

# IBD Digest

Happy summer! The weather is finally warming up, and the IBD and Behavioral Health study staff are excited to share some findings with you that we think you'll find interesting. Of course, none of this would be possible without your participation, so we want to give a big thank you to all of you for signing up, answering your questionnaires, and talking to us on the phone.

Our study is what's known as a mixed-methods study—that is, it involves multiple kinds of research approaches. When you answer the three sets of study questionnaires, that's providing us with **quantitative data**: information that can be measured numerically, in a quantifiable way. The scores from all the study participants can reveal trends about what impact the study is having on outcomes like IBD severity and anxiety and depression levels. We'll be analyzing this once we've hit our enrollment goals and collected data from all 990 participants, so don't forget to answer!

**Qualitative data** is more open-ended. Instead of rating something on a scale of 1 to 10 like you would in some of the questionnaires, qualitative interviews are more of a conversation to find out about someone's personal experiences and opinions. While not everyone in the study may be asked to participate in these interviews (and anyone may choose not to), we get valuable information from those study participants with whom we speak.

For this study, we're doing interviews with a few different groups of people at multiple points during the study, including with:

- **72 patients** within two weeks of their enrollment in the study (called baseline interviews), and another **72 patients** after their first 6 months in the study (called follow-up interviews).
- **15 providers** (like GI doctors, nurses, dietitians, and therapists) at the beginning of the study, and the same **15 providers** at the midway point of the study.

So far, we've completed interviews with the first 72 participants and the first 15 providers and done **analysis** on the transcripts of these interviews. Analyzing qualitative data involves careful reading of the transcripts, identifying common themes that people discuss, and considering what the themes might mean. The goal of our qualitative interviews is to understand how we can provide better care for IBD patients, both within the clinics in this study and for other sites that might benefit from trying a similar model.

On the next page, you'll learn a little bit more about some of our findings from the patient baseline interviews, specifically on how the COVID-19 pandemic affected patients with IBD.

## STUDY PROGRESS

As of **July 26, 2022**,  
we have enrolled

# 474

participants across the  
three study locations!

We are **48%** of the  
way to our goal.

## REMEMBER!

Participants are asked  
to complete questionnaires at  
three points:

- Upon enrolling in the study
- Six months after enrolling
- One year after enrolling

You will be paid \$20 each for the  
initial and six-month  
questionnaires and \$40 for the  
final questionnaire.



## Study Findings: Impact of the COVID-19 Pandemic

When reviewing qualitative data—that is, the transcripts of our conversations with study participants—the goal is to see what common themes are repeated. We noticed several different themes came up again and again while we were reviewing the data.

**Increases in stress, anxiety, and depression.** Participants that we spoke with—much like many people across the world—mentioned that the pandemic made them feel more anxious and/or depressed. This was particularly true in the early part of the pandemic in 2020, when not much was known about how to treat COVID-19 and widespread lockdowns were the norm. For some, this rise in stress made their IBD symptoms worse.

**Concerns about being immunocompromised.** Several people mentioned being worried that their IBD medications put them at an increased risk of getting COVID-19. Though this was mentioned a few times, repeated research has shown that biologic medications do **not** put individuals with IBD at a higher risk of contracting or having negative outcomes from the disease.\*

**Feelings of loneliness and social disruption.** Some participants mentioned feeling isolated from their friends or family. Younger patients, particularly college students, reported feeling like the pandemic put their life off track, causing them to miss out on time with their friends and important life milestones like graduation and living on campus.

**Demonstrations of resiliency.** Despite all of this, there were a number of participants who demonstrated resiliency: the ability to adapt to a new situation. Some reported that the pandemic gave them the opportunity to be closer with family and neighbors while they were at home more. Others said the ability to work from home made their lives much easier, especially when they were experiencing a flare of their IBD symptoms.

**What can we do with this information?** Resiliency is a very important concept for people who are managing chronic conditions like IBD. Research shows that people who are more resilient may be less anxious, have less significant disease activity, visit the hospital and emergency room less often, and report having a better quality of life.\* In the IBD Total Care Clinic at UPMC, your providers can help you develop resiliency by assisting you in managing your condition over the long term and by providing support and education via therapy.

The study team is hoping that sharing these results with patients like you can help people learn about resiliency and get other providers to consider incorporating resiliency training into their treatment strategies. **Please let us know if you would like to see more about this, or what questions or reactions you have.**

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DISCLAIMER: All statements in this newsletter, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

## Meet the Study's Qualitative Co-Investigator



### Cara Nikolajski, MPH, PhD

Director, Research Design and Implementation, UPMC Center for High-Value Health Care; Qualitative Co-Investigator

**How did you get involved in public health research?** I was a sociology major in college and loved learning about the ways in which other societies and cultures view and treat

diseases. After college, I knew I wanted to go back to school, and I was drawn to public health because it gave me the opportunity to learn population-level approaches to preventing/treating diseases and improving people's health and wellness. I love the challenge of identifying important health issues that need to be addressed and coming up with ideas about how to answer important research questions.

### What is your favorite part of doing qualitative research?

Questionnaires and other numerical forms of data are such an important component of a research study, but interviews and focus groups provide me and the study team with the opportunity to understand the intricate details of a person's personal situations, thoughts, and attitudes, which can't easily be captured in a survey. I love when a person feels comfortable talking with me and telling their story.

