Inflammatory bowel disease (IBD) patient & provider needs assessment

My IBD Life: Key survey results

Fielding dates: June 27 - July 5, 2022
n=1,026 patients with IBD and 117 gastroenterologists
63% of patients report comorbid conditions, including anxiety, depression, IBS and chronic pain

- More than one in three people diagnosed with IBD have also been diagnosed with **anxiety** (36%) or **depression** (35%). The incidence rate of anxiety and depression among patients with IBD is significantly higher than the general U.S. population (19%\(^1\) and 8%\(^2\) respectively).

- Women have even higher rates of anxiety (47%) and depression (42%) than other patients with IBD.
  - Patients of color report lower rates of diagnosed anxiety (26%) and depression (23%), though the incidence rate of both is still significantly higher than among the general U.S. population.

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**ASKED OF ALL PATIENT RESPONDENTS (n=1026)**

Responses to: “Have you ever been diagnosed by a health care professional with any of the following conditions? Please select all.”

\(n=\) the number of respondents who provided an answer to this question.

* Compared to data from AGA IBD Needs Assessment of 2017

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Providers are more concerned about treating patients’ physical health than mental/emotional health—and feel mental health is sufficiently addressed in their patients’ IBD care

<table>
<thead>
<tr>
<th>Statement</th>
<th>Response</th>
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<tbody>
<tr>
<td>Other people do not understand that my patients could be at high risk for COVID-19 because they are immunocompromised.</td>
<td>7.28</td>
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<tr>
<td>My patients’ access to treatment for IBD has been impacted by the COVID-19 pandemic.</td>
<td>7.16</td>
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<td>Cost has been a barrier to my patients’ accessing quality IBD treatment.</td>
<td>7.08</td>
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<tr>
<td>Mental and emotional health are sufficiently addressed in my patients’ IBD care.</td>
<td>6.97</td>
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<td>My patients are at high risk for COVID-19 because they are immunocompromised.</td>
<td>6.85</td>
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<tr>
<td>I am more concerned about treating my patients with IBD physically than emotionally.</td>
<td>6.49</td>
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<td>My patients express concern about other people not viewing IBD as a serious condition.</td>
<td>6.03</td>
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<td>My patients’ IBD journey has been impacted by their race, ethnicity, culture, sexual orientation, gender identity and/or age.</td>
<td>5.82</td>
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<tr>
<td>My patients have a difficult time discussing their symptoms with me and other health providers.</td>
<td>5.63</td>
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<tr>
<td>My patients regularly visit other health care providers for IBD-related care.</td>
<td>5.27</td>
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ASKED OF ALL PROVIDER RESPONDENTS  (n=117)

Responses to: “Below is a list of statements that may apply to patients with IBD. For each one, please indicate how much you agree, using a scale from 0-10. (0=Strongly Disagree, 10=Strongly Agree).”

n = the number of respondents who provided a response to this question.
Providers feel more equipped to treat patients physically than emotionally

- My patients have regularly visited my office for IBD care: 9.21
- I’ve provided my patients with the resources and information they need to manage their IBD: 8.9
- IBD limits how my patients live their day-to-day lives: 8.51
- Physical health, related to IBD, is sufficiently addressed in my patients’ IBD care: 8.4
- I am more equipped to treat my patients with IBD physically than emotionally: 8.34
- My patients are satisfied with their overall IBD care: 8.27
- Every time they leave the house, my patients have to consider bathroom logistics: 8.11
- My patients have a difficult time discussing their symptoms with friends, family, or coworkers: 8.09
- I am concerned about how IBD affects my patients’ reproductive health: 8.07
- My patients’ access to preventative care for IBD has been impacted by the COVID-19 pandemic: 7.92
- Insurance has been a barrier to my patients’ accessing quality IBD treatment: 7.57
- My patients often have difficulty managing their diets in social settings: 7.53
- IBD has prevented my patients from having physical intimacy: 7.36
- My patients want to try to treat their IBD using diet and/or alternative therapies: 7.29

ASKED OF ALL PROVIDER RESPONDENTS (n=117)

Responses to: "Below is a list of statements that may apply to patients with IBD. For each one, please indicate how much you agree, using a scale from 0-10. (0=Strongly Disagree, 10=Strongly Agree)."

n = the number of respondents who provided a response to this question.
Patients are most concerned about how IBD affects mental or emotional health—and their daily lives

