

Trinity College

Trinity College Digital Repository

Senior Theses and Projects

Student Scholarship

Spring 5-19-2024

Medical Trauma in Pediatric and Adult Patients with Crohn's and Ulcerative Colitis

Catherine Raupe
catherine.raupe@trincoll.edu

Follow this and additional works at: <https://digitalrepository.trincoll.edu/theses>



Part of the [Health Psychology Commons](#)

Recommended Citation

Raupe, Catherine, "Medical Trauma in Pediatric and Adult Patients with Crohn's and Ulcerative Colitis".
Senior Theses, Trinity College, Hartford, CT 2024.
Trinity College Digital Repository, <https://digitalrepository.trincoll.edu/theses/1083>

Trinity College
HARTFORD CONNECTICUT

Medical Trauma in Pediatric and Adult Patients with Crohn's and Ulcerative Colitis

A thesis submitted in partial fulfillment for the Bachelor of Science degree in Psychology

Catherine Raupe

Department of Psychology, Trinity College

Professor Brian Chin, PhD and Dr. Bradley Jerson, PhD

Fall 2023 – Spring 2024

Acknowledgements

I would like to thank Professor Brian Chin for his amazing mentorship throughout this process. Your genuine interest in and dedication to your students has been very encouraging. Without your guidance, experience, and wealth of knowledge in the research process, it does not seem possible that I would complete this thesis.

I would also like to thank Dr. Bradley Jerson for inviting me to join his research team at Connecticut Children's Infusion Center. Without your help, I would not have been able to complete my thesis on this topic. Working with you and the team has added to my knowledge of the research process and has inspired me to pursue further education in health psychology and research.

Finally, I would like to thank my friends and family for their encouragement during this process and allowing me to practice my presentations in front of them. Thank you for being a shoulder to lean on and a listening ear through the more stressful times!

Table of Contents

Abstract	5
Introduction	6
<i>Crohn's Disease and Ulcerative Colitis</i>	6
<i>Types of Treatment for Crohn's and Ulcerative Colitis</i>	7
<i>Medical Trauma</i>	9
<i>Literature Review</i>	9
<i>Gaps in the Literature</i>	14
<i>Research Questions and Hypotheses</i>	16
Methods and Materials	16
<i>Participants</i>	16
<i>Procedures</i>	17
<i>Measures</i>	18
<i>Data Analysis Plan</i>	19
<i>Ethical Considerations</i>	19
Results	20
<i>Descriptive Statistics</i>	20
<i>Aim 1: Are micro-medical procedures associated with depression and anxiety symptoms?</i>	20
<i>Aim 2: Are micro medical procedures associated with PTSD symptoms?</i>	20
Discussion	21
<i>Limitations</i>	23

<i>Conclusion</i>	24
References	26
Figure 1.	30

Abstract

Inflammatory Bowel Disease is a term that is used to classify Crohn's Disease and Ulcerative Colitis. It is abundantly clear from past literature that hospitalizations and surgery can lead to PTSD (Taft et al., 2019). However, past research has not examined the impact that smaller procedures, such as infusions, can have on an individual's mental health. Patients at Connecticut Children's Infusion Center were recruited during their infusion appointments. After obtaining consent, patients completed questionnaires measuring their felt stigma and concealment, PTSD, and depression and anxiety symptoms. The research team completed medical chart reviews to identify the types of medications participants were taking and the amount of blood draws and infusions they have had in the past year. Our hypotheses were (1) repeated micro-medical procedures will be positively associated with symptoms of anxiety and depression in individuals with Crohn's and Ulcerative Colitis, and (2) repeated micro-medical procedures will be positively associated with symptoms of medical trauma in individuals with Crohn's and Ulcerative Colitis. Hypothesis one was not supported. However, there was a positive correlation between number of medication types and PTSD symptoms in pediatric patients and adult patients, which is consistent with hypothesis two. Specifically, pediatric patients who were taking rectally-administered medication had higher PTSD scores than patients who were not. Surprisingly, we did not find associations between PTSD scores and patients' number of blood draws and infusions or between micro-medical procedures and anxiety and depression.

Introduction

Crohn's Disease and Ulcerative Colitis

Inflammatory Bowel Disease (IBD) is the term used to classify Crohn's and Ulcerative Colitis (UC), which are characterized by chronic inflammation in the gastrointestinal tract (GI) (Centers for Disease Control and Prevention [CDC], 2022). Crohn's disease and Ulcerative Colitis are both commonly present in older children, teenagers, and adults, and diagnoses require a combination of endoscopy or colonoscopy procedures as well as various other imaging studies.

Crohn's disease can affect any area in the GI tract, starting at the mouth and ending at the anus (Crohn's & Colitis Foundation, 1967). It is most commonly observed in the small intestine and forms ulcers and open sores that produce mucous, and cause bleeding. A few of the many symptoms of Crohn's disease include diarrhea, rectal bleeding, abdominal cramps, pain, and constipation, which can lead to bowel obstruction and frequent urges of bowel movements that typically feel incomplete. According to the Crohn's and Colitis Foundation (1967), Crohn's disease can cause complications outside of the GI tract. Patients may experience sore and swollen joints, vision changes, redness or pain in the eyes, rashes, fever, fatigue, osteoporosis, and many other complications. In more severe cases, a patient may require surgery that removes a portion of their GI tract and a colostomy bag to be placed.

