



Caring for young adult men with inflammatory bowel disease: Clinician and patient perspectives

Amy K. Bugwadia^{a,b,c}, Sydney Reed^{b,c,*}, Adam Finkelstein^d, Peter Park^{c,e}, Colin Quinn^f, Sneha Dave^{b,c}, Nikhil Jayswal^g, Grady Stewart^{b,c,h}, David Kohlerⁱ, Noel Jacobs^j, Grant E. Barber^k

^a Stanford University School of Medicine, United States

^b Generation Patient, United States

^c Crohn's and Colitis Young Adults Network, United States

^d Penn State College of Medicine, Penn State Milton S. Hershey Medical Center, United States

^e Anne Burnett Marion School of Medicine, Texas Christian University, United States

^f UPMC Children's Hospital of Pittsburgh, Department of Pediatric Gastroenterology, Hepatology, and Nutrition, United States

^g IBD Patient Support Foundation, India

^h Infusion Access Foundation, United States

ⁱ Icahn School of Medicine at Mount Sinai, Department of Pediatrics, United States

^j Oklahoma City University, United States

^k Stanford University, Division of Gastroenterology and Hepatology, United States

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ABSTRACT

Inflammatory bowel disease (IBD) presents unique challenges for young adult men that extend beyond physical symptoms, encompassing psychosocial dimensions affecting all aspects of life. This article draws insights from a roundtable discussion facilitated by the Crohn's and Colitis Young Adults Network (CCYAN), focusing on the experiences of young men living with IBD. It sheds light on the intersections of IBD and men's sexual and reproductive health, fertility, and mental well-being while identifying gaps in care. The article offers recommendations for clinicians and emphasizes the role of care partners and social support, underlining the need for dedicated support structures to improve the lives of men living with IBD.

1. Introduction

Men's health in the context of inflammatory bowel disease (IBD) extends beyond the physical symptoms, delving into psychosocial dimensions that significantly impact all aspects of life. The pediatric prevalence of IBD increased by 133% from 2007 to 2016, with a slightly higher prevalence of all forms of IBD occurring in boys than in girls.¹ While demographic patterns shift among older patient cohorts, certain facets of IBD, such as elevated mortality rates from colorectal cancer, disproportionately affect men.² Despite the prevalence and cascading health disruptions that IBD can introduce to male populations, there exists a conspicuous shortage of literature focusing specifically on the

experiences of men living with this condition. Furthermore, the intersection of young adulthood and IBD in men remains under-researched and under-addressed.

The Crohn's and Colitis Young Adults Network (CCYAN) is an international community and platform for young adults with IBD, working to address the unique needs of the adolescent and young adult (AYA) patient population. The CCYAN facilitated a roundtable discussion that brought young adult IBD patients together with various medical professionals, including physicians, nurses, psychologists, and trainees/medical students, to examine the experiences of young men living with IBD. This multistakeholder conversation began with a presentation by Dr. Grant Barber, a Clinical Assistant Professor at Stanford University

* Corresponding author at: Generation Patient, United States.

E-mail addresses: sydney@generationpatient.org (S. Reed), sneha@generationpatient.org (S. Dave).

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School of Medicine, and Grady Stewart, a young adult man with IBD.

In this article, we illuminate some of the diverse challenges faced by men with IBD by presenting key insights from this roundtable discussion, focusing on the interplay between IBD and men's sexual and reproductive health and fertility, as well as needs for future research. Additionally, we explore the nexus of mental health, isolation, and societal pressures, identifying gaps in whole-person care, proposing actionable recommendations for clinicians, and emphasizing the role of care partners and social support.

2. Impacts of IBD on men's sexual health, reproductive health, and fertility

The psychosocial impacts of living with IBD include social functioning at school and in the workplace, mental health, and the development of interpersonal relationships, which encompasses both sexual and reproductive health. In the context of sexual health, one survey of 347 IBD patients discovered that over 50% feel that the disease negatively affects their sexual relationships and that common drivers include impaired body image, the need for a tolerant partner, self-consciousness, and libido.³ Ostomies had an especially adverse impact on body image. The subset of young adults (YA) with IBD who identify as men have unique considerations when approaching their medical and psychosocial care. Sexual function can be impacted in IBD, with males who have IBD often experiencing erectile dysfunction and decreased libido. Drivers of sexual dysfunction in this community are multifactorial and can include mental health challenges, disease-related concerns, pain, fatigue, and hormonal imbalances resulting from systemic inflammation and active disease.^{4,5}