- Every time I leave the house, I have to consider bathroom logistics. 7.03
- I am concerned about how IBD affects my mental or emotional health. 6.51
- I want to try to treat my IBD using diet and/or alternative therapies. 6.49
- IBD limits how I live my day-to-day life. 6.47
- I regularly visit my gastroenterologist for IBD care. 6.42
- My health care providers are more concerned about treating my IBD physically than emotionally. 6.30
- My health care provider has given me all the resources and information I need to manage my IBD. 6.25
- Other people don’t view my IBD as a serious condition. 6.25
- My physical health is sufficiently addressed in my IBD care. 6.19
- I am satisfied with my overall IBD care. 6.06
- I often have difficulty managing my diet in social settings. 5.96
- I am at high risk for COVID-19 because I am immunocompromised. 5.96
- I have a difficult time discussing my symptoms with friends, family or coworkers. 5.80

Consistent with 2017 research, in which 75% of HCPs reported more concern about physical care.

ASKED OF ALL PATIENT RESPONDENTS (n=1026)

Responses to: "Below is a list of statements that may apply to people with IBD. For each one, please indicate how well each applies to your experience living with IBD, using a scale from 0-10. (0=Does not apply to my experience, 5=Applies somewhat well to my experience, 10=Applies very well to my experience)."

n = the number of respondents who provided a response to this question.

* Compared to data from AGA Shared Decision-Making Report of 2017
Patients still want additional information on IBD treatment options, medications—and now mental/emotional health

ASKED OF ALL PATIENT RESPONDENTS (n=1026)
Responses to: "What additional tools or types of information, if any, would you find helpful to receive from your IBD care provider?"

- Information on IBD treatment options: 37%
- Information on medication (i.e., how long before they work, possible side effects): 35%
- Information on diet/nutrition as it relates to IBD: 30%
- Information on general IBD symptoms: 27%
- Information on preventative measures (e.g., vaccines, supplements): 27%
- Information on impact of IBD on emotional/mental health: 25%
- Information on impact of IBD on quality of life: 25%
- Information on mental health treatment options: 25%
- Information on financial assistance available to patients with IBD: 21%
- Information on cost of medications: 21%
- Information on impact of IBD on social life: 19%
- Information on how to navigate insurance: 17%

Compared to 2017:
- Information on Mental Health Support: 17% in 2017*
- Information on Diet/Nutrition: 39% in 2017*
- Information on Social Support: 11% in 2017*

* Compared to data from AGA IBD Needs Assessment of 2017
Patients still want additional information on IBD treatment options, medications—and now mental health (continued)

- Information on impact of IBD on physical intimacy/sexual activity: 16%
- Information on the different types of surgeries: 16%
- Information on accommodations for school, university or the workplace: 14%
- Information on how IBD affects various races, ethnicities, cultures, sexual orientations, gender identities and/or age groups: 14%
- Information on managing IBD during the COVID-19 pandemic: 14%
- Information on transitioning to a new gastroenterologist due to relocation: 13%
- Information on impact of IBD on ability to have/father children: 12%
- Information on transitioning from a pediatric to adult gastroenterologist: 8%
- I do not need any additional information or tools: 5%

ASKED OF ALL PATIENT RESPONDENTS (n=1026)

Responses to: "What additional tools or types of information, if any, would you find helpful to receive from your IBD care provider?"

n = the number of respondents who provided a response to this question.
### Black patients more likely to feel IBD journey impacted by their personal identity

**ASKED OF ALL PATIENT RESPONDENTS (n=1026)**

Responses to: "Below is a list of statements that may apply to people with IBD. For each one, please indicate how well each applies to your experience living with IBD, using a scale from 0-10. (0=Does not apply to my experience, 10=Applies very well to my experience)."