Ulcerative Colitis affects the large intestine and, similar to Crohn's disease, forms ulcers and opens sores that produce mucous, which results in frequent bowel movements (Crohn's & Colitis Foundation, 1967). The common symptoms of UC include loose and urgent bowel movements, bloody stool, abdominal cramping and pain, and persistent diarrhea accompanied by blood in the stool. Additional symptoms of UC include anemia (low red blood cell count), loss of appetite, weight loss, nausea, fever, fatigue, and delayed growth and development in children.

Both Crohn's disease and Ulcerative Colitis are characterized as chronic illnesses. A chronic illness is a disease with no current known cure and is a condition that the individual will have for the duration of their life (Hwang, 2001). Crohn's disease and Ulcerative Colitis are treated through symptom management using various kinds of medications with the goal of remission. A patient with Crohn's disease or UC is considered to be in remission when they consistently experience minimal to no symptoms. However, despite being in remission, a patient may experience active disease-causing symptoms, which doctors call a flare. Elements such as food or stress in the individual's life can be a causing factor of a flare, which can last from a few days to several months and vary in severity (Crohn's & Colitis UK, 1979). A patient with Crohn's or UC will experience cycles of remissions and flares throughout their life (Crohn's & Colitis Foundation, 1967).

Types of Treatment for Crohn's and Ulcerative Colitis

The most common types of treatment for Crohn's and Ulcerative Colitis are pharmacological with a few diet modifications. The pharmacological medications range from oral medications to infusions, self-injections, and rectal medications (Crohn's & Colitis Foundation, 1967). The medications include a long list of side effects, a few of which are fatigue, rash, injection site reactions, nausea, headache, joint pain, and nasal stuffiness. Certain medications may dampen an individual's immune system and can put them at risk of becoming immunocompromised. An individual who is considered to be immunocompromised is more susceptible to contracting illnesses and diseases and is advised to avoid crowded areas ("What You Need to Know, 2020).

An additional form of treatment is the elemental diet, which substitutes food with a liquid meal replacement that is the most 'elemental' breakdown of food. Patients have the option of

Medical Trauma in Pediatric and Adult Patients with Crohn's and UC

drinking the liquid meal replacement or having a nasogastric tube (NG tube) placed. During the elemental diet, patients do not eat other food with the purpose of giving their GI tract a reprieve from digestive activity (Cleveland Clinic, 2021).

Another form of treatment is to deliver the medication through the individual's vein (intravenously) using either gravity or a pump to regulate the rate of administration of the medicine; this method is called an infusion (Infusion 101, 2020). The term infusion encompasses IV push, subcutaneous, and intramuscular injections. According to a video on the *National Infusion Center Association's* website, an IV push is when the medicine is administered slowly and intravenously by syringe. A subcutaneous is injected under the skin, and intramuscular is injected into the muscle. Once the medication is administered, a nurse will typically monitor vital signs every thirty minutes to watch for side effects and infusion reactions.

When a patient arrives for their infusion, the nurse will take their temperature and weight and check their vital signs. If a patient has a fever, it can be a sign of infection, which can postpone the infusion until a later date. The patient's weight is taken as certain medications require an accurate weight at the time of the appointment to determine the correct amount of medication that should be administered (How Remicade is Given, n.d.). After vital signs and weight are taken, the patient is brought to their room or chair to have their IV placed while the pharmacy prepares the medication for administration. A typical infusion center will have only a certain number of private rooms and a large open room with multiple chairs and sometimes no privacy curtain. Infusions can vary in length from 30 minutes to 8 or more hours. Patients are additionally required to remain in the chair for 30 minutes after the infusion is done to monitor for a reaction (How Remicade is given, n.d.).

Medical Trauma

Medical Trauma is defined as a traumatic stress response due to interactions with the medical system (Philadelphia College of Osteopathic Medicine, 2023). Symptoms include re-experiencing the event(s), which can occur through flashbacks or nightmares, and avoiding situations that may trigger memories of the event (Taft et al., 2023). Patients may also experience low mood and increased irritability (Taft et al., 2023). In pediatrics, medical trauma has been seen to decrease adherence to medical treatments and lead to a poorer quality of life (Bardach et al., 2023). Treatments for Crohn's and Ulcerative Colitis involve chronic exposure to potentially traumatic or distressing events, such as multiple needle sticks, failed peripheral venous catheter placement, and potential allergic reactions to medications. A failed IV placement can be particularly painful as the medical professional placing the catheter misses the vein, resulting in the needle end of the catheter coming into contact with the soft tissue around the vein ("Blown vein," 2023). This contact can be extensive in just one attempt, and it is common for more than one attempt to be required.

However, patients are unable to stop receiving infusions even after a particularly traumatic event as the medication is needed to remain in remission. Thus, a pediatric patient who experiences a failed peripheral venous catheter placement or a vasovagal response during the IV placement must continue the treatment per their doctor's advice with the knowledge that another vein may be missed. Our study defines the repeated blood draws, infusions, and self-injections associated with IBD treatments as *micro-medical procedures*.

Literature Review

One million patients in the US and 2.5 million in Europe live with an IBD diagnosis (Kahn et al., 2023). Rates of PTSD within the US are estimated to be around 6% to 8%, and

approximately 1 million adults in the US are diagnosed with illness-associated PTSD annually (Taft et al., 2019). In a study by Cuneo et al. (2023), 90% of their respondents had cared for a pediatric patient with a chronic illness whom they thought was impacted by pediatric medical traumatic stress (PMTS). It is estimated that 25% of new IBD diagnoses occur in children or adolescents (Easterlin et al., 2020), and according to Christian-Brandt et al. (2019), two-thirds of children in the United States will experience a traumatic event by adulthood.