Medications such as opiates and corticosteroids can also impact sexual function.⁵ Sulfasalazine is associated with a reversible decrease in sperm count, which corrects after stopping the medication.⁶ Fortunately, a recent meta-analysis found no effect from paternal Tumor Necrosis Factor (TNF) biologics, thiopurines, or methotrexate on fertility or baby outcomes; however, the data lacked inclusion of non-TNF biologics or other advanced therapies.⁷ Additionally, surgical treatments for IBD, namely ileal pouch-anal anastomosis (IPAA), can impact sexual function, with male patients reporting symptoms of sexual dysfunction (including post-surgical erectile dysfunction, retrograde ejaculation, and dyspareunia) at varying rates, ranging from 3% to 25%.^{8,9} Despite this, most patients in multiple survey studies indicate their overall quality of life improved after surgery. In qualitative studies, patients have also reported an increase in sexual satisfaction following IPAA surgery, which is likely secondary to increased disease control and symptomatic relief.¹⁰⁻¹² Together, these factors point to the complexity of balancing patient goals, quality of life, and the impacts of surgical interventions.

Working in partnership with patients to effectively manage their condition is especially crucial for young adults with IBD, as research has shown a correlation between increased disease activity and decreased preparedness to transition to adult care (as measured by the validated Transition Readiness Assessment Questionnaire [TRAQ]) and lower quality of life scores as measured by the validated Short IBD Questionnaire.¹³ In addition to standard IBD disease activity indices such as the Crohn's Disease Activity Index (CDAI) and the Simple Clinical Colitis Activity Index (SCCAI), providing comprehensive care to men with IBD can include the implementation of sexual activity indices and questionnaires, pre-and post-operative sexual health assessments, lab evidence of hypogonadism, and ongoing conversations about medication side effects. These strategies can help inform treatment plans and shared decision-making processes. For example, for men who are trying to conceive, considerations can include optimizing medical therapy, stopping sulfasalazine, and providing counseling about medications that currently lack robust reproductive health data.

3. Addressing current gaps in research: recommendations for future studies

Current literature on IBD and its effects on male fertility has largely focused on the impacts of IBD treatments, including steroids, azathioprine, sulfasalazine, methotrexate, cyclosporine, infliximab, and adalimumab. Effects that result from such medications can include erectile dysfunction,⁸ low testosterone,¹⁴ low sperm count, poor sperm function,¹⁵ and decreased libido secondary to depression. Surprisingly, while the potential sexual health side effects of these treatments can be significant, it was recently found in a survey of 793 IBD patients that over 60% had never received preconception counseling from their gastroenterologist or IBD care team,¹⁶ highlighting a need for improved communication on behalf of providers regarding the possible sexual and reproductive effects of these medications. As more targeted biologics and advanced therapies enter the market, YA male patients will be interested in understanding the data surrounding the effects of these treatment options on sperm, testosterone, and sexual function/performance.

Given the paucity of research at the intersection of male fertility and IBD treatments, current and future research efforts must focus on the effects of IBD treatments on male fertility. One such study shared during the roundtable was the Stanford Semen in IBD Men on Biologics and Advanced Therapies (SIMBA) study, which Dr. Grant Barber and colleagues initiated to assess the effect of IBD medications on sperm count. As one of the first of its kind to prospectively assess the changes in semen parameters such as sperm count and DNA fragmentation before and after starting biologic or advanced therapy, this study helps fill essential knowledge gaps and will inform the shared decision-making conversations between clinicians and young men with IBD.

4. Mental health, isolation, and societal pressures

The existing literature extensively outlines the detrimental impact of IBD on mental health, with social isolation and societal pressures serving as prominent contributors. Mental health challenges are heightened in YA with IBD due to the transitional nature of this life stage, which is characterized by significant change, exploration, risk-taking, and identity development. The management of mental health in these patients is further complicated by an increased prevalence of psychological and mood disorders within this age group.¹⁷ Anxiety and depression, in particular, are heightened in YA with IBD,^{17,18} creating a reciprocal relationship where IBD symptoms and medications can contribute to anxiety, which, in turn, worsens symptoms.¹⁹ Moreover, the rates of undiagnosed depression and anxiety among individuals with IBD remain high. In a study of 242 IBD patients that utilized the Structured Clinical Interview for DSM-IV-TR Axis I Disorders (SCID), a gold-standard diagnostic tool for psychiatric diagnoses, 40.1% met the SCID criteria for depression, yet one-third of these individuals did not have a formal diagnosis of depression from their clinician. Similarly, 30.6% met the SCID criteria for anxiety, yet two-thirds of these individuals did not have a formal diagnosis of anxiety from their clinician.²⁰ This study also brought attention to a gender-based discrepancy, indicating that males with IBD were more likely to have an undiagnosed depressive disorder.²⁰ This is supported by broader research about YA men's mental health, which indicates that boys tend to disengage from the health care system starting in adolescence, have lower mental health literacy as compared to women, and experience increased self-stigma and shame resulting from societal expectations of men.²¹

