Ulcerative colitis is common in the United States, affecting a half million of Americans, according to data from Crohn’s and Colitis Foundation of America. Approximately 25 to 33 percent of patients eventually undergo colectomy (surgical resection of colon and rectum) and bowel reconstruction (creation of ileal pouch). Total proctocolectomy with ileal pouch-anal anastomosis (IPAA) is the surgical treatment of choice for patients with medically refractory ulcerative colitis, ulcerative colitis with dysplasia or cancer, and patients with familial adenomatous polyposis. Diarrhea, abdominal pain, urgency, and pelvic discomfort are common after the surgery. Pouchitis with those symptoms is the most common long-term complication.

However, these most frequently reported symptoms in patients with IPAA are not specific for pouchitis. Our recent study showed that symptom assessment alone is not sufficient for the diagnosis of pouchitis, and that pouch endoscopy and biopsy may be required for diagnosis. Based on symptom, endoscopy and histology assessment using the Pouchitis Disease Activity Index criteria (the most commonly used and validated diagnostic instrument for pouchitis), we examined 61 consecutive symptomatic patients with ulcerative colitis and IPAA, and found that 43 percent of patients with symptoms suggestive of pouchitis had no endoscopic or histologic evidence of pouchitis or cuffitis (inflammation of rectal cuff or anal transition zone). In addition, there was no evidence of celiac disease, cytomegalovirus infection, or Crohn’s disease in these patients. These patients have a condition resembling irritable bowel syndrome, which our clinical investigators at The Cleveland Clinic termed irritable pouch syndrome (IPS).

IPS is common in patients with IPAA, and this new disease category has become increasingly recognized. Patients with IPS comprise a substantial portion of outpatient clinic visits in the IBD clinic in tertiary care centers. Clinical features of pouchitis, cuffitis and IPS overlap, with the most common symptoms being increased stool frequency, abdominal cramps and pelvic discomfort. The only way to differentiate the three disease entities is by pouch endoscopy. Patients with IPS also share clinical features of IBS, such as abdominal pain, bloating, urgency and pelvic discomfort, which are largely relieved with defecation. Similar to irritable bowel syndrome, weight loss, bloody bowel movement and fever are not features of IPS.

IPS is common in patients with IPAA, and this new disease category has become increasingly recognized.

In a recent study, we found patients with IPS, similar to those with pouchitis or cuffitis, had significantly poorer quality-of-life scores than patients with normal pouches. Appropriate diagnosis and treatment are important for improving a patient’s quality of life.

Currently, the diagnosis of IPS is based on the exclusion of structural and inflammatory conditions (such as pouchitis, cuffitis, pouch stricture or leak, and Crohn’s disease) using pouch endoscopy. If a patient has symptoms of abdominal or perianal pain, diarrhea, or pelvic discomfort while having a normal pouch endoscopy, he or she is diagnosed as having IPS.

There are no published controlled drug trials for the treatment of patients with IPS. At The Cleveland Clinic, we have adopted some safe and effective drug regimens in patients with irritable bowel syndrome to treat patients with IPS. The first-line therapy includes low-dose antidepressants and antispasmodic agents. We believe that safer and more effective agents will become available once we learn more about the cause and mechanism of this new disease.

Frequency
The most common structural cause and mechanism of IPS are unknown and are currently under investigation. There has been no study to directly address the issue of IPS. We hypothesize that abnormal pouch sensitivity to pain and pressure
My name is KJ, and I’m 42 years old, having lived with a J-pouch for 12 years now! I’ve always been an active person, involved in sports early on, and then following college, I became a writer in the advertising field, as well as a musician. (Nearly 1 1/2 years ago, I finally decided to live my life’s dream and become a full-time and incredibly busy musician.) Prior to being diagnosed with ulcerative colitis in the early 80s, I was told by doctors that my symptoms were flu-like related.

Well the “nothing illness” began to take its toll and because of it, life continued to go haywire as I continued to bleed and lose energy. But then my regional physician in Williamsport, PA, took me on as a patient, and recommended The Cleveland Clinic and Dr. Victor Fazio. I was given a full day of tests in Cleveland and told the next day would be J-pouch surgery. Back then, occasionally they could perform a one-step surgery where no temporary exterior pouch would be necessary - or would carry through with the two- or three-step method as they are currently performing. I was lucky to be able to sample the one-step method. And although I had some tough roads in front of me in battling lots of pouchitis early on and some stomach discomfort, it was still much better than the days prior to surgery when I would sneak off from my office work to lie on the bathroom floor in agony (but rarely missing a day’s work) or sleep each night on the bathroom floor after making nearly 10 trips a night there already.

Although I must admit that from time to time I still battle pouchitis, I’ve experimented and have found a solution that seems best for my body. On “bad bouts,” I ban myself from all solid food intake of any kind for two days, drink plenty of water and “flush” my system without the use of any drugs. I also do my best to continue to stay away from, or at least decrease my consumption of, too many salads in a row, meats, soda, chocolate or corn products. This works for my body, but you should consult your physician.

As you can see by my Web site at www.kjsmile.com, I love my post-pouch life and continue to live it to its fullest.

Although as a singer/songwriter, I haven’t written a song about the pouch yet(!) I do consider a humorous one from time to time and who knows – you might hear it on the radio down the road. Humor’s so therapeutic!

Thanks to The Cleveland Clinic and the true believers in positive attitude, today, much of what I do involves positive life/self-esteem assemblies for young people. I’m able to show people firsthand what a positive attitude and what choosing to overcome life’s challenges can do. Life’s our gift, so seize the day!

