Implementing and Evaluating Virtual Mindfulness-Based Stress Reduction for Adults with Inflammatory Bowel Disease

by

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Abstract

Inflammatory bowel diseases (IBD), which include Crohn's disease and ulcerative colitis, are chronic diseases of the gastrointestinal tract. Individuals living with IBD suffer from chronic symptoms of fatigue and malnutrition and unpredictable flares of acute symptoms including abdominal pain, diarrhea, and rectal bleeding. The unknown timing and duration of flares can cause feelings of stress, anxiety, and depression in those with IBD which in turn can induce flares in individuals or increase their duration. Despite the connection between these psychiatric co-morbidities and flares, an interdisciplinary approach, that includes integrated mental health care, is often not used when treating people with IBD, despite the evidence that suggests it may improve IBD-related outcomes.

Mindfulness-based stress reduction (MBSR) is an eight-week program that helps individuals overcome stress, alleviate anxiety and improve quality of life. The techniques learned in MBSR can help mediate the negative effects of stress. MBSR is deliverable by psychiatrists to large groups and may also be delivered virtually allowing it to be more accessible than traditional psychiatric therapy groups, that ordinarily require participants to make additional trips to the hospital.

The aim of this study was twofold: to assess the feasibility of a virtually-delivered MBSR group program for patients with IBD, and then subsequently to evaluate participants' experiences in the program. This project used a mixed methods approach and gathered both quantitative and qualitative data. The first study, a feasibility trial, recruited patients with self-identified stress or anxiety via referral from their gastroenterologist. The second study, a qualitative interview

follow-up, recruited patients that participated in the MBSR group and examined the barriers and benefits of the program, as well as the participants' experiences in the group.

Sixteen of 64 (25%) referred patients agreed to participate in MBSR with the most common reason for decline being noted as a lack of time. The enrolled participants reported a variety of age, gender, disease type and severity, and employment statues; however, only female participants completed the program. The 7 (43.8%) participants who completed the program saw encouraging effects including decreased anxiety and depressions scores and increased health-related quality of life, with both improvements remaining stable at 6-month follow-up. The participants that agreed to participate in the interviews described perceived benefits from the program including increased coping strategies and improved disease management techniques. All five interview participants described positive experiences in the program and noted they would recommend the program to others. The participants identified the main barrier of the intervention as the time commitment, with all of them noting the intensity of the intervention was challenging. An interesting finding of the interviews was that all participants expressed a desire for integrated mental health care within their current IBD care.

This study assessed the feasibility and preliminary effectiveness of virtually-delivered MBSR for patients with IBD. Only 25% of patients with anxiety or depression symptoms were willing to participate in the intensive 8-week virtual mindfulness group with the biggest barrier to participation being the time required. For participants that completed MBSR, the long-term effects were promising, and participants expressed positive experiences and a variety of perceived benefits. Importantly, the interest in this intervention and the feedback from

participants provides evidence that IBD patients want to receive interdisciplinary IBD care, with a strong focus on mental health.

Preface

This thesis is an original work by Kaitlyn Chappell. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Mindfulness-Based Group Therapy for Adults with Inflammatory Bowel Disease”, Pro00108955 and “Experiences of Mindfulness-Based Stress Reduction and Other Wellness Practices Among Patients with Inflammatory Bowel Disease”, Pro00119852.

Chapter 2 of this thesis is being prepared for publication as a systematic review with K.Chappell, O. Chinbaatar, KJ Goodman, and K. Kroeker as contributing authors. I was responsible for the development, data collection and analysis, and manuscript composition. O. Chinbaatar assisted with the data collection and analysis and contributed to manuscript edits. KJ. Goodman and K. Kroeker were the supervisory authors and were involved with concept formation and manuscript composition.

Chapter 3 and Chapter 4 of this thesis are being prepared for two separate publications. The authors will include K. Chappell, A. Bihari, D. Meakins, M. Marsh-Joyal, KJ Goodman, JM. Le-Mellédo, F. Peerani, A. Lim and K. Kroeker as contributing authors.

Parts of this thesis have been previously presented at Canadian Digestive Week 2023 and Digestive Disease Week 2023.

Dedication

To the patients who made all of this possible. Your desire to make healthcare better continues to inspire me. You made it clear that mental health is just as important as physical health, and I hope that shines through in this thesis.

Acknowledgements

The past two years of study, and the work that makes up this thesis, would not have been possible without the leadership and guidance from my supervisor, Dr. Karen Kroeker. Her unwavering support of my research, her encouragement and confidence in her students, and her advocacy for her patients are all well represented in this body of work. Her mentorship has been invaluable throughout my master's program, and she remains an inspiration and leader for all women in medicine and research. She approaches the problems in her practice and research with curiosity and tenacity, and the way she models these characteristics has shaped my way of thinking, and me, in ways I could have never imagined. And to Dr. Robert Bailey, who is the greatest supporter of women in GI that I know, thank you for all of the encouragement, and most importantly for introducing me to Dr. Kroeker.

I also owe a great deal of gratitude to my supervisory committee members, Dr. Karen Goodman and Dr. Jean-Michel Le Mellédo. They provided guidance and support and helped me navigate the challenges that I encountered throughout my project. They ensured my project was well-rounded and offered me valuable advice on feedback on at every point of my project's development. I am also extremely grateful that I had the opportunity to work with Dr. Diana Meakins and Dr. Melanie Marsh-Joyal. They were both extremely supportive of my project and me, and I always walked away from our conversations feeling inspired to try and make a difference in patients' lives. Together they introduced me to the field of psychiatric research and made a very good case for choosing psychiatry as a future career. I would not have made it through this project without their support.

I would also like to acknowledge, Allison Bihari, who has mentored me since we first met when I was 18. She first introduced me to Dr. Kroeker, helped me work through more problems than she probably realizes, and made navigating grad school significantly less lonely. Her friendship and support have meant the world to me. All of my friends have been integral to me making it to this point. They spent hours listening to me practice presentations and giving me feedback and were always there to distract me from my workload. To my partner, Connor, there is no one who has been in my corner through this process quite like you, and so thank you for the constant support and encouragement and for reminding me to be proud of all of my accomplishments.

To my mom, dad, and sister: you have all been the best supporters throughout this journey, and I am so grateful for that. You provided me with endless support even if most of things I talked about were outside of all of your areas of expertise. Thank you for always encouraging me to chase my dreams and making sure I knew that I was capable of seeing this project through. To Steve and Pam, who have fostered my desire to learn and explore medicine since the beginning, I owe you both so much gratitude for helping me get here. This would not have been possible without you.

I am extremely grateful to Pfizer Canada and their funding. I was elated to have their support in giving patients' a voice, which is something that is often forgotten about in research. And finally, to all of the participants in this study: there was nobody who supported and motivated me more than all of you. There were many times where I felt discouraged, but listening to how all of you felt about the care you were receiving and how you wanted to improve it for others like you made everything worth it. I am so proud to have been a part of this project with all of you, and I hope that the findings allow me to continue to advocate for the kind of well-rounded care that you all described.

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List of Abbreviations

ACE: Adverse Childhood Event

ACT: Acceptance and Commitment Therapy

AHS: Alberta Health Services

CAD: Canadian dollar

CBT: Cognitive Behavioural Therapy

CD: Crohn's disease

CRP: C-Reactive Protein

FCP: Fecal Calprotectin

GDH: Gut-direct hypnotherapy

HRQoL: Health-related quality of life

IBD: Inflammatory Bowel Disease

IBDQ: Inflammatory Bowel Disease Questionnaire

MAAS: Mindful Attention and Awareness Scale

MBI: Mindfulness-Based Intervention

MBCT: Mindfulness-Based Cognitive Therapy

MBSR: Mindfulness-Based Stress Reduction

PRO: Patient-reported outcome

PHQ-SADS: Patient Health Questionnaire – Somatic, Anxiety, and Depression Symptoms

QoL: Quality of life

RCT: Randomized control trial

SCS: Self-Compassion Scale

SCS-SF: Self-Compassion Scale – Short Form

SIBDQ: Short Inflammatory Bowel Disease Questionnaire

UC: Ulcerative colitis

USD: US dollar

Chapter 1: Introduction and Background

Chapter 1.1: Research Rationale and Statement

This study was initiated by co-primary investigators Dr. Karen Kroeker, Dr. Diana Meakins, and Dr. Melanie Marsh-Joyal. The goal of the study was to pilot a stress and anxiety management intervention that would allow psychiatric services to be integrated into IBD patient care and to grow the field of research relating to the potential benefits of integrating psychiatric services into IBD care. This study builds on existing relationships between specialists working in the healthcare system in an attempt to offer the best care to IBD patients.

The authors of this study have no conflicts of interest to declare with regards to the development or results of this study. The follow-up interview study received funding from a Pfizer Canada Quality Improvement Grant titled "Addressing the Needs of Patients with Mental Health Issues and Inflammatory Bowel Diseases" [76111355].

Chapter 1.2: Inflammatory Bowel Diseases

Inflammatory bowel diseases (IBD), including Crohn's disease (CD) and ulcerative colitis (UC) are incurable diseases of the digestive tract. The suspected etiology of IBD includes an interaction of genetic, immunological, and environmental factors[1,2]. Patients are commonly diagnosed with IBD in young adulthood and experience symptoms including diarrhea, abdominal pain, and fatigue. These symptoms can be debilitating and may result in the need for hospitalization or surgery in some cases. In combination with the incurable nature of the disease, the disease course, which includes acute flares of these symptoms, can impact the quality of life (QoL) of persons with the disease significantly[3,4].

Chapter 1.2.1: IBD and Mental Health

IBD can have a negative impact on a patient's mental health and increase their feelings of psychological distress[5–8]. There is a large body of evidence suggesting the existence of a bi-directional relationship between the gut and brain[9–13], and in light of this, IBD has been classified

as a mind-body disease. More recently, research has begun to investigate mental health factors as contributing to the pathogenesis of IBD and many high-quality studies have observed significant relationships between symptoms of phycological distress, including anxiety and depression, and clinical disease symptoms[7,14–18]. In addition to this, many studies continue to find an association between mental distress, perceived stress and flares in people with IBD[19–22]. Further, perceived stress and symptoms of anxiety and depression can negatively impact quality of life in patients with IBD[23,24], which will be discussed in Chapter 1.2.1:

Psychiatric co-morbidities are common in people with IBD. A recent study from the United States, examining over 260 million emergency department visits, found that compared the general population, adults with IBD are at a ten-fold greater relative risk for suicide, a ten-fold greater relative risk for an anxiety disorder or depression disorder diagnosis, and a 32-time greater relative risk for substance use disorders[25]. Looking at psychiatric symptoms, feelings of anxiety and depression are also extremely common in people with IBD. It was recently estimated that 35.2% of patients with IBD experience clinical symptoms of anxiety and 25.1% of patients also experience clinical symptoms of depression[26]. When their disease is active, the occurrence of these clinical symptoms is even higher in patients with IBD, with anxiety and depression symptoms occurring in 57.6% and 38.9% of IBD patients, respectively[26]. On top of these co-morbid psychiatric symptoms, approximately 25-33% of patients with IBD experience symptoms of psychological distress and post-traumatic stress symptoms from medical procedures, hospital stays, symptoms of their disease, and pain[27–29]. Further, these feelings of psychological distress cause functional impairment (i.e., interference with one or more major life activity) in those with IBD over twice as often as they do in the general population[29]. Mixed methods studies have found that individuals with active IBD commonly associate the reason for their ongoing symptoms with mental health issues[30], yet most of their mental health concerns remained untreated[29–31].

Chapter 1.2.1.1: Barriers to Appropriate Mental Health Care

There are a variety of reasons why people with IBD may not be receiving the appropriate mental health care, but previous patient-identified barriers include a lack of knowledge about resources

and cost[29,32]. Neither of these are particularly surprising. People with IBD often self-manage large parts of their disease including diet, medication, pain, and psychological well-being[33], and the required self-management and coping skills can be overwhelming, leaving little time for personal research about mental health resources. The financial barrier is also unsurprising as the cost of IBD to patients can be extremely high. A recent study from the United States revealed that patients with IBD incurred over twice the out-of-pocket costs compared to non-IBD controls[34]. Even in Canada, where universal healthcare reduces many out-of-pocket expenses, approximately one in ten Canadians prescribed medication does not adhere to their medication regimen due to cost[35] and three in four Canadians with unmet mental health needs reported personal circumstances including cost as barriers to care[36].

Chapter 1.2.2: IBD and Quality of Life

In addition, and in part due to the impact of IBD on mental health, people living with IBD often find themselves caught in a cycle of poor quality of life and severe symptoms of disease. This cycle occurs because the physical and mental symptoms of the disease can reduce patients' quality of life[5,6,37,38] and poor quality of life is associated with lower adherence to provider recommendations[39] and malnutrition,[40] which may increase disease severity[41]. The strength of this cyclical effect is often exasperated during disease flares[4,5,37]. The poor quality of life experienced by people with IBD can also be due to psychosocial factors. IBD can impact a person's ability to be active and enjoy leisure activities[6,42], interfere in their relationships[6,37,42], and decrease their ability to work[6,37,43,44].

Chapter 1.2.3: The Cost of IBD on the Health Care System

Considering the interactions between mental health, poor quality of life, and the symptoms of IBD, as established above, these unmet mental health needs are not only concerning for patients, but for the health care systems in which they are treated. Around the world, IBD is associated with high healthcare usage and high costs to the healthcare system[44–47]. In 2023 in Canada, the direct costs to the healthcare system, dominated by prescription drugs and hospitalization, is estimated to be between $3.33 billion Canadian dollars (CAD) per year[48]. The indirect costs which include lost productivity, early retirement or death, and out-of-pocket expenses is

estimated to cost an additional $2.05 billion CAD per year bringing the total cost of IBD care to between $5.38 billion CAD annually, which is almost double the cost estimated in 2018[48]. Integrated models of IBD care, which include access to an interdisciplinary team and a focus on mental health, have been shown to be effective in decreasing healthcare utilization and cost to the healthcare system in multiple studies, specifically by reducing the amount of hospitalizations[49,50].

Chapter 1.3: Canadian IBD Care

The number of people across the world diagnosed with IBD has increased significantly in the past 50 years[1], and Canada has among the highest incidence and prevalence of IBD in the world[1,51]. In Alberta, there are over 34,000 people diagnosed with IBD[52] and this number is expected to rise to 50,000 by 2030[51,53]. The rising number of people with IBD has led to a greater emphasis on the importance of addressing mental health in IBD care.

Chapter 1.3.1: A Missing Piece

As established above, many studies have investigated the relationship between mental health, quality of life, and disease severity. Leading gastroenterologists from around the world have published recommendations and editorials about the benefits of and need for integrated care[54–58] with many of these publications authored by Canadian researchers[6,59,60]. This desire for integrated care has also been expressed by IBD patients[6,58,61].

Despite this concordance between IBD physicians and patients about the importance of integrated interdisciplinary care with a focus on mental well-being, Canadian clinical practice guidelines for the management of CD and UC includes no recommendations for the screening or treatment of mental health co-morbidities[62,63]. There are several possible reasons for this missing piece in clinical practice guidelines, namely the logistic difficulties of shifting to an integrated care model. In order for a mental health intervention or pathway to be integrated into Canadian IBD care, it would have to be delivered by healthcare professionals who are able to bill the healthcare governing body to ensure that cost is not a barrier to patient access. This means that the intervention would most likely have to be facilitated by a psychiatrist, nurse, or social

worker, which is often not the case in the published trials that investigate the effectiveness of psychological or mind-body interventions. Many of these trials report positive psychosocial improvements for IBD patients, but they employ privately contracted psychologists to facilitate the interventions, and may also include check-ins with research assistants[64,65]. Although this may increase the efficiency and internal validity of the trial, features such as these can these trials uninformative about the effectiveness of the interventions, given that effectiveness measures the success of the intervention in real-world conditions.[66,67]. The importance of exploring the feasibility of interventions will be explored below in Chapter 1.5.

Chapter 1.4: Mindfulness-Based Interventions

In recent years, the term "mindfulness" has been used to describe a wide variety of notions including the psychological trait, the practice of cultivating mindfulness, a state of awareness, and the psychological process[68]. A popular definition of mindfulness is that defined by Jon Kabat-Zinn, who described it as "paying attention in a particular way: on purpose, in the present moment, and non-judgementally", and claims that "this kind of attention nurtures great awareness, clarity, and acceptance of present-moment reality."[69]. This awareness and non-judgemental acceptance are meant to act against the features of psychological distress and the maladaptive tendencies associated with it[68,70].

Mindfulness has been an important practice in Buddhist traditions for centuries, but it has only gained popularity in Western medicine practices in the last 50 years through the development of Mindfulness-Based Interventions (MBIs)[71]. Kabat-Zinn was one of the first to study mindfulness meditation-based interventions, the first of which he called a "Stress Reduction and Relaxation Program"[71]. Kabat-Zinn and his collaborators would continue to study MBIs through the 1980s and 1990s, and eventually develop and rigorously evaluate an 8-week intervention called Mindfulness-Based Stress Reduction (MBSR)[70,72]. In the early 2000s, a similar MBI, one that incorporates elements of cognitive behavioural therapy into the intervention, called Mindfulness-Based Cognitive Therapy (MBCT) would also be developed[73]. Since their creation, MBIs have been extensively tested in a variety of populations, both outside medical settings[74,75] and within them[76–78].

MBSR supports participants by teaching them to approach their thoughts with openness and acceptance and helps them learn to focus on and be non-judgmental of the present moment[71]. MBSR also cultivates mindfulness through its practices which have been found to have a protective effect on mental health[70,79,80]. The protocol is clinically standardized 8-week protocol and includes eight weekly 2.5-hour group session, a full day retreat after week six, and daily home practice. Within the medical setting, MBSR has been shown to be effective in reducing fatigue[78], improving health-related quality of life[81], and reducing stress, anxiety, and depression[82–84] in a variety of patient populations.

MBSR is a group-based intervention, usually featuring between 8-12 participants, although the size of the group can vary depending on the number of facilitators involved. The qualifications required to become an MBSR facilitator, also called instructor or teacher, are tightly regulated and require rigorous training through a "teacher training pathway". This pathway was created at University of Massachusetts Center for Mindfulness, the center where Jon Kabat-Zinn created MBSR. There are training centers around the world approved to deliver the training pathway, and the pathway usually takes between 3-6 years to complete. Certified instructors are often psychiatrists, psychologists, and counselors. MBSR was first designed as an in-person intervention, and prior to the COVID-19 pandemic and the associated rise in telehealth, there were few studies that adapted MBSR to a virtual mode of delivery. A recent trial found the live online delivery of MBSR was equally as feasible and effective as the in-person delivery[85]. Despite the positive findings from this trial, there is a lack of robust studies using non-inferiority designs that evaluate if the live online delivery of MBSR is equivalent to the in-person delivery. A review of MBSR and MBCT delivered using videoconferencing, found that this modality of delivery was feasible and acceptable and added there was tentative support for its efficacy[86]. They noted that a majority of groups delivered using videoconferencing featured smaller group sizes, with the average group size being 4-5 participants. Further, the review emphasizes that future studies should focus on evaluating feasibility, acceptability, engagement, and safety. There are few other guidelines or recommendation for adapting MBIs or other psychotherapy groups for virtual delivery.