In regard to the prevalence of PTSD in IBD, there have been a variety of statistics from several different studies. Taft et al. (2021) estimated that traumatic stress occurs in 9% to 27% of the patients who experience an acute medical event. When examining Crohn's and Ulcerative Colitis, it has been approximated that patients with CD are more likely to experience post-traumatic stress (PTS) than those with UC. 5.6% of the participants in a study by Taft et al. (2021) had a prior diagnosis of IBD-related post-traumatic stress (PTS), and 9.6% of the participants met the full diagnostic criteria for PTSD. Another study by Taft et al. in 2023 estimated that 12% to 25% of the general population have medically induced PTS. The same study reported that women and racial-ethnic minorities were disproportionately affected, with 25% of patients reporting significant PTS symptoms (Taft et al., 2023). In an earlier study by Taft et al. in 2019, researchers reported that 1 in 5 patients with IBD may be affected by PTSD, and a greater proportion experience subclinical PTSD.

Along with high rates of PTSD in patients with IBD are significant comorbidities. Taft et al. (2019) reported that in pediatric and adult IBD, patients are more likely to experience anxiety and depression. Easterlin et al. (2020) had similar findings, reporting that pediatric IBD patients are at an increased risk for depression and anxiety as well as poor health-related quality of life, difficulties with social and school functioning, and attempted suicide. A study by Cushman et al.

(2021) found that behavioral/emotional problems, including depression, affected up to 31% of youth with IBD. In 2022, Lawton et al. estimated that 15% of youth with IBD experience symptoms of depression, and 20% of adults and 16% of pediatric IBD patients report clinically significant symptoms of anxiety.

In terms of PMTS, PTSD, and PTS, these diagnoses can have a significant effect on patient care outcomes. Cuneo et al. (2023) reported that PMTS has been associated with decreased adherence to medical treatments and a poorer quality of life. PMTS symptoms additionally led patients and their families to distrust their care teams, refuse treatments, and delay care (Cuneo et al., 2023). It has been seen that poorer psychosocial functioning is associated with nonadherence, risk of relapse, worsened disease activity, and higher health costs, which leads us to expect this same outcome in patients with PTS (Cushman et al., 2021). Taft et al. (2021) found that increased PTS symptoms corresponded with increased anxiety, depression, fatigue, and pain interference. In their study, one-quarter of the participants had moderate to severe symptoms of re-experiencing the event(s), avoidance, negative mood, and increased arousal. Those with greater levels of negative mood and increased arousal were observed to have significantly lower chances of being in clinical remission (Taft et al., 2021).

Children who are impacted by chronic illnesses are at a specific vulnerability for pediatric medical traumatic stress (Cuneo et al., 2023). Christian-Brandt et al. (2019) established that the risk factors for PMTS are younger age, experiencing more invasive procedures, high illness severity, and longer length of stay in intensive care units. In addition to these factors were a patient's perception of the trauma or life threat and patient and caregivers' stress response. According to Taft et al. (2019), psychological distress occurs from symptoms of burden, self-management stressors, social stigma, and treatment side effects. It is not uncommon for patients

with Crohn's disease and Ulcerative Colitis to feel as though they are a burden to others and often stress about remembering medication, doctor's appointments, and procedures.

In terms of what leads to trauma, it is abundantly clear that patients experience an extensive amount of trauma during hospitalizations. In 2019, Taft et al. found that IBD patients reported an intense fear during surgery and hospitalizations, as well as fair to poor surgery and hospital experiences. Taft et al. (2021) reported that patients who had at least one hospitalization showed symptoms of re-experiencing and increased arousal and met the full diagnostic criteria for IBD-related PTS. In addition to this, Taft et al. (2021) reported that patients who had significant re-experiencing PTS symptoms were 2.18 times more likely to have been hospitalized due to IBD. Half of Taft et al.'s (2021) participants reported that their IBD symptoms and flares were sources of trauma, and in contrast to their 2019 findings, surgery received little endorsement as a source of medical trauma.

In a follow-up study by Taft et al. done in 2023, they found that 40% of participants cited a hospitalization as a source of medical trauma, and patients reported that poor communication and information exchange were major contributors to their hospital trauma. There was little research done on infusions and medication regarding medical trauma. Easterlin et al. (2020) found that anxiety of the unknown and managing patient's pain and anxiety during IV placement were the biggest challenges for patients. Patients reported anxiety leading up to the IV placement as well as during, which would last until they returned home. Patients using corticoid steroids reported distressing side effects such as psychiatric symptoms and stigmatizing physical changes (Pothemont et al., 2021). Immune-suppressing medications were associated with anxiety related to potential side effects such as hair loss and susceptibility to illness (Pothemont et al., 2021).

Medical Trauma in Pediatric and Adult Patients with Crohn's and UC

A few patients reported that they would experience frequent absences from school and disrupted normalcy due to infusion appointments, which were difficult to explain to peers (Easterlin et al., 2020). Patients who had experienced an NG tube placement reported that they felt extreme levels of discomfort, pain, and anxiety (Pothemont et al., 2021).

When considering these various procedures and treatments patients undergo, one would assume that they are performed from a trauma-informed care lens. However, a study by Cuneo et al. (2023), which surveyed several clinicians caring for pediatric patients with chronic illnesses, discovered that only one-half of providers reported trauma-informed care training was available to them, and only 38% had received said training. Of the participants, 70% reported feeling that their institution had inadequate resources for patients to address PMTS symptoms, and it was found that PMTS-focused trauma-informed care was uncommon. In terms of standardization, there is no standardized approach to promoting the psychological well-being of IBD patients (Kahn et al., 2023).