- **My IBD journey has been impacted by my race, ethnicity, culture, sexual orientation, gender identity and/or age.**
  - 3.57

- **Family, friends, and coworkers don’t understand that I am high risk for COVID-19 because I am immunocompromised.**
  - 5.45

- **I regularly visit other healthcare providers for IBD care.**
  - 5.42

- **Cost has been a barrier to accessing quality IBD treatment.**
  - 5.17

- **My access to preventative care for IBD has been impacted by the COVID-19 pandemic.**
  - 5.09

- **My access to treatment for IBD has been impacted by the COVID-19 pandemic.**
  - 5.02

- **IBD prevents me from having physical intimacy.**
  - 4.86

- **I am concerned about how IBD affects my reproductive health.**
  - 5.01

- **Insurance has been a barrier to accessing quality IBD treatment.**
  - 4.72

- **I have a difficult time discussing my symptoms with health care providers (e.g., doctor, nurse practitioner, physician assistant, dietitian, psychologist).**
  - 4.52

- **My mental and emotional health is sufficiently addressed in my IBD care.**
  - Compared to 4.7 rating among Black patients; 4.5 among all patients of Color

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**ASKED OF ALL PATIENT RESPONDENTS (n=1026)**

Responses to: "Below is a list of statements that may apply to people with IBD. For each one, please indicate how well each applies to your experience living with IBD, using a scale from 0-10. (0=Does not apply to my experience, 10=Applies very well to my experience)."

* n = the number of respondents who provided a response to this question.

* Compared to data from AGA Shared Decision-Making Report of 2017
Patients & providers alike are less satisfied with social and emotional care

- All patient and provider respondents are less satisfied with emotional and social care than physical care for IBD.
- Patients aged 18–39 are less satisfied with their care than the overall patient population.
- Overall, women are the least satisfied with their physical, emotional and social IBD care.

ASKED OF ALL PATIENT RESPONDENTS (n=1026); ASKED OF ALL PROVIDER RESPONDENTS (n=117)

Patient responses to: "How satisfied are you with your [physical/emotional/social] IBD care? (1=Very dissatisfied, 5=Very satisfied)."
Provider responses to: "How satisfied are your patients with their [physical/emotional/social] IBD care? (1=Very dissatisfied, 5=Very satisfied)."

n = the number of respondents who provided a response to this question.
Providers’ biggest challenge is insurance authorizations

ASKED OF ALL PROVIDER RESPONDENTS (n=117)

Responses to: “Below are some challenges providers may face when caring for patients with IBD. Please indicate how much you agree with each one, using a scale from 0-10. (0=Strongly Disagree, 10=Strongly Agree).”

n = the number of respondents who provided a response to this question.

* Compared to data from AGA IBD Needs Assessment of 2017

- It is difficult to deal with insurance authorizations for IBD medications.
- My patients are frustrated by their IBD.
- My patients have comorbid conditions that complicate care.
- It is difficult to deal with the amount of time and effort needed to take care of patients with IBD.
- My patients are not able to afford IBD care.
- My patients delay IBD care.
- It is difficult to discuss how IBD impacts patients’ mental or emotional health.
- I do not have all of the support I need.
- My patients do not comply with IBD treatment or recommendations.
- It is difficult to keep up with the standard of care for the treatment of patients with IBD.
- It is difficult to discuss how IBD impacts patients’ physical health.
- My patients feel uncomfortable discussing their IBD symptoms.
- I do not have all of the information I need.
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- It is difficult to discuss how IBD impacts patients’ physical health.
- My patients feel uncomfortable discussing their IBD symptoms.
- I do not have all of the information I need.
The research findings previewed here are the result of online surveys fielded from June 27 to July 5, 2022, among patients with IBD and providers. Patient survey respondents included 1,026 U.S. adults aged 18-59 who reported having been diagnosed IBD (IBD, ulcerative colitis, Crohn’s disease or indeterminate colitis). Provider survey respondents included 117 U.S. gastroenterologists who reported treating 5 or more patients with IBD in the past three months. Survey samples were designed to reflect the composition of each respective population, but findings are subject to various sources of error—including sampling error, coverage error, error associated with nonresponse, error associated with question wording and response options, and more. Additional survey data is available upon request.
Learn more about the My IBD Life campaign

This research was conducted as a part of the My IBD Life campaign, which was created to equip patients with the resources and tools they need to take back control of their lives. Campaign materials were developed in partnership with people living with IBD and health care providers to address the unmet needs identified in this survey. Resources were developed in an accessible and health literate format and include personal stories on building emotional resilience, conversation guides and 3D models to help patients visualize IBD in their bodies. Additionally, the site features tools to help patients prepare for different life moments such as medical procedures, vacations, dating and intimacy, and navigating the workplace. Please visit the My IBD Life website, www.MyIBDLife.gastro.org, to view, download and interact with the new resources.

The My IBD Life Campaign is supported by an independent grant from Bristol Myers Squibb.