IBD: Life with a Pouch or Stoma: Lessons learned in 30 years

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Janus is the Roman god of gates and doors (*ianua*), beginnings and endings, and hence represented with a double-faced head, each looking in opposite directions.
Overview

• Crohn’s patients: Fortunately, stomas are uncommon for Crohn’s patients
  – Historical perspective/ lessons learned
    • Resection to ‘negative margins’
    • ‘Short gut’ patients
    • Total parenteral nutrition (TPN)
  – Famous people with stomas
  – Support resources

• Ulcerative colitis: Lessons learned with J-pouches
  – Historical perspective/ lessons learned
    • Technical aspects impacting outcomes/ quality of life issues
  – Indications
  – Patient selection
  – Evolution of operative strategy
  – Outcomes and coping tips
Famous people with stomas

- President Dwight Eisenhower
- Vice-President Hubert Humphrey
- Speaker of the House ‘Tip’ O’Neill
- Queen Mother Elizabeth of Great Britain
- Moshe Dayan, form Defense Minister of Israel
- Rolf Bernisschke, ex-kicker for San Diego Chargers
- Al Geiberger, senior PGA golfer
- Shannen Doherty, actress
- Anastacia, songwriter, singer, dancer
Surgical therapy

• 57% of patients in a population-based cohort required at least one resection

• National Cooperative Crohn’s Disease Study found 78% required surgery by 20 years from symptom onset
  – Mekhajian HS et al. *Gastroenterol* 1979, 77:907-913

Major shift last 30+ years has been bowel preservation- recognition that surgery does not cure Crohns’ Dx
Ileocolic resection with end-to-end reconstruction
Crohn’s disease & stomas

• Fortunately, stomas are uncommon for CD
• Historical perspective/ lessons learned
  – Resection to ‘negative margins’
  – ‘Short gut’ patients
  – Total parenteral nutrition (TPN)
    • Stanley Dudrick & Jonathan Rhoades/ U Penn
    • 12 Beagle puppies: puppy chow v. TPN
• Current strategies: Bowel preservation
  – Limited resections
  – Stricturoplasty
Inflammatory Bowel Disease

Ulcerative colitis - surgery with curative intent
25-40% of UC patients require surgery
Acute fulminant ulcerative colitis
Indications for surgery: *Disease Activity &/or Cancer Risk*

**Disease activity:**
- Acute, refractory flare
- Non-acute / chronic indications for surgery - Intractability
  - Acute or chronic

**Cancer risk:**
- Dysplasia or malignancy
  - Cancer risk management
Surgical alternatives:

1. ‘Open’ or Laparoscopic total abdominal colectomy, proctectomy, and Brooke permanent ileostomy

2. ‘Open’ or Laparoscopic total abdominal colectomy and ileorectal anastomosis
   Leaves at risk rectum- survey Q6 months

3. *‘Open’ or Laparoscopic Proctocolectomy and Ileal Pouch-Anal Anastomosis (IPAA)*

* = Restorative proctectomy, typically performed in 2-3 stages, with temporary protective diverting ileostomy above the ‘J’ or ‘S’ pouch
Proctocolectomy with Brooke ileostomy
Ileo-anal J-pouch anastomosis

- J-pouch
- IPAA
Patient selection factors

- Age
- Fertility/ fecundity

What about the ‘other’ IBD patients?
- Indeterminate IBD
- Crohn’s disease- can we do a pouch?
Age

• Most UC patients are young
  – should be offered proctocolectomy and IPAA
• UC bimodal age distribution
  – older patients are also referred for surgery
• Long-term results are available with IPAA, but little data focused on IPAA in the elderly
• Mayo Clinic surveyed 1386 IPAA patients
  – Median age at operation 32 years (range 5-65 years); only 16% > 45 years, none > 65 years
  – Functional outcomes
    • Nocturnal stool frequency, daytime and nocturnal incontinence, and need for constipating medications
    • Worse in patients > 45 years
Age – counter point

- 28 of 227 patients were > 50 years at IPAA
- Of the 28, 10 between 60-70 years, 5 from 70-80
- No significant differences between age groups for major complications (i.e., pelvic sepsis, pouch-related fistula, and anastomotic leakage)
- Pouch-anal stenosis more common in the elderly
- Functional outcomes - no different among groups
- Advanced age is not an absolute contraindication to IPAA
- Data suggest that healthy older patients with good sphincter tone have functional results comparable to younger patients
Fertility & Fecundity

• Most patients with CUC are childbearing age
• Impact of surgery on fertility is important
• Patients s/p restorative proctocolectomy, end ileostomy, or a Koch pouch can expect a normal pregnancy & delivery; type of delivery (vaginal or cesarean section) depends on obstetric issues; no long term pouch dysfunction reported (short term issues seen)
• No contraindication to vaginal delivery, though women with a scarred, stiff perineum might best avoid vaginal delivery
Indeterminate IBD diagnosis

- **Guideline**: Creation of an ileo-anal pouch requires certainty that the IBD diagnosis excludes Crohn’s disease
  - Majority opinion considers Crohn’s a contraindication to IPAA
    - High risk of pouch complications and failure
    - As high as 10-20% of UC patients may fall into the indeterminate group
  - Subset of Crohn’s ‘Colitis only’?
    - Small early experience
Complications with restorative proctectomy (total proctocolectomy with IPAA, open or laparoscopic)

