality of life may be dependent on surgical expertise.
- Ileal pouch-anal anastomosis (IPAA) reduces colorectal cancer risk, particularly in familial adenomatous polyposis.

### What is New

- We highlight inconsistencies in pediatric J-pouch literature and identify knowledge gaps.
- We propose surveillance guidance for pediatric IPAA in the supplement.
- Reports on emerging surgical techniques suggest avoidance of a temporary diverting ileostomy may be well-tolerated.

## 2 | METHODS

A narrative review of the literature was performed examining peer-reviewed publications between 2013 and 2023 in OVID, PubMed, and the Cochrane library. Search criteria included “Pediatric,” “Ileal Pouch Anal Anastomosis,” “Inflammatory Bowel Disease,” “Ulcerative Colitis,” “Crohn's disease,” “Familial Adenomatous

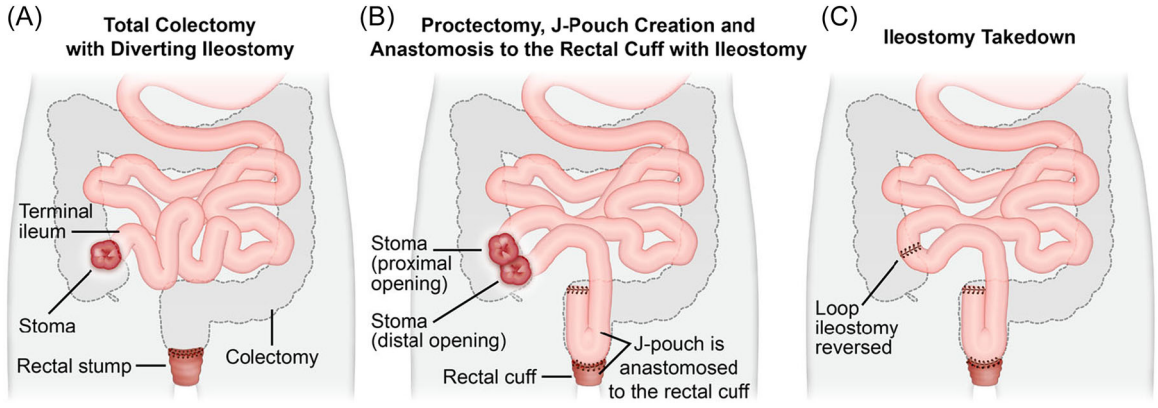



**FIGURE 1** Cartoon schematic of IPAA. Stage 1(A) consists of colectomy and diverting ileostomy. Stage 2 (B) follows with a diverting ileostomy, proctectomy and J pouch creation and anastomosis to rectal cuff. Stage 3 (C) is ileostomy takedown. IPAA, Ileal pouch-anal anastomosis.

