



Medical trauma in young adults with inflammatory bowel disease: The role of trauma-informed care

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ABSTRACT

Medical trauma is a profound concern for those with chronic conditions like inflammatory bowel disease (IBD), especially young adults. This trauma, arising from both the disease itself and necessary medical interventions, manifests as an accumulation of traumatic experiences impacting a patient's physical and psychological well-being. The Crohn's and Colitis Young Adults Network (CCYAN) conducted a roundtable discussion involving young adult IBD patients and healthcare professionals focused on medical trauma and its implications in the treatment of young adults with IBD. This article summarizes the key insights from this discussion, including medical trauma in IBD as an accumulation of 'micro-traumas,' the impacts of such trauma and disruptions in care regardless of post-traumatic stress diagnosis, the role of adverse childhood experiences and trauma-informed care, practical strategies to cultivate trust during individual patient encounters, and recommendations for providing trauma-informed care within the clinical setting.

Introduction

Medical trauma manifests as a distinctive form of trauma, stemming not only from the disease itself but also from the necessary medical interventions required for its treatment. This concern becomes a persistent reality for individuals living with chronic medical conditions like inflammatory bowel disease (IBD), which involves a barrage of medical appointments, fluctuating symptoms, treatments, and medical procedures. The resultant medical trauma is a comprehensive, full-body experience that includes both physical and psychological responses that can have serious implications for the ongoing care of IBD patients, particularly adolescent and young adult (AYA) patients, who will live with this condition for decades to come.

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 AYA patient population. The CCYAN facilitated a roundtable discussion between young adult IBD patients and medical professionals, including physicians, nurses, psychologists,

and trainees/medical students, to understand the role of medical trauma in the lives of AYA patients with IBD and the opportunities to incorporate trauma-informed approaches within the care of these individuals. This roundtable session began with a presentation by Dr. Laurie Keefer, an academic health psychologist and the Director for Psychobehavioral Research with the Division of Gastroenterology at Mount Sinai, and Nikhil Jayswal, a young adult IBD patient and founder of IBD Patient Support Foundation (India). The discussion that followed defined the scope of medical trauma in the context of micro-traumas that can be beyond the diagnostic criteria of post-traumatic stress disorder, its impacts and disruptions in care, and the personal nature of trauma, including experiences outside of the medical setting that could inform patient risk for traumatization. We discuss the role of trauma-informed care in supporting young adults with IBD, including strategies to build trust within individual patient encounters and system-wide approaches to tailor care to patient's individual trauma histories.

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Medical trauma in IBD: an accumulation of ‘micro-traumas’

During the roundtable discussion, Dr. Keefer noted that many traumatic experiences originate from an external factor (e.g., a crime, assault, bullying), and, when possible, separating oneself from the precipitating factor can provide a reprieve and relief from this trauma. In contrast, the experience of medical trauma arises from within the body, and thus, the person experiencing that trauma is unable to separate themselves from this experience physically or emotionally. One roundtable participant, a medical social worker who also lives with IBD, brought attention to the misconception that medical trauma can only result from one significant event, while in reality, living with a chronic condition itself can be traumatizing. This can result from an accumulation of “micro-traumas” that people living with IBD experience, such as the unpredictable nature of the disease, prolonged pain and symptoms affecting one’s activities of daily living and quality of life, as well as clinician-inflicted trauma during difficult medical encounters. One IBD patient and researcher at the meeting mentioned that loss of bodily autonomy can be at the core of medical trauma. One patient described his experiences living with Crohn’s disease in India and the trauma that developed from chronic pain that was left untreated due to limited access to pain medication, mistreatment by healthcare providers, and the conditions he endured while being treated in overcrowded public hospitals. Several other patients echoed the sentiment that these ongoing challenges can accumulate and lead to trauma over time.

Some patients acknowledged that they had a tendency to minimize or downplay their traumatic experiences, while others admitted that they had not understood that the distress they encountered was trauma to begin with. One clinical social worker provided an example of a patient who had undergone multiple surgeries and was unaware that what she had gone through was considered trauma. This highlights the stigma and uncertainty that can surround the definition of medical trauma and the role that it plays in the lives of people living with chronic conditions such as IBD. As roundtable participants pointed out, when this trauma is not recognized, patients are less likely to be able to access the relevant psychosocial support that they need and deserve.

It is also important to acknowledge that healthcare professionals should refrain from judging whether a medical experience could or could not be considered a trauma. Trauma is deeply personal, and not everyone experiences medical events the same way—prior experiences with the health system, intergenerational trauma, and other personal life experiences (medical and non-medical) can lead to a seemingly “smooth” medical event being perceived as traumatic. Further, healthcare professionals may find themselves dismissing the label of trauma if a patient can re-engage with the previous traumatic event (e.g., agreeing to a new hospitalization, surgery, or feeding tube). In these cases, it is important to recognize that engaging in the event is still re-traumatizing and that the patient may appear hypervigilant, require more sedation, experience more post-procedural discomfort, or have a slower recovery. In other words, trauma-informed care is still indicated in patients without a label of post-traumatic stress.

