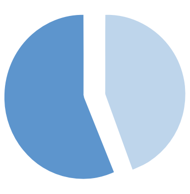
UCnarrative

Living with Ulcerative Colitis:

Shedding Light on Unspoken Challenges

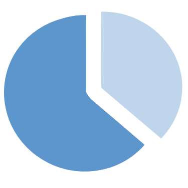
A 2017-2018 10-country survey of 2,100 adults with a history of primarily moderate-to-severe ulcerative colitis (UC)[i] and 1,254 gastroenterologists (GIs) revealed that UC may have short- and long-term impacts on everyday activities and life choices. The survey suggests that some people with a history of UC accept certain UC-related symptoms, like abdominal pain, as part of a new reality that they can't change.

The survey suggests that among those surveyed with a history of UC, the disease may impact life in various ways...



65%[ii]

felt like UC controls their life rather than them controlling their disease.[1]



68%

felt they would be a more successful person if they did not have UC.[1]

67%

often felt like they spend more time in the bathroom than anywhere else.[1]

...and GIs surveyed reported that many of their patients may be accepting certain UC-related symptoms as part of a new reality.

67% said that more than half of their patients believe urgency in going to the bathroom is just part of living with UC.[2]

54% said that more than half of their patients believe pain and cramping are just part of living with UC.[2]

UC's impact may extend to emotional health and wellbeing, yet these topics are rarely addressed.

Nearly
1 out of 3

of those surveyed with a history of UC (30%) said they wish that their GI better understood how UC affects their mental health.[1]

And about
half

of GIs surveyed (51%) never discuss the impact of UC on patients' mental/emotional health.[2]

However,
Nearly
half

of those surveyed with a history of UC (48%) said they don't feel comfortable talking to their GI about emotional concerns.[1]

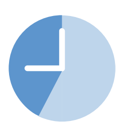
32%

of those surveyed with a history of UC having less of an impact on their sex life and personal relationships is an important goal for managing their UC; however, about half of patients (55%) said they don't feel comfortable talking about these topics with their GI.[1]

And, only
4%

of GIs surveyed said this is one of the top three topics to prioritize during routine appointments.[2]

Hesitancy to speak up and lack of time at appointments could create missed opportunities for intervention and education. Among those surveyed with a history of UC...



said they wished they had more time at appointments with their GI.[1]

said their GI rarely has time to address all of their questions/concerns.[1]

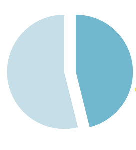
46%
said they worry that if they ask too many questions, their GI will see them as a difficult patient and it will affect their quality of care.[1]

49%
said they often regret not telling their GI more during visits.[1]

Resources, such as patient organizations, are available but may be underutilized.

60% of those surveyed with a history of UC and

84% of GIs said they agree that patient organizations are important to the management of UC.[1,2]



However

46%
of those surveyed with a history of UC said they have interacted with (ie, reached out, been referred by a healthcare professional, or relied on for information) patient organizations.[1]

48%
of GIs surveyed said they recommend patient organizations to fewer than half of their patients.[2]

Moving Beyond Just Living with UC

Tips from the UC Narrative Advisory Panel 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 organizations, with resources available.

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,[iii] comprised of people living with UC, as well as leading gastroenterologists, IBD nurses, a psychologist, and patient organizations from 10 countries, is working to better understand the clinical symptoms of UC, as well as the complex impact this disease has on individuals in their personal (social and emotional) and professional lives.

About the Global UC Narrative Survey and Survey Methodology

The UC Narrative patient survey was conducted online and via telephone[iv] by Harris Poll on behalf of Pfizer between August 23, 2017 and February 9, 2018, among 2,100 adults ages 18+ residing in Australia (215), Canada (215), Finland (105), France (169), Germany (210), Italy (210), Japan (210), Spain (214), the United Kingdom (251), and the United States (301) 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 or internist's office[v] 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. Raw data were not weighted at the individual country level, and are therefore only representative of the individuals who completed the survey.

The primary goal of the survey was to characterize the experiences of UC patients who are believed to be living with moderate to severe disease or those who may be living with poorly controlled disease. The choice to focus on these patient types was based on the assumption that these groups (versus those with milder disease) were more likely in need of support and resources, which the survey could help better identify.