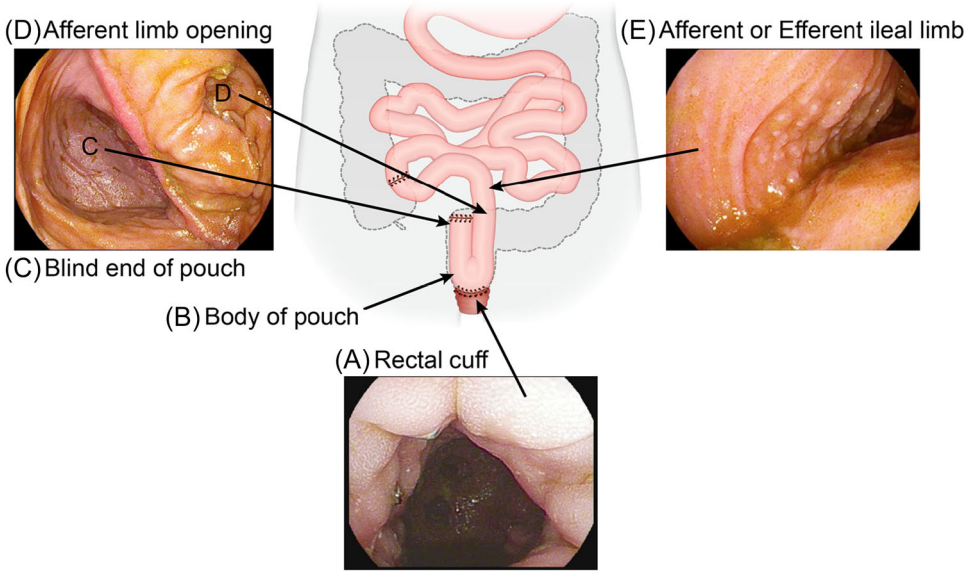



**FIGURE 2** Endoscopic images of the J-pouch in relation to J-pouch anatomy. (A) rectal cuff/anal transition zone; (B) pouch body (C) blind end (D) afferent limb opening; (E) afferent or efferent limb.

Polyposis," "ileal pouch," "J-pouch," "outcomes," and "quality of life." Inclusion criteria included IPAA in IBD (UC, Crohn's or both) and/or FAP with surgical intervention occurring in childhood. Studies that examined exclusively adult populations were excluded from the review. Most studies included patients under the age of 22 (see Supporting Information S1: Table S1). There were two studies that exceeded 22 years of age. One study compared adult and pediatric (defined as less than 19 years of age) populations and another included young adults up to 29 years of age.[10,11]

During the preparation of this study the authors used ChatGPT to decrease word count, and improve language and readability. After using this tool the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

## 3 | INDICATIONS FOR IPAA IN CHILDREN

The European Crohn's and Colitis Organization (ECCO) recommends surgical consideration for acute severe refractory colitis particularly after two different medical treatments have failed within seven days of therapy initiation.[12] Surgery depends on multiple factors including nutritional status, use of immunosuppression, and institutional clinical practice.[12] For FAP, surgical intervention may be recommended for patients given the definite risk of CRC by middle age, though this will depend on polyp burden and concern for dysplasia.[6] Typically, patients will undergo colectomy within the first two decades of life.[6]

## 4 | SURGICAL METHODS AND OUTCOMES FOR IPAA

### 4.1 | IPAA one-, two-, and three-stage procedures

There are different approaches for pouch creation which depend on factors including severity of the disease, nutritional status, and family preferences.[1] For patients with severe disease a three-stage approach is commonly performed (see Figure 1). This consists of colectomy and diverting ileostomy creation.[1] After a healing period, stage two includes proctectomy and ileal pouch creation with a diverting ileostomy, followed by takedown of the diverting ileostomy in the third stage.[1] For some patients, particularly those with severe colitis, the three-stage approach allows for healing between procedures and optimization of nutrition. In the two-stage surgery, the first stage will consist of proctocolectomy, pouch formation and ileostomy creation. The second stage is reanastomosis and ileostomy closure.[13] The one-stage procedure completes the proctocolectomy and IPAA creation in one operation without an ileostomy.[13] In select FAP cases, ileo-rectal anastomosis may be considered to preserve the rectum, though it carries an increased cancer risk.[14]

Staging for colectomy and re-anastomosis may affect long-term outcomes in patients following IPAA. Kennedy et al.[15] studied IPAA in pediatric patients with FAP and found those with a one-stage procedure had more anastomotic leaks (17.2% vs. 0%, $p = 0.002$) and reoperation (20.7% vs. 4.6%, $p = 0.02$) compared to two-stage operations.[15] However, one-stage procedures led to better

continence than two-stages procedures (incontinence 10.7% vs. 36%, $p = 0.018$, respectively).[15] In pediatric patients with UC, Dipasquale et al.[16] found an increased hazard ratio for pouchitis (2.86, $p = 0.028$) following three-stage IPAA compared to the two-stage; however, this was limited as there was no discussion of surgical expertise involved that may have affected results.