To address the lack of trauma-informed care in pediatric chronic illness, one researcher suggests that we conceptualize IBD anxiety as a distinct construct from generalized anxiety disorder. According to Stellway et al. (2023), pediatric psychology has distinguished between disease-specific distress and psychopathology as separate constructs. Standard interventions for anxiety, such as cognitive-behavioral therapy (CBT), may be ineffective for an individual with IBD-related distress. CBT is used to approach a fear as irrational and absolute thinking; however, for a patient with IBD, fears that may seem irrational to the average person are very rational when in the context of IBD flares (Stellway et al., 2023).

In response to the trauma that patients with IBD experience is resilience, as resilience cannot occur without said trauma (Lawton, 2022). According to Lawton (2022) we must

understand the trauma that IBD patients experience before we can understand the construct of resilience. However, it is clear that significant areas of trauma patients experience are under-researched. It is important that we research these areas, as youth with IBD are more likely to deplete their emotional coping resources faster than healthy peers (Cushman et al., 2021).

Gaps in the Literature

There is an abundance of literature that examines hospitalizations and medical trauma in patients with Crohn's and Ulcerative Colitis. However, few have looked at micromedical procedures and their impact on an individual over time. Easterlin et al. (2020) reported on IV placement and anxiety, but there was no reported data on IV placements that were done incorrectly and led to a failed peripheral catheter placement and the impact this has on patients. Patients are exposed to these procedures frequently and often are at risk of having a missed or injured vein. It is crucial that providers understand the symptoms of trauma in IBD patients in order to examine resilience and targets for treatment (Lawton, 2022).

Additionally, there was an insufficient amount of prior literature on medical trauma in Crohn's and Ulcerative Colitis. There is an abundance of research on medical trauma for various other diseases, but very few studies were specific to Crohn's and Ulcerative Colitis. It is concerning that there is a deficit in research on this when it was observed in the Cuneo et al. (2023) study that a significant portion of providers caring for pediatric patients with chronic illness have not been trained in trauma-informed care. Furthermore, Taft et al. (2021) observed that patients who were younger reported more PTS symptoms across all groups and were more likely to meet the criteria for IBD-related PTS. It is also suggested that traumatic stress is underdiagnosed in patients with IBD (Taft et al., 2021).

It is important that the causes of trauma are thoroughly investigated for patients with IBD, as it is hypothesized that inflammation can be a risk factor for PTSD development (Taft et al., 2021). This places patients with Crohn's and UC at a higher risk of developing a trauma disorder, hence why it is vital that healthcare providers be informed of what may cause a patient trauma. Further factors that place individuals at risk are anxiety combined with poor communication or feeling unheard by their provider (Taft et al., 2023). It is, unfortunately, not uncommon for patients to feel that they are not listened to by providers, and multiple studies listed this as a trauma-inducing factor.

Patients are repeatedly exposed to potentially traumatic events without trauma-informed care. Cuneo et al. (2023) reported that the most common misconceptions among providers were that families and patients do not cope well on their own after a serious injury, that significant pediatric medical traumatic stress levels are unavoidable in pediatric patients with chronic illness, and that pediatric medical traumatic stress screening measures are not available. There is a lack of resilience programs built into not only surgical appointments, but everyday appointments as well.

Potentially traumatic events for patients with IBD are unavoidable procedures. Because a large majority of self-injection and infusion medications are biologics, patients can build up antibodies to them (Arthritis Foundation, 1948). These antibodies cause the medications to no longer be effective, and the patient must then switch from an infusion to a self-injection or another infusion medication if oral medications are ineffective. The process of receiving an infusion can be quite overwhelming. Upon arrival, patients immediately have their vitals taken and their IVs placed. They are given little time to adjust and regulate themselves after the IV

placement and before the medicine is administered. If a patient finds the placement distressing, they are not given time to adjust.

Research Questions and Hypotheses

This study examines the association of micro-medical procedures with depression, anxiety, and medical trauma in patients with Crohn's and Ulcerative Colitis. Our research questions are: (1) Are micro-medical procedures (i.e., repeated blood draws, infusions, and self-injections) associated with anxiety and depression symptoms in patients with IBD, and (2) are micro-medical procedures associated with symptoms of medical trauma in patients with IBD? We hypothesize that (a) repeated micro-medical procedures will be positively associated with symptoms of anxiety and depression in individuals with Crohn's and Ulcerative Colitis, and (b) repeated micro-medical procedures will be positively associated with symptoms of medical trauma in individuals with Crohn's and Ulcerative Colitis. Patients will answer questions through a REDCap survey regarding anxiety, depression, and medical trauma in relation to Crohn's and Ulcerative Colitis. The data collected will be analyzed to examine this relationship and determine if there is an effect.

Methods and Materials

Participants

The data presented were collected from patients recruited from Connecticut Children's Division of Digestive Disease, Hepatology, and Nutrition's IBD program. Recruitment occurred in-person during patients' scheduled appointments or via phone. Study procedures were approved by the center's Institutional Review Board.