Chapter 1.5: Feasibility & Pilot Trials

For many years, authors have struggled to agree on the definition, purpose, and design of feasibility and pilot studies[87–90]. The terms feasibility and pilot are often used interchangeably or in combination with each other which can result in a wide variety of study aims and outcome measures. In addition, many feasibility and pilot studies are never published, and the ones that are published often wrongly place emphasis on statistical significance and effectiveness, instead of feasibility[87].

Recently, Eldridge et al. developed conceptual framework using a Delphi survey and consensus meeting that defined feasibility and pilot trials and their purposes[91]. The framework establishes feasibility as an encapsulating idea which randomized pilot studies, non-randomized pilot studies, and other feasibility studies all fall under. They add that a feasibility study "asks whether something can be done, should we proceed with it, and if so, how" and that a pilot study adds an extra dimension to a feasibility study and "is a study in which a future study or part of a future study, is conducted on a smaller scale to ask the question whether something can be done, should we proceed with it, and if so, how."[91]. This framework[91] and guidance from CONSORT[92], along with many other recommendations[87–90], all emphasize that feasibility studies should focus primarily on feasibility outcomes and that an emphasis on hypothesis testing is inappropriate. They recommend that feasibility outcomes focus on acceptability, implementation, integration, and expansion and note that outcomes related to efficacy or effectiveness should be reported as preliminary.

Feasibility studies are especially useful in helping fill important gaps that rigorous trials, such as randomized control trials (RCTs), may not be able to explore[67]. RCTs are often conducted in highly controlled environments that may not reflect the real-world setting[66,67] and so feasibility studies offer the chance to explore the realities of the clinical or community settings in which the intervention of interest may eventually be implemented. It is therefore important that relevant practitioners and/or community members are involved when conceptualizing and designing feasibility studies. Further, it is suggested that a mixed methods approach to feasibility studies may yield richer results[67]. In conclusion, feasibility studies provide opportunities to assess the

acceptability of interventions and may offer more insight into their integration into a clinical or community setting. They should be scrutinized to the same extent as full-scale studies and researchers should always attempt to publish the results in peer-reviewed journals[67,87,89].

Chapter 2: Literature Review

Chapter 2.1: The Feasibility of Telehealth-Based Psychological and Mind-Body Interventions for People with IBD

As established in Chapter 1.2.1 people with IBD suffer from high rates of psychiatric co-morbidities, symptoms of anxiety, symptoms of depression, and symptoms of psychological distress. The growing awareness of the gastroenterology industry to these co-morbid mental health concerns has led to an increase in studies investigating psychological and mind-body interventions in people with IBD. Many reviews have summarized the efficacy of these interventions in the IBD population [76,93,94]; however, evaluations of effficacy often neglect patient-reported outcomes (PROs) and rarely evaluate if these interventions are feasible in terms of their ability to be integrated into IBD care. For these reasons, we chose to conduct a review that focuses on the feasibility and acceptability of psychological and mind-body interventions in people with IBD.

Generally, psychological and mind-body interventions are of two types, either self-directed or therapist-assisted. Self-directed interventions allow the participant to learn the content themselves through manuals, websites, or apps. Self-directed interventions can be self-paced, or they can follow a timeline. Therapist-assisted interventions involve instruction or help from a therapist, facilitator, or instructor of some type, and are generally more intensive, featuring regularly scheduled meetings with the facilitator. They can be delivered in a one-on-one or group setting. An app that helps users learn about and change their behaviour, using computerized cognitive therapy (cCBT), would qualify as a self-directed intervention, whereas an intervention such as MBSR would qualify as a therapist-assisted intervention.

The delivery of healthcare services using telehealth modalities including phone and videoconferencing increased significantly during the COVID-19 pandemic[95,96]. Despite this rapid shift away from in-person healthcare, both gastroenterologists and their patients agreed that telehealth appointments were acceptable, with some even preferring telehealth delivery for non-emergent visits[97–99]. A recent study evaluating engagement rates in psychiatric care during the pandemic reported stable engagement rates when comparing telehealth-based care to in-person

care, suggesting the telehealth delivery of psychological and mind-body interventions may be acceptable[96]. Because of these changes to standard care, and the potential accessibility benefits associated with telehealth care for rural and remote populations[100], we aimed to explore if it was feasible to offer psychological and mind-body interventions via telehealth for people with IBD.

This review was registered on the International Perspective Register of Systematic Reviews (PROSPERO) on February 17, 2023 (CRD42023395973), and our final literature search occurred on March 10, 2023. We searched Embase, MEDLINE (via Ovid), CINAHL, Scopus, and PSYCHINFO databases for publications using a three-pronged search term strategy, with terms focusing on telehealth-delivery, psychiatric and mind-body interventions, and IBD. A librarian specializing in health and medical research was consulted throughout the search term development. A summary of the search terms is included in Table 2.1.1 and a detailed search strategy is included in Appendix A-1. Study inclusion and exclusion criteria are included in Table 2.1.2.

Table 2.1.1: Summary of Search Terms

IBD	
Category: Inflammatory Bowel Disease	Variations: enterocolitis
Category: Enterocolitis	German, Variation: proctitis
Category: Proctitis	Variations: proctitis
Category: Ileitis	Word: Inflammatory Bowel Disease
Word: Crohn	German, word: Inflammatory Bowel
Word: Ulcerative Colitis	Word: IBD
German, word: Ulcerative Colitis	Word and Category: Crohn's
Word: Regional enterocolitis Word: Ileitis	Word and Category Ulcerative Colitis
Telehealth	
Word: online	Variation: ehealth
Variation: online	Word: web-based
Word: internet	Category: videoconferencing
Word: telehealth	Word: computer
Variation: tele-health	Word and Category: Communication
Variation: telemedicine	Word and Category: Computer Assisted Instruction
Word and Category: telemedicine	Word and Category: Telenursing
Word: Video-	Category: remote consultation

Telehealth	
Word: videoconferencing Word: virtual Word: remote Word: ehealth	Word and Category: telecommunication Words: platforms Word and Category: Mobile apps
Psychological and Mind-Body Interventions	
Word and Category: Yoga Word: Relax- Category: Relaxation Therapies Category: Mind-Body Therapies Word and Variation: mind-body Category: spiritual Therapies Word and Category: Patient Education Category: Psychotherapy Word: Psychotherapy Word: Psychological Interventions Category: Counseling Word and Variation: Psychoeducation Word: Counselling Word: Psychiatric Category: Health Education	Word: Cognitive Therapy Word: Stress Management Word: Managing Anxiety of Depression Word: Behaviour Modification/Therapy/ Change Word and Category: CBT Word: Cognitive Behaviour Therapy Word: Coping Word: Group Therapy/Treatment/Intervention Word: Acceptance Commitment Word and Category: Acceptance and Commitment Therapy Word: Supportive Therapy/Care/ Treatment/Intervention Word: Hypnotherapy Word: Goal Setting Word: Dialectical Behvaiour Therapy

Table 2.1.2: Inclusion and Exclusion Criteria

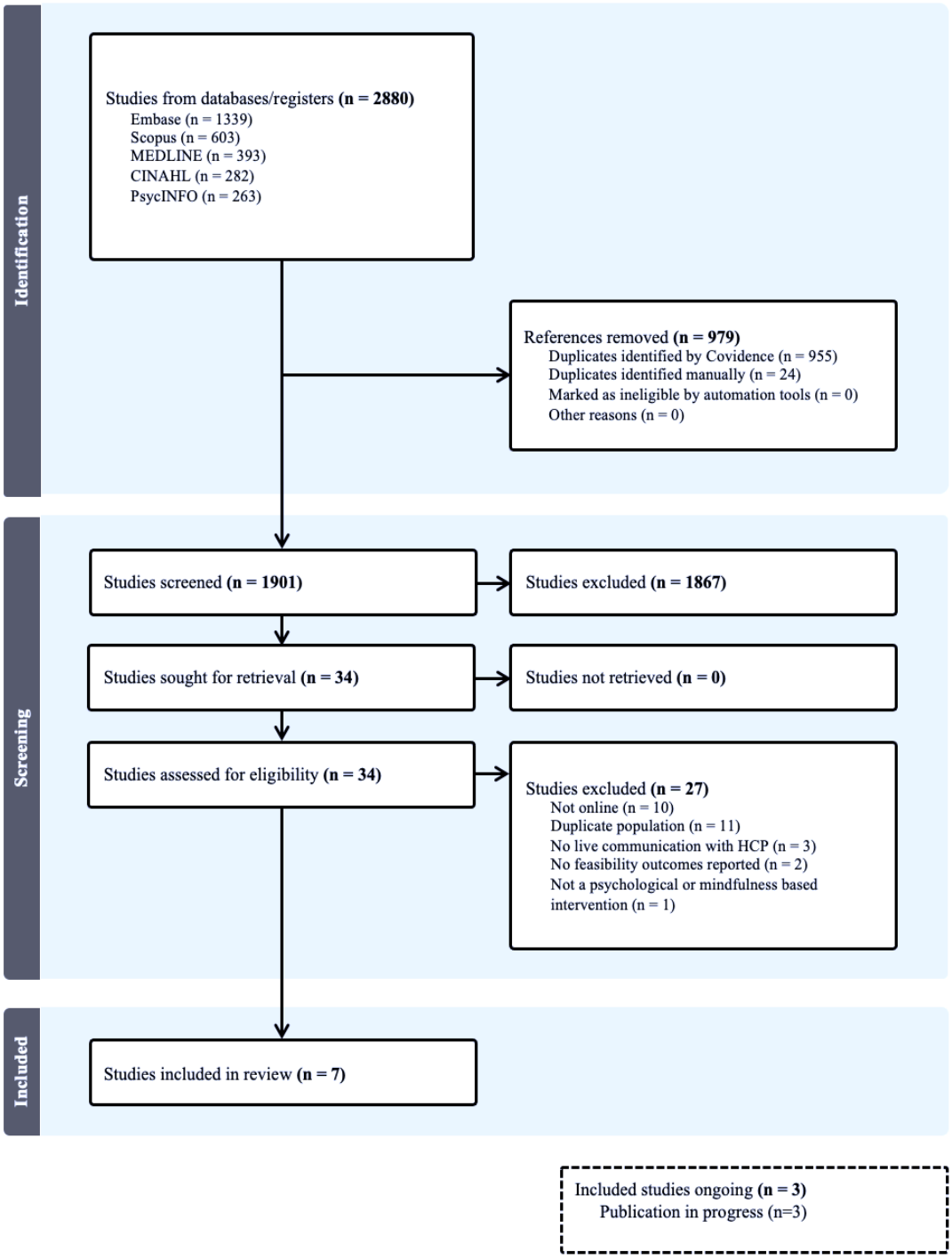
Inclusion Criteria	**Exclusion Criteria**
a. Populations that include persons with any type of IBD diagnosis including Crohn's disease, ulcerative colitis or indiscriminate colitis; clinically diagnosed. b. Adults aged 18+ and adolescents aged 12+.	a. Populations that include persons with symptoms of general gastrointestinal upset or IBS but without a clinical IBD diagnosis. b. People with IBD who also have a neurocognitive disorder and/or developmental delay.

Inclusion Criteria	Exclusion Criteria
c. Any non-pharmacological and non-biological psychological, psychiatric, or mind-body intervention; must be delivered using telehealth and must allow for live communication with health care provider.	c. Interventions supplemented with pharmacological or biological treatment. d. Interventions that are messaging based, self-directed, and/or not delivered via telehealth.

Following searches on each individual database, all the results were exported to Covidence[101] where duplicates were removed. In stage one of screening, two independent reviewers, Otgonbayar Chinbaatar and I, identified relevant publications based on their title and abstract. Any disagreements were decided by a third reviewer, Dr. Karen Kroeker. In stage two, we screened relevant publications based on their full texts. If the full text was not available or only an abstract was available, the authors of the publication were contacted and asked to provide the full-length article. Disagreements during this stage were discussed until a consensus was reached. I performed the data extraction for this literature review. The final systematic review will involve extraction and consensus by both, Otgonbayar and myself. Extracted data included authors, year of publication, country of origin, design, setting and recruitment details, participant characteristics (IBD subtype, mean age, and gender), sample size, intervention type, length and delivery, feasibility-based outcomes, and any relevant effectiveness-based outcomes.

After excluding duplicate and irrelevant publications, seven studies were included in the review. All stages of screening are presented in the PRISMA flow diagram[102] in Figure 2.1.1. Of note, two of the included studies are currently only available as abstracts, and one of the included studies is only available as a published protocol. When the authors of these three studies were contacted, they all confirmed full manuscripts were complete and in the process of being published, and so the preliminary findings were included in this literature review. The complete findings from these three studies will be included in the final systematic review once they are published.

Figure 2.1.1: PRISMA Flow Diagram



A summary of the characteristics of the seven studies included in the review[103–109] is available is Table 2.1.3. Five of the seven studies[104,105,107–109] were published in the last year, and all seven studies were published in the last ten years. Five of seven[103–106,108] were self-described as pilot or feasibility studies, and four of seven had both intervention and control arms. The included studies were conducted in a variety of countries including the United Kingdom[103,109], the United States[104,106], Australia[105,108], and Israel[107]. Most of the studies had modest sample sizes ranging from 9-139. Five of the seven studies[103,105,107–109] were conducted in adult populations and two of seven[104,106] were conducted in adolescent populations. There was a mix of male and female participants and IBD subtypes across all the studies.

Details regarding the specific intervention used in each study are included in Table 2.1.4. The studies featured a mix of psychological and mind-body based interventions with both previously established and adapted protocols. Included in the interventions were elements of Acceptance and Commitment Therapy (ACT)[108,109], MBSR[104,107], and Cognitive Behavioural Therapy (CBT)[103,106,107], Gut-Directed Hypnotherapy (GDH)[105]. All interventions were delivered using telehealth, with six of the studies[103,104,106–109] using videoconferencing and one[105] using an unspecified type of telehealth. Of the five study reports that provided details on the facilitator delivering the intervention, four of the facilitators were healthcare professionals with three of the interventions[103,106,108] being delivered by psychologists/therapists and one of the interventions[107] being delivered by social workers. The fifth intervention[109] was delivered by members of the study team, none of whom had professional training. Five of the interventions[103,106–109] featured one-on-one delivery, one of the interventions[104] featured group-based delivery, and one[105] was unspecified.

Table 2.1.3: Summary of Included Studies Characteristics

Study	Country	Design	Recruitment	Recruitment Period	Sample Size	Adult/ Adolescent, mean age	% IBD Subtype (CD/UC/ IBD-U)	% Male/ Female
Artom et al.[103] (2019)	UK	Pilot RCT	In-person; single center	January 2017 to June 2017	31	Adult, 37 (intervention) and 39.13 (control)	67/23/10	33/67
Mascarenhas et al.[104] (2022)*	United States	Feasibility trial	N/A	N/A	23	Adolescent, 14	N/A	39/61
Lores et al.[105] (2022)*	Australia	Pilot RCT	N/A	July 2020 to August 2021	37	Adult, 42	100/0/0	46/54
Hommel et al.[106] (2013)	United States	Pilot feasibility trial	Phone; single center	N/A	9	Adolescent, 13.7	77/22	67/33
Goren et al.[107] (2022)	Israel	RCT	In-person, social media, websites; multi center	July 2018-July 2020	139	Adult, 33.6 (intervention) and 32.4 (control)	100/0/0	46/54
Evans et al.[108] (2022)**	Australia	Randomized feasibility trial	Social media and websites	1 year‡	50‡	Adult	N/A	N/A
Lavelle et al.[109] (2022)	UK	Case Series	In-person; single center	October 2019 to August 2021	12	Adult, 36.4	42/42/17	25/75

*abstract
**protocol
‡ expected

Table 2.1.4: Intervention Characteristics of Included Studies

Study	Intervention	Delivery	Group or Individual	Duration	Details	Facilitator
Artom et al.[103] (2019)	Cognitive Behavioral Therapy (CBT)	Telephone and video-conference (Skype)	Individual	8 one-on-one sessions (one 1-hour session and seven 30-minute sessions)	Standard CBT with a focus on management of fatigue	Therapist; privately contracted
Mascarenhas et al.[104] (2022)*	MBSR	Video-conference	Group	8 group sessions	N/A	N/A
Lores et al.[105] (2022)*	Gut-directed hypnotherapy (GDH)	Telehealth	N/A	7-weeks	7-week gut directed hypnotherapy course	N/A
Hommel et al.[106] (2013)	Individually tailored multi-component treatment	Video-conference (Skype)	Individual	Four 60-90-minute one-on-one sessions	Topics including education, organization, behaviour modification, problem solving, monitoring adherence, family functioning	Doctoral-level clinical psychologist or post-doctoral psychology fellow
Goren et al.[107] (2022)	Cognitive Behavioural and Mindfulness Based Stress Reduction with Daily Exercise (COBMINDEX)	Video-conference	Individual	7 one-on-one sessions of at least 1 hour and 10 minutes of home practice two times a day	Program with elements of CBT, MBSR as well as daily exercise Daily home practice logged in app, missed home practice resulted in call from facilitator	Social worker

Study	Intervention	Delivery	Group or Individual	Duration	Details	Facilitator
Evans et al.[108] (2022)**	Acceptance and Commitment Therapy for IBD	Video-conference and website	Individual	8 sessions (4 sessions are one-on-one with facilitator and 4 sessions are self-directed)	ACT-based program with topics including: creative hopelessness, fusion, acceptance, commitment and overcoming barriers	Provisionally registered psychologist
Lavelle et al.[109] (2022)	Acceptance and Commitment Therapy (ACT)	Video-conference, Zoom	Individual	2 sessions with homework and additional phone consultation two weeks after second session	ACT based program with workbook with topics of creative hopelessness, acceptance, grounding and self-compassion	Study team, no professional training

*abstract
**protocol

The trial design and outcomes collected in each study are reported in Table 2.1.5. Four of the seven[103–105,108] study reports selected primary outcomes focusing on feasibility, and only one[107] did not identify any feasibility-based outcomes as primary or secondary outcomes. All examined some aspect of the intervention's effectiveness or efficacy, with the most common measure of effectiveness or efficacy being Health Related Quality of Life (HRQoL). Three of the seven studies[103,104,108] also included a nested or follow-up qualitative study, either interviews or a focus group.