### 4.2 | Anastomotic technique: Hand-sewn versus stapled

There are two methods utilized for anastomosis: the hand-sewn approach and the stapled approach to connect the ileal pouch to the anus. The stapled pouch connects to the anal transition zone (ATZ) with single or double staples and the hand-sewn approach requires removal of the anorectal mucosa (mucosectomy) so that the IPAA can be sutured to the internal anal sphincter circumferentially.[1] Both approaches are comparable in terms of postoperative complications, QoL, and ATZ dysplasia rate. There are lower rates of cuffitis, however there is concern for higher rates of fecal incontinence, anastomotic stricture, and pouch failure in the hand-sewn group.[17,18]

### 4.3 | Open, laparoscopic, and minimally invasive methods

The procedure can be performed in an open or via a laparoscopic approach. Family preference, nutritional status, prior surgical and medical history, disease involvement, and surgeon expertise may factor in the approach. In pediatric IPAA, Linden et al. found that although laparoscopic methods took a longer time, there was significantly less small bowel obstruction (SBO) in this group.[19] Hospital stay was the same between the two groups.[19] Minimally invasive techniques (i.e., robotic approaches) are also being explored. In a small pediatric cohort robotics assisted IPAA had similar complication rates when compared to laparoscopic surgery, and lower complication rates when compared to the open procedure.[20]

Traditionally with IPAA, a diverting ileostomy is created before anastomosis of the pouch. More recently there have been investigations comparing this to diversion free IPAA. In a meta-analysis of adult literature between the two approaches, pouch failure and anastomotic strictures were less common in non-diverted patients compared to those with an ileostomy; however, they were unable to analyze by indication for the procedure.[21] They found repeat operations were more common in nondiverted patients.[21] Another group studying adult outcomes similarly found the risk of stricture and SBO also lower in the nondiverted group.[22] There were no differences in reports of anastomotic leak, fistulas, or hernias.[22] Lower cost was also associated with nondiverted patients (i.e., re-operation, procedures, readmission, etc.).[22]

## 5 | SHORT-TERM POSTOPERATIVE COMPLICATIONS OF IPAA IN CHILDREN

Short-term complications are defined as occurring within 30 days of the anastomotic surgery (see Supporting Information S1: Table S2). Ikeuchi et al.[23] found SBO and surgical site infection (SSI) were the most common (20.3% and 13.7%, respectively) in pediatric patients with UC. Another investigation found 21% of pediatric patients had early complications of which the most common was postoperative ileus.[24] A systematic review performed by Lightner et al. in pediatric UC and FAP[25] support these early complications in order: SBO 14%, SSI 10% and ileus 10%.

## 6 | LONG-TERM POSTOPERATIVE COMPLICATIONS OF IPAA IN CHILDREN

### 6.1 | Pouchitis

Long-term complications were defined as negative outcomes occurring greater than 30 days after IPAA (see Supporting Information S1: Table S2). The most common long-term complication is acute and/or chronic pouchitis in 11%–56% of cases (Supporting Information S1: Table S1). This refers to histologic inflammation within the J-pouch, which may present with clinical (increased fecal urgency, tenesmus, blood in stool, etc.) and endoscopic (edema, loss of vascularity, ulceration, friability, and granularity) features.[26] The cause of pouchitis remains unclear making prevention and treatment difficult.[27] Interestingly, pouchitis is more frequent among patients with UC or IBD as opposed to those with FAP (see Supporting Information S1: Table S1). This suggests genetics, host pathology (such as the microbiome and dysbiosis), as well as underlying immune dysregulation particularly in IBD as a possible etiologies.[28] The microbiome and dysbiosis is among the top etiologic candidate, since most cases are responsive to antibiotic therapy (i.e., antibiotic responsive pouchitis). However, some patients may benefit from immunosuppressive treatment regimens, particularly when suspected to have an immune-mediated pouchitis.[28,29] There is conflicting evidence in the use of primary prophylaxis (i.e., probiotics, antibiotics, and dietary modifications).[9]

