UCnarrative

Around the World, People Living With Ulcerative Colitis Share Common Experiences

Global Survey Offers a Glimpse Into the Impact of this Chronic Disease

A global survey suggests that, around the world, people with a history of ulcerative colitis (UC) generally share similar life impacts while living with the disease. UC, a type of inflammatory bowel disease (IBD) that can cause debilitating cramping and bloody diarrhea, may impact people both physically and emotionally – leading people with the disease to adapt to a new reality in which they may choose to alter their studies and/or careers, avoid relationships, and even delay or avoid starting a family.[1,2]

Pfizer is sharing key findings from the global UC Narrative survey[1,2] conducted by Harris Poll, which gathered data from 2,100 adults with a history of primarily moderate-to-severe UC and 1,254 gastroenterologists (GIs) from 10 countries. For example, the survey explored several aspects of living with the disease ranging from physical symptoms to patient-physician communication to emotional health and intimacy.

Visit Pfizer.com/UCNarrative to learn more about the UC Narrative initiative, or scroll down to learn more about important insights from the survey and ways people living with UC may be able to better navigate their disease management.

Ulcerative Colitis: Inside and Out

Insights to Educate and Empower People Living With UC Across the Globe

As the global incidence of UC grows, so does the need for resources and support for those living with the disease. A 2017-2018 10-country survey of 2,100 adults with a history of primarily moderate-to-severe UC and 1,254 gastroenterologists (GIs) revealed that UC may have short- and long-term impacts on everyday activities and life choices. For example, 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.

> **We must challenge the notion that ulcerative colitis means that people must give up their life goals or things they enjoy. Certainly, the disease is life-changing, but the more that people living with UC, caregivers and healthcare providers examine the way they share information and talk about goals, the better chance people living with UC have to thrive.**
>
> – Luisa Avedano *I. CEO, European Federation of Crohn's and Colitis Associations (EFCCA) and Global UC Narrative Advisory Panel Member*

See full survey methodology and limitations below

LIFE IMPACTS

LIFE, INTERRUPTED:

Life-changing, 67 percent of those surveyed strongly (24.1%) or somewhat (43.1%) agreed that they often felt like they spend more time in the bathroom than everyone else. Additionally, 65 percent of those surveyed strongly (22.1%) or somewhat (43.1%) agreed that they felt like their disease controls their life rather than their controlling their disease.[1]

The survey found that on their worst day, those surveyed said they take, on average, nearly **10 trips to the bathroom (excluding trips to urinate)**, and on their best day, nearly **4 trips**.[1]

> **A potential outcome of this level of disruption, both real and perceived, is that people living with UC may be giving up the things that are most important to them.**
>
> – Luisa Avedano *I. CEO, EFCCA and Global UC Narrative Advisory Panel Member*

IS IT REALLY REMISSION?

Those surveyed who reported their UC was in remission (67%), meaning that their disease is controlled with few to no symptoms, **still reported passing the bathroom quite often**, especially on their worst day, as compared to those who said their UC was not in remission.[1]

In Remission	Not In Remission
Best day = 3	Best day = 4
Worst day = 9	Worst day = 12

EMOTIONAL HEALTH

Survey Findings

84% of adults with a history of UC strongly (42.1%) or somewhat (43.1%) agree that UC is **mentally exhausting**.[1]

Nearly one-third (30.6%) of those surveyed said they **wished their GI better understood** how UC affects their mental health – but 51.9 of GIs said they never discuss the impact of UC on their patients' mental/emotional health.[1,2]

Community Perspective

"For me, the level of mental exhaustion expressed by patients is the most striking impact uncovered by the study. It's a difficult thing for most doctors to perceive or understand."

"We need to encourage our patients to tell us how they are feeling."

– Alessandro Armuzzi, MD *Gastroenterologist Italy*

Empowering Ideas

Track how you are feeling on a daily basis – and make a point to share it with your healthcare team during your next appointment. If you notice that you are consistently feeling sad – seek out a mental health professional.

RELATIONSHIPS

Survey Findings

32% of those surveyed said that UC having **less impact on their sex life and personal relationships** was important to them in managing their UC.[1]

55% of those surveyed strongly (19.1%) or somewhat (36.1%) agreed that they **don't feel comfortable talking about their sex lives and personal relationships** with their GI – and most GIs (96.1% didn't feel this is one of the top three topics important to prioritize during routine appointments.[1,2]

Community Perspective

"I can relate to why people said it's so hard to talk about intimacy. When you don't feel good or feel good about yourself – it can really disrupt a relationship. **But, having people who know what you are going through is actually a critical part of dealing with UC.** Being open about UC can really free you."

– Rasheed C.

Patient with history of UC Canada

Empowering Ideas

Many patient advocacy groups have developed **"discussion guides" to help navigate difficult conversations** with romantic partners. Look for a local resource to help. In addition, talking to other people who have been through similar situations can give you ideas about what to say. Finally, if intimate relationships are being negatively impacted – **speak with your GI or nurse. They want to help.**

MISSED ACTIVITIES & EVENTS

Survey Findings

Adults with a history of UC estimated missing, on average, **anywhere between five and 33 events** (e.g., days of work or school, social events, travel plans, or child events) in the previous 12 months.[1]

Community Perspective

"I was amazed that most people aren't actually missing more events; it definitely suggests how resilient so many UC patients are. However, in looking at many of the other findings around the impact of UC, I have to wonder if sometimes they are **pushing themselves so they don't let down friends and family**."