Table 2.1.5: Design and Outcomes of Included Studies

Study	Design	Random-ization Details	Primary Outcome	Secondary Outcomes	Qualitative Follow-Up?
Artom et al.[103] (2019)	Pilot RCT	Control arm given fatigue information sheet	Feasibility and acceptability	Patient-centered measures including fatigue and QoL	Yes, interviews
Mascarenhas et al.[104] (2022)*	Feasibility trial	N/A	Feasibility and acceptability	HRQoL	Yes, focus group
Lores et al.[105] (2022)*	Pilot RCT	Control arm given treatment as usual	Feasibility	Disease activity, bowel & mental health symptoms, and HRQoL	No
Hommel et al.[106] (2013)	Pilot feasibility trial	N/A	Adherence to medication	Feasibility and acceptability	No
Goren et al.[107] (2022)	Random-ized trial	Waitlist control arm	Disease activity	HRQoL, fatigue, and mindfulness	No
Evans et al.[108] (2022)**	Random-ized feasibility trial	Active control arm taught a non-ACTforIBD program	Feasibility	Efficacy and cost-effectiveness	Yes, interviews

Study	Design	Random-ization Details	Primary Outcome	Secondary Outcomes	Qualitative Follow-Up?
Lavelle et al.[109] (2022)	Series of Single Case Experim-ental Design	N/A	Psychological flexibility	Adherence	No

*abstract
**protocol

The results from the six completed studies[103–107,109] are summarized in Table 2.1.6. Four of the studies[103,106,107,109] assessed patient interest in the interventions, defined as recruitment success or intervention uptake, with participation rates ranging from 35-75%. Participant attrition was reported in all six study reports, and was relatively low, with rates ranging from 0-33%. Most studies also assessed additional measures of feasibility or acceptability, either quantitative or qualitative, and the acceptability of the interventions and the telehealth delivery was high across all studies. Five studies[103,104,106,107,109] assessed the preliminary effectiveness of their intervention, and four of these five studies[103,106,107,109] revealed improvements in their participants. The most common improvements, revealed in three of the five studies[103,107,109], were participant reported quality of life and mental health symptoms. Interestingly, investigators of all six studies[103–107,109] concluded that the interventions used in their studies were feasible.

Table 2.1.6: Summary of Results Reported by Authors of Included Study Reports

Study	Uptake	Attrition	Other Feasibility or Acceptability Data	Effectiveness	Reported Conclusion (feasible: yes/no)
Artom et al.[103] (2019)	44.2%	33%	- Participant satisfaction was 8.6/10 - Therapists found the delivery feasible	- Reduction to fatigue and increase in QoL at 3, 6, 12-months post-intervention	Yes
Mascarenhas et al.[104] (2022)*	N/A	23.3%	- 87% rated the quality as good or excellent - 74% would recommend to others	- No change to HRQoL or stress	Yes

Study	Uptake	Attrition	Other Feasibility or Acceptability Data	Effectiveness	Reported Conclusion (feasible: yes/no)
Lores et al.[105] (2022)*	N/A	5%	- 73% of participants were extremely satisfied with intervention - Only 24% of participants completed objective symptoms assessments	N/A	Yes
Hommel et al.[106] (2013)	42.9%	0%	- Parents of child found the intervention more acceptable than the child (results from Feasibility Acceptability Questionnaire)	- Increased adherence to 5-ASA medication but decreased adherence to immune-suppressants - $101.87 and 247.1 minutes of travel saved per participant	Yes
Goren et al.[107] (2022)	35.0%	21.4%	N/A	- Reduction to fatigue and psychological symptoms and improvements to HRQoL	Yes
Lavelle et al.[109] (2022)	75%	16%	- Median score on adherence questionnaire that measured participant understanding of intervention was 3/11 (range 1-8)	- 50% of participants noted reduced stress - <25% reported improvements to anxiety, none reported improvements to depression	Yes

*abstract

Note: Evans et al. study excluded since results are not yet published

The current review provides an overview of the feasibility of telehealth-based psychological and mind-body interventions for people with IBD. The majority of the studies included in this review were published within the last year and recruited participants during the COVID-19 pandemic,

suggesting the pandemic-associated increase in distance care led to a marked increase in telehealth based psychological interventions. Previous systematic reviews have evaluated the efficacy of a variety of psychological and mind-body interventions for people with IBD, although all of these reviews have focused on interventions that are delivered face-to-face [76,93,94]. A 2018 review attempted to evaluate the efficacy of online psychological interventions for people with IBD and IBS; however, their search did not yield many results, and the final review evaluated eleven studies of which only two were conducted in a population with IBD[110].

Overall, the findings of this review suggest that delivering psychological and mind-body interventions to people with IBD using telehealth is feasible. Intervention uptake rates were high across all studies and attrition remained low. Attrition is one of the most common challenges when offering psychological and mind-body interventions[111,112] and low drop-out rates in pilot trials often provide support for studying interventions in large-scale RCTs. This review includes smaller studies, which are often excluded in reviews that evaluate effectiveness, with rich mixed-methods data that highlight PROs. PROs, including QoL and perceptions of treatment, are included in all of the studies in this review, and aid in providing a well-rounded assessment of the acceptability of interventions as well as perceived benefits that are not captured by symptom questionnaires[113]. Engaging patients as stakeholders in research through the use of PROs is associated with higher patient satisfaction and improved care coordination[114,115], and therefore, improvements to PROs should be strongly considered when considering implementing any new intervention.

Something missing from this review are any assessments of safety. None of the studies in this review identified potential safety issues or modifications that would need to be made to ensure participant and provider safety when using telehealth or videoconferencing to deliver care. Furthermore, only three of the studies[103–105] in this review included information on patient-identified barriers to care or suggestions to improve delivery or access to the intervention. In addition, none of the study reports mention any considerations for implementing the intervention into standard IBD care. Feasibility and pilot trials offer an opportunity to evaluate and consider any barriers before attempting a large-scale trial or implementing the intervention in clinical care. Future studies should consider investigating these patient-identified challenges when

assessing the acceptability of telehealth-based psychological and mind-body interventions for people with IBD.

Finally, this review suggests that adapting MBSR for virtual delivery using teleconferencing is feasible for adults with IBD in Edmonton, Alberta.

Chapter 3: Methods

Chapter 3.1: Feasibility Trial

Chapter 3.1.1: Development

This project was developed as a collaboration between the IBD Unit (Division of Gastroenterology, Department of Medicine) and the Department of Psychiatry at the University of Alberta. The study team included expertise from both departments, with Dr. Karen Kroeker providing input as a gastroenterologist and IBD specialist and Dr. Diana Meakins and Dr. Marsh-Joyal offering their opinions as psychiatrists. The burden of comorbid anxiety and depression in patients with inflammatory bowel disease is high and the need for target treatments was recognized by Crohn's and Colitis Canada with a Grant Call in 2020. A large focus of collaborating was to utilize existing programs, so that referral for the gastroenterologists and billing for the intervention by the psychiatrists would be simple.

The design was originally a large-scale randomized control trial that would include 200 participants over three years with groups being offered in-person at the University of Alberta Hospital. Under the guidance of the study team, the research coordinator, Dr. Lily Olayinka, began developing the project by choosing the assessment tools and designing the flow of the trial. After re-assessing the requirement for the number of participants to reach statistical power given the high attrition rates often seen psychiatric interventions, the project pivoted its design to a smaller-scale feasibility trial, as a graduate student project.

As discussed in Chapter 1.4 of this thesis, a therapeutic intervention based in mindfulness was chosen due to the role that mindfulness plays in mediating the negative effects of stress, anxiety, and depression on mental health[70,79,80]. MBSR was then selected because it has proven to be effective in a large range of populations, including patients with IBD. Furthermore, MBSR is already offered by psychiatrists in Alberta and a psychiatric based intervention means referrals are relatively easy for gastroenterologists. The materials for the intervention, including the workbook and audio files, were provided by Dr. Catherine Phillips[116]. A summary and breakdown of the MBSR program is included in Table 3.1.1

Table 3.1.1: Summary of MBSR Program by Week

Session	Learnings
1	• Introduction to MBSR and group expectations • Understanding the concepts of mindfulness, autopilot, and meditation ➢ Techniques: awareness of breath (AOB), body scan Home Practice: - Reflections on intent of practice and awareness - Complete body scan daily - 1 mindful meal
2	• Understanding the role of perception and attitude in our experiences • Introduction to life-affirming attitudes ➢ Techniques: sitting mediation Home Practice: - Reflections on attitudes and awareness - Record one pleasant event per day - Complete body scan and a sitting meditation daily - Continue to practice awareness
3	• Understanding the mind-body connection ➢ Techniques: mindful movement Home Practice: - Reflections on mind-body connections - Record one unpleasant event per day - Alternate completing body scan or mindful movement lying down daily - Practice sitting mindful exercises daily - Continued reflection on autopilot
4	• Understanding stress and stress reactivity • Understanding the importance of stress reduction

Session	Learnings
	Home Practice: - Reflection on sources of stress and the body's reaction - Alternate completing body scan or mindful movement lying down daily - Practice sitting meditation with AOB - Continued reflection on awareness of feeling stuck
5	• Understanding and building resiliency • Deepening the understanding of stress and coping • Cultivating mindful responding
	Home Practice: - Reflections on the feelings of stress - Record a difficult or stressful communication each day - Alternate sitting meditation, body scan, and mindful movement lying down daily - Continued reflections on awareness and breathing as an anchor
6	• Understanding interpersonal mindfulness and thoughts and feelings as stressors • Understanding assertive communication and mindful responding ➢ Techniques: Aikido
	Home Practice: -Reflections on how stress changes thoughts and communication - Alternate sitting meditation, body scan, and mindful movement lying down/standing daily - Continued practice of mindful awareness
Weekend	**Silent retreat** • Practicing internal reflection and awareness
7	• Understanding how mindfulness can be integrated into daily life • Cultivating a personalized mindfulness practice
	Home Practice: - Reflections on lifestyle choices and living intentionally - Practice any of the techniques without the recordings for 45 minutes each day - Continue integrating mindfulness and awareness into day-to-day life

Session	Learnings
8	• Wrapping up • Deepening the understanding of how mindfulness can be personally integrated into daily life
	Home Practice: - Reflections on the program and future practice - Continue the momentum of practice

The objective of this study was to assess if a psychiatrist delivered MBSR group was feasible for a larger intervention trial for IBD patients in the Edmonton Zone. Due to the COVID-19 pandemic and improved access and acceptability of virtually delivered health care services[98], we decided to offer the MBSR groups virtually to adhere to the changing public health guidelines and to help keep patients safe. We also felt virtual delivery would improve accessibility for those living outside of the city by eliminating the time and distance that would be required to commute to the hospital and attend in-person groups[117].

To accommodate patients who were working or studying full-time, we agreed to conduct groups in the evening. Inclusion and exclusion criteria included both gastrointestinal and psychiatric specifications and is detailed in Table 3.1.2.

Table 3.1.2: Detailed Inclusion and Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**
a. Have a known diagnosis of inflammatory bowel disease, confirmed with endoscopy/histology and/or imaging. b. Ability to communicate and write in English (English does not have to be the first language).	a. History of or current psychotic symptoms. b. History of dissociative symptoms, severe active untreated drug use, severe non-suicidal self-injury

Inclusion Criteria	Exclusion Criteria
c. Ability to give informed consent. d. Adult (aged 18-65). e. Ability to commit to attend the 8 weekly sessions of 2.5 hours duration and a 7-hour all day weekend session between week 6&7. f. Ability to commit to do home practice of 30 – 45 minutes per day over the 8 weeks of the session. g. Physician/Self-identified anxiety and/or depressive symptoms. h. Stable IBD medication for at least 2 months. i. Stable psychiatric medication for at least 6 weeks.	behavior, acute or chronic suicidal ideation. c. History of or current cognitive impairment. d. Deemed unsuitable for participation in MBSR group therapy sessions by qualified psychiatrist. e. Have recently been prescribed or on corticosteroids. f. Have undergone surgery within 6 weeks of start date.

Chapter 3.1.2: Recruitment

Patients were recruited in two ways: via referral from their gastroenterologist or self-referral via study poster advertisements. Recruitment began in January 2022. We invited gastroenterologists and nurses working in gastroenterology clinics in Edmonton to join one of two 15-minute study information meetings at the beginning of January. After the meetings, all Edmonton-area gastroenterologists and their clinic staff received an email that detailed the inclusion and exclusion criteria and how they could refer their patients into the study. This document was a tool physicians could reference if they were considering referring their patient to the study. It is attached in Appendix B-1. We placed study posters throughout AHS sites including the University of Alberta and the Royal Alexandra Hospitals as well as throughout Covenant Health Sites including the Grey Nuns and Misericordia Hospitals. Multiple gastroenterologists placed

the posters in their clinics, and we placed more posters in buildings in the University of Alberta. A copy of the poster is attached in Appendix B-2. We began accepting referrals after distributing the posters and completing the information sessions.

To ensure clarity, "patient" refers to any person who was referred into the trial, and "participant" refers to a patient, as previously defined, once they enrolled in the group. The target for the start of the first group was late March 2022. As the study coordinator, I contacted most patients over the phone after they were referred to the trial following an appointment with their gastroenterologist or after they referred themselves to the trial by engaging with the poster (i.e., scanning the QR code or reaching out via the contact information). I was able to meet a small handful of patients in person when they were referred to the trial following an in-person appointment with their gastroenterologist. During the initial discussion with patient, I followed the general recruitment script (included in Appendix B-3) and explained MBSR to patients and informed them what was involved in the study, the potential benefits and risks, and the confidentiality of their data. Patients who declined were given the options to provide a reason for declining, and it was noted if they agreed to disclose it. Interested patients could read and sign an e-consent form if they wished to continue in the study. The e-consent was emailed to participants using REDCap[118] and is attached in Appendix B-4. After completing the consent form, they entered the screening phase of the study, and completed a PHQ-SADS questionnaire. After submitting the questionnaire, as the study coordinator, I calculated the participants' stress, anxiety, and depression score. If the score was above a five, which indicates at least the presence of mild symptoms, they could proceed to the next step of the screening process which involved a 60-minute semi-structured assessment with a psychiatrist. They were conducted virtually by out collaborating clinical psychiatrists (Drs. Meakins, Marsh-Joyal, or MacArthur). During the interview, they performed a general psychiatric assessment to ensure that participants would not be harmed by participating in the group. Performing psychiatric assessments is common practice before anyone can participate in group therapy in Alberta, and ensures the safety of the participant themselves, the other participants, and the practitioner. After the interview, eligible participants had one week to consider their participation before confirming their preferred start date. If participants wished to discontinue the screening process at any point, the study

coordinator verbally debriefed them. A chart illustrating the flow of patients through the trial was adapted from the 2010 CONSORT Statement[119] and is included in Appendix B-5.
Two weeks prior to starting the groups, participants received the required pre-group surveys via email and the study coordinator contacted them to complete a physical and clinical assessment of their symptoms. The pre-group surveys included a demographics form and multiple questionnaires assessing the study's secondary outcomes. Demographic information was collected closer to the start of the intervention instead of at the screening step because it included current medication information, and we wanted this record to be as accurate as possible. At this point in time, I also sent a letter to the participants' gastroenterologist to let them know their patient had enrolled in the study and was starting treatment. The letter is appended in Appendix B-6.

Chapter 3.1.3: Outcomes

As discussed in Chapter 1.5 many researchers have attempted to develop a framework for the implementation of feasibility and pilot trials. Using current recommendations and definitions suggested by the literature[91,92,120], our study was developed as a non-pilot feasibility trial with primary outcomes focusing on feasibility and secondary outcomes focusing on effectiveness. The overarching aim of the trial was to assess any organizational or contextual factors that may be necessary to consider if a pilot randomized control study were to be planned or if the intervention were to be more widely offered.

Chapter 3.1.3.1: Primary: Feasibility

The primary aim of this study was to assess the feasibility and acceptability of MBSR for our participant group. Four primary outcomes assessed feasibility: recruitment success, adherence, attendance, and attrition. We defined recruitment success as it related to trial uptake: the number of participants referred in comparison to the number of participants who enrolled in the group. We defined adherence as the number of minutes that participants who completed the group practiced per day. This assessment of adherence was selected based on several reviews evaluating adherence in MBSR groups. Further, we defined attendance as the number of sessions the participants that completed the group attended. The number of participants who withdrew from the group or who did not meet completion criteria was the trial's assessment of attrition.

We defined completion as recommended by the original MBSR protocol[70–72]; participants are considered to have completed MBSR if they attend six of eight of weekly sessions and also attend the weekend session. A summary of the primary outcomes is in Table 3.1.3.

Table 3.1.3: Primary Outcomes and Their Evaluation

Outcome Measure	Evaluation
Recruitment Success	Trial uptake. Number of participants referred will compared to the number of participants enrolled. Reason for declining to participate noted if provided.
Attendance	The number of weekly MBSR sessions attended and if the weekend session was attended. There were eight weekly sessions and one weekend session.
Adherence	Average number of home practice minutes completed per day. Adherence rate calculated by comparing the reported daily average to the required daily average of 45 minutes which allows our rate to be compared to other studies.
Attrition	Number of participants who do not complete the program. MBSR considered not completed if more than 2 sessions are missed or the weekend session is not attended.

Chapter 3.1.3.2: Secondary: Effectiveness

The secondary outcomes of the trial were to assess the effectiveness of MBSR in the participants who completed it across a variety of domains. Details of the secondary outcome measures are below in Table 3.1.4.

Demographic data was also collected and included information including age, type of IBD, age at diagnosis, employment status, and a list of medications.

We decided to assess for childhood trauma in the participants using the Adverse Childhood Experience (ACE) Scale. The ACE Scale[121] is a 10-item questionnaire that assesses childhood rearing and maltreatment contexts. Previous studies have associated higher ACE scores with mental illness indicators[122] including emotional distress[123], and poorer general health outcomes[124–126]. Although clinically, there is nothing physicians can do to alter the trauma a patient may have experienced during childhood, ACE scores could be useful as a tool to help

identify patients who may have higher mental health needs now or in the future, and in this study, could add context to the population of patients who chose to engage in our program. Furthermore, mindfulness can act as an intermediary for the negative psychological health effects associated with higher ACE scores[80] which means MBIs such as MBSR may help mediate the negative effects caused by high ACE scores.

Further information regarding the tools used to assess secondary outcomes are detailed below:

The Patient-Health Questionnaire – Somatic, Anxiety and Depressive Symptoms Scale (PHQ-SADS)[127] is a three-part scale used to assess anxiety, depression, somatization and general stress symptoms. It combines the depression and panic assessments from the PHQ-9, the anxiety assessment from the GAD-7, and the somatic symptom assessment from the PHQ-15. The PHQ-SADS can be self-administered and includes severity scores which can help when communicating the results. Scores range from 0-27 with scores between 0-4 considered a no significant symptoms, scores of 5-9 considered mild symptoms, scores of 10-14 considered moderate symptoms, scores of 15-20 considered moderately severe, and scores of 20-27 considered severe. Generally speaking, a score above 10 is considered clinically concerning[127].