Recognizing and treating pouchitis is important as it can lead to further complications, including J-pouch

failure.[24] Scoring systems have been developed to standardize the definition of pouchitis, including the Pouch Disease Activity Index (PDAI) and the modified PDAI (mPDAI). PDAI is an 18-point system incorporating clinical (stool frequency, bleeding, and fever), endoscopic (edema, loss of vascularity, etc.), and histologic findings (polymorphonuclear leukocyte infiltration, ulceration).[26] Alternatively, the mPDAI, which excludes the histological component, has similar sensitivity and specificity as the original PDAI (Supporting Information S1: Table S3).[30] Without delay in histologic processing, treatment for pouchitis could be initiated more rapidly. The variability in defining pouchitis by PDAI, mPDAI as well as other methodologies have likely contributed to the varied incidences of pouchitis observed in pediatric studies.

There is variability in timing of pouchitis, ranging from shortly after pouch creation to years following.[28] Nonsteroidal anti-inflammatory drugs (NSAIDs), environmental triggers (e.g., pollution, diet, illness) as well as a history of autoimmune conditions are among the predisposing factors.[28] Koike et al.[31] found that about 32% of pediatric patients developed pouchitis within 5 years of surgery based on mPDAI. Another investigation found that 45% of patients developed pouchitis with a median time of 2 years from surgery using the PDAI.[16] Cowherd et al.[32] observed 54% of pediatric patients with UC ($n = 68$) to develop pouchitis within 24 months of ileostomy closure after colectomy, however this study group utilized a previously validated electronic medical record coding system.[33] Other factors, which have been examined to modify the risk of pouchitis post-IPAA in children were age, indication, disease severity, surgical method of IPAA, and preoperative medication use (see Supporting Information S1: Table S1). Dipasquale et al.[16] ($n = 85$) found a younger age at colectomy, chronic active colitis, and a three-stage IPAA may increase pouchitis risk.

Direct comparisons between IPAA in pediatric IBD and FAP have been limited. Quinn et al.[6] found 22.1% of patients ($n = 25$) developed pouchitis after IPAA secondary to FAP. Dharmaraj et al.[27] compared UC to FAP and found that pouchitis was a complication in 56% (24/43) with UC as opposed to 12% (2/17) of those with FAP. They also found that patients with UC who had worse Pediatric Ulcerative Colitis Activity Index (PUCAI)[34] scores were more likely to develop pouchitis following colectomy.[27] Similarly Huang et al.[35] observed that patients with IPAA for FAP were less likely to experience pouchitis and J-pouch failure, but were more likely to experience SBO when compared to patients with UC. Obstruction in FAP was associated with adhesions and ileostomy torsion, whereas the majority in UC was secondary to adhesions.[35] These findings can help guide surveillance and IPAA counseling for families.

## 6.2 | CD-like inflammation (CDLI) of the pouch

Another complication for those undergoing IPAA for UC, is de novo CD or transformation of the underlying IBD from a UC like picture to CDLI. A 2019 meta-analysis proposed unifying features to better define the transformation.[36] Characteristics include (1) presence of fistula in the pouch or afferent limb (2) stricturing of the pouch body, inlet or afferent limb (3) pre-pouch ileitis (above the level of the pouch).[36] One consideration with the presence of fistula is whether this is truly a manifestation of CD verses a postoperative complication. We identified five studies reporting on this outcome with a frequency of up to 28% and a median time of 20 years post-surgery.[11] Risk factors for transformation include young age at diagnosis and at time of surgery, family history of CD, and specific serological markers (i.e., anti-*Saccharomyces cerevisiae* immunoglobulin-A).[37–39] Martinelli et al.[40] reported CDLI in 17.1% of pediatric UC patients with J-pouch in their retrospective study with a median time of 25 months. They also found that prior pouchitis was positively associated with CDLI.[40]

Importantly, CDLI has been observed more commonly in pediatric patients than adults. Barnes et al.[36] found CDLI to average 10.3% in adult patients with IPAA for UC from 12 studies. Dierden et al.[41] also found that CDLI occurred more frequently in pediatric UC patients with IPAA as opposed to adults (15% vs. 6%, $p = 0.095$) over the study period (2000–2015). Beyond age, other risk factors for transformation included initial presentation of nonbloody diarrhea ($p = 0.01$) and presurgical weight loss over 10% ($p = 0.007$).[42]