During our roundtable discussion, several patient participants made note of specific symptoms significantly affecting the mental health of men with IBD, such as urgency, pain, and bleeding. The discussion underlined the disruptive nature of these symptoms and the associated stigma, leading to profound feelings of shame, isolation, and fear of judgment being commonplace among male patients, especially when surrounded by peers who don't share their experiences. Consequently,

individuals may struggle with catastrophizing and hypervigilance, especially in managing these symptoms within social contexts, coupled with an ever-present fear of urgency in public, which deters patients from engaging in social settings where they may not have access to the necessary facilities.

The prevailing cultural and societal stigma associated with men discussing emotions and health significantly exacerbates the direct stress of managing IBD symptoms. Issues related to body image, stemming from symptoms of active disease and medication side effects, as well as the societal pressures and expectations to succeed early in life, add an additional layer of stress. Further insights from male IBD patients at our roundtable revealed difficulties in striking a balance between managing symptoms, advocating for care, and pursuing long-term goals, all of which can significantly impact their engagement with the healthcare system. Participants expressed reluctance to introduce vulnerability regarding their health, leading to neglect of follow-up appointments due to a lack of clear communication or support.

These issues are further magnified by the lack of IBD awareness in the general public, putting an additional burden on patients to advocate for themselves in the context of school and the workplace.^{22,23} Common challenges and major points of stress for young men with IBD include accommodations for frequent restroom access (e.g., during exams) and granting time off for sick days or doctor's appointments, causing some participants to resort to telephone follow-up appointments during work hours.²² Furthermore, roundtable participants pointed out societal expectations of men to "be strong" and "not show emotion" and noted that advocating to receive IBD-related accommodations can put men in an uncomfortable position of vulnerability, forcing them to disclose health-related information. This phenomenon is consistent with other research that indicates that men are up to two times more likely than women to report stoic ideologies (e.g., resistance to strong emotions, apathy towards death or mortality, reservedness and independence), which have been linked to delayed help-seeking behavior.²⁴ This information becomes even more concerning in the context of potential mental health repercussions, with evidence suggesting an increase in poor mental health outcomes and death by suicide^{25,26} in men socialized to conform to traditional masculine norms (namely, attitudes towards help-seeking, vulnerability, and self-reliance).^{27,28}

Advocacy efforts and increasing IBD awareness have initiated a positive shift, gradually diminishing the stigma around mental health discussions, particularly among men with IBD. However, there is still a substantial need for greater support infrastructure dedicated to men living with IBD, which can be addressed during individual patient encounters and through institutional programs.

5. Addressing current gaps in whole-person care: recommendations for clinicians

Given the impacts of IBD on men's sexual health, reproductive health, and fertility, as well as the role of mental health, isolation, and societal pressures, it is essential for gastroenterologists to address these topics with YA men with IBD as part of routine follow-up care.²⁹

Normalizing the discussion of sexual health and broaching the topic with patients is crucial for physicians to create a safe environment and facilitate providing superlative care.⁵ In particular, Ghazi et al. (2015) recommend gastroenterologists ask questions related to specific potential areas of concern, assess the patient's response, provide education, and refer them to another specialist if needed. Questions can elucidate patients' concerns about intimacy or body image or bring to light experiences of erectile dysfunction or psychosocial concerns. Similarly, during a previous CCYAN roundtable focused on sexual and reproductive health for young adults with IBD, interdisciplinary clinicians and patients recommended physicians ask caregivers or parents to leave the room prior to discussing sexual health, to start with open-ended questions and to use neutral language.³⁰ For example, clinicians can ask, "Sex can look different for different people... what kind of sexual

contact/activity do you engage in? Examples include oral sex, vaginal sex, and anal sex".³⁰ This direct conversation can allow the gastroenterologist and IBD care team to screen for sexual and reproductive disorders in this at-risk population and to identify patients who may benefit from specific referrals to a psychologist,³¹ social worker,³² psychiatrist,³³ and/or sex therapist.³⁰

Reproductive health and fertility are also crucial topics to address with YA men with IBD, particularly in light of the lack of data surrounding the long-term effects of certain biologic and advanced IBD therapies. Roundtable participants highlighted the importance of being open and honest with patients about the current data when discussing potential treatment options. Moreover, as new research emerges, clinicians can have ongoing conversations to provide updated patient information, which can help guide the shared decision-making process.