Inclusion criteria consisted of (a) having a diagnosis of Crohn's or Colitis, (b) in active treatment for IBD at Connecticut Children's, (c) being between the ages of 12-26, and (d) completing a minimum of 50% of the survey. Exclusion criteria were (a) having a psychiatric hospitalization within the past six months, (b) being unable to provide assent, (c) not being fluent in English, (d) having a caregiver who is unable to provide consent, and (e) having a caregiver who is not fluent in English. A total of 17 participants completed the survey. Participants received a \$25.00 gift card for completion of the survey.

Procedures

Patients were approached during their infusion appointment, and after providing the informed assent and obtaining their caregivers, or the patients, informed consent, participants completed a REDCap survey using an iPad or personal phone, laptop, or tablet, which included (a) the Psychological Sense of School Membership (PSSM), (b) the Connor-Davidson Resilience Scale (CD-RISC), (c) the Felt Stigma and Concealment Questionnaire, (d) the Child PTSD Symptoms Scale for the DSM-5 (CPSS-V SR) or the PTSD Symptoms Checklist for the DSM-5 (PCL-5), (e) the Pediatric PROMIS - 43 Profile or the PROMIS v1.1 Pediatric Profile 49 (from the PROMIS Pediatric Health Profile). The CPSS was used for participants under 18 years of age and the PTSD Symptoms Checklist was used for participants 18 and older. Data from the PSSM, CD-RISC, and Felt Stigma and Concealment Questionnaire are reported elsewhere. The survey took approximately 40 minutes to complete. Demographics of participants were self-reported. Study recruitment occurred between March 2024 and April 2024.

After participants' completion of the survey, a medical chart review was conducted. The following information was recorded through an extensive review: diagnosis, patient age at diagnosis, patient's current age, Crohn's disease activity index (CDAI), Ulcerative Colitis

activity index (PUCAI), Medical interventions (oral 5-ASA, steroids, immunomodulators, biologics, hospitalization, surgery, other), method of medication (oral only, oral and self-injection, oral and infusion, infusion only, dietary management alone, other), number of lab test results, and number of infusions in the past year. Data were analyzed in April 2024.

Measures

Child PTSD Symptoms Scale for the DSM-5 (CPSS-V SR)

The Child PTSD Symptoms Scale for the DSM-5 (CPSS-V SR) is a revised version of the Child PTSD Symptoms Scale. It is a 27-item self-report that assesses PTSD *DSM-5* diagnosis and symptom severity. 20 items assess *DSM-5* PTSD symptoms that are answered on a Likert scale from 0 (not at all) to 4 (six or more times a week/almost always). Seven items assess how daily functioning is impacted. Total severity scores range from 0-80 and are calculated by summing the first 20 items. Impairment scores range from 0 to 28 and the overall impairment score does not contribute to the overall severity score.

PTSD Symptoms Checklist for the DSM-5 (PCL-5)

The PTSD Symptoms Checklist for the DSM-5 (PCL-5) was developed in 1990 at the National Center for PTSD. The PCL was revised in 2010 after the initial draft criteria for PTSD in the *DSM-5*. The PCL-5 added three items to assess blame, negative emotions, and reckless or self-destructive behavior. It was additionally reworded to reflect the changes of PTSD symptoms and changed the rating scale from 1-5 to 0-4 so that the total score of no symptoms reflected a 0 and not 17. There are three versions of the PCL-5, which follow as not assessing Criterion A, defining Criterion A, and a Life Events Checklist for *DSM-5*. Items are scored as sums to measure for PTSD symptom severity and symptom clusters.

PROMIS Pediatric Health Profile

The National Institute of Health developed the Patient Reported Outcomes Measurement Information System (PROMIS). There are several different self-report questionnaires for individuals ages 8-17 years old. The questionnaires are developed around five general health domains and include one measure for pain intensity. The five health domains are physical function, pain, fatigue, emotional health, and social health. The PROMIS scales are nondisease-specific scales and can therefore be applied to any type of disease.

Data Analysis Plan

SPSS or R Statistical Computing was used to conduct several descriptive statistical tests. Bivariate correlations were computed to evaluate relationships between micro-medical procedures and anxiety, depression, and medical trauma. A p value of .05 was used to determine statistical significance.

Results were calculated separately for participants over the age of 18 and under the age of 18, given that the scales used to assess PTSD, anxiety, and depression symptoms differed depending on age.

Ethical Considerations

This study was approved by the Institutional Review Board of Connecticut Children's Hospital. In compliance with the Institutional Review Board, chart reviews were performed to gather data from routine clinical care and determine eligibility.

Results

Descriptive Statistics

Of the 17 participants, eight identified as female, eight as male, and one as genderqueer/gender non-conforming. The mean age of participants was 18.1, and 15 identified as white. One participant identified as black and another as Hispanic/Latinx. 70% of participants were diagnosed with Crohn's disease and 30% with Ulcerative Colitis. The average age of diagnosis for children was 13.1, and the current age was 16.1 years old. For adults, the average age of diagnosis was 11.6, and the current age was 19.8. On average, it had been eight years since diagnosis for adults and three years since diagnosis for children.

Aim 1: Are micromedical procedures associated with depression and anxiety symptoms?

We used a bivariate correlation to test whether the number of blood draws, injections, and medication types were associated with depression and anxiety symptoms in pediatric and adult patients. Contrary to hypothesis one, none of the micro-medical trauma variables were correlated with depression and anxiety symptoms in pediatric patients (all $p > .10$) or adult patients (all $p > .19$).

Aim 2: Are micromedical procedures associated with PTSD symptoms?

We used a bivariate correlation to test whether number of blood draws, injections, and medication types were associated with PTSD symptoms in pediatric and adult patients.