## 6.3 | J-pouch failure

J-pouch failure defined as creation of a permanent diverting ileostomy is another adverse outcome after IPAA (Supporting Information S1: Table S1). Pouchitis and CDLI have been associated with increased J-pouch failure rates.[23,43] A Japanese pediatric study noted that one-third of their patients with pouchitis experienced J-pouch failure. However, almost 92% of patients successfully retained their J-pouch for over ten years postoperatively.[23] Polites et al.[43] retrospectively examined up to 30-year outcomes in pediatric patients with UC ($n = 175$) following IPAA and 16% of patients had CDLI by 20 years. Pouch survival was 61% in those with CDLI as opposed to 92% in those who retained their UC diagnosis.[43]

It must be noted that not all diverting ileostomies are permanent diversions as some indications for diversion, such as obstruction and fistula, may be a temporary measure. For patients desiring to have intestinal continuity,

pouch removal with redo pouches have been offered in some scenarios as an alternative approach with comparable outcomes to those of adults; however, this procedure may be limited by remaining small bowel length and the expertise of the surgeon should be considered as this operation may technically be more difficult.[44]

## 7 | FERTILITY CONCERNS IN WOMEN POST-IPAA

Of the pediatric studies examined in this review (see Supporting Information S1: Table S1), only one discussed fertility outcomes.[11] Approximately half of the females in their cohort considered themselves to have had a difficult pregnancy (though this category was undefined) and more than half had difficulty conceiving.[11] An adult meta-analysis and systematic review studying the impact of IPAA on female fertility revealed the relative risk of infertility was 3.91 when comparing post- and pre-IPAA.[45] Gorgun et al.[46] investigated the impact of laparoscopic versus open-abdomen approaches to IPAA on adult fertility outcomes. While the conception rates were comparable between the two groups (61% vs. 65%), the time to conception was significantly shorter in the laparoscopic group ($p = 0.01$).[46]

## 8 | QoL AFTER IPAA

Studies on QoL in pediatric IPAA are limited (see Supporting Information S1: Table S4). Zmora et al.[47] assessed 26 patients with UC who underwent IPAA before age 18, using the short form-36 questionnaire for adults (≥18 years) and the child health questionnaire for children (<18 years). They found QoL comparable to the general population in adults but lower in children. Uchida et al.[48] reported postsurgical QoL measures similar to healthy children, noting that neither incontinence nor pouchitis episodes impacted QoL scores. Dipasquale et al.[16] observed significant improvements in all domains of life post-IPAA using the health-related quality of life questionnaire.

## 9 | FOLLOW-UP AND SCREENING APPROACHES

Standardized care for pediatric patients with IPAA has not been established. Patients with dysplasia or colorectal cancer at the time of IPAA surgery, J-pouches exhibiting type C mucosa, and patients with primary sclerosing cholangitis are recognized to be high risk for malignancy.[49–51] Type C mucosa can be described as severe atrophy and inflammation of the tissue, which can become dysplastic.[52] A metanalysis of pouch cancers in adult patients found a pooled incidence in UC to be 0.3% and in FAP to be 1%.[53]

Current adult guidelines differ in managing patients with IPAA without risk factors (see Table 1).[49] Despite these adult guidelines, there remains significant variation in J-pouch surveillance as shown by Samaan et al.[54] in their retrospective study ($n = 272$). They found 35% of adult patients did not have a pouchoscopy in the follow-up period (median follow-up period of 10.5 years), including 12% of those categorized as high risk, and only 30% had endoscopy with surveillance documented as the primary indication.[54] This poses a dilemma for pediatric patients, since Olen et al.[5] highlighted that children diagnosed with IBD have a higher cumulative lifetime risk for colorectal cancer (CRC) than those patients who are diagnosed as adults.

