Inflammatory Bowel Disease – Ulcerative Colitis

Patient and family information, brought to you by the Education Committee of APSA

Overview - "What is it?"

Ulcerative colitis is a disease which causes severe inflammation of the colon (see Figure 1). This results in severe pain, fevers, cramps, weight loss, and diarrhea which is often bloody. Ulcerative colitis (UC) is thought to be due to the body's immune system over-reacting against the intestine. This results in bleeding and damage to the cells of the colon. The colon becomes less effective in its function of absorbing water and salt.

Ulcerative colitis can also be associated with a special kind of liver failure called PSC (primary sclerosing cholangitis). Patients with this condition experience jaundice (yellowing the skin) and sometimes require liver transplant.

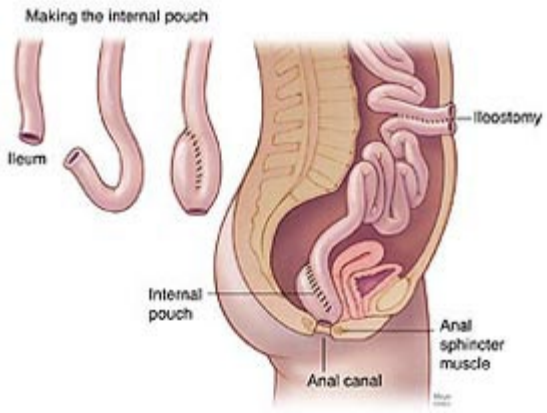

Figure 1: Ulcerative Colitis
(Image credit: Coran: Pediatric Surgery, Seventh Edition, 2012, Elsevier Saunders.)

Ulcerative colitis affects girls and boys equally and is most commonly diagnosed in adulthood (age 30s). However, UC can be diagnosed at any age and occurs in about 2-4 out of every 100,000 people. In children, the inflammation is more likely to affect the entire colon.

Signs and Symptoms - "What symptoms will my child have?"

Early signs: Ulcerative colitis usually presents with diarrhea—frequent loose bowel movements that may have blood, mucus and/or pus. The child may have of a constant feeling of needing to move his or her bowels and cramping. Many children have loss of appetite and energy, partly because of a low blood count because of bleeding in the stool. Some children have severe disease when they first come to treatment with fevers, severe abdominal pain and bloody diarrhea. These children have "fulminant colitis" and need more urgent medical, and sometimes surgical, treatment.

Later signs/symptoms: Many children experience a loss of appetite over time with associated weight loss and decreased energy levels. They may also have trouble sleeping due to frequent bowel movements at night. Additional symptoms that some children experience include delay in bone development and puberty, joint pain, kidney stones, eye irritation and skin lesions.

Diagnosis - "What tests are done to find out what my child has?"

Labs and tests: The diagnosis of UC is usually suspected based on a combination of history and physical exam findings. It is important for your doctor to try to distinguish between inflammatory bowel disease (Crohn disease and ulcerative colitis) and an infection such as food poisoning. Blood tests should be done to check blood count, electrolytes and nutritional markers.

Abdominal X-rays: can see the pattern of gas within the intestines.

Computed tomography (CT) scan: may be obtained, depending on the symptoms of the child.

Colonoscopy: In this procedure, a flexible lighted telescope is introduced in the anal opening. The doctor is able to see the inner lining of the colon and take pieces (biopsy) of tissue that can be looked at under the microscope. This is how diagnosis is established.

Conditions that mimic this condition: Crohn disease, indeterminate colitis, infectious colitis (Clostridium difficile, Salmonella, Shigella, E.coli and Campylobacter)

Treatment - "What will be done to make my child better?"

Medicine: The goal of therapy is to improve symptoms and prevent flare-ups in the future.

- *Steroids*: most common first line of therapy used to reduce inflammation. Most children treated with steroids will go into remission, however if steroids are taken for a prolonged period of time there can be significant side effects. If the ulcerative colitis is mostly affecting the rectum and last part of the colon, steroid enemas can be used with much fewer side effects.

- *Non-steroidal medications:* effective in treating mild to moderate symptoms and include sulfasalazine, 5-aminosaliciliates (5-ASA) and mesalamine can be used to achieve remission.
- *Azathioprine*: can be used once remission has been achieved to prevent long-term steroid use
- Infliximab, an antibody against TNF-alpha, has been used in children in both the short and long term to try to reduce the need for steroids.

Regardless of the medications that are chosen, it is very important to continue to take them to prevent symptom recurrence.

Surgery: The only "cure" for ulcerative colitis is complete removal of the colon and rectum. This is usually done if medical therapy fails to control symptoms, or if the side effects of medical treatment are too severe.

