AMA

What doctors wish patients knew about inflammatory bowel disease

JAN 6, 2023

Sara Berg, MS
Senior News Writer

Copyright 1995 - 2021 American Medical Association. All rights reserved.

Listen **to this article.**

AMA NEWS WIRE™

Copyright 1995 - 2021 American Medical Association. All rights reserved.

AMA News Wire

What doctors wish patients knew about inflammatory bowel disease

Jan 6, 2023

- Listen on Simplecast

Some people are faced with having to rearrange their lives around the symptoms of painful abdominal cramping, persistent diarrhea and rectal bleeding. But that doesn't have to be the case. These uncomfortable symptoms may indicate inflammatory bowel disease (IBD). Receiving a proper diagnosis of IBD and understanding how to find relief will be key to getting back to enjoying daily activities without the threat of disruptive chronic inflammation.

IBD is an umbrella term that is used to describe disorders that cause chronic inflammation of the gastrointestinal (GI) tract, according to the Crohn's and Colitis Foundation. The two most common forms of IBD are Crohn's disease and ulcerative colitis with about 3.1 million adults in the U.S. diagnosed with one form of the disease.

The AMA's What Doctors Wish Patients Knew™ series provides physicians with a platform to share what they want patients to understand about today's health care headlines.

For this installment, two gastroenterologists took time to discuss what patients need to know about inflammatory bowel disease. They are:

- Claudia Gruss, MD, a clinical educator with the Yale-affiliated gastroenterology fellowship program at Norwalk Hospital and an American Gastroenterological Association delegate in the AMA House of Delegates.
- Sarah Streett, MD, a clinical professor of gastroenterology and hepatology, and director of IBD Education at Stanford Medicine.

It's not irritable bowel syndrome

IBD and irritable bowel syndrome (IBS) are "confused a lot because their abbreviations are so similar," said Dr. Streett, noting that "irritable bowel syndrome is much more common."

Copyright 1995 - 2021 American Medical Association. All rights reserved.

“In people who have irritable bowel syndrome, they have symptoms that are linked to digestive function, but they do not have objective findings such as inflammation in the GI tract,” she explained.

“Inflammatory bowel diseases are disorders where there is inappropriate inflammation in different segments of the GI tract,” Dr. Streett said. “It is diagnosed by doing a colonoscopy to look for and biopsy areas that are inflamed.”

“Some of the symptoms overlap, but they're really completely two different diseases and syndromes,” said Dr. Gruss. Additionally, “if you have IBS, it is not a precursor of IBD.”

Symptoms of IBD vary

“The symptoms of IBD really vary and they reflect the part of the GI tract that’s most involved depending on the person’s disease,” said Dr. Streett. “Ulcerative colitis—which involves inflammation in the colon and not the small intestine—is typically most severe in the last part of the colon called the rectum.

“And because of that, people with ulcerative colitis tend to have rectal bleeding that they can visibly see, urgency because the rectum is not holding onto stool until we can go to the bathroom and looser stools,” she added. “Crohn’s disease can have those symptoms, but they can also be absent if there isn’t inflammation in the distal colon and the inflammation is higher up.”

“Crohn’s disease is patchy, and it is often in the small intestine, both the small intestine and the colon,” Dr. Streett said. “When inflammation is in the small intestine, it can be more subtle in its symptoms and sometimes can take a longer time to be identified.”

Visit a doctor if symptoms don’t resolve

“You should see a doctor when you have gastrointestinal symptoms that do not resolve or improve after a few days,” said Dr. Gruss. “Or you have what I call the red flags such as bloody diarrhea, high fever, nausea and vomiting, especially of bile or feculent (stool-like) material or really severe abdominal pain and weight loss.

“It may indicate that you may have an inflammation of the bowel and not just a common infectious gastroenteritis,” she added.

“If you have been diagnosed with IBD, you should see a gastroenterologist who takes care of a lot of patients with IBD because it’s a field where the treatment options change rapidly,” said Dr. Streett.

Copyright 1995 - 2021 American Medical Association. All rights reserved.

Environmental triggers may be at play

“There's a lot of interest in the environment, and that's in particular because in the last 10 years or so, rates of IBD—Crohn's and ulcerative colitis—are rising in many of the countries in the east where they had been rare,” said Dr. Streett. “Something within a generation is triggering the onset of IBD.”

“Certain environmental triggers may make it more likely that one might develop inflammatory bowel disease, such as smoking in people with Crohn's disease, high-fat diets, antibiotics and nonsteroidal inflammatory medication use, which would be an ibuprofen type of medication,” Dr. Gruss said.

Genetics play a role in IBD

“It does have—to some degree—a genetic component. So, if a family member or multiple family members have been diagnosed with inflammatory bowel disease, your risk is higher,” said Dr. Streett. “In children who are diagnosed at a very young age, they have a stronger genetic determination of their IBD—a stronger genetic factor.

“But there are over 240 different gene quirks that have been linked to people being at increased risk of getting IBD, so that tells us it's a very diverse group of disorders and most people who have them don't get IBD, thankfully.”

“About 5% to 20% of people who have inflammatory bowel disease have a first-degree relative—meaning a parent, child or a sibling—with the disease as well,” Dr. Gruss said. “So, children of parents with one parent who has IBD are at greater risk than the general population, but the risk is low.