Roundtable participants from various disciplines emphasized the importance of addressing psychosocial wellness during medical appointments. Pediatric and adult care gastroenterologists both acknowledged the limited timeframe of appointments, noting that it is difficult to address psychosocial care comprehensively in the time generally allotted for a medical visit. As appropriate, IBD patients are referred by their gastroenterologist to a psychologist or social worker, and roundtable participants noted that this separate referral can ensure that these topics are given the attention and care they deserve. Clinicians at the roundtable also pointed to the embedded care model, which is used in an increasing number of pediatric IBD care centers. This model does not require a separate referral to a psychologist or social worker; rather, appointments with psychosocial providers are routine parts of care, with patients having a comprehensive health visit focused on overall well-being instead of solely symptom treatment at least once a year. However, providing this type of care (either via referrals or an embedded care model) is not always feasible within all clinics or institutions, especially given that not every institution currently has these psychosocial support professionals within their clinics.

Roundtable participants reached the consensus that although psychosocial topics may not be fully addressed within a medical appointment, a personal recommendation from or mention of psychosocial care directly from a gastroenterologist can help normalize and destigmatize the use of psychosocial resources, especially for young men with IBD. For example, a gastroenterologist can say, "Many of my male patients around your age have found our support groups helpful in navigating their IBD." As one roundtable participant stated, "You don't know what you don't know... if you haven't experienced peer support, you don't realize how beneficial it can be." This participant emphasized that the physician is uniquely positioned to engage more men in psychosocial programs because the gastroenterologist may be a young man's only touchpoint or connection to the IBD community.

These topics and strategies for gastroenterologists to address with young adult men with IBD are summarized in [Table 1](#). Ultimately, addressing and normalizing the discussion of sexual health, reproductive health, and psychosocial care resources will address crucial gaps in the whole-person care of these individuals.

6. The role of care partners and social support for young men with IBD

Care partners (e.g., parents, close friends, significant others) provide integral support for young men with IBD during the transition to adulthood and independent living. Support is especially crucial for YA, who often lack a robust support system, and for men, who often strive to "be strong" and not ask for support due to social pressures or norms. Therefore, there is a need for more screening and access related to psychosocial care for men with IBD, including access to mental health professionals specializing in chronic illness. Counseling services should provide general educational resources to increase awareness and understanding of IBD and its impact on relationships. Additionally, services should focus on addressing specific challenges and goals that men

Table 1
Topics for gastroenterologists to address with young adult men with IBD.

Psychosocial Topic for Clinician to Address	Example of Patient-Centric Way to Discuss this Topic
Normalize and address sexual health topics, including concerns about body image, erectile dysfunction, or other psychosocial concerns	“I recognize that discussing sex and sexual health can feel a bit awkward or uncomfortable. I bring up this topic because it is common and normal for men with IBD to experience impacts on sexual health, such as erectile dysfunction and body image concerns. Would you feel comfortable discussing these topics, either now or later? Are there any areas about these that you have questions about?”
Use open-ended, neutral language when discussing sexual health	“Sex can look different for different people... what kind of sexual contact/activity do you engage in? Examples include oral sex, vaginal sex, and anal sex.”
Discuss the impacts of IBD therapy on reproductive health and fertility, acknowledge the current knowledge gaps, and plan to revisit the conversation to provide updated clinical guidance as necessary	“The impact of [treatment] is currently being researched, so we don't yet have long-term data on the impact of this medication on fertility. That being said, we can certainly revisit this conversation again as new information continues to come out. In the meantime, we will continue to monitor your overall health. Do you have any questions for me?”
Recommend psychosocial care resources to patients during their medical appointments	“Many of my male patients around your age have found our support groups helpful in navigating their IBD.”

with IBD may have, including body image concerns. For example, one roundtable participant illustrated the benefit of discussing these concerns with the care team, sharing his experience treating a young man whose desire to build muscle played a role in his decision to accept biologic treatment. This clinician noted that once the care team identified this patient's goal and acknowledged it meaningfully, his engagement pattern with the care team greatly improved, and he was ultimately able to begin a treatment plan that served shared goals from a medical and body image perspective. This illustrates how shared decision-making between the care team and patient is an integral form of support for YA with IBD.