To achieve the goal of focusing on those with moderate to severe disease, self-reported medication history was used as a proxy for disease severity. Patients with "moderate to severe" disease were defined as those who have ever taken a biologic or immunosuppressant for their UC, or have taken steroids for four or more of the past 12 months. Patients with a "milder" form of the disease were defined as those who have never taken a biologic or immunosuppressant, and those who have taken steroids for three or fewer months of the past 12 months. The research excluded patients who have never taken a prescription medication for their UC or have only ever taken a 5-ASA to control their UC. More than 80 percent of total completes were from patients whose disease was classified as "moderate to severe," using this definition, with "milder" patients capped at no more than 20 percent of total survey completes. Results from the UC Narrative patient sample survey may not reflect the experiences of the broader UC population.

The UC Narrative physician survey was conducted online and via telephone[iv] by Harris Poll on behalf of Pfizer between August 23, 2017 and February 9, 2018, among 1254 adults ages 18+ residing in Australia (90), Canada (80), Finland (17), France (154), Germany (152), Italy (157), Japan (151), Spain (151), the United Kingdom (153), and the United States (149)[vi] who practice as a gastroenterologist, internist with a gastroenterology focus, gastroenterology internist, or gastroenterology surgeon,[vii] do not primarily practice in a long-term care facility or hospice setting, see at least 10 patients with UC each month (or a minimum of five patients with UC per month in Japan), with at least 10 percent of these patients currently taking a biologic medicine for their UC (physicians were asked to think about their experiences treating patients in their practice whose UC was moderate-to-severe thoughout the survey), and provided informed consent to complete the research. Physician results in the United States were weighted by region and years in practice by gender. In all other countries, physician results were weighted by age and gender to ensure alignment with the actual proportions in the population of gastroenterologists in each country.[viii] UC Narrative physician sample survey may not reflect the experiences of all gastroenterologists.

For both patient and physician data, for the global, 10-country total, a post-weight was applied to adjust for the relative size of each country's adult population within the total adult population across all countries surveyed. The unweighted sample sizes reflect the total number of patients and physicians who completed the survey in each country, while all reported percentages are calculated based on the weighted global total described here. Proportionate weighting for combining multicountry data into a single total is a common practice because it relies on externally recognized population data to achieve a global total that more accurately represents the real-world relative to the adult populations surveyed. There are limitations to this approach; when countries surveyed have widely varying population totals, the data from smaller countries may get weighted down within the total, thus reducing their share of voice when grouped together with the larger countries.

In the United States, the research method and survey questionnaires were reviewed and received institutional review board (IRB) approval from WIRB-Copernicus Group. Language referencing data of those who agree with the statement includes those who indicated both "strongly agree" or "somewhat agree" within the survey.

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[i] Patients with "moderate-to-severe" disease were defined as those who have ever taken a biologic or immunosuppressant, or have taken steroids for four or more of the past 12 months. Patients with a "milder" form of the disease were defined as those who have never taken a biologic or immunosuppressant, and those who have taken steroids for three or fewer months of the past 12 months. The research excluded patients who have never taken a prescription medication for their UC or have only ever taken a 5-ASA to control their UC. More than 80 percent of total completes were from patients whose disease was classified as "moderate-to-severe," using this definition, with "milder" patients capped at no more than 20 percent of total survey completes.

[ii] Language referencing data of those who agree with the statement, includes those who indicated both "strongly agree" or "somewhat agree" within the survey.

[iii] Where permitted, some members of the Global UC Narrative Advisory Panel were paid honoraria for their participation. Pfizer provided travel and accommodation, as well as a modest compensation, to Advisory Panel members who represent patient advocacy organizations for time spent developing the survey and attending meetings to review the survey findings.

[iv] Telephone interviews were conducted among patients in France, the United Kingdom (UK), and the United States (U.S.), and among physicians in Australia and Canada.

[v] Managing physician varied by country: in Australia, France, Spain, the UK, and the U.S., patients must have visited a gastroenterologist's office; those in Canada, Finland, Germany, Italy, and Japan must have visited a gastroenterologist or an internist's office.

[vi] Gastroenterologists in the U.S. also were duly licensed in the state they practice, did not practice in Vermont, were board certified, and were not associated with Kaiser Permanente.

[vii] Medical specialty varied by country: in Australia, France, Spain, the UK, and the U.S., all physicians were gastroenterologists; in Canada, Germany, and Italy, gastroenterologists and internists with a gastroenterology focus qualified; in Finland, gastroenterologists, gastroenterology surgeons, and internists with a gastroenterology focus qualified; and in Japan, gastroenterology internists, gastroenterology surgeons, and internists with a gastroenterology focus qualified.

[viii] Physician results were not weighted in Finland due to smaller sample size.

1. Data on file. Pfizer Inc., New York, NY. [UC Narrative Patient Survey. 2018.]
2. Data on file. Pfizer Inc., New York, NY. [UC Narrative Physician Survey. 2018.]

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