The Short Inflammatory Bowel Disease Questionnaire (SIBDQ)[128] is a tool used to assess disease-specific health related quality of life (HRQoL) in people with IBD. The 10-item questionnaire is adapted from the Inflammatory Bowel Disease Questionnaire (IBDQ) and assesses quality of life across 4 dimensions – bowel, systemic, social, and emotional. Scores range from 10-70 with each of the ten statements receiving a Likert scale score from 1-7. Lower scores indicate worse quality of life. Scores between 10-44 indicate severely impaired HRQoL, scores of 45-59 indicate moderately impaired HRQoL, and scores of 60-70 indicate slightly impaired HRQoL.

The Mindful Attention and Awareness Scale (MAAS)[129] is a tool used to assess dispositional mindfulness. The 15-item questionnaire focuses on respondents open and receptive awareness and their ability to focus their attention on what is taking place in the present. Each statement is

scored on a Likert scale of 1-6 and the final score is an average of all responses. Higher scores indicate higher levels of dispositional mindfulness.

The Short Form Self-Compassion Scale (SCS-SF)[130] is a scale that assesses respondents' ability to be kind and understanding to themselves in instances of pain and failure. It is a 12-item scale adapted from the Self-Compassion Scale (SCS) and the correlation between the two scales is extremely high[131]. Each statement is scored on a Likert scale of 1-5 and the final score is an average of all responses. Final scores range from 1-5 with higher scores indicate higher levels of self-compassion with scored between 1-2.5 being considered low self-compassion, scores between 2.5-3.5 being considered moderate, and scores between 3.5-5 considered high[132].

The Harvey Bradshaw Index (HBI)[133] is an index used to assess symptoms common in CD. It is often used in clinical practice to assess clinical disease activity. I administered the HBI after being debriefed on how to use and discussed any uncertainty about the clinical assessments with the study team.

The Partial Mayo Score (PMS)[134] is a tool used to assess symptoms of UC. It includes the non-invasive components of the complete Mayo Score and is often used in clinical practice to assess disease activity. I administered the PMS after being debriefed on how to use it and discussed any uncertainty about the clinical assessments with the study team.

Laboratory measures included C-reactive protein (CRP) and fecal calprotectin (FCP) levels. CRP is a biomarker of inflammation in the blood, and correlates well with disease activity in IBD[135]. FCP measures calprotectin levels in the stool and is strongly associated with colorectal inflammation in IBD patients[136]. I extracted both measures from participants medical charts and recorded them along with the date of the result. We included all lab measures that were reported within the following parameters: within two months before group start, within one month of group completion, within two months of 6-month follow-up.

Table 3.1.4: Details of Secondary Outcome Measures

Abbreviated Name	Long Name	Evaluation of	Notes
ACE	Adverse Childhood Experience	Trauma within the context of childhood relating to rearing environment, abuse, and neglect	Generates a score between 0-10
PHQ-SADS	Patient Health Questionnaire – Somatic, Anxiety and Depressive Symptoms Scale	Stress, anxiety, and depression symptoms	Includes PHQ-9, GAD-7, and PHQ-15 questionnaire
SIBDQ	Short Inflammatory Bowel Disease Questionnaire	Health-related quality of life	10-item shortened version of the 32-item IBDQ
MAAS	Mindful Attention and Awareness Scale	Dispositional mindfulness	
SCS-SF	Short Form Self-compassion scale	Self-compassion	12-item shortened version of the 26-item SCS
HBI	Harvey-Bradshaw Index	Clinical disease activity in CD	
PMS	Partial Mayo Score	Clinical disease activity in UC	
CRP	C-Reactive Protein	CRP levels in blood, inflammatory marker	Lab value, blood
FCP	Fecal calprotectin	FCP level in stool sample, GI tract inflammatory marker	Lab value, stool

Chapter 3.1.4: Data Collection

Throughout the recruitment process and the intervention, primary outcome data collection occurred. I collected trial uptake data during the recruitment process by recording the names of patients referred into the trial and detailing all instances of contact I had with them. If patients declined to participate in the trial, I recorded their reason for declining if they chose to disclose it. The rest of the feasibility outcomes were related to enrolled participants; therefore, they were collected after the completion of the groups. An additional adherence questionnaire was sent to participants along with the secondary outcome questionnaires they had to complete at the end of the intervention. In the adherence questionnaire, participants reported the number of sessions they attended as a marker of their attendance, and their responses were confirmed with attendance data collected by the psychiatrists who led the groups. Participants also reported the average number of minutes they practiced per day outside of the group. Before they received the questionnaire, we emphasized being honest when reporting their practice minutes and reminded participants that their response would only be used for the study and would not be disclosed to the psychiatrists delivering the mindfulness sessions. The number of participants who discontinued or finished the program, but did not meet completion criteria (e.g., the participant attended until the end of the program but missed more than two of the weekly sessions or the weekend session) was collected throughout the intervention and used to assess for attrition. To have considered to have completed the program, participants had to have attended at least six of eight weekly sessions and the weekend session. This definition of completion is the standard for MBSR, as first recommended by the programs original protocol[70,71].

We collected demographic, ACE score, and secondary outcome data by emailing surveys to participants using REDCap electronic data capture tools hosted at the University of Alberta[137]. REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources. Demographic and ACE data was only collected once, before the beginning of the MBSR groups. Collection of the rest of the secondary

outcomes data occurred at three separate time points. Baseline or pre-group data was collected up to two weeks before the MBSR group started. Post-group data was collected at least one week following the completion of the group. 6-month data was collected between 24-26 weeks after participants completed the group. Laboratory data was extracted from patient charts as it became available.

Chapter 3.1.5: Analysis

Chapter 3.1.5.1: Feasibility Data

Analysis and extraction of feasibility records resulted in a small data set. I analysed the extracted data using STATA 17.0[138] and presented it using descriptive statistics. The analysis included the calculation of median, mean, standard error, and exact confidence intervals for each of the outcomes. Means with exact confidence intervals are used for most data sets; although in certain cases, median and range are also reported to get a better sense of the trends in the data sets. Standard error and exact confidence intervals were used because of the small sample size.

Chapter 3.1.5.2: Effectiveness Data

The analysis of secondary outcome data was like that of the feasibility data. The sample size of the effectiveness data was between 6-16 participants depending on the timepoint and measure; therefore, the analysis included a variety of small sample tests and correlations in order to generate and communicate more details about the data. Spearman's Rank-Order Correlation was selected because the data was ordinal and did not follow a normal distribution. The correlations reported by this non-parametric analysis allows for the exploration of trends in our sample. The use of descriptive statistics includes means, standard error, and exact confidence intervals. Standard error and exact confidence intervals were once again chosen because of the small sample size.

Chapter 3.1.6: Rigour

Although this trial featured a small sample size and the non-feasibility design did not merit some of the techniques used to ensure rigour in larger scale trials such as randomized control trials, it

was still important to limit bias throughout the trial. All data was deidentified, meaning participant identity was absent. This was important because I oversaw the recruitment, enrollment, and supervision of the participants, and I was also responsible for data extraction and analysis. The goal of deidentifying of the data was to limit my bias as well as to reduce the impact my assumptions may have on the results and the associations we explored.

Most of the scales used to assess symptoms in this study were self-administered by participants. To ensure rigour within self-administration, the participants were briefed on how to answer all the questionnaires and were instructed to reach out to me if they needed any of the surveys clarified. Furthermore, participants were explained the importance of being truthful when answering the questions, and an effort was made to ensure that participants understood that their answers would not be linked to their name, nor would any of their healthcare providers be able to access this data. The study coordinator also highlighted that they would not be judged for their answers, especially when talking about self-reporting the number of minutes they had practiced. The intent of insisting participants be honest when self-reporting was to attempt to limit the impact that social desirability bias may have on participants' answers[139,140].

Chapter 3.2: Patient and Participant Interviews

The qualitative component of the study was designed with the goal of adding more context and information to the data collected in the feasibility trial. As recruitment and enrollment for the feasibility trial was slower than expected, and the goal of the interviews was to explore possible reasons why.

Chapter 3.2.1: Rationale and Qualitative Perspective

With the goal of the gathering more information on the feasibility trial, this study attempted to collect data around two central research questions:

1. What were participants' expectation of and experiences in MBSR and how would they describe the benefits and barriers to the program?
2. How do our participants define and purse mental and physical wellness?

The aim of the first question was on the trial itself and the hope was that the data would provide more context to the feasibility and acceptability of MBSR. The aim of the second question was to provide supplementary information that could be helpful in tailoring MBSR or other interventions to better suit the needs of IBD patients with comorbid anxiety and/or depression in the future which was something we believed would be crucial for the next steps of developing a mental health intervention or pathway in IBD care.

Chapter 3.2.1.1: Interpretive Description

The interviews were designed from the philosophical perspective of interpretive description as described by Thorne et al.[141,142]. This method draws elements from grounded theory, naturalistic inquiry, and ethnography[141]. It allows the investigators to build on previous research in the field and to make linkages between new findings and existing knowledge[142]. One of the goals of interpretive description is to generate data that has the potential to be applied in some way, such as for planning an interventional strategy[141], which fits well into the aim of our feasibility trial.

Chapter 3.2.2: Interview Development

Chapter 3.2.2.1: Semi-Structured Interview Rationale

Semi-structured interviews were selected as the investigative tool for multiple reasons. Firstly, the use of guiding questions allows the interviewer the opportunity to ask probing or follow-up questions dependent on participants initial responses. This adaptability can lead to the emergence of new or unexpected themes and gives the interviewer the authority to explore these topics with the participant[143]. Semi-structured interviews are also convenient from a scheduling standpoint as they only require the attendance of two people – the interviewer and the participant. Considering these interviews were to be conducted over a long stretch of time (throughout recruitment and all the way until the groups are complete), we were concerned that having to find a common time that would work for multiple participants at once, something required in a focus group, may be difficult and could lead to less people being able to participate.

Chapter 3.2.2.2: Interview Guide Development

The first version of the interview guide was first developed and submitted as part of a qualitative and community-based research class (SPH 623). After discussion with the study team, several revisions were made from June 2022 to August 2022. The aim was to use interpretive description to describe the subjective experiences of participants within MBSR as they related to the feasibility of the intervention and their experience trying to improve their wellness in the past.

The revisions resulted in a more concise guide, that covered fewer topics and included more opportunities for targeted probing questions. A summary of the two main sections of the interview is included in Table 3.2.1, and the complete interview guide is included in Appendix B-7. An audit trail with all the changes made to the interview guide is included in Appendix B-8.

Table 3.2.1: Summary of Interview Guide

Part 1: MBSR

Primary goal: identify patient perspectives on MBSR and the barriers and benefits associated with it.

- Questions relating to expectations, benefits, barriers, and recommendations.

Part 2: Wellness

Primary goal: investigate how participants define wellness and their experience trying to improve their wellness in the past.

- Exploring definition of wellness, impact of IBD on wellness, previous experiences trying to improve wellness and reasons behind these choices

Chapter 3.2.2.3: Sampling Rationale

After finalizing the guide and receiving ethics approval, recruitment began in August of 2022. Participants were eligible to participate if they had been referred to the feasibility trial. We aimed to include three unique groups in the interviews:

1. Those that declined to participate in MBSR.
2. Those that enrolled in MBSR and then did not complete the intervention.
3. Those that enrolled in and completed MBSR.

Purposeful sampling, which refers to selecting from a population with the characteristics required for a sample[144], was used to select for participants for our interviews. This type of non-probability sampling was chosen because it was important our sample included only those who were knowledgeable on our phenomenon of interest, which was an interest and/or experience with MBSR. We hoped to include as many participants as possible, with an emphasis on the group who completed MBSR, as they were the only ones who had experiences in the program itself. We had hoped the groups that discontinued or declined MBSR would provide additional information into the barriers to joining and completing the group.

Interpretive description recognizes all participants' experiences within an intervention can different, and with this in mind, focuses on gathering a deeper understanding of participants' experiences with the understanding that variation and outliers may be present[145]. All this considered, reaching saturation is not a priority of this type of inquiry, and our main goal was to gather as many participants experiences as possible and explore the similarities and differences between them.

Chapter 3.2.3: Recruitment

In accordance with our ethics requirements, only participants who were referred to MBSR after the approval of the interview study were contacted about interviews. Recruitment for the second and final MBSR group concluded at the end of August 2022, meaning only participants referred during the month of August were eligible to be interviewed. Only five patients were referred to MBSR during the month of August, so this brief timeline for recruitment resulted in a smaller than anticipated pool of eligible participants. Participants who had enrolled in MBSR were also eligible, and this resulted in an additional 16 eligible participants.

Following a general recruitment script, attached in Appendix B-9, I contacted all eligible participants by phone. An electronic consent form, attached in Appendix B-10 was sent to all interested participants using REDCap[118] and once signed, interviews were scheduled. All interviews took place over Zoom [146] and the audio and video recordings were downloaded after

they were completed. The Zoom links were created by Alberta Health Services and has security features including end-to-end encryption to ensure participant and provider safety.

Chapter 3.2.4: Data Analysis

Chapter 3.2.4.1: Thematic Analysis

I utilized thematic analysis to generate themes. Thematic analysis, as described by Braun and Clarke[147], reports patterns in the data as a range of themes. In contrast to many other types of analysis, including content analysis[148], the themes and their value are not based on quantity, but rather on whether they capture something important in relation to the research question[147,149]. Thematic analysis is flexible in that it can provide details about the entire data set, or about its specific aspects. We drew on principles of both inductive and latent thematic analysis. Inductive analysis focused on generating codes based on the data itself and then building themes from those codes[150]. Latent analysis examines the underlying ideas and intentions of the data, going beyond the semantic meaning[150].

Chapter 3.2.4.2: Transcription, Coding, and Analysis

After conducting the interviews, I used the audio and video recordings to transcribe them verbatim. This process allowed me to refamiliarize and immerse myself with the data, which is crucial for skillful coding and analysis[147]. I used NVivo (released in 2020)[151] for both coding and analysis.

The coding strategy was based on framework suggested by Braun and Clarke[147]. The strategy of using condensed meaning units (CMUs) was adapted from framework developed by Grandheim and Lundham[152]. Although the latter framework was intended for use with content analysis, using CMUs as a tool to summarize participants answers without interpreting them allowed for increased organization, visualization and an extra aspect of rigour. This made the coding and collating process easier, both for the critical friend and me. Next, leaning on the process laid out by Braun and Clarke[147], I systematically created codes based on the interesting and relevant CMUs. I defined each code and periodically reviewed the data organized under them to confirm it continued to relate to the code and its' definition.

The creation of themes continued to rely on the tenets of thematic analysis. First, I collated related codes and used them to develop a series of relevant themes. Next, I reviewed the themes and their associated codes and ensured they worked in relation to each other. Finally, I defined the themes. The entire process was recorded in an audit trail that is attached in Appendix B-11. Selecting important themes was based on largely on the theme's relevance to the research question, a concept integral to thematic analysis, as described above.

Chapter 3.2.5: Rigour

Ensuring rigour is an important focus for researchers using qualitative research methods, just as it is for those using quantitative methods[153]. Although their definitions remain a topic of debate in qualitative methods, it is generally accepted that the principles of creditability, dependability, confirmability, and transferability, originally put forward by Lincoln and Guba[154] are important principles for qualitative rigour[155–157].

We employed many of the strategies associated with credibility, of which the purpose is to ensure that the results are true and believable from the perspective of the participants[156]. Everyone involved in developing the interview and the analysis process had extensive experience working with IBD patients which we hoped allowed us to better understand the participants' intentions and identify relevant themes. All members of the research team also had training with qualitative methods through formal classes and/or previous research studies.

To ensure dependability, which ensures the findings are repeatable within the same cohort[156], we consulted multiple stakeholders and developed a detailed study protocol. I also kept an audit trail of the interview guide development, data coding, and data analysis processes.

With regards to confirmability, of which the purpose is to increase the confidence that the results could be confirmed by other researchers'[156], we used reflexivity and triangulation techniques. I demonstrated reflexivity by keeping detailed reflexive journals of my experience and thoughts immediately following the completion of each interview. We used a "critical friend"[158] as a method of triangulation. The critical friend, Allison Bihari, is a PhD candidate who has an in-

depth understanding of qualitative methods and the IBD population. She reviewed the CMUs and codes and provided input on the identified themes and their definitions. Her input helped to mitigate bias during the analysis process and ensured that the themes were representative of the data.

The purpose of transferability is to establish the idea that the findings can be generalized to a larger population or context[156]. Our method of sampling was very specific due to our original research question, but we worked to ensure transferability by developing descriptive data. Our work to ensure confirmability may also be helpful to increase transferability.

A researchers' positionality, defined as how their world view and position in the social and cultural context of the research [159] might influence their assumptions and subsequently their results, is also important to consider when conducting rigorous qualitative research[160]. As the main investigator for the interviews, I recognize that there are many ways my experiences could have impacted all aspects of the interviews. I am a Euro-Canadian female in my early twenties and do not have IBD or a chronic disease. I have some experience with chronic disease and its effects on mental health from supporting two of my immediate family members through similar situations. I currently live in a large city; however, I grew up in a rural area and have some knowledge as to the barriers to accessing healthcare. I have previously participated in mindfulness-based interventions and continue to practice the techniques I learn on a daily basis.

Chapter 4: Results

Chapter 4.1: Feasibility Trial

The results from the feasibility trial were analysed using STATA 17.0[138] . "Patient" refers to any person who was referred into the trial, and "participant" refers to a patient, as previously defined, who enrolled in the group.

Chapter 4.1.1: Primary Outcomes

The primary outcomes focused on assessing the feasibility of MBSR and are detailed in Chapter 3.1.3.1.

