

ADVANCES IN IBD

Current Developments in the Treatment of Inflammatory Bowel Diseases

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Transferring IBD Patients From Pediatric to Adult Care

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G&H What is the prevalence of inflammatory bowel disease among pediatric patients and how early in life has it been known to manifest?

GF It is estimated that 10% of patients with inflammatory bowel disease (IBD) are under the age of 18 years. The disease, in the form of either Crohn's disease (CD) or ulcerative colitis (UC), can be seen as early as the first month of life. In infants, it is seen more frequently; however, the peak years of pediatric onset are those of early adolescence, at which time CD is more common.

G&H Are there particular challenges in examining infants and establishing a diagnosis of IBD?

GF The diagnosis of IBD in infants is not necessarily difficult if there is chronic diarrhea and bleeding, but if there are other presentations, such as diarrhea with no blood, chronic anal fissure, or poor growth, then the diagnosis is definitely challenging. Blood tests, endoscopy, pathologic findings on biopsy, and radiographs are all used to make the diagnosis, just as in older children and adults. Fortunately there are specially designed small scopes that allow us to examine infants by colonoscopy.

In the first few months of life there is also a common condition of allergic colitis, most often caused by hypersensitivity to cow's milk protein, that manifests as bloody stools. This condition needs to be differentiated from UC. If a patient first presents with poor growth and diarrhea, IBD can also be mistaken for celiac disease.

G&H How can IBD affect the physical development of younger patients?

GF Growth is a major issue for pediatric IBD patients. Problems with growth stem from a number of factors and a slow down in growth is more common in CD than UC. One cause is the inflammatory process itself, where circulating inflammatory cytokines turn off the growth process. Children can actually present with a slow down in growth, having fallen several percentiles on the growth curve, while suffering minimal intestinal complaints. Growth failure can therefore be the major presenting symptom in pediatric IBD, with insignificant gastrointestinal manifestations. Because CD can involve the small intestine, where food is absorbed, malabsorption of nutrients can also play a role in poor growth. Lack of appetite due to stomach complaints can also lead to poor nutrition and a consequent slowing of growth.

Drugs utilized in IBD therapy also affect growth. Corticosteroids in particular, if used long-term, can stop growth. All of these factors, if not controlled, can stunt growth permanently and a fair number of young patients end up shorter than they would have been based on their genetic disposition, because of the disease and its treatments.

IBD can also delay pubertal development. Most patients eventually catch up but the delay can have psychological ramifications, as can short stature and the near constant need for a bathroom in patients with acute or poorly controlled disease. These issues can impair patients' function in school and lead to depression and isolation. If medical intervention does not resolve symptoms satisfactorily, all of these problems can be carried into adulthood and have long-term effects on patients.

G&H Does the overall treatment strategy for pediatric patients differ from that used in adults with IBD?

GF We use the same drugs and biologic agents in treating children as are used in adults. A challenge faced by pediatric gastroenterologists is that dosing studies for many of these drugs are not available in children. As a result we are forced to extrapolate from adult doses and use our best judgment as to how high to raise a dose in order to obtain maximum effect without toxicity.

I think that pediatric gastroenterologists try their best to avoid steroids because the outward effects and growth problems associated with their use are so significant. At the same time, they are often the only therapy to bring about a quick disease response and, in spite of side effects, they are still used quite often.

So-called top-down therapy using biologics is often discussed in order to avoid the use of steroids. However, there are concerns about using biologic therapies as first line in pediatric patients. A child with disease onset at age 5 may have 20-plus extra years of disease compared to an adult-onset patient, and the long-term effects of biologic therapies are not known. However, there are some situations where biologic therapies as initial treatment might be appropriate. Children with extensive disease, stunted growth, and severe perianal involvement are candidates for initial biologic therapy. Although we use biologic agents frequently, most pediatric gastrointestinal doctors are concerned about the longer exposures our patients are going to have compared to adults and we are more cautious about starting biologic therapies.

G&H How do you judge when to transfer a pediatric patient to the care of an adult gastroenterologist?

GF The real issue regarding transfer of care is that of transitioning pediatric patients to independence. The ability to understand their disease, take care of themselves independently, find the appropriate doctors wherever they go, and respond to their symptoms without the help of a parent are key to the transition.

This process of education and taking responsibility needs to start very early. There is currently an emphasis throughout the United States on developing programs to facilitate this transition. Our professional society, the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) has published tentative suggestions for transitioning pediatric patients.

When children enter early adolescence, they typically want to achieve some level of independence. We try to

take advantage of this and start educating them at this point, so that by the time they are somewhere from 17 to 21, and are potentially going to transfer to an adult doctor, they have gained knowledge about their bodies and their disease. I think it is a process that requires several years. In this way we position kids early on by telling them to start learning the names and doses of their medications and taking their medications alone, without a parent's supervision. As they get a little older, we start asking them to make their own appointments for office visits. When patients reach mid-adolescence, we like to see them by themselves and let them tell us about their disease. The parents remain involved but we like to have a one-on-one with kids so that they are used to the standard patient-physician dynamic when they go over to the adult side of medicine.

We like to get adolescent patients interested in where they can find out about their disease in terms of online resources. It's important to evaluate whether they can talk about it with friends. How do they deal with their disease? Do they isolate themselves? Are they open enough to allow the support of their families? How are these strategies going to work as they go on to college and adulthood? How is the disease affecting the development of their sexuality and how are they coping with this part of life?

Beyond matters of psychosocial development, other practical issues play a role in the transition. If patients do not live close to a large city, they are probably not going to find a pediatric gastroenterologist and will either never see one or will transition earlier, simply to facilitate the receipt of care. We also teach pediatric patients about issues surrounding insurance. When patients get out of school and are off their parents' insurance, they need to understand that their pre-existing condition will be an issue. IBD is not a disease where patients can switch from job to job and be assured of continuous coverage and they need to make choices accordingly.

Pediatric patients with additional handicaps, such as cerebral palsy or other congenital defects, along with IBD, often require extended pediatric care because their physical and/or mental development is arrested and it is difficult for adult physicians to take on the care of a child who cannot function and is totally dependent on family.

G&H From the physician's perspective, what information needs to be prepared for the patient to transfer over to their new doctor?

GF Patients need to have actual copies of endoscopic records with pictures as well as the accompanying pathology reports. They need actual radiograph reports that show sites of disease. They should have a written history

of their surgeries, their medications, and their complications, which can be provided several different ways. A summary that encapsulates onset of disease, current state of progression, and complications that have occurred is the best way to provide this information because newly referred doctors do not want to look through hundreds of pages of material to sort things out.

We like patients to make appointments with new doctors then come back to see us at least once, to be sure that the new doctor has all the needed information and that the patient is really compatible. Because pediatricians tend to do more hand-holding, it can be a shock for young people when they get into an adult gastroenterologist's office. The worst-case scenario is that patients go to their new doctor once, do not establish a rapport, and, instead of returning to their pediatrician, they do not see anyone or get any care until they get sick, at which point they often have disease complications and problems.

Suggested Reading/Online Resources

North American Society for Pediatric Gastroenterology, Hepatology and Nutrition: www.naspgan.org.

Children's Digestive Health and Nutrition Foundation: www.cdhnf.org

Kids IBD: <http://www.kidsibd.org/asp/public/ContentPage.aspx?pName=PatientsResources&cpType=en&menu=none>

Crohn's and Colitis Foundation of America: <http://www.cfa.org/kidsteens>

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