

Facts & Fiction: Knowledge Gaps that Could Impact UC Patients' Health

A 2017 U.S. survey of 301 adults living with ulcerative colitis (UC) and 149 gastroenterologists (GIs) tested patients' knowledge of UC - and physicians' perceptions about their patients' knowledge. Here are the preliminary findings from the survey (see survey methodology below) that show there might be an opportunity to improve education and management of the disease.

THE FACTS:

Even if UC symptoms are under control, there may still be active disease or inflammation. UC patients typically experience periods of being symptom-free alternating with periods of having active disease symptoms (flare).³



36% of people with UC were not aware, that even if symptoms were under control, there could still be active disease or inflammation¹ (n=110/301)



71% of GIs thought that their UC patients understood this was false.² (n=106/149)

THE FACTS:

It is important to keep UC under control to reduce long-term complications.⁴



91% of people with UC knew that it is important to keep their disease under control to reduce long-term complications.¹ (n=273/301)



89% of GIs thought that their UC patients understood this somewhat or very well.² (n=132/149)

THE FACTS:

Patients with UC are at higher risk for developing colorectal cancer than the general population. Inflammation of the colon can cause continuous turnover of cells in the intestinal lining, increasing the risk of irregularities that may lead to colon cancer.⁵



19% of people with UC were not aware that uncontrolled inflammation is a risk factor for colorectal cancer.¹ (n=57/301)



74% of GIs thought that their UC patients understood that uncontrolled inflammation is a risk factor for colorectal cancer.²

More than UC

THE FACTS:

Up to **31%** of patients with UC experience symptoms outside of the colon, including musculoskeletal pain, skin lesions, and kidney, eye or liver disease.⁶



67% of GIs thought that their UC patients understood that UC may be associated with other conditions outside the colon...² (n=99/149)



28% of people with UC were not aware that UC may be associated with other conditions outside the colon.¹ (n=84/301)

For more information, visit Pfizer.com/UCNarrative

The UC Narrative is a global initiative created by Pfizer to engage the UC community to help identify how people living with ulcerative colitis are impacted by the disease.

The Global UC Narrative Advisory Panel,ⁱ comprised of people living with UC, as well as leading gastroenterologists, IBD nurses, a psychologist, and patient organizations, including the Crohn's & Colitis Foundation in the U.S., from 10 countries will work together to turn the insights gleaned from the survey into actions that can help identify real-world needs and concerns about living with UC.

About the UC Narrative U.S. Survey and Survey Methodology

The UC Narrative U.S. survey findings represent a subset of the UC Narrative global survey, which was developed with input from the Global UC Narrative Advisory Panel. In addition to providing input into the development of the survey, the Crohn's & Colitis Foundation recruited respondents (n=126/301) to complete the survey online. The preliminary findings from the U.S. surveys are being announced in collaboration with the Crohn's & Colitis Foundation during the Crohn's & Colitis Congress taking place in Las Vegas January 18-20, 2018. Survey results for all countries are anticipated in the spring of 2018.

The UC Narrative U.S. patient survey was conducted online and by telephone by Harris Poll on behalf of Pfizer between August 23 and October 23, 2017, among 301 adults ages 18+ residing in the U.S. who have been diagnosed with ulcerative colitis (UC), have had an endoscopic procedure to confirm their diagnosis, have not had a colectomy, have been to a gastroenterologist's office in the past 12 months, have ever taken a prescription medication for their UC (excluding those who have only ever taken 5-ASAs), and provided informed consent to complete the research. The research method and survey questionnaire were reviewed and received IRB approval from WIRB-Copernicus Group. Medication history was used as a proxy for disease severity,ⁱⁱ with "mild" patients capped at 20% of total completes. Data were not weighted, and are therefore only representative of the individuals who completed the survey. Patients who qualified for and successfully completed the survey were compensated for their participation.

The UC Narrative U.S. physician survey was conducted online by Harris Poll on behalf of Pfizer between August 23 and November 3, 2017, among 149 adults residing in the U.S. who are licensed to practice medicine, specialize in gastroenterology, do not mostly practice in a long-term care facility or hospice, see at least ten (10) UC patients each month, with at least 10% of these patients currently taking a biologic, and provided informed consent to complete the research. The research method and survey questionnaire were reviewed and received IRB approval from WIRB-Copernicus Group. Results were weighted by region and years in practice by gender to bring them in line with their actual proportions in the population of U.S. gastroenterologists. Physicians who qualified for and successfully completed the survey were compensated for their participation.

ⁱWhere permitted, members of the Global UC Narrative Advisory Panel were paid honoraria for their participation.