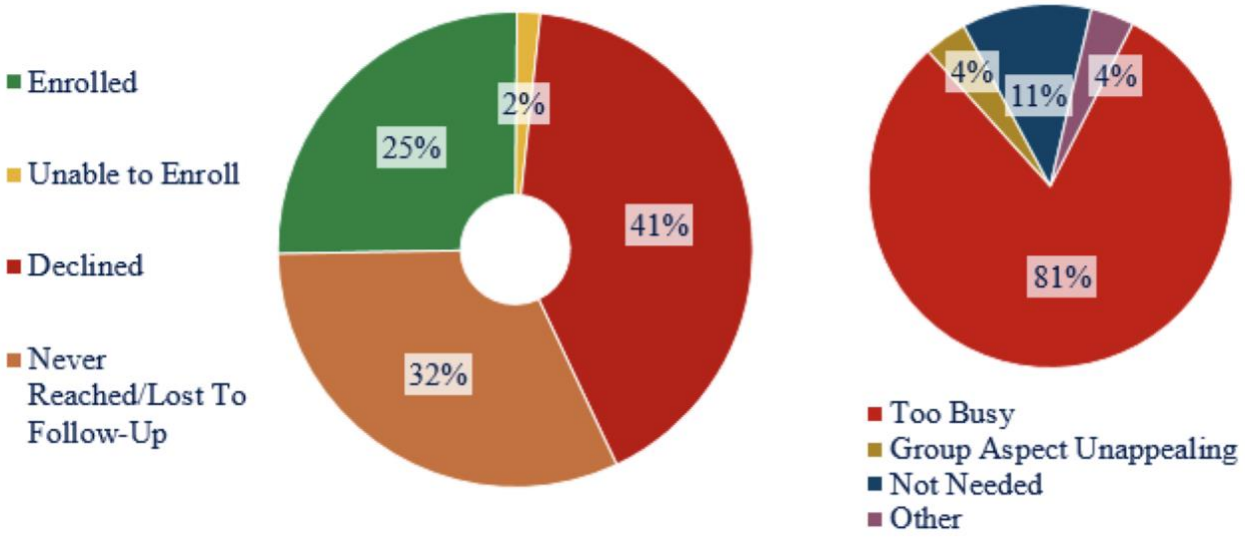
After eight months of recruiting, a total of 64 patients were referred to the trial. The majority (>93%) were referred by their gastroenterologist and just four self-referred via the study poster. Half of referrals came from a gastroenterologist working at an academic center, and the other half came from a gastroenterologist working at a non-academic center or clinic. Further, over three quarters (76.7%) of referrals came from male gastroenterologists. Overall, seven gastroenterologists in the Edmonton Zone referred patients to the study.

Of the 64 patients referred, 16 enrolled in one of two MBSR groups resulting in a trial uptake of 25%. The same group of three psychiatrists (Dr. Meakins, Dr. MacArthur, and Dr. Phillips) ran the groups. All three of them have additional training that allows them to deliver MBSR, and they all worked together to deliver the various parts of each MBSR session. The first group which included seven participants began in April of 2022 and the second group which included nine participants started in September of 2022. Both adhered to the same schedule with weekly meetings occurring on Wednesday evenings from 5:30pm to 8:00pm and the weekend session occurring on the Saturday between week 6-7 from 9am-2pm.

Of the 48 participants who did not enrol, 26 declined, 21 were never reached or lost to follow-up, and one met exclusion criteria (exclusion criteria are detailed in Table 3.1.2 above). The primary reason for declining was noted in all 26 patients that declined, with the most common reason

being a lack of time (81%). Figure 4.1.1 details the results of the referrals and the reasons for declining.

Figure 4.1.1: Result of Referral and Reasons for Declining



The attrition and attendance results relate to those that enrolled in MBSR. At the end of the trial, seven participants (43.75%) had completed MBSR resulting in an attrition rate of 56.25%. Relevant to note, is that in addition to the seven participants that successfully completed the group, there were two participants who were considered to have finished but not completed the group. Having finished, but not completed was defined in accordance with the original MBSR protocol[70,71] as participants who did not withdraw or discontinue but did not meet the criteria of attending 6/8 weekly sessions and the weekend session. Of the seven participants who withdrew or discontinued, four withdrew due to a lack of time, and an additional three discontinued without notice and were subsequently lost to follow-up. All seven participants who withdrew or discontinued did so before the before the third weekly session.

Adherence relates to the number of minutes of home practice that the participants who completed the group practiced per day. Although seven participants completed the group, one was lost to follow-up, and consequently adherence data is based on six participants. Individual participants practiced for an average of 21.67 minutes per day (CI: 13.1-30.2, range 10-30). As per the

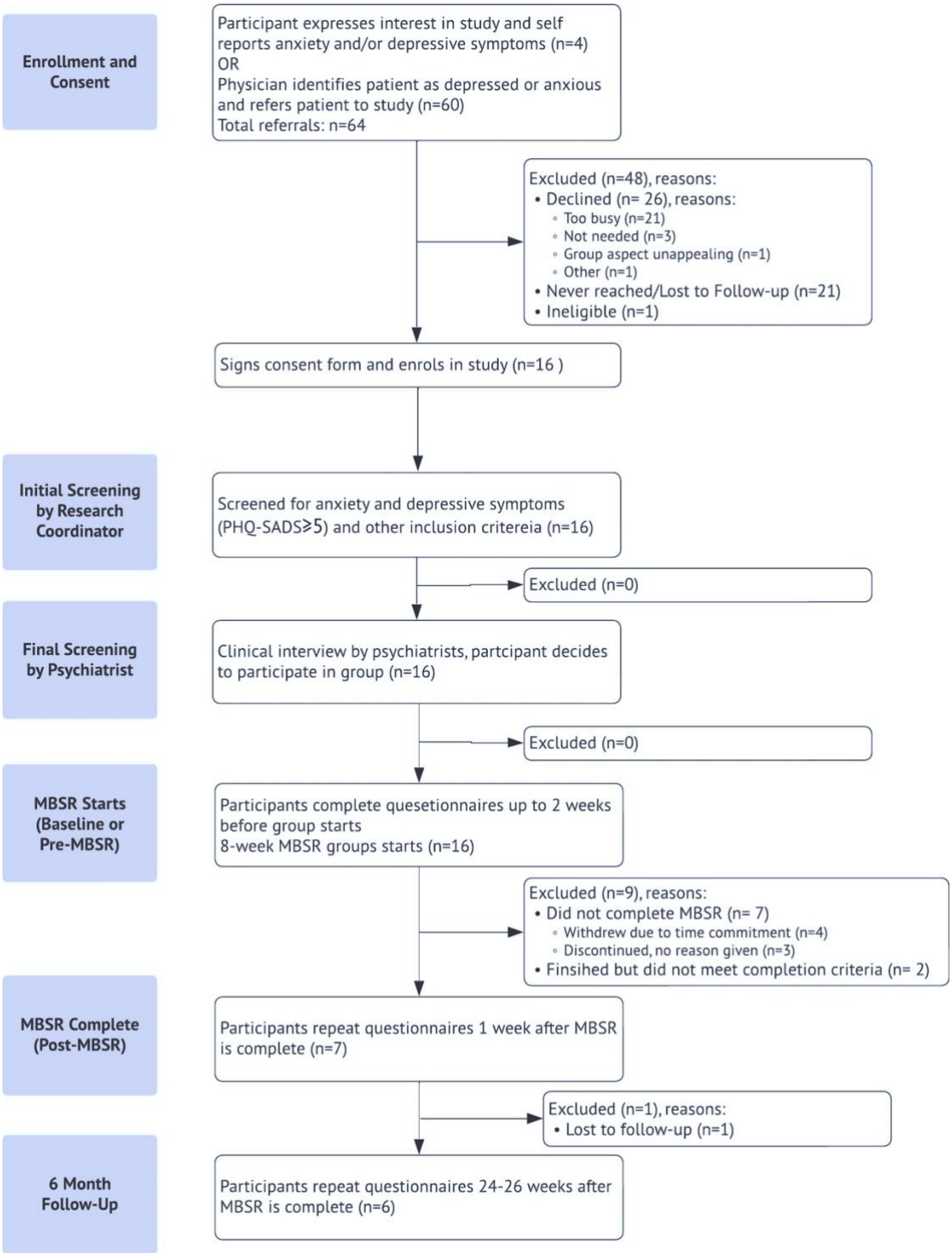
protocol of MBSR[70,71], the recommended home practice is 45 minutes each day; therefore, our participants average practice minutes represent an adherence rate of 48.16%.

Table 4.1.1 includes a summary of all the feasibility results. Figure 4.1.2, adapted from CONSORT recommendations[119], includes a flow diagram of participant progress with the trial data appended. Appendix B-5 includes the chart without trial data.

Table 4.1.1: Recruitment, Attrition, Attendance, and Adherence Results

Recruitment, n=64	n (%)
Enrolled	16 (25.0)
Declined	26 (40.6)
Lost to Follow-Up/Never Reached	21 (32.8)
Ineligible	1 (1.6)
Reasons for Declining (n=26)	*n (%)*
Too Busy/Lack of Time	*21 (80.8)*
Help Not Necessary	*3 (11.5)*
Group Aspect Unappealing	*1 (3.9)*
Not Enough Help	*1 (3.9)*
Attrition and Attendance, n=16	n (%)
Completed	7 (43.8)
Finished, but Did Not Complete	2 (12.5)
Discontinued	7 (43.8)
Reasons for Discontinuing (n=7)	*n (%)*
Lack of Time	*4 (57.1)*
No Reason Noted	*3 (42.8)*
Adherence, n=6	minutes (95% *CI*)
Average Practice per Day	21.7 (*13.1-30.2*)

Figure 4.1.2: Flow Diagram of Participant Progress



Chapter 4.1.2: Demographics

We collected demographic information from all 16 participants who enrolled in MBSR by distributing a demographic form to participants along with the rest of the pre-group surveys. Table *4.1.2* includes detailed demographic information from all participants and Table *4.1.3* includes demographic information broken down by participant.

Table 4.1.2: Detailed Demographic Information of Enrolled Participants

	n=	% of 16 participants
Gender		
Female	10	62.5
Male	6	37.5
Type of IBD		
CD	8	50.0
UC	8	50.0
Age		
18-24	3	18.8
25-34	3	18.8
35-44	6	37.5
45-54	3	18.8
55-65	1	6.3
Age at Diagnosis		
Under 18	4	25.0
18-29	7	43.8
30+	5	31.3
Years Since Diagnosis		
<5	5	31.3
5-10	5	31.3
>10	6	37.5
Employment Status		
Employed Full-Time	7	43.8
Studying Full-Time	4	25.0
Unemployed/Retired	2	12.5
Employed Part-Time	1	6.3
Self-Employed	1	6.3
Other	1	6.3

	n=	% of 16 participants
IBD Medications		
Biologic therapy only	9	56.3
Combination therapy (biologic and immunosuppressant)	4	25.0
5-ASA only	1	6.3
Biologic and 5-ASA	1	6.3
None	1	6.3
Psychotropic Medication		
No	7	43.8
Yes	9	56.3
1	*3*	*33.3*
2	*2*	*22.2*
3+	*5*	*55.6*
Psychotropic Medication by Type		
Antidepressant	8	50.0
Sedative/Hypnotic	5	31.3
Mood Stabilizer/Anticonvulsant	2	12.5
Antipsychotic	2	12.5
Other	2	12.5
Stimulant	1	6.3

Table 4.1.3: Demographic Information by Participant

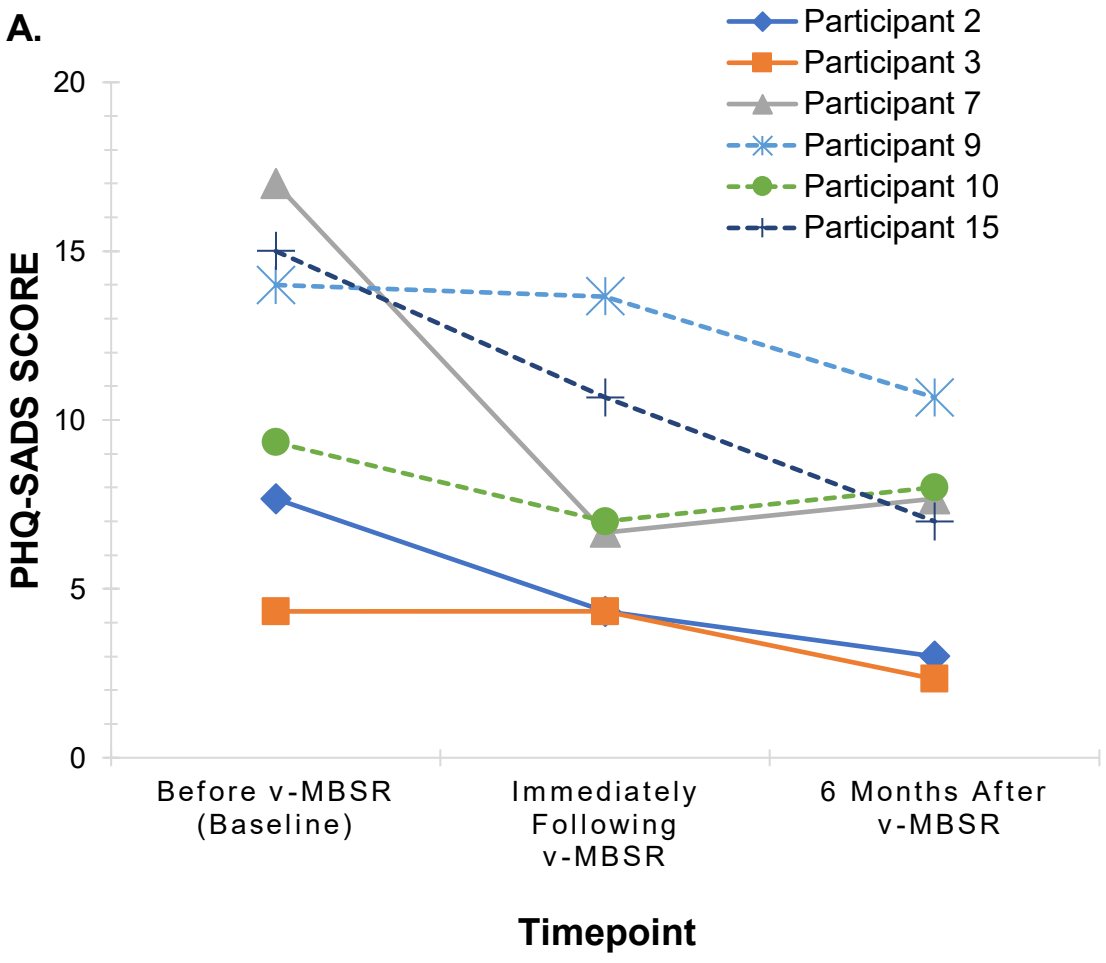
ID	Gender	Age	Employment or Student Status	Disease Type	Age at Diagnosis	Years Since Diagnosis	IBD Treatment	ACE	Number of Psychotropic Medications (Types)
1	F	37	Unemployed/ Retired	UC	14	23	Biologic	4	Three (AD)
2	F	35	Employed FT	CD	21	14	Combo Therapy	2	None
3	F	24	Studying FT	UC	20	4	Combo Therapy	0	One (AD)
4	F	28	Employed FT	CD	20	8	Biologic	4	Two (SH, ST)
5	F	55	Employed FT	UC	47	8	5-ASA	5	Four (AD, MSA, SH)
6	M	35	Employed FT	CD	22	13	Biologic	8	Two (AD, SH)
7	F	31	Employed FT	UC	28	3	Combo Therapy	5	None
8	F	53	Self-Employed	CD	17	36	None	4	Four (AD, AP, SH, Other)
9	F	50	Employed PT	CD	47	3	Biologic	2	One (AD)
10	F	27	Studying FT	CD	24	3	Biologic	2	None
11	M	40	Other, on short-term disability	UC	33	7	Biologic	1	Three (AD, MSA)
12	M	24	Studying FT	CD	12	12	Biologic	2	None
13	M	18	Studying FT	UC	15	3	Biologic and 5-ASA	0	None
14	M	40	Employed FT	UC	23	17	Combo Therapy	1	One (AP)
15	F	47	Unemployed/ Retired	CD	42	5	Biologic	9	Four (AD, SH, Other)
16	M	38	Employed FT	UC	31	7	Biologic	0	None

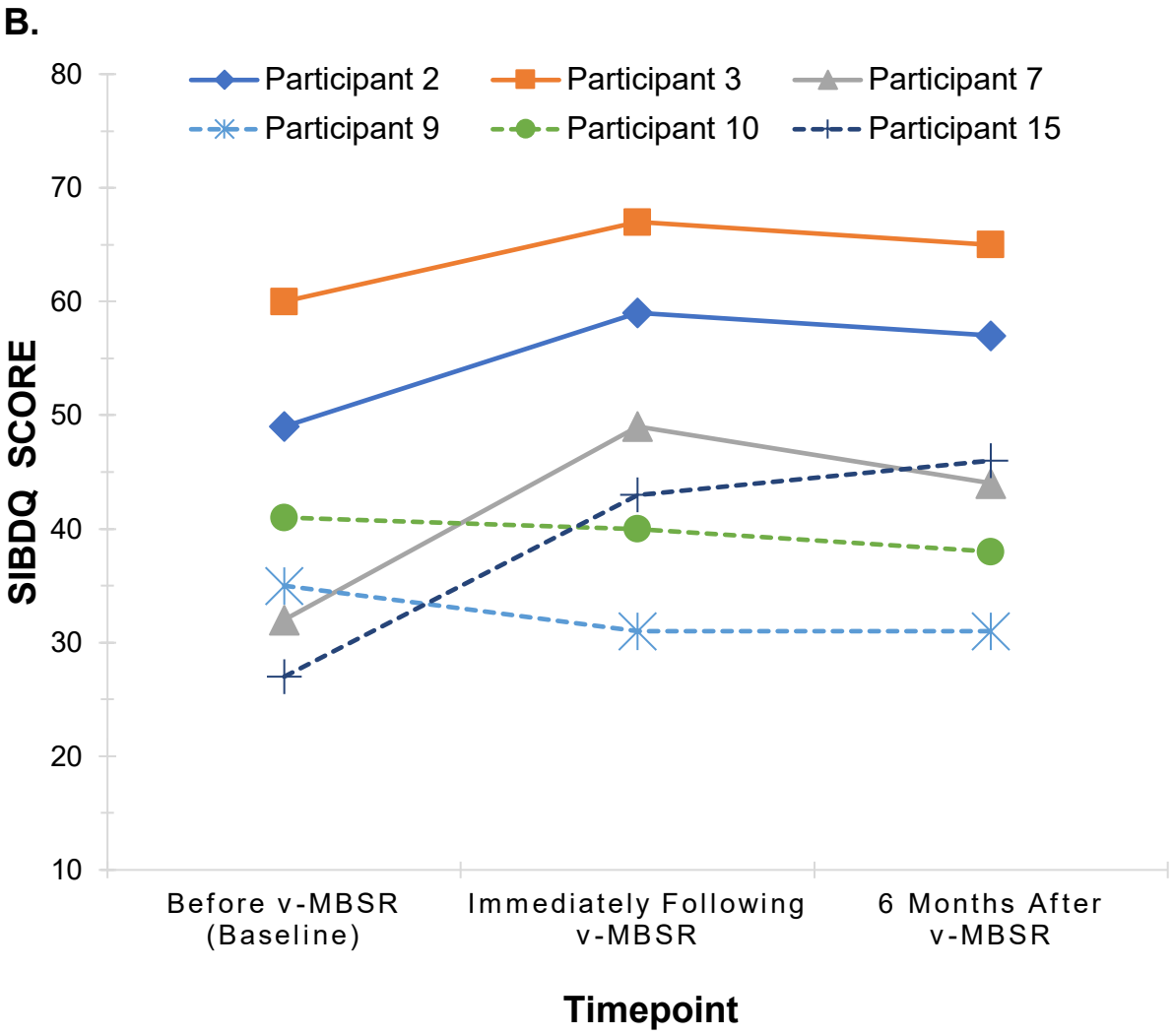
AD: Antidepressant
AP: Antipsychotic
MSA: Mood Stabilizer/Anticonvulsant
SH: Sedative/Hypnotic
ST: Stimulant