Trauma impacts and disrupts care regardless of post-traumatic stress disorder diagnosis

Currently, the diagnostic criteria for post-traumatic stress requires an individual to experience a sudden and catastrophic event.¹ This limited scope does not encompass the collective, ongoing experiences of those with conditions like IBD and thus can complicate the ability of clinicians to recognize trauma and provide necessary trauma-informed care and psychosocial support resources. While approximately 25% of people with IBD report experiences of post-traumatic stress symptoms, qualitative and quantitative studies have shown that the majority do not go on to meet the criteria for post-traumatic stress disorder (PTSD).^{2–4} Nevertheless, the absence of an official diagnosis does not prevent this trauma from profoundly disrupting an individual’s ongoing care. Within

the pediatric population, a meta-analysis of over 200 studies showed that approximately 30% of children with medical conditions have experienced significant pediatric medical traumatic stress.⁵ Moreover, research shows that 80% of chronically ill children and their families experience post-traumatic stress following a medical trauma, with 20 to 30% of parents and 15 to 25% of children experiencing persistent post-traumatic stress even when the traumas are no longer present.^{6,7} Thus, regardless of whether patients have a PTSD diagnosis, it is paramount to recognize that any individual living with IBD has likely experienced medical trauma and the implications that may have for their ongoing care. Post-traumatic stress symptoms arising from medical trauma—such as unrelenting intrusive thoughts and distress when confronted with reminders of the trauma—present significant challenges for chronically ill patients that can influence an individual’s adherence to treatment and willingness to engage with the medical system overall.

Many IBD patients may contend with substantial symptoms of anxiety, living in a state of constant hypervigilance and continuous apprehension about their health due to the unpredictability of their condition. This anxiety can be exacerbated by previous negative experiences in healthcare settings, such as painful procedures, instances of medical gaslighting, and perceived mistreatment by healthcare providers. For instance, one patient shared a personal story illustrating the development of post-traumatic stress following a doctor’s dismissal of her symptoms as anxiety when she was, in fact, experiencing anaphylaxis. The patient emphasized that not being taken seriously and having her symptoms attributed to anxiety resulted in a deep-seated mistrust of the medical system. This highlights how medical trauma can lead to an avoidance of seeking medical care, which may manifest as delays in essential medical appointments, low adherence to treatment plans, or outright refusal to seek medical assistance, even in urgent situations. This was exemplified further by several other patients, one describing how their fear of invasive procedures led them to delay necessary endoscopies, while another spoke about avoiding certain types of medications due to previous adverse reactions.

The role of adverse childhood experiences and trauma-informed care

Trauma-informed care (TIC) is not just a specialized approach for those diagnosed with post-traumatic stress or trauma; it’s a universal design that holds particular relevance in the healthcare setting.⁸ The significance of TIC is underscored by the prevalence of trauma, with studies indicating that 90% of American adults have experienced at least one traumatic event in their lives.⁹ This includes various forms of trauma, with a particular emphasis on adverse childhood experiences (ACEs), which have been linked to detrimental effects on both physical and mental health.⁸ Moreover, it was found in a study of 345 adults with IBD that 74.2% of these individuals have experienced at least one ACE.¹⁰

The importance of TIC becomes even more apparent when considering the unique needs of young adults with IBD. In addition to the challenges posed by the disease itself, the experience of medical trauma can be greatly influenced by the context in which a person lives, including the home environment, family dynamics, and socioeconomic factors. Adverse childhood experiences (ACEs) include traumatic events, stressful experiences, or unsafe situations that occur during one’s childhood, including but not limited to abuse, neglect, violence, and household adversity.¹¹ Although defined in the context of childhood, ACEs have been shown to impact health and well-being well into adulthood.¹² It is also critical to recognize that an IBD diagnosis does not occur in isolation, and using a biopsychosocial approach, we can better contextualize the impact of an individual’s intersectional identities and lived experiences, including ACEs, on their unique experience of medical trauma. Participants in our roundtable discussion emphasized the cumulative impact of various traumatic experiences. For instance, one participant shared that her health challenges as a young adult were

compounded by previous trauma she experienced as a young child while spending time in the hospital visiting her mother with metastatic cancer before her passing. She shared that now, as a young adult, she avoids hospitals, including emergency department visits, because of the childhood trauma she associates with these settings- not necessarily her IBD. This participant acknowledged that her IBD care has been negatively impacted in multiple instances because of this trauma-avoidant behavior. The consensus among participants highlighted the necessity of acknowledging both past and ongoing trauma in individuals with chronic conditions.