Support groups have been shown to offer benefits, including a connected community throughout a complex patient journey.³⁴ One roundtable participant described prior involvement in a young patient support group for boys aged ten to fifteen. The experience introduced the participant to IBD support groups and proved to be a significant source of social and emotional support at the time of diagnosis. One patient participant observed a scarcity of male attendance at IBD-focused psychosocial programs, indicating a broader challenge in engaging male patients with support networks. Participants suggested that having support group facilitators who identify as men can be one way of increasing engagement.

Both patient and clinician roundtable participants noted the benefits of IBD-specific summer camps, which have improved patient wellness, self-image, and sense of belonging.³⁵ Participants stated that while campers may have been more shy initially, the informal, low-pressure setting allowed campers and counselors to bond over time, engaging in meaningful conversations and exploring shared emotions. This format of support, which focuses more on bringing together IBD patients over non-IBD-related activities, can be particularly useful for men who may otherwise feel intimidated by engaging in a space dedicated specifically to discussing socioemotional topics.

Role models and mentors for young men with IBD (e.g., other men with IBD, fathers, and clinicians who identify as men) have a unique role in offering support. To facilitate productive discussions, these mentors should encourage sharing challenges faced by male patients, acknowledge the difficulty of discussing emotions, and normalize conversations

about risk-taking or “exploratory” behaviors. Participants highlighted lifestyle considerations such as relationships or intimacy as potential topics for discussion and noted the benefit of conversations resulting in action items. One clinician highlighted that he frequently observes fathers or father figures being excused for taking a severely less engaged, if not absent, role in their child's medical care but that the engagement of these male role models can play a pivotal role in strengthening young males' support network. Roundtable participants also noted that male-identifying clinicians can offer unique insight and support in creating a comfortable environment for YA men with IBD to discuss not only their symptoms and care goals but also their psychosocial health. Mental health professionals can further provide this type of support. One roundtable participant, whose child psychology practice was within a pediatric IBD center as part of the embedded care model, shared that his direct interaction with young patients starts as early as ten. As a result, patients of the practice feel accustomed to sharing their emotions, experiences, and questions with the healthcare team from a young age. As roundtable participants emphasized, these skills can enable young men to take a greater role in their own healthcare as they transition into adulthood, which is crucial given that self-efficacy, resilience, and disease knowledge are predictors of a successful transition from pediatric to adult care.³⁶

7. Conclusion

The challenges faced by men living with IBD demand increased attention. These challenges are compounded by societal expectations and stereotypes related to masculinity, which make symptom management on physiological, psychological, and psychosocial levels more difficult. Despite progress in advocacy and increased awareness of IBD positively impacting mental health discussions and challenging stereotypes among men with IBD, there remains a significant need for dedicated support structures, both within and beyond the healthcare setting. This roundtable discussion highlights the nuanced nature of men's health in IBD, exploring the interplay between IBD and men's sexual, reproductive, and mental health, emphasizing the imperative for ongoing research, evolving clinical practices, and robust support structures. By doing so, we can pave the way for a more holistic and empathetic approach to address the obstacles that men encounter while navigating the intricacies of living with IBD.

CRedit authorship contribution statement

Jayswal Nikhil: Writing – original draft, Writing – review & editing. **Kohler David:** Writing – original draft, Writing – review & editing. **Jacobs Noel:** Writing – review & editing. **Barber Grant E.:** Data curation, Writing – review & editing. **Dave Sneha:** Funding acquisition, Project administration, Writing – review & editing. **Bugwadia Amy K:** Writing – original draft, Writing – review & editing. **Reed Sydney:** Conceptualization, Funding acquisition, Writing – review & editing. **Finkelstein Adam:** Writing – original draft, Writing – review & editing. **Park Peter:** Writing – original draft, Writing – review & editing. **Quinn Colin:** Writing – original draft, Writing – review & editing. **Stewart Grady:** Writing – review & editing.

Declaration of Competing Interest

The authors do not have any relevant conflicts of interest to disclose.

Data availability

No data was used for the research described in the article.

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