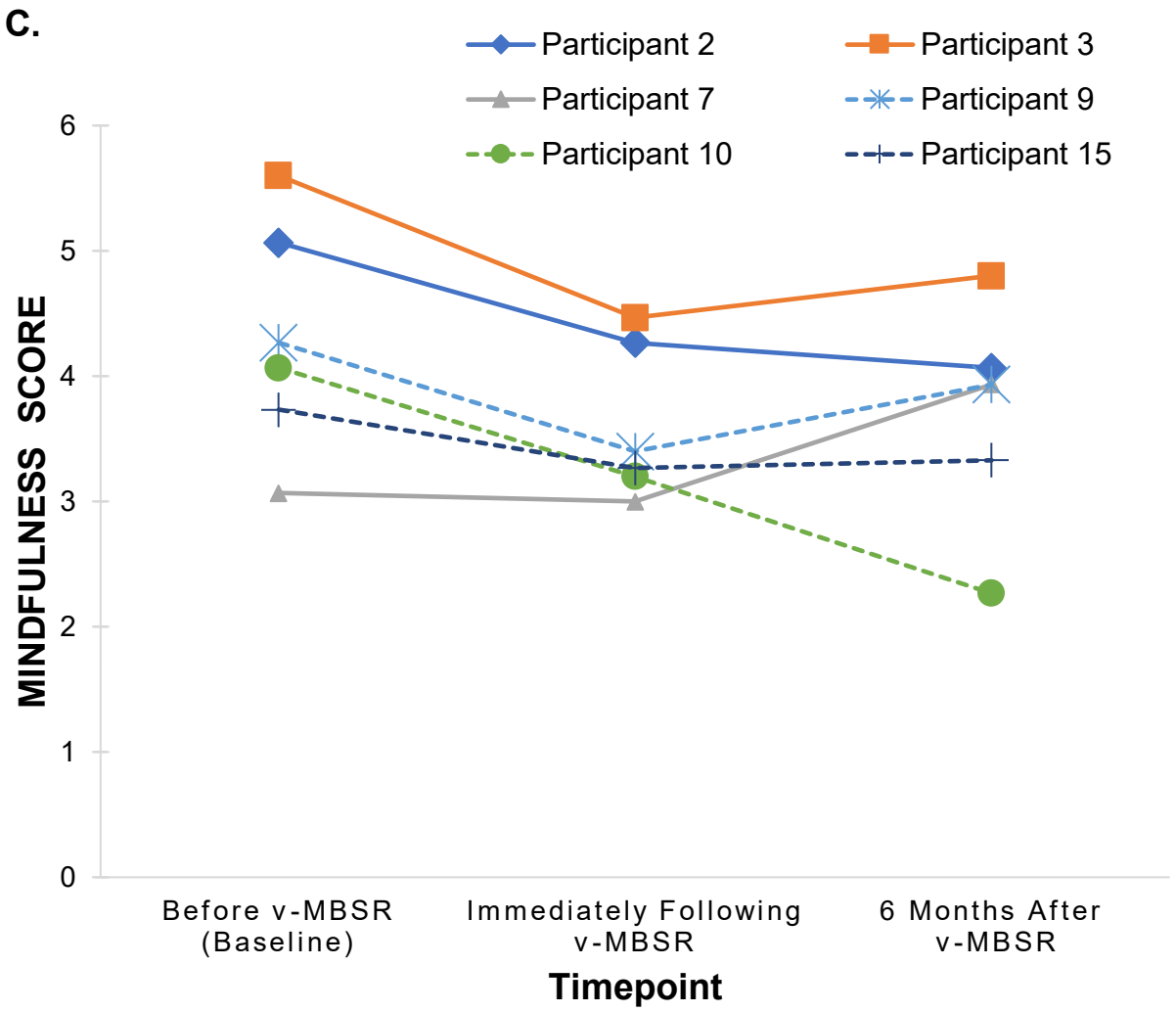
Chapter 4.1.3: Secondary Outcomes

We collected secondary outcomes (detailed in Chapter 3.1.3.2) from the trial at three different time points. Before the intervention began, data was collected from all 16 participants enrolled. Immediately after the intervention and 6-months after the intervention, we collected data from those that completed the intervention. One participant that completed the group was lost to follow-up; therefore, data was collected from the six remaining participants. Visual representations of individual participant changes to PHQ-SADS scores, SIBDQ scores, MAAS scores, and SCS-SF scores are available in Figure 4.1.3. Table 4.1.4 includes all participant data collected from the questionnaires. It is organized by participant number and includes their age, type of IBD, and ACE score.

Figure 4.1.3: Outcomes By Participant




B.
Participant 2
Participant 3
Participant 7
Participant 9
Participant 10
Participant 15
80
70
60
50
40
30
20
10
SIBDQ SCORE
Before v-MBSR (Baseline)
Immediately Following v-MBSR
6 Months After v-MBSR
Timepoint


C.
Participant 2
Participant 3
Participant 7
Participant 9
Participant 10
Participant 15
MINDFULNESS SCORE
0
1
2
3
4
5
6
Before v-MBSR (Baseline)
Immediately Following v-MBSR
6 Months After v-MBSR
Timepoint

D.

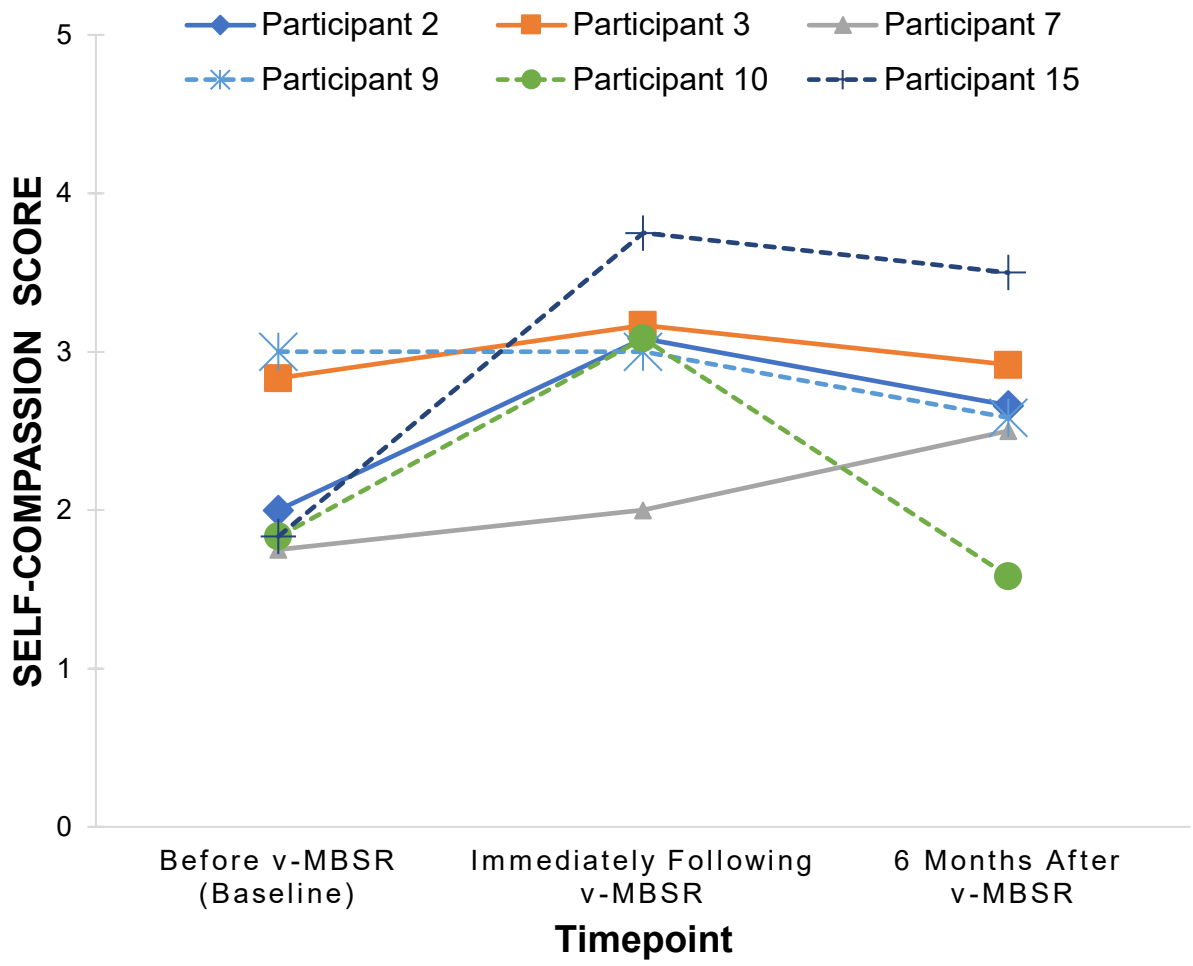

Participant 2
Participant 3
Participant 7
Participant 9
Participant 10
Participant 15
SELF-COMPASSION SCORE
5
4
3
2
1
0
Before v-MBSR (Baseline)
Immediately Following v-MBSR
6 Months After v-MBSR
Timepoint

Table 4.1.4: Secondary Outcomes Measures – Questionnaires

ID	Completed Program	PHQ-SADS			SIBDQ			MAAS			SCS-SF		
		Before	*After*	*6Mo*	*Before*	*After*	*6Mo*	*Before*	*After*	*6Mo*	*Before*	*After*	*6Mo*
1	*No, Finished*	17.3			33			3.1			1.8		
2	**Yes**	**7.7**	**4.3**	**3.0**	**49**	**59**	**57**	**5.1**	**4.3**	**4.1**	**2.0**	**3.1**	**2.7**
3	**Yes**	**4.3**	**4.3**	**2.3**	**60**	**67**	**65**	**5.6**	**4.5**	**4.8**	**2.8**	**3.2**	**2.9**
4	No	12.3			44			2.2			1.9		
5	No	10.0			46			3.3			1.9		
6	No	12.7			52			5.5			2.8		
7	**Yes**	**17.0**	**6.7**	**7.7**	**32**	**49**	**44**	**3.1**	**3.0**	**3.9**	**1.8**	**2.0**	**2.5**
8	**Yes†**	**15.7**			**33**			**3.5**			**3.3**		
9	**Yes**	**14.0**	**13.7**	**10.7**	**35**	**31**	**31**	**4.3**	**3.4**	**3.9**	**3.0**	**3.0**	**2.6**
10	**Yes**	**9.3**	**7.0**	**8.0**	**41**	**40**	**38**	**4.1**	**3.2**	**2.3**	**1.8**	**3.1**	**1.6**
11	No	21.3			28			2.8			2.1		
12	No	10.0			47			4.3			2.7		
13	*No, Finished*	10.3			30			4.3			2.2		
14	No	4.7			50			3.7			2.0		
15	**Yes**	**15.0**	**10.7**	**7.0**	**27**	**43**	**46**	**3.7**	**3.3**	**3.3**	**1.8**	**3.8**	**3.5**
16	No	6.7			48			5.6			2.7		
Mean in all participants		11.8			41			4.0			2.3		
Mean in completed participants only (95% CI)		**11.2** (6.1 - 16.3)	**7.8** (3.9 - 11.7)	**6.4** (3.1 - 9.8)	**41** (28 - 53)	**48** (34 - 62)	**47** (34 - 60)	**4.3** (3.3 - 5.3)	**3.6** 3.0 - 4.2)	**3.7** (2.8 - 4.6)	**2.2** (1.6 - 2.8)	**3.0** (2.4 - 3.6)	**2.6** (2.0 - 3.3)

†Lost to follow-up

Participant data relating to disease activity, including clinical and laboratory markers of disease, is also available in Table 4.1.5. Prior to starting the group, only one of the participants (Participant #2) was experiencing active inflammatory disease based on their CRP value. To note, at this timepoint, the participant's clinical indices score indicated they were in remission. Five of the participants (31%) were experiencing mild or moderate disease prior to starting the intervention based on their clinical indices score, but four of five of these participants had CRP values indicating their disease was in inflammatory remission (the remaining one participant was missing an up-to-date CRP value). At the time of 6-month follow-up, only Participant #2 and Participant #15 had elevated CRP values.

No participants had up to date FCP values available for all three timepoints, and most (81%) participants had no up to date FCP values available at all. Participants #13 and #14 had elevated FCP levels prior to starting the group and Participant #15 had elevated FCP levels when we collected 6-month follow-up data.

Table 4.1.5: Secondary Outcome Measures - Disease Activity

ID	Completed Program	Clinical Indices Score (Clinical Severity*)				CRP Value (Disease Status**)		
		Type	Before	After	6Mo	Before	After	6Mo
1	*No, Finished*	PMS	0 (R)			<0.5 (I)		
2	Yes	HBI	4 (R)	0 (R)	0 (R)	10.3 (A)	‡	10.0 (A)
3	Yes	PMS	0 (R)	0 (R)	0 (R)	<0.5 (I)	‡	<0.6 (I)
4	No	HBI	3 (R)			‡		
5	No	PMS	0 (R)			‡		
6	No	HBI	3 (R)			‡		
7	Yes	PMS	0 (R)	0 (R)	0 (R)	<0.5 (I)	‡	<0.5 (I)
8	Yes†	HBI	8 (M)			‡		
9	Yes	HBI	9 (M)	8 (M)	8 (M)	<5 (I)	‡	6 (I)
10	Yes	HBI	5 (m)	4 (R)	4 (R)	<0.5 (I)	<0.5 (I)	0.8 (I)
11	No	PMS	0 (R)			0.9 (I)		
12	No	HBI	3 (R)			3.3 (I)		
13	*No, Finished*	PMS	6 (M)			0.6 (I)		
14	No	PMS	1 (R)			‡		
15	Yes	HBI	9 (M)	8 (M)	4 (R)	<5 (I)	<5 (I)	13.7 (A)
16	No	PMS	0 (R)			‡		
* Severity score based on clinical indices score (R): Remission (m): Mild disease (M): Moderate disease						**CRP cut-offs for disease status Inactive (I) disease: <8mg/L Active (A) disease: ≥8mg/L		

†Lost to follow-up
‡lab value not available or out of date

As discussed in Chapter 3.1.3.2 previous studies have highlighted the link between higher ACE scores and an increase in a variety of mental illness symptoms including emotional dysregulation[27] . This trend existed in our population, with ACE scores and baseline PHQ-SADS scores demonstrating a Spearman's correlation coefficient of 0.5 (p-value: 0.04). The correlation can be visualized in Figure 4.1.4. This correlation was not surprising; however, one of our original goals of collecting ACE score data, was to assess if it could be useful in the future to identify patients who may benefit more from being referred to MBSR. The presence of this correlation meant the effectiveness of the treatment on reducing anxiety and depression would

have to be evaluated in relation to participants ACE scores and their baseline PHQ-SADS score to investigate if one of them was more strongly correlated with response to treatment. To evaluate both of these variables as potential predictors of responsiveness to treatment, I calculated the difference between completed participants pre- and post-group PHQ-SADS scores. I used this difference to represent the participant's responsiveness to the intervention. That is, the larger the decrease in the participants PHQ-SADS score, the more responsive I considered them to the treatment. I then compared this responsiveness score to either their ACE score or their baseline PHQ-SADS score and used Spearman's Rank Order Correlation to generate a correlation coefficient. The correlations can be visualized in Figure 4.1.5 with both correlations generating similar and strong correlation coefficients. Based on our results, it is difficult to determine if one of these baseline scores is more strongly correlated with participant's responsiveness to treatment, and a larger sample size would be necessary to observe any significant differences. This potential correlation may be of interest to future studies.

Figure 4.1.4: Correlation Between Baseline PHQ-SADS and ACE Score

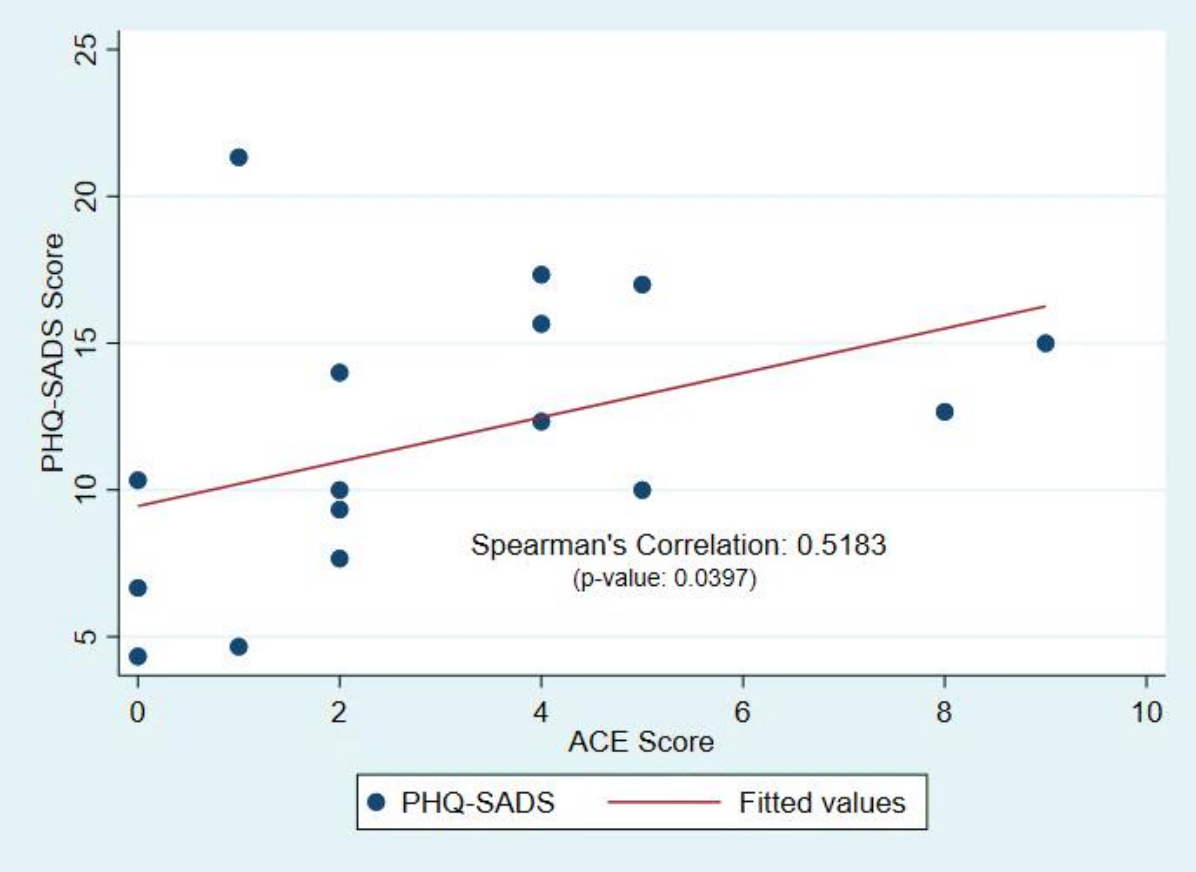
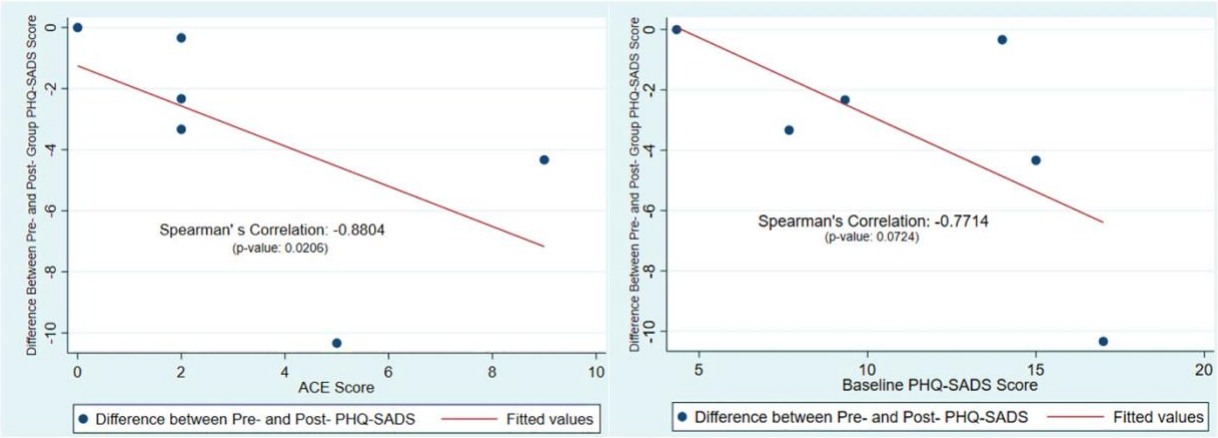