Consistent with Hypothesis 2, there was a positive correlation between number of medication types and PTSD symptoms in pediatric patients, $r(6) = .84, p = .009$, and adult patients, $r(7) = .71, p = .034$. However, we did not observe correlations between number of blood draws and PTSD symptoms in pediatric patients, $r(6) = -.18, p = .67$, or adult patients, $r(7) = .27, p = .49$, or number of injections and PTSD symptoms in pediatric patients, $r(6) = -.38, p = .36$, or adult patients $r(7) = .07, p = .86$.

A follow-up analysis was conducted to examine which medication types were most predictive of PTSD symptomology in each group. Of the patients, all but one were taking oral medications, all had received infusions, two administered self-injectables, five other medication types, and only one received dietary management.

For pediatric patients, there were four taking another medication type and four not taking another medication type. Of these four individuals, three were taking rectally administered medication, and one was taking sublingually administered medication. We used an independent samples t-test to compare the PTSD symptoms of patients who were and were not taking other medication types. When comparing pediatric patients who were and were not taking another medication type, we found higher PTSD symptoms in patients who were taking other medications ($M = 18.5$, $SD = 5.0$) compared to those who were not ($M = 1.8$, $SD = 2.4$), $t(6) = 6.06$, $p < .001$. This pattern is illustrated in Figure 1.

Discussion

This study aimed to address the under-researched area of micro-medical trauma in patients with Crohn's and Ulcerative Colitis. The effect that hospitalizations and surgeries have on patients has been extensively researched across the area of chronic illness. The aim was to research the procedures and appointments that IBD patients experience daily.

The results did not support the first hypothesis that repeated micro-medical procedures will be positively associated with symptoms of anxiety and depression in individuals with Crohn's and Ulcerative Colitis. There were no significant findings when analyzing anxiety and depression scores and the number of blood draws and infusions. As for the second hypothesis, that repeated micro-medical procedures will be positively associated with symptoms of medical trauma in individuals with Crohn's and Ulcerative Colitis, we found support when analyzing

PTSD scores and type of medication. Per the results, patients who were prescribed rectally administered medication had higher PTSD scores than patients who were not taking other medications. Contrary to the second hypothesis, we did not find a correlation between PTSD scores and the number of blood draws and infusions a patient has had. We did, however, find that for both adults and children PTSD scores were high for those who had more medication types.

A potential impact on the study was the environment in which patients were completing the survey. The majority of the patients completed the survey during their infusion appointment. During these appointments, nurses came in and out of their rooms to check vitals, which may have impacted the patient's ability to concentrate on the survey and provide accurate answers. The survey was estimated to take 40 minutes; however, participants were completing the survey within 15 minutes. Participants may have been unable to pay attention to the survey and read the questions in the depth necessary due to the distraction of the infusion center. Infusion pumps beeped periodically, there were sounds of children crying or in distress during IV placement, and some of the medications administered caused the patient to feel extremely fatigued. These various factors may have impacted the quality of the answers patients were providing.

A second potential impact was patients who have received therapy versus patients who have not. Patients who are actively in therapy or who had previously been in therapy may have developed various coping skills that lower their PTSD scores compared to participants who have not been in therapy. Patients learn in therapy different ways to cope with traumatic events and can work through the event(s) with their therapists. Patients who have not completed therapy have not learned these coping skills and may keep the trauma to themselves as opposed to working through it in a healthy manner.

Similarly to the second impact, younger patients may have less effective coping skills than older patients. A 12-year-old has had significantly less life experience than participants who are 26. Due to this, younger patients have not had the chance to develop natural coping skills as older patients have. An event that a younger patient finds particularly traumatic may be neutral for an older patient. The younger patient has not acquired the coping skills necessary to process the trauma when it occurs or after.

Limitations

The findings of this study should be read in the context of limitations. During the process of piloting the study, various bugs within REDCap occurred. Due to this, recruitment took place over a period of two weeks, which did not leave ample time to collect a robust sample size. There were also many minor challenges when recruiting and encouraging completion of the survey. Patients were, understandably, reluctant to complete the survey during their infusion appointment and opted to complete the study remotely at a later time. However, follow-up for completion of the survey was difficult as it was the patient's responsibility to complete the survey. At one point during recruitment, the survey stopped advancing from the demographics to the next measure. This glitch was quickly resolved but significantly slowed down that day's recruitment.

Second, the sample size of this study was relatively small and came from a specific population of IBD patients at the Connecticut Children's Infusion Center in Hartford, Connecticut. When examining prior studies, it appears that it is common for IBD study sample sizes to be small. The reluctance of IBD patients to participate in studies may be due to the challenges and stress of the disease. Many patients have various procedures, appointments, and surgeries they are undergoing and do not want to add participation in a study to their already

busy schedule. Additionally, our population was very specific, which limited our recruitment opportunities.

A third limitation was the process of reviewing patients' medical charts. For each participant, the total number of lab results (blood draws only) and injections (in the past year) was counted manually. A reliability check was conducted and showed only 76% reliability. Age at diagnosis, mode of medication, type of medication, current age, hospitalizations, and surgeries were also found manually through chart review. Due to time constraints, we were unable to generate a report from EPIC (the electronic health record system) for a more accurate review.