– Alisa Hart, BA (Hons), BMBCh, FRCP, PhD *Gastroenterologist United Kingdom*

Empowering Ideas

Develop a **simple word or phrase** to let your friends and family know when you'll need to cancel plans. You won't need to explain, and they'll know the situation. **Recognize that you aren't letting anyone down** if you need to cancel last minute – and that if you aren't feeling well, you should focus on yourself.

LIFE JOURNEY IMPACTS

Survey Findings

68% of those surveyed strongly (29.%) or somewhat (39.1%) agree that they felt like they would be a **more successful** person if they did not have UC.[1]

51% of surveyed GIs strongly (8.%) or somewhat (43.%) agreed they believed their patients **would approach their school or career differently** if they did not have UC.[2]

Community Perspective

"It's heartbreaking to know there are patients who are questioning their ability to be successful. I think **some people may be settling for living a life that is less than what they deserve or can achieve**."

– Alexandra Sechi, RN *IBD Nurse Australia*

Empowering Ideas

Make sure you are familiar with your company's or school's policy on absences and disability due to illness so you know how to manage any paperwork before you need to take time off.

CONVERSATIONS ABOUT CARE

Gaps in communication and education resources identified by the survey showcase some reasons why it may be difficult for some adults living with UC to address aspects of their new reality.

46% of adults with a history of UC strongly (17.%) or somewhat (28.%) agreed that they worry that if they ask too many questions, their **GI will see them as a difficult patient** and it will affect the quality of care they receive.[1]

84% of physicians strongly (29.%) or somewhat (60.%) agreed **patient advocacy organizations are important to the management of UC** – however, **48%** of GIs said they recommend patient advocacy associations to fewer than half of their patients.[2]

WITH YOUR GI:

- Set goals
- Be honest
- Ask questions if you have them
- Find trusted sources
- Build your support network

> **The UC Narrative survey gives us important new perspectives that build on previous research about the impacts of UC. One of these is the fact that it shows people living with UC that they are not alone. There are thousands of others having the same experiences, looking for resources and support. People living with UC must be empowered to speak up and encouraged to find help and hope!**
>
> – Luisa Avedano *I. CEO, EFCCA and Global UC Narrative Advisory Panel Member*

Visit **www.Pfizer.com/UCNarrative** to see more results from the UC Narrative global survey and more tips for living with UC.

About the UC Narrative

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

The Global UC Narrative Advisory Panel,[2] comprised of people living with UC, as well as leading gastroenterologists, IBD nurses, a psychologist, and patient organizations, from 10 countries helped develop the survey methodology and questions. The Global UC Narrative Advisory Panel will work together to turn the insights gleaned from the survey into actions that can help address real-world needs and concerns about living with UC. 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. The UC Narrative was developed in collaboration with the European Federation of Crohn's & Colitis Associations.

About the European Federation of Crohn's & Colitis Associations

The European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA) is an umbrella organization representing 36 national patient associations. EFCCA aims to improve the quality of life for people with IBD and give them a louder voice and higher visibility across Europe and beyond.

About the Global UC Narrative Survey and Survey Methodology

The UC Narrative patient survey was conducted online and via telephone[a] by Harris Poll on behalf of Pfizer between August 23, 2017 and February 7, 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[b] in the past 12 months, have ever taken a prescription medication for their UC (including those who have only ever taken 5-ASAs), and provided informed consent to complete the research. Results were then 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 5-ASAs 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[a] by Harris Poll on behalf of Pfizer between August 23, 2017 and February 7, 2018, among 1,254 adults ages 18+ residing in Australia (89), Canada (80), Finland (17), France (154), Germany (152), Italy (157), Japan (151), Spain (151), the United Kingdom (153), and the United States (149) who practice as a gastroenterologist, internist with a gastroenterology focus, gastroenterology internist, or gastroenterology surgeon,[c] 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 is moderate to severe throughout the survey), and provided informed consent to complete the research. Physician results in the United States were weighted by region and percent in practice by specialty. In the 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.[d] 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-Copernican Group. Language referencing data of those who agree with the statement includes those who indicated both "strongly agree" or "somewhat agree" within the survey.

a. 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 5-ASAs 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.

b. Medical specialty varied by country: in Australia, France, Spain, the UK, and the US, all physicians were gastroenterologists; in Canada, Germany, and Italy, gastroenterologists and internists with a gastroenterology focus qualified; in Finland, gastroenterologists, internists with a gastroenterology focus, and general practitioners qualified; in Japan, gastroenterologists, internists, gastroenterology surgeons, and colorectal surgeons qualified.

c. Physician results were not weighted in Finland due to the smaller sample size.

d. Pfizer Global Survey Data, 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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