• Technically demanding procedure
  – Historic perspective: 1980s mean of 7 operations

• Two, even three operations required
  – Total abdominal colectomy
  – Creation of ileo-anal pouch anal anastomosis, diverting ileostomy
    • Majority opinion practices diversion…
  – Ileostomy reversal
Small bowel obstruction

• Most common short & long-term complication after IPAA: Small bowel obstruction (SBO)
• Short-term: 1310 open IPAA patient at Mayo Clinic
  – Incidence of perioperative SBO 15%; 24% required early re-operation
• Long-term incidence of SBO relatively high
  – Review of the literature on late SBO after IPAA
  – 18% at 1 year; 27% at 5 years, and 31% at 10 years; majority responded to conservative management
  – Rate of operative treatment increased from 2.7% at 1 year; 7.5% at 10 years
  – Most common operative findings: pelvic adhesions (32%); adhesions to the ileostomy closure site (20%)
Pouch leak

- Pouch leakage and associated pelvic sepsis are potentially devastating
- Incidence ranges 5% to 14%
  - Compare to 4-6% for colorectal anastomosis
- Mayo Clinic study: Sepsis occurred in 74 (6%) of 1310 patients, 73 with pelvic sepsis
- Majority (63%) required operative intervention; remainder treated with either antibiotics, or a combination of antibiotics and CT-guided drainage
- In this series and others, rate of pouch leaks & pelvic sepsis declines with experience
Study of 42 of 114 (37%) patients who required reoperation for pouch complications had symptomatic anastomotic strictures.

No correlation between stricture formation and type of anastomosis (hand-sewn v. double stapled techniques).

Many anastomotic strictures can be treated with intermittent dilatation; can even be performed by patient after initial dilatation.
Fistulas

- Fistulas after IPAA are challenging
- Incidence of pouch-vaginal fistulas ranges from 4% to 12%
- Pouch-vaginal fistulas & more rare, pouch-perineal fistulas can occur either perioperatively or years later
- Early pouch fistula results from technical error, or a pouch leak with pelvic abscess
- Late pouch fistula raises the possibility of Crohn’s disease
- Most fistulas are low and originate at the anastomosis; occur equally with handsewn v. double-stapled anastomoses
Pouchitis

- Late complication of IPAA
- Incidence of pouchitis is difficult due to variations in presentation & diagnostic criteria variance; most series report ranges from 12% to 50%
- Acute inflammatory process
- Minority/ < 10% become chronic
- Chronic pouchitis may lead to pouch failure requiring pouch removal- fortunately, rare
- More common with extra-intestinal UC disease
- Suspect pouchitis: abdominal cramps, increased stool, watery or bloody diarrhea, & flu-like symptoms
- Often treated empirically; accurate diagnosis requires pouchoscopy with histologic evaluation
Quality of life lessons with J-pouches

• Preop counseling: 6-8 semi formed bowel movements, pretty good continence & night soiling

• Typical patient:
  – Young
  – Active lifestyle
Ileo-anal J-pouch anastomosis

- Preop counseling: 6-8 semi formed bowel movements, pretty good continence & night soiling. *What?*
- Shifts away from Mucosal proctectomy & shift to higher level for IPAA- ~3 cm
- Better function
- Risks- too high
Life with a new J-pouch

• Your body will need some time to adjust to having a J-pouch
• Information and recommendations that can help
  – Medications
    • Imodium/ Lomotil
    • Fiber
    • Steroids
  – Diet
Diet recommendations

- Incorporate new foods into your diet one at a time to see how they affect your output. Some foods may give you trouble initially, but may be ok later.
- Do not skip meals - tends to make stools more irritating and loose.
- Balancing starches with foods that tend to give diarrhea is helpful.
- Fluids important to prevent dehydration.
Diet tips

• Once your colon has been removed, you need more salt until your body adjusts. Pretzels/corn chips are good snacks.
• Hot and spicy foods will probably burn on the way out and should be avoided if your anal area feels irritated.
• Seeds and nuts can be irritating.
Diet tips

• Within 3-9 months after surgery, your body will have started to adjust to your J-pouch. At this point, try to eat all types of foods and see how they affect you.

• A dietitian, resources on the Internet, and/ or your local library are available for more information.

• Vitamins? OK- but chewable or liquid forms are better absorbed.
Frequency of bowel movements

- 30% have nine to 12 stools a day
- Older patients — those over 55 — have more stools than younger patients
- <8% percent of patients have less than four stools a day
- About 9% have over 13 stools a day
Night time stool

• \(~63\%\) — get up once or twice per night to pass stool, and about 24 percent of patients awaken three times or more during the night to have a bowel movement.

• This can be related to eating late, overeating or eating foods known to cause problems.
Tips to decrease number of stools at night:

• Don't eat late. Wait at least three to four hours after your last meal before going to bed.
• Take an anti-diarrheal medication before going to bed.
• Eat binding foods at dinner and avoid those foods that tend to cause diarrhea.
• Don't overeat at dinner.
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  – Evolution of operative strategy/ Laparoscopy, Shift north
  – Outcomes and coping tips
Summary

• Patient support groups & educational materials, as supplied by the Crohn's and Colitis Foundation of America (www.ccfa.org), improve overall patient management & satisfaction

• Jpouch.org

• Jpouch.com

• others.