KJ Reimensnyder-Wagner

I’m able to show people firsthand what a positive attitude and what choosing to overcome life’s challenges can do. Life’s our gift, so seize the day!
David G. Jagelman Inherited Colorectal Cancer Registries
Lisa LaGuardia, RN, BSN

The David G. Jagelman Inherited Colorectal Cancer Registries at The Cleveland Clinic was established in 1979. The registries follow families with hereditary colorectal cancer syndromes, which include familial adenomatous polyposis (FAP), juvenile polyposis, Peutz-Jeghers, and hereditary non-polyposis colorectal cancer (HNPCC). The main role of the registries is to prevent death from colorectal cancer, to promote knowledge of the risks and implications of a family history of colon cancer, to provide care to patients and their families, and to conduct important research.

To participate in the registries at The Cleveland Clinic, you will meet with a coordinator who will develop your family tree by taking a family history. It is very important to collect accurate information, since this information will be used to determine the risk factors and surveillance recommendations for all of the family. You will then be given a packet of information, including a consent for participation. The consent form includes information regarding the registries like confidentiality issues, and risks and benefits for participating.

Participation is voluntary and costs nothing. The coordinator will review the consent form and answer any questions you may have. Once a patient has read and signed the consent for participation, his/her family will be given a registry number and will be entered into our registries.

Once registered, patients will receive a newsletter twice a year providing valuable information about the different inherited colon cancer condition, new research and educational events like Colon Cancer Awareness Month in March.

About FAP
The David G. Jagelman Inherited Colon Cancer Registries is the largest single institutional registries in the United States and second largest in the world. We most commonly see patients with familial adenomatous polyposis (FAP) and are currently following more than 515 families and more than 3,000 patients with FAP. FAP is an inherited condition that most often affects the large intestine but can also affect the stomach and small intestine. Patients who are diagnosed with FAP usually have developed hundreds to thousands of polyps throughout the large intestine at a young age. If these polyps are left untreated, they can become cancerous at a very young age. It is recommended that a person at risk of having inherited this condition be examined at the age of 10 to 12 years old. If a person has polyps in the rectum then a colonoscopy should be done to check the entire colon. Once a diagnosis has been made and the severity of the condition has been determined, the type of surgical treatments will be recommended by your doctor.

The three most common surgical treatments are: total colectomy and ileorectal anastomosis (IRA), a colectomy with ileonal pouch (pelvic pouch), or proctocolectomy and ileostomy. Patients who have an IRA will need to have their rectum checked for polyps at least once a year. Patients who have a pelvic pouch will also need to have their pouches checked once a year. It is important to have these exams in order to prevent polyps from developing in the rectum or pouch. All patients at risk of developing this condition should also have a test called esophagastroduodenoscopy (EGD). An EGD should be done around the age of 20 and then every one to three years depending on the results. Sometimes patients may need additional tests such as a CAT scan or MRI of the abdomen. We urge patients and family members to comply with the follow-up tests that are recommended by your physician in order to prevent rectal cancer and any other problems.

continued on page 4

Reader’s Tips
I had UC for eight years before my surgery. I had my J-pouch surgery in August 1997 while trying to adopt a little baby from Russia. My surgery was pretty uneventful except for the fact that I had a wound that would not heal for more than 13 months. I had to have about six different procedures on my wound and home health care for about nine months. We went to Russia in December 1997 to adopt our little baby girl. I went with my wound and my bag. We adopted Marissa Natalia Smith on 12/22. She is an answer to a prayer we had so longed for and the best Christmas present we ever received. I had my take-down and more surgeries on my wound in March 1998. I have been very fortunate. I believe there is life after UC. I am living proof of what this surgery can do and I am so grateful to Tracy Hull, M.D., for her hard work and the sacrifices she has made in order to save lives like mine. Thank you Dr. Hull and CCF.

P.S. – Marissa was 6 years old on June 28 and finished her 1st year of school. What a blessing.

Kelly Lyn Smith
Tiffin, Ohio
Irritable pouch syndrome  
continued from page 1

(visceral hypersensitivity) and proximal small bowel bacterial overgrowth may play an important role in the development of IPS. Our recent pilot study showed that, compared to patients with normal pouch, patients with IPS had more sensitive perception to gas, pain and urge to defecate.

We are currently conducting a study using barostat (balloon test) to study the mechanism of IPS. The study proposal has been approved by the Institutional Review Board at The Cleveland Clinic. We plan to recruit 10 patients with normal pouch (i.e., no symptoms and with normal pouch endoscopy) to serve as controls in the study. The study protocol includes filling out clinical questionnaires and undergoing pouch endoscopy and barostat (balloon test). Each study session will need approximately 3 to 3.5 hours. If you are interested in participating in the study, call Dr. Bo Shen at 216/444-9252 or e-mail shenb@ccf.org. Selection criteria are:

• Age greater than 18 years old
• History of ulcerative colitis
• Currently no pouch symptoms (i.e., diarrhea, abdominal cramps/pain, pelvic discomfort, perianal pain or bloody bowel movement)
• No recent episodes of pouchitis within four weeks

There will be no charge for pouch endoscopy, barostat (balloon test) and parking. You will be compensated $200 for your time.

References


Reader’s Tips

When I came home after J-pouch surgery, I had a lot of perianal irritation while my body adjusted. What helped me was to apply zinc oxide (my case Desitin) and then a layer of aquaphor ointment on the zinc oxide.

Annette Ayerss  
Springhill, Tennessee