In FAP patients, the recommendation for surveillance screening following IPAA is pouchoscopy every 1–2 years.[8] However, only 25% of FAP patients with ileal rectal anastomosis comply with screening.[8] The cumulative risk for an adenoma in the J-pouch is 45% within 10 years following surgery.[8]

Development of long-term surveillance guidelines in the pediatric population for IPAA care could aid in prevention and timely treatment of complications. Here, we propose a guidance based on our review (see

**TABLE 1** Recommendations for adults post-IPAA screening for the indication of UC.

| Organization | High risk—previous dysplasia, primary sclerosing cholangitis, type C mucosa, refractory pouchitis | Low risk—no risk factors |
|---|---|---|
| British Society of Gastroenterology, 2010 | Annual | Every 5 years |
| American Society of Gastrointestinal Endoscopy, 2015 | Annual | No recommendation |
| European Crohn's and Colitis Organization, 2015 | Annual | Reports insufficient evidence for routine surveillance |

*Note*: Adult societal recommendations for endoscopic surveillance for UC.

Abbreviations: IPAA, ileal pouch-anal anastomosis; UC, ulcerative colitis.

supplement section Proposed Endoscopic Surveillance Recommendations).

## 10 | PREOPERATIVE COUNSELING FOR IPAA

A multidisciplinary approach involving pediatric surgeons and gastroenterologists is essential when discussing IPAA with families. Additional support from ancillary staff, such as dietitians (for malnutrition), psychologists, or social workers (for psychosocial or school-related concerns), should be included as needed.

The indication for surgery will determine the context of the discussion. In IBD patients, particularly those with acute severe colitis refractory to treatment, early surgical consultation may facilitate informed decision-making and coping. For FAP patients, the timing of surgery is often guided by patient and family preference unless endoscopic findings warrant urgent colectomy. Discussions should cover expected outcomes (see Supporting Information S1: Table S1), quality-of-life impacts (see "QoL after IPAA"), and the risk of pouch failure or need for a diverting ileostomy.

The procedure's staging should be discussed with the family, considering factors that influence the decision. For FAP patients, QoL may be adversely affected, as surgery is often prophylactic.

Clear explanations of terminology (e.g., pouch, ostomy, stoma, colectomy, and anastomosis) are critical and should be age-appropriate for the patient and comprehensible for the family. Postoperative care, including ostomy management, pouch surveillance (see "follow-up and screening approaches"), routine office visits, and eventual transition to adult care, should also be discussed (see Supporting Information S1: Table S5).

## 11 | CONCLUSION

Outcomes following pediatric IPAA demonstrates that patients generally fare well after the procedure. Short- and long-term outcomes, as well as complication rates, differ from those observed in adults. Factors that influence outcomes include the underlying indication (UC vs. FAP), surgical techniques, and disease severity at the time of surgery. These variables may help predict J-pouch failure and the need for ileostomy diversion.

We conclude that IPAA is not a cure for either FAP or UC but serves as a surgical intervention to improve QoL and long-term outcomes. Individual phenotype for IBD patients and surgical techniques significantly influence postoperative outcomes. Personalized medical management and counseling for pediatric patients with FAP and UC is essential for optimal outcomes.

Due to the retrospective design and small cohort sizes of most pediatric IPAA studies, definitive evidence on factors affecting pediatric outcomes remains lacking. Future studies should standardize pre- and perioperative care, postoperative surveillance, and the diagnosis of pouchitis to improve the quality and consistency of evidence.

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During the preparation of this study the author(s) used ChatGPT to decrease word count, and improve language and readability. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the publication. This manuscript has not been submitted for publication elsewhere.

### CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest. Anitta Philip, Allyson Wyatt, and Richard Kellermayer are grateful for philanthropic support from the Wagner and Klaasmeyer family that led to the Gutsy Kids fund. Lisa McMahon is an educational consultant for atricure and a consultant for Zimmer biomet, nonpertinent to IBD.

### DATA AVAILABILITY STATEMENT

Data sharing and availability is not applicable to this article as no new data were created or analyzed in this narrative review.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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