Conclusion

Prior research in IBD has found that patients can experience a great deal of trauma during hospitalizations and surgeries that can lead to the development of PTSD. The findings of our study, however, suggest that trauma can occur outside of hospitalizations and surgeries. While our definition of micro-medical procedures was specific to blood draws, self-injections, and infusions, this does not include all micro-medical procedures patients undergo. Oral medication, rectal medication, sublingual medication, and non-surgical gastrointestinal appointments could be considered micro-medical procedures. The findings were in contrast to Easterlin et al. (2020), who reported that IV placement was a significant source of patients' anxiety. In this study anxiety was not significantly correlated with the number of infusions a patient has had.

The findings of this study can provide insight into potential medication types that can contribute to PTSD symptoms in patients. Both adults and children had higher PTSD scores with more medication types. The medical community should be aware that it is not only hospitalizations and surgeries which can contribute to PTSD. These findings can inform what

trauma-informed care training should cover and how patients may experience trauma during various procedures, including those which are micro-medical.

It would be beneficial to repeat this study with a much larger sample size. Findings will most likely differ if the study were to be conducted with 150 participants as opposed to 17. The research should attempt to have a more even split between children and adult participants as well as Crohn's and Ulcerative Colitis. Additionally, it would be beneficial to conduct a qualitative study to identify the specific aspects of IBD that contribute to trauma. Focused interviewing may provide the opportunity to capture the patient's lived experience. The micromedical procedures researched in this study are only a small part of the everyday experiences patients with IBD have. In order to provide medical staff with adequate trauma-informed care training, potential traumatic events need to be identified. Future research should also conduct this study with separate samples of patients with only Crohn's disease and patients with only Ulcerative Colitis as the events patients find traumatic may differ amongst the two illnesses.

Patients with chronic illness, particularly those living with life-limiting challenges every day, must be provided with acknowledgment and support from medical staff. It is essential that when caring for these patients, medical providers are aware of the potentially traumatic events patients may experience. Having constructive research on all aspects of trauma to inform care delivery could relieve the burden of some of their life-limiting challenges and enable patients to have a better quality of life.

References

- Blevins, C.A., Davis, M.T., Domino, J.L. Weathers, F.W., and Witte, T.K. (2015). The Posttraumatic Stress Disorder Checklist for *DSM-5* (PCL-5): Development and Initial Psychometric Evaluation. *Journal of Traumatic Stress*, 28, 489-498. <https://doi.org/10.1002/jts.22059>
- Blown vein from IV: what happens next. (2023). *South Valley Vascular*.
<https://www.southvalleyvascular.com/post/blown-vein-from-iv-what-happens-next>
- Center for Disease Control and Prevention. (2022). *Inflammatory Bowel Disease (IBD)*.
<https://www.cdc.gov/ibd/what-is-IBD>
- Child PTSD symptom scale for DSM-5 (CPSS-5)*. ISTSS. (n.d.). [https://istss.org/clinicalresources/assessing-trauma/child-ptsd-symptom-scale-for-dsm-5-\(cpss-5\)#:~:text=The%20Child%20PTSD%20Symptom%20Scale,to%20identify%20an%20inex%20trauma.](https://istss.org/clinicalresources/assessing-trauma/child-ptsd-symptom-scale-for-dsm-5-(cpss-5)#:~:text=The%20Child%20PTSD%20Symptom%20Scale,to%20identify%20an%20inex%20trauma.)
- Christian-Brandt, S. A., Santacrose, E. D., Farnsworth R. H., MacDougall, A. K. (2019). When Treatment is Traumatic: An Empirical Review of Interventions for Pediatric Medical Traumatic Stress. *American Journal of Community Psychology*, 64, 389-404.
<https://doi.org/10.1002/ajcp.12392>
- Connor, M. K., & Davidson R.T. J. (2003). Development of a New Resilience Scale: The Connor-Davidson Resilience Scale (CD-RISC). *Depression and Anxiety* 18, 76-82.
<https://doi.org/10.1002/da.10113>
- Crohn's and Colitis Foundation of America (CCFA). (2014). *What is Crohn's Disease?*
- Crohn's and Colitis Foundation of America (CCFA). (2014). *What is Ulcerative Colitis?*
- Cuneo, A. A., Sifflet, C., Bardach, N., Ly, N., von Scheven, E., Perito, R. E. (2023). Pediatric

Medical Traumatic Stress and Trauma-Informed Care in Pediatric Chronic Illness: A Healthcare Provider Survey. *The Journal of Pediatrics*, 261.

<https://doi.org/10.1016/j.jpeds.2023.113580>.

Cushman, G. K., Shih, S., Stolz, M. G., Hinrichs, R. C., Jovanovic, T., Lee, J. L., Kugathasan, S., Dampier, C. D., DeWalt, D. A., DeWitt, E. M., Gross, H. E., Gipson, D. S., Hinds, P. S., Huang, I. C., Selewski, D. T., Thissen, D., & Varni, J. W. (2015). PROMIS(®) pediatric self-report scales distinguish subgroups of children within and across six common pediatric chronic health conditions. *Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation*, 24(9), 2195–2208.

[10.1007/s111360150953-3](https://doi.org/10.1007/s111360150953-3)

Easterlin, C. M., Berdahl, T. C., Rabizadeh S., Spiegel, B., Agoratus, L., Hoover, C., Dudovitz, R. (2020). Child and Family Perspectives on Adjustment to and Coping with Pediatric Inflammatory Bowel Disease. *Journal of Pediatric Gastroenterology and Nutrition* 71(1),16-27. <https://doi.org/10.1007/s11136-015-0953-3>

Goodenow, C. (1993). The Psychological Sense of School Membership Among Adolescents: Scale Development and Educational Correlates. *Psychology in the Schools*, 30, 79-90. [https://doi.org/10.1002/1520-6807\(199301\)30:1<79::AID-PITS2310300113>3.0.CO;2-X](https://doi.org/10.1002/1520-6807(199301)30:1<79::AID-PITS2310300113>3.0.CO;2-X)

How Remicade is Given [Website]. (n.d.). *Remicade Infliximab*.