**What are some of your personal research interests?** The research topics that I am most passionate about include birth control use, family planning, pregnancy experiences, and improving the lives of people who are at greater risk for negative health issues.

**What interests you about this study the most?** The U.S. health care system can be so difficult to navigate, especially for people who are living with complex chronic conditions. I am excited to learn how IBD patients can be better served through a more coordinated and holistic approach to care.

**What is the most rewarding part of your job?** I love the amazing group of colleagues that I get to work with and learn from each and every day, and I really enjoy all of the opportunities I have to be creative in developing and implementing research ideas.

**When you were 10 years old, what did you want to be when you grew up?** Either the CEO of a multimillion-dollar friendship bracelet-making company or a Broadway singer. I'm still shocked that neither of these opportunities worked out ...

\*Al-Ani AH, Prentice RE, Rentsch CA, et al. [Review article: prevention, diagnosis and management of COVID-19 in the IBD patient](#). *Aliment Pharmacol Ther*. 2020 Jul;52(1):54-72.

\*Keefer L, Gorbenko K, Siganporia T, et al. [Resilience-based integrated IBD care is associated with reductions in health care use and opioids](#). *Clin Gastroenterol Hepatol*. 2021 Nov;S1542-3565(21)01225-8.

Philippou A, Sehgal P, Ungaro RC, et al. [High levels of psychological resilience are associated with decreased anxiety in inflammatory bowel disease](#). *Inflamm Bowel Dis*. 2021 Aug;izab 200.

Sehgal P, Ungaro RC, Foltz C, et al. [High levels of psychological resilience associated with less disease activity, better quality of life, and fewer surgeries in inflammatory bowel disease](#). *Inflamm Bowel Dis*. 2021 May;27(6):791-796.

## Building Resilience

Wondering how to build up your own resilience levels? Luckily, our three site study investigators are experts! Drs. Stephen Lupe (Cleveland Clinic), Laurie Keefer (Mount Sinai Hospital) and Eva Szigethy (UPMC) have written about this very topic, particularly on how to become more resilient during the COVID-19 pandemic.\* Try one of their strategies to help strengthen your own resilience. **As always, if you have questions, you should follow up with your IBD Total Care team** (including Dr. Szigethy) for more information.

### *Try progressive muscle relaxation*

Progressive muscle relaxation, or PMR, can be used to help you release tension in your body before it negatively impacts your GI tract. Start by tensing the muscles in your dominant hand and arm and counting to 4, then release. Try focusing on how it feels to be tense versus relaxed. Continue this pattern of tensing your muscles and then releasing all through your body—from your head, neck, and shoulders down through your abdomen, legs, and feet. Focus on your breathing; think of breathing relaxation into your muscles and breathing tension out through your lungs. Try this for 5 minutes at first, and as you get more skilled, you can shorten this.

### *Focus on what's within your control*

People can often feel stressed by events that they have little to no control over. Putting this into perspective can help you develop your ability to cope with difficult or overwhelming events. Start by making two columns on a sheet of paper: one column for factors you can control (like your daily routine or deciding what you'll have for dinner), and the other for factors you can't (like traffic or a new COVID-19 variant). For what's within your control, you can use problem solving to help you decide how to move forward. For concerns beyond your control, consider what you could do to help yourself better cope, such as joining a support group.

### *Develop a healthy routine*

A daily routine can help you feel more stable, even when life gets off track. Try to wake up and go to bed at the same time each day, stick to a physical activity or exercise plan, and commit to healthy behaviors such as drinking enough water, eating a healthy diet, and getting enough rest.

### *Maintain good sleep hygiene*

Many aspects of life, from making good choices to developing a resilient attitude, can be impacted by the how much good sleep you're getting. In addition to sticking to a regular sleep schedule as part of your daily routine, set aside around 30 minutes before bed each night to turn off your smartphone, TV, and computer; engage in some relaxing activities, such as a bath or listening to calming music; and try to make your bedroom as cool and dark as you can.

### *Stay connected*

A good support system is an important part of resilience. Try to keep in regular contact with friends, family, or even other individuals with IBD. If you're comfortable, take advantage of the summer weather and try meeting up for a walk or an outdoor meal. If you're connecting from a distance, try a digital platform like Zoom or Facetime to schedule regular calls to check in and chat. You'll not only be doing yourself a favor, but will probably put a smile on the faces of the people you reach out to!

### *Practice gratitude*

Even when it feels like everything is going wrong, chances are there's something to be grateful for. This could be as simple as a beautiful day or watching a good movie that makes you laugh. Take a few moments each day to write down three things you're grateful for or that are going well in your life or in the world. Even better, try expressing your thankfulness to the people around you; if someone has made a difference in your day, let them know!

\*Lupe SE, Keefer L, Szigethy E. [Gaining resilience and reducing stress in the age of COVID-19](#). *Curr Opin Gastroenterol*. 2020 Jul;36(4):295-303.



## Contact

If you have any questions, please contact a member of the research team at **412-208-5235** or email us at **IBDStudy@upmc.edu**. We can help you:

Address concerns about your Vincent Payment Card.

Update your contact information.

Resolve issues you may be having with the RxWell app.

Schedule a time to complete your follow-up questionnaires.