Trauma-informed care is not only about treating a condition; it's about recognizing and addressing the broader spectrum of experiences that shape a patient's journey and cultivating a healthcare environment grounded in trust, communication, and tailored support. The presence of supportive adults in a young person's life can increase the impact of ACEs and how they manage their disease. For example, as one Roundtable participant shared, an IBD diagnosis in childhood can potentially serve as a protective factor since the longitudinal care journey can expose abused and or neglected young people to trusted adults, including clinicians and caregivers. This highlights the importance of care team members intentionally building relationships with their patients.

Cultivating trust during individual patient encounters

Intentional trust-building between clinicians and patients is an integral component of trauma-informed care. The roundtable participants emphasized the importance of collaboration and teamwork in addressing trauma in healthcare settings. Healthcare professionals were encouraged to validate patients' experiences and fears, offering support and resources, including coping strategies and effective communication tools. It was underscored that patients may not always be conscious of when they may be experiencing re-traumatization or how to verbalize this, making it crucial for clinicians to approach every individual using a trauma-informed lens.

Both clinicians and patients at the roundtable emphasized that it is the responsibility of all clinicians, not just psychologists, to create safe and welcoming environments for patients to explore their emotions. Regardless of how "routine" it may seem, any medical appointment can be emotionally taxing for patients. On an individual level, asking questions such as, "Is there anything I can do to make this visit more comfortable for you today?" can go a long way in building long-term trust and rapport. Additionally, the simple statement, "If you would like to bring someone with you during your [visit/procedure/treatment], please feel free," can be especially crucial for young adults undergoing the transition-of-care process. After transitioning to adult care, many young adults may feel they can no longer bring a caregiver to their appointments out of fear of being perceived as less independent.¹³ Proactively offering young adults the option of bringing a caregiver, such as a family member or another loved one, to their appointments and procedures can help normalize this and remove the burden from the patient.

One young adult with IBD emphasized the importance of physicians recognizing the delicate nature of the treatment plans, such as a new therapy or surgery. Roundtable participants juxtaposed the intent of clinicians (which may simply be to lay out medical management options in an efficient and unbiased way) with the impact on patients (which may include retraumatization and resurfacing of anxiety). Similar to how clinicians verbalize the steps of a physical exam and ask for patient permission prior to proceeding, clinicians can verbally signpost the content of their conversation to help empower their patients and mitigate unintended emotional impacts. Some examples of phrases that clinicians can use include: "This may be a hard conversation to have since it'll include a discussion about treatments, including surgery. Is it okay if we proceed?" and "How much information about the potential surgical procedure do you want from us right now? What would you

prefer we save and talk about at another time?" These open-ended questions that center the autonomy and comfort of the patient can help young adults with IBD feel more partnered with and in control. A summary of clinician practices and corresponding example quotes can be found in [Table 1](#).

As crucial as the precision of language is in building trust, nonverbal communication is equally significant. Roundtable participants emphasized that clinicians' body language, such as making eye contact with patients and facing them (rather than the computer or electronic medical record) while speaking, can ensure that a patient feels heard. These practices for intentional listening have been echoed in the literature on best practices for fostering presence and trust within clinical encounters.¹⁴ Similarly, the body language of the patient can also be an indicator of how they are feeling. This is particularly true of young adults with IBD who have experienced medical trauma and may not always verbalize the fact that a situation may be uncomfortable or emotionally unsafe. Thus, clinicians can take the initiative to explore the patient's emotions by "noticing, naming, and validating" them.¹⁴ In these ways, trust can be fostered within an individual patient encounter.

Tailoring care to individual trauma histories: a system-wide "trauma action plan"

Tailoring care to individual patient preferences and trauma histories is another critical component of trauma-informed care identified by roundtable participants. The young adult participants with IBD all stressed the need for all healthcare providers, regardless of their medical specialty, to recognize and respect patients' unique trauma backgrounds and preferences. One patient suggested the implementation of a "trauma action plan" that could be incorporated into an electronic medical record (EMR), which is particularly beneficial for young adults with specific needs and fears related to medical settings. Upon discussion between multidisciplinary clinicians and patients during the roundtable, this trauma action plan was envisioned as something that begins with a screening questionnaire that patients would be invited to complete prior to their visit. This open-ended questionnaire would allow patients the space to disclose any past traumas that they would like their care team to be aware of, including past traumatic medical encounters, and to request certain accommodations during the visit when possible. Examples of the types of accommodations that can be offered to patients are included in [Table 2](#).

