ADVANCES IN IBD

Current Developments in the Treatment of Inflammatory Bowel Disease

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Quality Measures for Pediatric IBD Patients

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G&H How common is inflammatory bowel disease among children?

RC It is thought that there are approximately 65,000 children in the United States with Crohn's disease or ulcerative colitis. Like adults, children can have abdominal pain, diarrhea, bloody stools, and weight loss.

Many pediatric patients with inflammatory bowel disease (IBD), particularly Crohn's disease, have growth impairment. For this reason, we try to diagnose the patient as early as possible and treat the disease in a way that avoids or corrects growth impairment.

G&H What kind of growth impairment can result from pediatric Crohn's disease?

RC Children may fail to grow in height at a normal rate. Unless this impairment is corrected, they will not reach their full adult height potential.

G&H Why does Crohn's disease affect growth?

RC Growth is influenced by many factors. Children with Crohn's disease may have malabsorption of nutrients. The disease can also produce anorexia due to a lack of appetite. Vomiting can also be a problem, although this symptom is not very common.

There is evidence that the inflammatory process releases cytokines that inhibit appetite and increase the metabolic rate. This combination results in poor weight gain and interferes with the normal hormonal processes that lead to growth.

G&H Do children develop IBD mainly because of genetics?

RC As in adults, a minority of pediatric patients have a family history. Genetic variants have been identified in children and adults. However, more commonly, the cause of pediatric IBD is similar to that of adult IBD. Genetics, an altered immune system, and environmental triggers interact in a way that leads to this gastrointestinal disease.

A subset of patients present with disease that appears to be IBD and is characterized by abnormal interleukins or other inflammatory mediators. These patients are typically diagnosed within the first several years of life.

G&H When should IBD be suspected in a pediatric patient, rather than a more common condition?

RC When patients develop abdominal pain, diarrhea, bloody stools, anemia, and an elevated sedimentation rate, with any symptom lasting more than a week or two, then an infection is unlikely to be the cause. In patients with these symptoms, a clinician would have a high suspicion for IBD. Alternatively, if a patient presents with a fistula, particularly a perianal fistula, or other perianal disease, then IBD should be suspected.

Sometimes, patients present with subtle and intermittent abdominal pain that continues for quite a while. Mild weight loss may not be noticed for some time. Some patients have a below-average growth rate but do not appear to have any gastrointestinal symptoms until a careful medical history is obtained—and even then, such

symptoms may be missed. Thus, the disease can present in a hidden way, and there may be a lag time between the onset of symptoms and the time of diagnosis.

G&H How can the quality of care be measured for pediatric IBD patients?

RC Quality measures should address both the best care and the best outcomes. The level of care being provided is assessed using process measures, which, as the name implies, measure the processes of care being provided. These measures would examine, for example, the following questions: Is the patient receiving the correct dose of medication? Is blood testing being performed to monitor the patient appropriately? Is the patient being evaluated often enough, considering the severity of the disease? When the patient has an appointment with his or her clinician, are the right measures being taken? Is the severity of the disease being assessed at each visit? Is the extent and phenotype of the disease being assessed? Is the nutritional status being assessed? Is the growth rate being measured?

Most pediatric gastroenterologists would agree that these process measures are part of appropriate and necessary care. One of the most important process measures is noting at each encounter whether a pediatric IBD patient has active or inactive disease. After assessing disease status, the clinician would note whether the patient has a corticosteroid-free remission; in other words, not only is the disease inactive, but the patient also does not require prednisone to achieve or maintain remission or inactive disease. If the patient has inactive disease lasting 12 months or longer, then that inactivity would be considered sustained.

Pediatric IBD clinicians should also keep track of the percentage of patients who are not being treated with prednisone. Prednisone impairs growth and has side effects in pediatric patients, just as it does in adult patients.

G&H Should prednisone be avoided then, even though it is indicated for the treatment of pediatric IBD?

RC Prednisone is commonly used in the treatment of IBD, usually as a short-term drug. It is very effective in inducing relief of some symptoms and can improve physical function. Often, prednisone is prescribed to induce inactive disease.

However, the long-term side effects of prednisone are significant. In adults and children, these side effects can include high blood pressure, diabetes, changes in mood and psychological status, osteoporosis, cataracts, and other issues. Therefore, avoidance of prednisone is important for pediatric gastroenterologists caring for children with Crohn's disease or ulcerative colitis.

G&H How can a patient's nutritional status be defined?

RC There are a number of ways to define nutritional status. Typically, having good nutritional status means having a normal weight for one's height and age. It is also important to monitor the status of micronutrients such as vitamin D, vitamin B12, and folate. With pediatric IBD patients, it is also important to make sure that their weight is normal, especially since normal weight is necessary to achieve normal linear growth.

G&H What are the greatest challenges in ensuring that pediatric IBD patients receive the best quality care?

RC In my estimation, the biggest challenge is creating a system for clinicians to work in that allows for monitoring the measures discussed earlier. Ideally, every pediatric gastroenterologist caring for children with Crohn's disease or ulcerative colitis should have a systematic way of collecting and documenting all of the necessary data so that these measures can be followed from every visit. Such a system would enable the physician to know how any particular patient is doing. The physician would also be able to assess the entire patient population at the practice and answer questions such as the following: What percentage of patients have inactive disease or are in remission? What percentage of patients are not taking prednisone? What percentage have sustained remission?

If a pediatric gastroenterologist can see the status of all patients at once, then he or she can more easily assess how well each patient is being treated and how well the care being provided is working. Having the capacity to systematically and routinely collect the data needed to track process and outcome measures on a regular basis is very important.

The measures themselves are fairly straightforward and noncontroversial. Just by monitoring these measures, a clinician can determine how well he or she is doing in providing the necessary care to patients and, most importantly, identify which patients are not doing well so that they will be given the care they need.

G&H What is ImproveCareNow?

RC ImproveCareNow is a growing network of more than 70 care centers, encompassing more than 20,000 children with IBD and 600 physicians. I am the Executive Network Director of this organization.

Currently, approximately 40% of all children cared for by pediatric gastroenterologists are treated at centers that belong to ImproveCareNow. Being part of this net-

work provides pediatric gastroenterologists with a way to collect the data discussed earlier and to pool that data into a collective registry.

G&H How does ImproveCareNow assist pediatric gastroenterologists once the data are provided?

RC Through its registry, ImproveCareNow can inform each practice about how the overall practice or individual clinicians are doing—where each is for every measure. Clinicians can find out information, such as what percentages of patients at their practice have active disease or are in remission; are or are not taking prednisone; have normal growth; are receiving the recommended doses of medication; are being seen frequently enough; and are being assessed properly at the time of their visits. The data can also be used to provide a checklist of information to prepare the clinician prior to a visit with any particular patient. With this checklist, the clinician has quick access to all of the information needed to determine what should be done at a given visit.

ImproveCareNow also provides a report that enables population management. Even when patients are not at the clinic, the clinician can still easily and systematically review how they are doing. The pediatric gastroenterologist can quickly identify which patients are not receiving the recommended doses of treatment, which patients have not been seen in the past 6 months, and so on. Then, rather than waiting for the patient to have a relapse, the clinician can use the data and quality measures to reach out to the patient and adjust the medication dose or schedule an appointment.

Dr Colletti has no relevant conflicts of interest to disclose.

Suggested Reading

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