The goal of the surgery is to remove the diseased colon (colectomy) and connect the small intestine with the anus (ileoanal anastomosis). This allows control of bowel movements in the future, however, this connection to heal an ileostomy is formed temporarily. This brings the intestine to the skin and the child will poop into a bag. This is reversed with another surgery after healing has occurred. There are two approaches to this operation:

- *Open laparotomy:* The intestine is removed through an incision on the abdominal wall. The incision is usually vertical, in the middle.
- *Laparoscopy:* In laparoscopic surgery for UC, several small cuts (incisions) are made. Through one of the cuts, a video camera is placed. The surgery itself is done using small instruments placed through the other incisions. One incision is made a little longer to get out the intestine.

Preoperative preparation: Any child with recurrent and severe symptoms should be considered for surgery. Sometimes surgery will need to be performed urgently if there is significant bleeding or severe abdominal distension and fevers to save the child's life. However, usually the surgery can be planned and scheduled. Before surgery, the family will meet with the surgeon and often an enterostomal (ostomy) therapist to discuss the best location for a stoma and to answer any questions. If the child is anemic or malnourished this may need to be corrected before surgery with a blood transfusion or additional nutritional support. Sometimes the child will need to have a "bowel prep" before surgery where a hyperosmolar solution is given to clean out the colon.

Postoperative care: Most children will stay in the hospital for about a week after surgery. Diet will be slowly reintroduced, and if the child is on steroids they will be tapered over a few weeks. The family will be taught how to care for the ileostomy. Usually, a second surgery is planned in 2-3 months to close the ileostomy.

Risks/Benefits

Immediate risks: There is always a small risk of injury to the bowel, bladder or other internal organ during the surgery, although this is uncommon. If a small bowel pouch is created there is a risk of leak but having a temporary ileostomy is thought to minimize this risk.

Long-term risks: One of the most common problems after creation of a small bowel pouch is inflammation of the pouch or "pouchitis". This can present with crampy abdominal pain, fever, increased bowel movements and fatigue. This can usually be treated with antibiotics. Occasionally children who have problems after surgery with pouchitis or difficulty gaining weight will be found to have Crohn's disease or "indeterminate colitis" instead of UC. This may require that the child remain on some anti-inflammatory medications to reduce these symptoms. Other potential problems include a bowel obstruction or stricture that may require dilations or further surgery.

One of the major benefits of surgery is that this can cure ulcerative colitis. This is especially important for children who have frequent symptoms and problems with weight gain and growth.

Home Care - "What do I need to do once my child goes home?"

Diet: There is no specific diet required, however some patients find that avoiding spicy or acidic foods and chocolate helps decrease the number of bowel movements after surgery. Many children have a hard time gaining weight initially after having their colon removed and therefore need a high-calorie diet with a balance of protein, carbohydrates, and fat.

Since the colon's main function is to reabsorb water, it is important for the child to replace losses in the stool. Using sports drinks that have salt and other minerals is a good drink to keep on hand to avoid dehdydration. This is particularly important while the ileostomy is in place.

Activity: Returning to regular activities as soon as possible is encouraged and depending on the type of surgery and the child, this generally ranges from 2-4 weeks.

Wound care: In general, there is minimal wound care required after surgery. The incisions need to be kept dry for 48 hours. If the child has an ileostomy, there will be education on how to care for the stoma prior to discharge from the hospital.

Medicines: Most medications that were used prior to surgery will no longer be needed afterwards, but steroids will need to be slowly tapered over several weeks. Most children will be started on medications to reduce the number of bowel movements (either fiber supplements or Imodium®).

What to call the doctor for: You should seek medical assistance if the child is having persistent fevers, increasing abdominal pain or vomiting, or seems dehydrated (not urinating very often, increased bowel movements, seems very thirsty). It is important to know that DEHYDRATION is the most common reason for readmission in these children.

Follow-up care: A follow-up visit with the surgeon will be arranged, usually within 2-4 weeks of discharge from the hospital. Follow-up will also be arranged with the gastroenterologist to discuss long-term management and recurrence prevention.

Long Term Outcomes - "Are there future conditions to worry about?"

Children who undergo surgery for ulcerative colitis for the most part have improved quality of life. However, most patients will have loose and more frequent stools after surgery (5-7 stools at best). Some will have urgency and a degree of incontinence (particularly at night). To get a better outcome, children often need a food diary to regulate their stooling pattern. Children will need to be screened every few years with sigmoidoscopy to ensure that the small amount of rectum that remains does not develop any evidence of cancer.

There is some evidence that young women may have trouble getting pregnant after this surgery although this is very controversial. The laparoscopic approach seems to be superior than the open approach when it comes to minimizing this complication.

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