Figure 4.1.5: Correlation Between Responsiveness and either ACE or Baseline PHQ-SADS



Considering the correlation between our participants ACE and PHQ-SADS scores at baseline (Figure 4.1.4), we wanted to investigate if there was any difference in these scores when comparing the group that completed the intervention and the group that did not complete the intervention. Table 4.1.6 and Table 4.1.7illustrate this comparison as well as others including the mean baseline scores, demographic information, and disease information of the participants that completed the group and those who discontinued, withdrew, or otherwise did not meet completion criteria. When we compare the demographics of the those that completed and those that did not, we can see that those that completed were all female, older in age, were more likely to have Crohn's disease, less likely to be working or studying full-time, had higher average ACE scores, and were more likely to be receiving care from a gastroenterologist practicing at a non-academic center. When comparing the baseline scores of both groups, those that went on to complete had higher anxiety and depression scores, lower quality of life, and higher dispositional mindfulness. Despite all of these trends, the confidence intervals around the means overlap significantly when we compare the two groups, and so drawing conclusions based on these observed differences is not strongly supported by the data. A larger sample size would be required to properly examine if the group that completed the intervention and the group that did not complete the intervention had any different characteristics at baseline.

Table 4.1.6: Characteristics of Participant by Completion Status

	All Participants (n=16)	Complete Participants (n=7)	Incomplete Participants (n=9)
	n *(%)*	n *(%)*	n *(%)*
Participant Gender, *Female*	10 *(62.5)*	7 *(100)*	3 *(33.3)*
Employment Status, *Full-Time Work/Study*	11 *(68.8)*	4 *(57.1)*	7 *(77.8)*
Taking Psychotropics, *Yes*	9 *(56.3)*	4 *(57.1)*	5 *(55.6)*
Disease Type, *CD*	8 *(50.0)*	5 *(71.4)*	3 *(33.3)*
	Mean *(95% CI)*	**Mean *(95% CI)***	**Mean *(95% CI)***
Age	36.4 *(30.6-42.2)*	38.1 *(27.3-49.0)*	35.0 *(26.7-43.3)*
Years Since Diagnosis	10.4 *(5.6-15.1)*	9.7 *(0.0-21.0*)*	10.9 *(6.2-15.6)*
ACE Score	3.06 *(1.61-4.51)*	3.43 *(0.71-6.14)*	2.78 *(0.71-4.84)*
Baseline Scores			
PHQ-SADS	11.8 *(9.2-14.3)*	11.9 *(7.5-16.3)*	11.7 *(7.8-15.6)*
SIBDQ	41.0 *(35.7-46.2)*	39.6 *(29.0-50.2)*	42.0 *(35.0-49.0)*
MAAS	4.0 *(3.5-4.6)*	4.3 *(3.3-5.3)*	3.9 *(3.0-4.8)*
SC	2.3 *(2.0-2.6)*	2.2 *(1.6-2.8)*	2.2 *(1.9-2.5)*

*95% CI imprecise due to outliers, range 3-36

Table 4.1.7: Characteristics of Referring Physician by Participant Completion Status

	All Participants (n=16)	Complete Participants (n=7)	Incomplete Participants (n=9)
	n *(%)*	n *(%)*	n *(%)*
Location of Referring Physician, *Academic Center*	9 *(56.3)*	2 *(28.6)*	7 *(77.8)*
Gender of Referring Physician, *Female*	3 *(18.8)*	1 *(14.3)*	2 *(22.2)*

Chapter 4.2: Interviews

21 patients were contacted for a semi-structured interview. This included patients who had participated (fully or partially) and those who declined MBSR. In total, nine participants were reached and five accepted the invitation to participate in an interview. I conducted five interviews, and all five participants had completed MBSR. The interviews took place over Zoom[146] between October 2022 and December 2022. They ranged in length from 19 minutes to 71 minutes and the median interview length was 28 minutes (IQR: 24-33).

Chapter 4.2.1: Participant Characteristics

Two of the five interview participants were enrolled in and completed the first MBSR group in April 2022, and they were interviewed in October approximately four months after completing the MBSR sessions. The other three were enrolled in and completed the second group in September 2022, and they were interviewed in November of 2022, all within one month of completing the MBSR sessions. During the interviews, participants were asked basic demographic questions. Their answers were combined with the information collected in the feasibility trial and are included in Table 4.2.1.

Table 4.2.1: Interview Participant Characteristics

ID*	Gender	Age	Employment or Student Status	Dependents in House	Type of IBD	Age at Diagnosis	Psychotropic Medications? (Type)
2	F	35	Employed Full-Time	None	CD	21	None
3	F	24	Studying Full-Time	None	UC	20	Yes, one (Antidepressant)
9	F	50	Employed Part-Time	One child over 18	CD	47	Yes, one (Antidepressant)
10	F	27	Studying Full-Time	None	CD	24	None
15	F	47	Working Part-Time	One child under 18	CD	42	Yes, four (Antidepressant, sedative/hypnotic, others)

*Participant ID number from the feasibility trial

Chapter 4.2.2: Themes

The majority of the themes from the interviews related to two areas of the feasibility trial: participant-specific data and the program-specific outcome data. Additional participant-specific data included participants' previous experiences and difficulties when trying to improve their health, their motivations to engage in MBSR, and their expectations. Additional program-specific feasibility data included barriers and facilitators of participating and additional program-specific effectiveness data included perceived benefits, positive experiences, future intentions, and recommendations. Two additional themes related to wellness and IBD also emerged from the interview, and they were organized separately from the themes that were related to the trial.

After creating the themes, the research team and I integrated them into the quantitative data from the trial. The goal of this strategy was to use the results from the interviews to add context and information to the feasibility trial data. Detailed information regarding each theme will be described below.

Chapter 4.2.2.1: Participant-Specific Themes

Interview themes relating to participant-specific characteristics: fit into three major categories: participants' motivations to engage in MBSR, participants expectations before starting MBSR, and participants previous experiences and difficulty trying to their improve well-being. All five of the participants were motivated to engage in MBSR by at least one of the following factors: previous experience with mindfulness, a desire to improve their quality of life and disease management through learning, their own research, specific group features including the group being taught by a professional, and recommendations from others including their family, friends, and/or their healthcare provider. The three most common motivations for enrolling were personal research, the desire to improve through learning, and recommendations from others.

Four of five participants had limited or negative expectations with regards to the group. These expectations related to their general participation in the group as well as specific negative expectations relating to the length of the weekly meeting. All five participants had previously engaged in activities in an attempt to improve their well-being. They had all tried physical health improvements including diet and exercise and four of five participants had tried mental health improvements including finding supportive social circles and seeing a mental health care practitioner such as a therapist or psychiatrist. Four of the participants reported previous struggles trying to improve their well-being. These struggles mainly included a lack of discussion about mental health with their IBD specialist and difficulty finding a mental health care practitioner that understood IBD.

Chapter 4.2.2.2: Program-Specific Themes

Themes relating to the program itself fit into 4 main categories: program barriers and facilitators, experiences within the program, perceived benefits of participating in the program, and endorsements and future intention. When asked to identify barriers to participating in the program, all five participants identified the time related to home practice. One participant noted that the inflexibility of the weekly session was a barrier, and one other participant noted that the online format made attendance easier.

All five participants described their experience in MBSR as positive and added being able to participate in the group with other people with IBD contributed to their positive experience. Two of five participants also added that their participation led to changes to their attitudes and perceptions which contributed to the positive experience. When asked about the benefits of the program, all five participants noted that the main benefits arose from the new techniques they were able to develop. All five participants shared that they developed coping skills that allowed them to better manage their anxiety and stress in addition to new focus and mindfulness tools. Four of five participants also noted they benefited from novel techniques that allowed them to manage disease symptoms and pain.

All five participants said they would recommend MBSR to others, and three participants emphasized that they would continue to practice mindfulness going forward and would share their experience and tools with others.

Chapter 4.2.2.3: Additional Themes

Two additional themes emerged from the interview, although they related to wellness and IBD and not the trial. The first theme emerged when we asked participants to define wellness and how their disease influences their definition. In response, all participants defined wellness as being multifaceted and including physical and mental elements. Additionally, two of five participants specifically described wellness as balance. All five participants noted that IBD negatively impacts their physical health, and four participants also discussed the disease's negative impact on their mental health and overall wellness.

The second theme emerged organically as there was no questions related to the topic in the interview guide. Despite not being prompted, all five participants expressed a desire for increased emphasis on interdisciplinary IBD care and related training for IBD specialists. They all also expressed a desire to have more conversations with their IBD specialist about mental health.

A summary of all of the themes from the interview is available in Table 4.2.2 and the full theme table with relevant quotes can be found in Appendix C-1.

Table 4.2.2: Summary of Topics and Themes

Relating to Feasibility Trial	Topic	Themes
Participant-Specific	**Motivations to Engage in MBSR (n=5)**	Previous Experiences with Mindfulness (n=2)
		Improvement Through Learning (n=3)
		Personal Research (n=3)
		Group Features (n=2)
		Recommendations from Others (n=3)
	Expectations Before Starting MBSR (n=4)	Limited (n=4)
		Negative (n=4
	Past Experiences and Difficulties Trying to Improve Well-Being (n=5)	Attempts to Improve Physical Wellness (n=5)
		Attempts to Improve Mental Wellness (n=4)
		Struggles (n=4)

Relating to Feasibility Trial	Topic	Themes
Program-Specific	**Barriers and Facilitators** **(n=5)**	Time was a Barrier (n=5)
		Online Access was a Facilitator (n=1)
	Experiences in the Program **(n=5)**	General Positives (n=5)
		Peers with IBD Contributed to Enjoyment (n=5)
		Improved Perception and Attitude (n=2)
	Perceived Benefits from New Techniques Learnt **(n=5)**	Disease Management: Symptoms and Pain (n=4)
		Coping Skills: Stress and Anxiety Management (n=5)
		Mindfulness and Focus Tools (n=5)
	Endorsements and Future Intentions **(n=5)**	Positive Recommendations (n=5)
		Intentions With Mindfulness Going Forward (n=3)

Relating to IBD	Topic	Theme
Care and Disease Management	**Defining Wellness and the Impact of IBD** **(n=5)**	Wellness is Multifaceted (n=5)
		IBD has a Negative Impacts on Health and Wellness (n=5)

Relating to IBD	Topic	Theme
Care and Disease Management	**Mental Health Care Within IBD Care** **(n=5)**	Desire for Increased Emphasis on Interdisciplinary Care and Increased Training for IBD Specialists (n=5)
		Desire for More Discussions About Mental Health with IBD Specialist (n=5)

Chapter 5: Discussion

Thus far, I have presented a literature review of the acceptability of adapting psychological and other mind-body interventions to telehealth delivery for people with IBD, a trial that examines the feasibility, acceptability, and effectiveness of a virtually delivered MBSR for IBD patients, and an interview study that discusses participants experiences in MBSR and their previous experiences trying to improve their wellness. To our knowledge, this was the first trial evaluating the feasibility of integrating virtual MBSR into IBD care in Canada and was also the first to explore IBD patients' experiences in MBSR. The key findings of this thesis include:

1. The feasibility and acceptability of virtual MBSR for people with IBD
2. The effectiveness and benefits of virtual MBSR for people with IBD
3. The possible integration of virtual MBSR and its future as a treatment option for people with IBD in Alberta

Chapter 5.1: Feasibility and acceptability

The primary outcomes of the trial focused on assessing the feasibility of virtual MBSR for adults with IBD. The interviews with participants then expanded on potential barriers of participating in the intervention. Together, this mix of quantitative and qualitative data provides insight into the acceptability of virtual MBSR for patients with IBD in Edmonton, Alberta. There are two other studies that have examined MBSR as a treatment for people with IBD – a 2014 RCT by Jedel et. al[161] and a 2016 controlled trial by Neilson et. al[162]. Despite both studies reporting that they were intended to be pilot studies that could act as precursors to large scale RCTs, both of them elected to evaluate the intervention's effectiveness as the primary outcome. Notwithstanding this, some feasibility data can be inferred from the tables and figures, and both studies will be used to compare and contrast the results we observed in our trial.

As a preliminary assessment of interest and acceptability, we examined trial uptake and our results demonstrated that one quarter of interested participants elected to enroll in MBSR. In an RCT, Jedel et. al. invited 200 UC patients from the Greater Chicago area to participate with 110 found to be ineligible. Of the 90 patients who were eligible, 35 were not interested and

subsequently declined to participate representing a trial uptake rate of 61.1%. This RCT showed a trial uptake that was over double what was observed in our trial. There could be several reasons for this significant difference in recruitment success. Firstly, participants in the Jedel et al. study were compensated with 300USD for their participating in the study which could have served as a motivating factor when patients were considering participating. The participants in our study were not compensated. Secondly, their recruitment was conducted in-person in contrast to our study where recruitment was mainly conducted over the phone. In-person recruitment has previously been shown to contribute to increased willingness to participate in research[163]. In a controlled trial, Neilsen et. al invited 97 patients from an IBD clinic in Melbourne to participate in MBSR and 37 declined. Then, of the 60 who agreed to participate, 27 chose to participate in the control group instead of the intervention. Combining both of these groups, 64 patients declined the treatment, which represents a trial uptake rate of 34%. The Neilson et al. uptake is closer to what we observed in our study but was still higher which could be once again attributed to the in-person recruitment that they were able to conduct. In our study, over 80% of patients reported declining to participate due to a lack of time and all five interview participants indicated that the time commitment was a barrier to participate. This was similar to the reasons for declining general participation Neilson et. al study and is a theme that has been identified in previous studies[32]. The main reason for declining to participate in the intervention arm of the Neilson trial was due to the distance required to travel for treatment. Travel distance was less of a concern in our study because MBSR was delivered virtually, and no patients noted it as a reason for declining to participate making it a potential advantage of our delivery modality.

The patients who enrolled in our study had similar demographics to the participants who received treatment in both other studies. The Jedel et. al study had 27 participants enrolled in the intervention arm and the Neilson et. al study had 33 participants in their intervention group whereas our study had 16 enrolled. All three of our studies enrolled participant populations were dominated by women and had average ages between 36-46. The Jedel et. al study included only participants with UC whose disease was in remission. The Neilson et. al study was similar to ours in that it included participants with both inactive or active CD and UC. Over 60% of the participants in our study were working or studying full-time. This percentage fell between the rates reported by the two other studies. In the Jedel et. al study, over 75% of participants were

working full-time and none were studying full-time, and in the Neilson et. al study, only 40% of participants were employed full-time and 6% were studying full-time.

Although different tools were used to assess for baseline anxiety and depression symptoms, the results can be compared by using each respective scale's descriptions of score severity. In the Jedel et. al study, the average anxiety score was slightly below what is considered to be clinically concerning. In the Neilson et. al study, the average anxiety score was considered to be borderline abnormal. The average participant in our study had what was considered a moderate anxiety and depression score that is commonly considered to be clinically concerning[127]. It is not possible to accurately compare all of the scores using only the respective scale's descriptors since these descriptors are based on ranges of numerical scores, but it appears that our study's participants may have had higher anxiety levels at baseline, although all three studies' average score descriptors were comparable. Similar to the assessment of anxiety, all of the studies used different scales to evaluate participant quality of life before starting MBSR. Again, using the average score descriptors to compare, the participants in the Jedel et al. study reported only slightly impaired quality of life and the participants in the Neilson et al. study reported good quality of life. This is in contrast to the average participant in our study, who reported severely impaired quality of life. To emphasize again, it may not be most appropriate to compare quality of life scores based on the scale score descriptors; however, our study required patients who were referred to report that they were struggling with stress or anxiety which may have contributed to the average lower quality of life and higher anxiety score.