Additionally, “the risk is greater with Crohn's disease than ulcerative colitis. And if you have two parents with IBD, then the risk of you developing IBD is actually quite high,” she explained. “Unfortunately, then you're dealing with more than 50% risk.”

Age of onset is between 15 and 35

The cause of IBD is “one of the great medical mysteries,” said Dr. Streett. “We know that IBD tends to affect otherwise healthy, younger people about one-quarter to somewhere between a quarter and one-third of people get IBD when they’re under the age of 18, so as children.”

Copyright 1995 - 2021 American Medical Association. All rights reserved.

But “the peak age of onset overall is somewhere between 15 and 35 years old,” she said. “Once you’re diagnosed with IBD, we don’t know yet how to turn the process off at a fundamental level. In other words, we don’t know how to reverse the underlying process.”

Finding a diagnosis is a process

“There are things that you look for. First of all, IBD is a chronic disease. There are some acute infections that can be confused with IBD at first, so you need to rule out those infections,” said Dr. Gruss, noting that “certain medications can also cause inflammation of the colon and small bowel.”

Beyond that, “the diagnostic test for IBD is a colonoscopy,” said Dr. Streett, noting “in blood work there can be signs that there’s inflammation but these are not specific.”

Treatment is individualized

“In most cases, you’re not talking about a cure. We don’t know what causes IBD, so we don’t know how to cure it,” said Dr. Gruss. “With ulcerative colitis, there is a potential cure, but it’s obviously a big deal to have your whole colon removed which involves major surgery.”

“Most of the time we control the diseases with medication so that we don’t have to go to that route,” she said. “And just like with rheumatoid arthritis, we don’t know what causes it, but we know how to treat it ... and, in most cases, get people into remission and keep the disease under control , decreasing the chances of a complication.”

“But treatment has to be highly individualized,” Dr. Gruss added, “because different people respond to medication very differently.”

Some foods worsen IBD symptoms

“As we start to understand how important the gut microbiome is—the community of bacteria, viruses and fungus that live in our gut—we know that the microbiome or the microbial communities are important to our digestive health and in other areas of our systems,” said Dr. Streett.

“It’s highly individualized as to what foods irritate and make symptoms worse. In inflammatory bowel disease, we note that caffeine may cause anyone to run to the bathroom,” said Dr. Gruss. “And with somebody with inflammatory bowel disease, that could make symptoms worse.

Copyright 1995 - 2021 American Medical Association. All rights reserved.

“Also, there is a very common entity called lactose intolerance, which is due to deficiency as one gets older of the lactase enzyme, which is responsible for breaking down milk products in the gut,” she added. “Now, generally, IBD does not cause lactose intolerance, but if you have lactose intolerance, it can cause diarrhea and make your symptoms of IBD worse.”

Additionally, “in studies that look at people at more risk for developing IBD in the future, it is people who have eaten a more processed food-heavy diet,” said Dr. Streett, noting that “IBD doesn’t appear to be a food allergy the way celiac disease is an allergy to gluten.”

Other foods may help IBD symptoms

“Eating things that make a healthy microbiome may be helpful and that’s true for not just IBD,” said Dr. Streett. “So, eating and drinking things that are fermented—that have live bacteria in them—has been associated with having a more robust microbiome.”

“And what’s the right diet for each person varies depending on where their IBD is in their GI tract—if it’s caused narrowing or other complications,” she said. If there is a narrowing, a diet that limits raw fruits and vegetables may be recommended.

“Most of the diet work that’s been done is in Crohn’s disease because they usually have the most trouble with dietary issues. There was a study just recently published comparing the specific carbohydrate diet and the Mediterranean diet,” Dr. Gruss said. “And they found that the Mediterranean diet was not inferior to the specific carbohydrate diet, and it is a heck of a lot easier to follow and a healthy diet for everyone in the family.”

“There has also been a lot of press about eating what’s called the low FODMAP diet, which stands for fermentable oligosaccharides, disaccharides, monosaccharides and polyols,” Dr. Gruss explained. “But the problem with the low FODMAP diet is that although you’re really decreasing the high-gas fruits and vegetables that somebody would eat, it’s an incomplete diet and shouldn’t be used on a long-term basis because you won’t be getting some essential vitamins and minerals that you need.”

Surgery may be needed

“Unfortunately, historically, up to one-third of patients with ulcerative colitis and up to 70% of patients with Crohn's disease have require surgery at some point in the course of their disease,” said Dr. Gruss. “With the new medications that haven't been around that long, we're getting patients into longer remissions. “And there's some preliminary evidence suggesting that aggressive treatment with these new medications is cutting down on the need for surgery,” she added.

Copyright 1995 - 2021 American Medical Association. All rights reserved.

You’re not alone

“This is a very difficult kind of disease to have. It’s very personal,” said Dr. Streett, noting “it really impacts how you feel and what you can do.”

That is why “it’s so important to partner with a health care team that is motivated to work with you to put your IBD into remission so that you can lead the life and meet the goals that are important to you,” she said. “The resiliency of people with IBD really inspires me and I just hope to give people as much empowerment to not give up and to keep trying to get their disease into remission.”

URL: https://www.ama-assn.org/delivering-care/public-health/what-doctors-wish-patients-knew-about-inflammatory-bowel-disease
Copyright 1995 - 2021 American Medical Association. All rights reserved.