<https://www.remicade.com/rheumatoid-arthritis/infusion-process.html>

How to Prepare for your Infusion [Slides]. (n.d.). *National Infusion Center Association*.

<https://infusioncenter.org/how-to-prepare-for-your-infusion/>

Hwang, W., Weller, W., Ireys, H. (2001). Out-of-pocket medical spending for care of chronic

- conditions. *Health Affairs*, 20(6), 267-278. <https://doi.org/10.1377/hlthaff.20.6.267>
- Infusion 101 – A Beginner's Introduction to Infusion Therapy [Video]. (2020, March 9).
National Infusion Center Association. <https://infusioncenter.org/infusion-therapy-101/>
- Kahn, S., Sebastian, A. S., Parmar, P. M., Ghadge, N., Padda, I., Keshta, S. A., Minhaz, N., Patel, A. (2023). Factors influencing the quality of life in inflammatory bowel disease: A comprehensive review. *Disease a Month*, 70(1), 1-12.
<https://doi.org/10.1016/j.disamonth.2023.101672>
- Laird, T. K., Smith, A. C., Hollon, D. S., Walker, S. L. (2020). Validation of the Health-Related Felt Stigma and Concealment Questionnaire. *Journal of Pediatric Psychology*, 45(5). 509-520. <https://doi10.1093/jpepsy/jsaa030>
- Lawton, C. R. (2022). "The Tough Get Going": Understanding the Role of Resilience and a Multidimensional Conceptualization of Mental Health Among Patients With Inflammatory Bowel Disease. *Inflammatory Bowel Diseases*, 28(6), 977-979.
<https://doi.org/10.1093/ibd/izab233>
- Pothemont, K., Quinton S., Jayoushe, M., Jedel, S., Bedell, A., Hanauer, B. S., Mutlu, A. E., Taft, H. T. (2022). Patient Perspectives on Medical Trauma Related to Inflammatory Bowel Disease. *Journal of Clinical Psychology in Medical Settings* 29(3).
<https://doi.org/10.1007/s10880-021-09805-0>
- Reed, B. (2021). Stressful life events, depression, and the moderating role of psychophysiological reactivity in patients with pediatric inflammatory bowel disease. *Journal of psychosomatic research*, 141.
<https://doi.org/10.1016/j.jpsychores.2020.110323>.
- Stellway, J. E., Cummings, C., Paternostro, J., Stoeckel, M., Muir, L., Harris, M. A. (2023).

Medical Trauma in Pediatric and Adult Patients with Crohn's and UC

Disease related distress in pediatric IBD: Development and validation of the Crohn's and colitis distress scale. *Clinical Practice in Pediatric Psychology*, 11(2), 147-156.

<https://doi.org/10.1037/cpp0000444>

Taft, H. T., Bedell, A., Craven, R. M., Guadagnoli, L., Quinton, S., Hanauer, b. S. (2019). Initial Assessment of Post-traumatic Stress in a US Cohort of Inflammatory Bowel Disease Patients. *Inflammatory Bowel Disease*, 25(9), 1577-1585.

<https://doi.org/10.1093/ibd/izz032>

Taft, H. T., McGarva, J., Omprakash, A. T., Tomasino, K., Pandit, A., Mutlu, A. E., Hanauer, B. S. (2023). Hospitalization Experiences and Post-traumatic Stress in Inflammatory Bowel Disease: Opportunities for Change. *Inflammatory Bowel Diseases*, 29(5), 675-683.

<https://doi.org/10.1093/ibd/izac148>

Taft, H. T., Quinton, S., Jedel S., Simons, M., Mutlu, A. E., Hanauer. B. S. (2021). Posttraumatic Stress in Patients with Inflammatory Bowel Disease: Prevalence and Relationships to Patient-Reported Outcomes. *Inflammatory Bowel Disease*, 28(5) 710-719.

<https://doi.org/10.1093/ibd/izab152>

The National Child Traumatic Stress Network. (n.d). *Complex Trauma*.

[https://www.nctsn.org/what-is-child-trauma/trauma-types/complex](https://www.nctsn.org/what-is-child-trauma/trauma-types/complex-trauma#:~:text=Complex%20trauma%20describes%20both%20children's,as%20abuse%20or%20profound%20neglect.)

[trauma#:~:text=Complex%20trauma%20describes%20both%20children's,as%20abuse%20or%20profound%20neglect.](https://www.nctsn.org/what-is-child-trauma/trauma-types/complex-trauma#:~:text=Complex%20trauma%20describes%20both%20children's,as%20abuse%20or%20profound%20neglect.)

What you need to know about being immunocompromised during COVID-19. (2020). Penn

Medicine. [https://www.pennmedicine.org/updates/blogs/health-and](https://www.pennmedicine.org/updates/blogs/health-and-wellness/2020/may/what-it-means-to-be-immunocompromised)

[wellness/2020/may/what-it-means-to-be-immunocompromised](https://www.pennmedicine.org/updates/blogs/health-and-wellness/2020/may/what-it-means-to-be-immunocompromised)

Figure 1.

PTSD Symptoms in Children with IBD taking Other Medication