Once this screening is completed, it will be documented within the patient's EMR. This would allow the patient's care team, such as the gastroenterologist or perioperative nurse, to proactively review the patient's preferences and tailor their care accordingly. Additionally, this screening questionnaire can also be used as a way to identify which patients may need to be referred to a mental health professional who can help co-develop a more detailed trauma action plan.

Table 1
Recommendations to build trust with young adults with IBD.

Clinician Action: Ways to Build Trust	Example Quote: What to Say to Patients
Proactively offering support at the beginning of a medical appointment	"Is there anything I can do to make this visit more comfortable for you today?"
Normalizing that a caregiver is welcome to accompany the young adult during a medical appointment, treatment (e.g., infusion), or hospital stay	"If you would like to bring someone with you during your [visit/procedure/treatment], please feel free!"
Signpost each part of a conversation during a medical appointment to prepare the young adult for potentially re-traumatizing topics	"This may be a hard conversation to have since it'll include a discussion about treatments, including surgery."
Ask for input from the young adult about how much they feel comfortable discussing	"How much information about the potential surgical procedure do you want from us right now? What would you prefer we save and talk about at another time?"

Table 2

Examples of trauma-informed care accommodations to offer patients.

As much as reasonably possible, accommodating the patient's caregiver (in hospital rooms, during preoperative preparation, during appointments, during treatments, etc.), depending on what the patient prefers
When possible, allow patients to keep their own loose-fitting comfortable clothes rather than mandating hospital gowns
Create a calmer environment in the hospital room perioperative suite by offering to dim the lights and providing extra pillows and blankets
Inviting patients to listen to music or employ other distraction techniques during uncomfortable or painful bedside procedures

We recognize that there are barriers to creating and implementing this type of “trauma action plan” screening. Not every clinic may be supported with the infrastructure to make this change, and many clinics may not have an interdisciplinary care team, including gastro-psychologists and social workers, to provide this whole-person psychosocial care. Roundtable participants emphasized that “something is better than nothing” and that even in a piecemeal fashion, clinicians across the continuum of care adopting these approaches can improve the care of young adults with IBD.

Moreover, young adults with IBD who were diagnosed in childhood may be used to a different.

level of support in pediatric care compared to adult care.^{15,16} Specifically, roundtable participants contrasted their experiences in the inpatient setting in pediatric care with the care they now receive in adult care, noting that dedicated psychosocial support professionals, including Child Life Specialists, were more accessible when they were pediatric patients. Moreover, many accommodations listed in Table 2 are routinely offered to pediatric patients but far less commonly in adult care. This can be a difficult adjustment for young adults with IBD after navigating their transition of care, as it can put these individuals in a position of “forced advocacy” as they now need to ask for accommodations that they had grown up with. Roundtable participants emphasized the need for system-wide changes, including implementing “trauma action plans” and wider use of trauma-informed care principles and accommodations in adult care, as outlined in Table 2.

Conclusion

Medical trauma is a pervasive and ongoing concern for individuals facing lifelong conditions like inflammatory bowel disease (IBD), especially among young adult patients. Roundtable participants recognized that this trauma does not exclusively result from one significant event but is multifaceted, encompassing the capricious nature of the disease, persistent pain, and symptoms that significantly impact daily life. Irrespective of an explicit post-traumatic stress disorder (PTSD) diagnosis, it is crucial to acknowledge that individuals living with IBD likely contend with medical trauma continually, resulting in post-traumatic stress that presents formidable obstacles to a patient's adherence to treatment and willingness to engage with the medical system. Recognizing present and past trauma, including adverse childhood experiences (ACEs), and the critical role of trauma-informed care in healthcare settings is especially critical in the context of whole-person care for individuals with chronic conditions. There is a need for intentional trust-building and communication between clinicians and patients, and best practices for this during medical appointments and hospital visits have been summarized in Tables 1 and 2. Furthermore, roundtable participants advocated for the creation of a “trauma action plan,” a customized, holistic approach to care based on individual patient preferences and trauma histories. By integrating these principles into healthcare practices, clinicians can contribute to a more compassionate and supportive environment tailored to the unique needs of young adult IBD patients navigating the complex landscape of medical trauma.

CRedit authorship contribution statement

Jayswal Nikhil: Conceptualization, Writing – review & editing. **Keefer Laurie:** Conceptualization, Writing – review & editing. **Kohler David:** Writing – review & editing. **Bugwadia Amy K.:** Writing – original draft, Writing – review & editing. **Shapiro Mara:** Writing – original draft, Writing – review & editing. **Dave Sneha:** Funding acquisition, Project administration, Writing – review & editing. **Reed Sydney:** Writing – original draft, Writing – review & editing.

Data availability

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

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