ⁱⁱ"Mild" patients were defined as those who have ever taken a 5-ASA, steroids for 3 or less of the past 12 months, or another medication for their UC, but have never taken a biologic or immunosuppressant, and have not taken steroids for 4 or more of the past 12 months. "Moderate to severe" patients were defined as those who have ever taken a biologic or immunosuppressant, or have taken steroid for 4 or more of the past 12 months.

1. Data on file. Pfizer Inc, New York, NY. [UC Narrative Patient Survey, 2017.]

2. Data on file. Pfizer Inc, New York, NY. [UC Narrative Physician Survey, 2017.]

3. Loftus E. Progress in the Diagnosis and Treatment of Inflammatory Bowel Disease. *Gastroenterology & Hepatology*. 2011;7(2, Suppl. 3):3-15.

4. Higgins PDR. New Keys to Maintenance Treatment in Ulcerative Colitis. *Digestive Diseases* (Basel, Switzerland). 2010;28(3):483-489. doi:10.1159/000320406.

5. Flores et al. Impact of mucosal inflammation on risk of colorectal neoplasia in patients with ulcerative colitis: a systematic review and meta-analysis. *Gastrointestinal Endoscopy*. 2017;6(86):1007-1011.

6. Levine JS, Burakoff R. Extraintestinal Manifestations of Inflammatory Bowel Disease. *Gastroenterology & Hepatology*. 2011;7(4):235-241.

Living with Ulcerative Colitis: Shedding Light on Unspoken Challenges

A 2017 U.S. survey of 301 adults living with ulcerative colitis (UC) and 149 gastroenterologists (GIs) suggests that some patients may be suffering from symptoms that may impact their life choices. Here are some preliminary findings from the survey (see survey methodology below) that show how the daily impact of the disease combined with communication breakdowns may be creating a “new normal” for patients, along with some tips that may help some patients discuss UC disease management with their GIs.

Could feeling like they have to “power through” the impact of their disease cause people living with UC to alter their life choices?

The survey suggests that the impact of UC can be significant...



64% of patients felt like UC controls their life rather than them controlling their disease.¹ (n=194/301)



69% of patients felt they would be a more successful person if they did not have UC.¹ (n=209/301)



63% often felt like they spend more time in the bathroom than anywhere else.¹ (n=190/301)

...and GIs reported that many of their patients may be accepting certain UC-related symptoms as the “new normal.”



66% of GIs said that more than half of their patients believe urgency in going to the bathroom is just part of living with UC.² (n=98/149)



53% of GIs said that more than half of their patients believe pain and cramping are just part of living with UC.² (n=79/149)

UC’s impact may extend to mental health and intimacy, yet these topics are rarely addressed.

About



1 out of 3 patients (34%) said they wish that their GI better understood how UC affects their mental health.¹ (n=102/301)

And nearly



half of GIs (49%) never discuss the impact of UC on patients’ mental/emotional health.² (n=74/149)



However, **46%** of patients said they don’t feel comfortable talking to their GI about emotional concerns.¹ (n=137/301)



46% of patients said that UC having less of an impact on their sex life and personal relationships is important to them in managing their UC (n=139/301);¹ however, half of patients said they don’t feel comfortable talking about these topics with their GI (n=152/301).¹



And, **3%** of GIs said this is one of the top three topics to prioritize during routine appointments.² (n=5/149)

Patient hesitancy to speak up and lack of time at appointments could create missed opportunities for intervention and education.



More than half of patients (56%) said they wished they had **more time** at appointments with their GI.¹ (n=170/301)



42% said their GI rarely has time to address all of their questions/concerns.¹ (n=126/301)



40% said they worry that if they ask too many questions, their GI will see them as a difficult patient and it will affect their quality of care.¹ (n=119/301)



45% of patients said they often regret not telling their GI more during visits.¹ (n=135/301)

Resources are available between appointments to help close information gaps; yet, the survey suggests that the gap is occurring at the office.



55% of patients (n=167/301) and **86%** of GIs (n=128/149) said they agree that patient advocacy organizations are important to the management of UC.^{1,2}



55% of patients said they have interacted with (i.e., reached out, been referred by a healthcare professional, or relied on for information) a advocacy organizations.¹ (n=165/301)

However



On average, GIs said they recommend advocacy organizations to **52%** of their patients.²

Moving Beyond Just Living with UC

Tips to Help You Reset the Conversation with your GI



1. Think of the day-to-day things in your life that you enjoy or wish you were able to do again. Use those as the starting place for setting goals with your GI, and to make sure that the plan for managing your disease is on track.



2. Run out of time but not questions? Find out from your GI the best way to communicate with him or her if you still have more to ask. He or she might suggest that you send an email or talk to a nurse.



3. Make a point to share information about your emotional health regularly with your GI.



4. Remember that you are not alone. There are many patient support groups and advocacy organizations, like the Crohn’s & Colitis Foundation, with resources that might be able to fill in the gaps between appointments.

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