

Social media help identify medication concerns of inflammatory bowel disease patients

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Cedars-Sinai researchers analyzed thousands of social media posts to determine the biggest concerns patients with inflammatory bowel disease (IBD) have about their prescribed treatments.

The No. 1 patient concern: Risks of side effects from [biologic medications](#) even when risks are remote.

Biologics are antibodies that work by blocking certain immune system signals or immune cells in the body from causing inflammation in the intestinal tract. They can alter the course of disease, leading to reduced symptoms and fewer hospitalizations. Yet biologics can be costly, and some have risks such as serious infections, increased risk for lymphoma and joint pain.

Although there are several available IBD [treatment options](#), biologic medications are a mainstay treatment for those with moderate-to-severe forms of the disease.

"Physicians need to do a better job explaining the risks and benefits of medications," said Christopher Almario, MD, one of the investigators on the study. "When people hear 'risk of lymphoma,' that's all they focus on even though the risk is very, very low, while the chance of getting better from the medication is quite high."

Friday is World IBD Day, when patient groups across the globe hold events to raise awareness about Crohn's disease and [ulcerative colitis](#), known together as [inflammatory bowel disease](#).

Almario, along with Bibiana Martinez, MPH, Francis Dailey, MD, and Brennan Spiegel, MD, analyzed more than 15,000 posts on [social media](#) and health-related websites between June 2012 and June 2015. Their study, published in

Inflammatory Bowel Diseases, the official journal of the Crohn's and Colitis Foundation, shows patients are much more concerned with the possible side effects than they are with cost of the drugs.

The study shows:

- Fifty-four percent of posts discussed negative side effects, whether these individuals experienced the side effect or were merely fearful.
- Twenty-seven percent of posts were from patients asking for advice even though these patients had recently spoken with their physicians.
- Only 8 percent were interested in discussing the cost of their medication.

"Social media clearly is telling us that patients have difficulty navigating the pros and cons of these medications," Almario said. "We physicians need to step up and help our [patients](#) accurately assess their treatment options."

Provided by Cedars-Sinai Medical Center

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