Looking at the attrition rates of enrolled participants, there were large differences between the attrition rates we observed in our study compared to those observed in the the Jedel et al. and the Nielson et al. study. The former reported an attrition rate of 11.5% while the latter reported an attrition rate of 18%. This is stark contrast to our study which reported a 57% attrition rate. Interesting in our study as well, was that despite the mix of female and male participants at baseline, only female participants successfully completed the intervention with all of our male participants discontinuing or failing to complete. All three of our studies had the same definition of attrition, so this difference in attrition rates between our study and the other two trials is particularly surprising. Although psychiatric services often suffer from high rates of no-show[112] ,

there are several high quality quantitative, qualitative, and meta-analysis studies across the world[112,164,165] that have identified travel as one of the largest barriers to accessing healthcare and therefore missing or discontinuing treatments. Further, the literature review conducted in Chapter 2 of this thesis suggested that it is feasible to adapt and offer psychiatric interventions virtually. Our review did include more one-on-one interventions than group-based interventions, and so it is possible that group delivery is less feasible when compared one-on-one delivery. In contrast to this hypothesis, studies comparing individual and group-based therapies in other populations have found that the attrition rate in group-based therapies is lower than the attrition rate in individual therapies[166,167]. It is possible that adapting MBSR to be delivered virtually in our study was what contributed to the high attrition rate, due to our study population (i.e. IBD patients in Alberta) feeling uncomfortable or being unable to receive telehealthcare; however, a recent survey of IBD patients in Alberta found that over 80% of respondents were comfortable using virtual care options and agreed they were satisfied with telehealth as a treatment modality[98]. Another possibility is that offering the intervention virtually decreased the quality of relationships formed between participants and the instructors thereby reducing a motivating factor of attending the group. This phenomenon has not been well-established but was reported in a recent study looking at the perceived satisfaction with relationships with peers and instructors in students attending classes face-to-face versus virtually[168]. Similarly, a qualitative study also reported that adapting group therapy to virtual delivery led to the formation of superficial relationships with other participants[169] . In conflict with this theory, a 2022 study showed that there were no significant differences in attrition rates when comparing MBSR delivered in-person or virtually[85]. All factors considered, our high attrition rate is not in accordance with the attrition rates reported in other MBSR trials in patients with IBD[161,162] nor is it within with the 16-29% average attrition rates reported in reviews of MBIs[170,171]. Studies should continue to investigate whether the engagement, satisfaction, and attrition rates observed in virtual MBSR is non-inferior to those rates observed in in-person MBSR.

The participants in our study reported an average of 21.7 minutes of daily home practice which is the measure we used to define adherence. This was very similar to the participants in the Neilson et al. study, who reported an average of 25 minutes of daily practice. Our participants' average 21.7 minutes of practice represented an adherence rate of 48.2% if we compare it to the average

minutes of practice required by the MBSR protocol which is approximately 45 minutes[70]. Two recent systematic reviews with meta-analyses assessing adherence to home practice in MBSR reported adherence rates of 39.6%[172] and 64%[173], and so the observed rate of 48.2% in our study was comparable to the majority of the literature. The latter review also reported that adherence to home practice had a small but significant positive correlation with intervention outcomes[173]. Our study population was too small to examine this potential effect, but it could of interest to examine in future larger studies.

Chapter 5.1.1: Challenges, Limitations, and Conclusions

There are several limitations to assessing the feasibility of virtual MBSR in our sample of patients with IBD with the most significant being our small sample size. Three of four of our primary feasibility outcomes (adherence, attendance, and attrition) are evaluated by looking at the group of patients who enrolled in the intervention which in our study was only 16. Because of this, we are lacking the statistical power to explore any reasons that may explain our observed outcomes. For example, the group of participants that completed MBSR and the group of participants that did not complete MBSR differ with regards to their average baseline scores, but their confidence intervals overlap, and so our statistical precision for estimating the difference is poor. If we had a larger number of participants, we may have been able to estimate the difference more precisely, which would provide stronger evidence for policy decisions (i.e., who to offer MBSR to in the future), had we had a larger sample. Although there are limitations to exploring the reasons behind the results we observed, the primary outcome results themselves, such as the recruitment and attrition rates, could still be used to provide limited guidance to decisions regarding the future of MBSR for IBD patients in the Edmonton Zone or Alberta as a whole.

Our interviews included only participants who completed MBSR, so we are also limited by the barriers that we may have been able to capture. Even though all five interview participants completed the intervention, they were all able to identify a barrier, and further to that, all five of them identified the same barrier of time. However, our data is still limited by our inability to explore the perspective of participants who did not complete the intervention and/or did not enrol in the first place on the topic of barriers to treatment. The notion of time as a barrier to treatment

is supported by other studies, as discussed above, but we should still be aware there may be more participant-identified barriers we were unable to capture with our limited sample.

Another limitation, specifically, to the generalizability of our results, is that we only recruited in one major city in Alberta. We only advertised the intervention and attempted to recruit patients to gastroenterologists from the Edmonton area. Recruitment was conducted at multiple locations in the city and included both academic and non-academic centers, but the patients receiving care in Edmonton hospitals and clinics may not be representative of all IBD patients in Alberta. In contrast to this limitation, our study was conducted in the 'real-world' clinical setting which may offer a better idea of its true ability to be integrated into practices in Alberta. Efficacy evaluations, often randomized control trials, are often done in highly controlled settings and results are often not generalizable to clinical or community settings[66,67]. Our study was conducted using resources and referral pathways that already exist in Alberta which provide results that more accurately reflect clinical and community restraints. Considering these limitations, the overall feasibility of virtual MBSR can be more accurately considered.

Bowen et al.[67] identifies and defines eight areas that the overall success of feasibility trials can be evaluated. The first four suggested areas of evaluation include acceptability, demand, implementation, and practicality. The interviews with participants that completed the intervention found it acceptable with all five participants saying they had positive experiences and would recommend it to others. Most of those that declined or discontinued the intervention did so because of a lack of time and this barrier was also emphasized in all of our interviews, and so while this indicates the intervention may not be acceptable for all IBD patients, it could be acceptable for those who are interested and have the ability to dedicate the required time over eight weeks. Demand was relatively high, especially considering the challenges we faced advertising the study due to most clinic appointments being conducted over the phone which limited recruitment opportunities. Multiple gastroenterologists from a variety of academic and non-academic sites in the city referred patients to the study, and with more time to advertise the intervention, it is possible that more gastroenterologists may be aware of the treatment and willing to refer their patients. The implementation of the intervention using existing pathways was successful. Gastroenterologists could refer their patient directly through the existing

electronic healthcare database which made the implementation relatively simple. Psychiatric interviews with interested participants could be a potential limiter in the future since they are time intensive; however, almost all psychiatric counselling in Alberta already requires an interview or screening call beforehand, and the screening calls could potentially be performed by other mental health professionals such as nurses. Virtual delivery was practical for participants and did reduce the amount they had to travel to receive care. In the interviews, one participant noted that they would not have participated in the group had it meant they had to make extra trips to the hospital or a clinic.

The other four suggested areas of to evaluate the overall success of feasibility trials include adaptation, integration, expansion, and limited-efficacy testing. Integration of the intervention into the healthcare system was smooth. MBSR is a group that is already offered as a part of psychiatric services in Alberta and there are several psychiatrists who are qualified to deliver the program. Expanding offerings of the intervention to other cities in Alberta was not evaluated in our study, and there are many factors that would need to be considered to expand the intervention to all IBD patients in Alberta. The virtual aspect of the intervention serves as an advantage when considering potentially expanding the delivery to a larger geographic area. Because psychiatrists who are qualified to deliver MBSR can offer the intervention from a distance, the patient would be able to engage in MBSR assuming they have access to a computer and internet. The limitation for delivering virtual care is licencing of the psychiatrists delivering the program which is currently provincially based. The largest barrier to expanding the intervention would be raising awareness of its existence and ensuring physicians are comfortable referring their patients. In order to offer the intervention outside of large cities with academic centers, gastroenterologists and family physicians in rural areas would have to understand which patients are good candidates for MBSR and how they can refer them. This could be difficult, but with time and advertisements, hopefully most physicians would be aware of MBSR as a treatment option. For physicians to be comfortable using MBSR, there would have to be adequate safety protocols in place that would ensure patients' who have high anxiety or depression symptom burden are directed to access appropriate emergency psychiatric resources if necessary. A series of interviews or surveys may have to be conducted to gauge practitioners comfort referring their patients to psychiatric care, and an education resource may have to be

distributed to physicians to increase their confidence referring their patients. Finally, although our sample was very small, the effects of MBSR were promising and will be discussed more in the Chapter 5.2. Looking at all of these areas together, it seems MBSR could be a promising treatment option for Alberta IBD patients who are dealing with high levels of anxiety, depression or stress, as long as they have the time to dedicate to the group.

Chapter 5.2: Effectiveness and Benefits

Many systematic reviews have found MBSR to be an effective tool to enhance participant quality of life and decrease anxiety in a variety of populations including medical professionals[77,174], cancer patients[78,81], and people with chronic diseases[82–84]. In patients with IBD, it has been found to be effective at reducing anxiety[161,162] and have a protective effect on the negative impacts flares can have on quality of life[161]. Similarly, participants with IBD in a recent randomized control trial attending a mental health program that included MBSR as a core component noted increased quality of life, reduced psychological symptoms of distress, and reduced fatigue[107]. The participants that completed MBSR in our study noted very similar effects, and these effects persisted at the six-month follow-up. Our sample was much smaller than the other trials and reviews, but we observed promising decreases in our participants' PHQ-SADS scores and increases in their quality-of-life scores even six months after completing the program. Even taking the limitation of our small sample, we considered our results promising due to the size and sustainability of the changes and their associated confidence intervals.

The interviews we conducted also provided rich data regarding the effectiveness of the program through the perceived benefits the participants noticed. To our knowledge, no previous studies have explored IBD patients' experiences in MBSR through interviews. A similar study, by Schoultz et al.[175] explored IBD patients' experiences in MBCT and their findings will be discussed in contrast with ours throughout this section.

All of our participants who completed the interviews reported generally positive experiences in the program, highlighting the non-specific benefits of the group. This was in spite of four of the participants noting negative or limited expectations before beginning the intervention. All five participants also described feeling relaxed and supported in the group and two of the participants

felt that the positive experience led to a shift in their attitudes making them feel empowered and like they had a new outlook on life. All participants credited these feelings at least partially to being in a group with their peers and described feeling comfortable because the other participants had IBD. The feeling of being supported was something noted by the participants of the Schoultz et al.[175] and is not surprising as cohesion is a characteristic of group therapeutic interventions that has been previously associated with positive treatment outcomes and experiences[176].

In the interviews, participants were also asked to describe some of the specific benefits of MBSR, and all participants attributed the benefits to the new techniques they were able to learn and develop. Four of the participants discussed that these new techniques allowed them to better manage their disease, especially their symptoms and pain levels. All interview participants also felt their coping skills improved allowing them to better manage their stress and anxiety, something they noted was often a trigger for their disease. Having a sense of control over symptoms and disease is extremely important for patients with IBD and losing this sense of control often leads to feelings of anxiety, depression, and stress[177]. All of the participants also benefited from learning new mindful and focus tools. They highlighted that these tools translated to all aspects of their lives, and that being able to be mindful and have focus allowed them to solidify their sense of perceived control. The process of learning and being actively involved in their healing were themes that emerged from the Schoultz et al. [175] interviews as well.

Overall, the quantitative results showing promising improvements to anxiety and quality of life and the qualitative results describing participants' positive experiences and the perceived benefits of the program, provide strong evidence for the effectiveness of MBSR in our participants who completed the program. Previous trials and reviews have established that MBSR can be effective for many populations, including for patients with IBD, and our trial showed no evidence to contradict this.

Chapter 5.2.1: Challenges, Limitations, and Conclusions

The largest challenge in evaluating the effectiveness MBSR in our sample is our sample size. Only seven participants completed the program, and one was subsequently lost to follow-up,

leaving us with only six participants with complete data sets. Our analysis lacked sufficient data for statistically precise estimates of differences between groups, and we were also unable to use any regression models to assess for the possibility of confounders. Importantly, measuring the effectiveness of MBSR was only a secondary outcome of our study and recommendations do not support drawing conclusions about effectiveness from feasibility trials[67,87,91,92,120]. When we consider the participants' perspectives highlighted in the interviews, it seems fair to consider the preliminary effectiveness of virtual MBSR as promising in patients with IBD, and also that there is a need for further larger studies to explore this effectiveness.

Another limitation to the effectiveness of our trial is that all of the questionnaires we used to assess for our outcomes were self-administered. Allowing patients to self-report their symptoms, both psychological and physical, introduces individual differences in symptom assessment into the measures. We attempted to mitigate this by using validated questionnaires and by also collecting laboratory data, but the chance of differences in interpretation still remains. Our interviews could also have been influenced by social desirability bias; participants may have felt pressure to report more positive experiences in attempt to be more helpful or because they felt like they had to after having access to the group[178]. Before starting the interviews, I explained to participants their thoughts would be anonymous and encouraged them to tell the truth about their experience, whether it was positive or negative, in an attempt to reduce this bias.

Chapter 5.3: The Future of Integrated MBSR and Mental Health Care

This idea of this study came from a desire to offer integrated mental health care to IBD patients in Alberta, and the results of the trial and the interviews leave us with some unanswered questions that warrant discussion.

There remains the broad question of if integrated mental health care is something IBD patients in Alberta want. Although in the introduction I discussed many studies and editorials that highlighted a need for this type of integrated care, there is very little data from the perspective of Canadian IBD patients about if view a shift towards interdisciplinary care as important or how they envision it care within their current IBD treatment plans. Our trial received an average of four referrals a month during the eight-month recruitment period, and we received referrals from

seven unique gastroenterologists. Although not all of the patients that were referred to the trial enrolled in MBSR, it does suggest that there was a substantial number of patients who were interested in getting help managing their stress, anxiety, or depression and/or that these symptoms were severe enough that they asked for help from their gastroenterologist. In addition, we identified multiple themes detailing participants' perspectives on their disease and mental health from the interviews. For example, four of five participants discussed previous attempts to improve their emotional and mental well-being and the struggles associated with trying to do so. One of the main difficulties they all noted, was a lack of discussion about their mental well-being with their gastroenterologist. Furthermore, when they were asked to define what wellness meant to them, all five described wellness as something more than physical, and mentioned that their mental well-being plays a significant role in being able to feel well, in being able to control their disease, and in being able to deal with their physical symptoms. All five participants also emphasized that their disease has a substantial negative effect on their physical, mental, and overall wellness. Specifically, they mentioned that the disease can be mentally draining and that the thought of being admitted to hospital causes significant anxiety. Perhaps most surprising to us, since there were no interview guide questions about integrated care, was that all five participants mentioned a desire for mental health care to be a standard part of their IBD care plan. Without prompt, they all described wanting to have more conversations with their gastroenterologist about their mental health, and mentioned the idea that a well-rounded approach to IBD care would feature mental health care alongside prescriptions and symptom management. The qualitative and quantitative findings from our study suggest that IBD patients in Alberta want to discuss their mental health and need help managing it alongside their physical health. This desire underscores the current recommendations from gastroenterologists about integrating mental health care into IBD care and emphasizes these changes should not be a future innovation in IBD care, but something that patients can access in the present.

Following the discussion about the necessity of interdisciplinary IBD care in Alberta, there remains uncertainty regarding how a program such as virtual MBSR might be used to improve feelings of stress, anxiety, and depression in the patient population. Our trial was conducted using pathways and resources that already exist within the healthcare system in Alberta. Keeping this in mind, the number of referrals our trial received and the ease of sending a referral suggests

it would be possible and feasible to integrate virtual MBSR into a future mental health care pathway. In contrast to the successes with the referral process for gastroenterologists, we struggled to retain participants in the intervention. We thought reducing the barrier of travel by offering the group virtually would increase uptake and completion rates, but this was not the effect we observed. Although there may be a concern about participants discontinuing virtual MBSR, the participants in our study who completed the program reported sustained improvements in both mental health symptoms and quality of life. Our analysis lacked sufficient data for statistically precise estimates of differences in terms of characteristics between the group of participants that completed and the group that discontinued in our study; however, other studies have investigated factors associated with attrition. Granted, these predictors were examined in populations different than our population of interest (i.e., adults with IBD), but they may still be able to provide some guidance in terms of suggesting who may be able to complete and benefit from virtual MBSR. These other studies suggest there are no significant differences in race, education, or gender of the people who complete MBSR compared to those that discontinue it[179–182]. Previous studies that also have investigated patients' self-reported reasons for discontinuing and have identified a variety of reasons including the time commitment being more than expected, MBSR not suiting their needs, changes to personal situations, and onset of physical illness[72,183]. These self-reported reasons focus on personal circumstances could therefore be hard to predict and control for, but they may be useful to mention to patients who are considering enrolling in MBSR. One study found that participants with lower quality of life and higher psychiatric symptom burden were more likely to complete MBSR[79] which is in accordance with findings of a review of psychiatric treatments[111]. These findings could suggest that a time-intensive treatment like virtual MBSR may be best suited for IBD patients who are struggling significantly with their symptoms of stress, anxiety, or depression. If gastroenterologists had access to a screening tool for psychiatric symptoms, they could evaluate patients current psychological state at appointments, similarly to how they might evaluate their current physical symptoms using the Harvey-Bradshaw Index or Partial Mayo Score. It would then be possible to identify patients who score very high, and this group of patients could be referred to virtual MBSR. Patients with more moderate scores could be directed towards other mental health resources.

MBSR could also be offered in a stepped approach to mental health care for patients with IBD. A stepped model of care would allow patients to access a less time-intensive resource for stress, anxiety, and depression first. For example, there are many evidence apps and websites currently being explored to help with these symptoms in people with IBD that allow the user to work by themselves and at their own pace. For the patients who do not find this first resource to be enough help, or for those who use it and find their ability to improve has plateaued, virtual MBSR could be offered to them as the next step to care. This would hopefully lead to a population of patients enrolling in MBSR who are more likely to complete, due to higher symptom burden or high levels of motivation. The virtual MBSR groups could also be expanded to include patients with other chronic or physical diseases to help decrease the number of IBD patients required to run the groups. All five of our interview participants indicated that they enjoyed that their peers in the group all had IBD, but expanding the patient population could make the groups more cost-effective and could increase the frequency of groups and the flexibility in attending them.

Chapter 5.4: Conclusion

To conclude, IBD patients, providers, and researchers agree that mental health is an important part of the pathophysiology of IBD and needs to be incorporated into standard IBD care. There was a large interest in a free, virtual, and psychiatrist-led stress reduction intervention and participants that completed the intervention saw significant and sustained improvements to their psychiatric symptoms and quality of life. The largest barrier to enrolling and completing the group was the time commitment. All things considered, virtual MBSR could be a promising treatment for a certain sub-set of IBD patients, most likely those who experience a high burden of stress, anxiety, or depression symptoms. Virtual MBSR could be quite easily integrated into a mental health pathway for Alberta patients with IBD and could serve as a helpful tool for gastroenterologists to have in their toolkit for helping their patients feel better, both physically and mentally.

Chapter 5.4.1: Future Directions

Future research studies should investigate if telehealth-based group interventions are non-inferior to their face-to-face equivalents. It could also be relevant to investigate and compare the characteristics of those who may be more likely to complete and benefit from intensive mindfulness-based interventions. This characterisation could allow these interventions to be targeted a specific sub-population of people with IBD and may lead to lower attrition rates. In terms of the larger scope of mental health care in IBD, future studies should partner with IBD patients to design or select an intervention that suits their needs. A stepped approach to care may be necessary, and building a mental health care pathway that considers IBD patients' opinions will ensure a well-rounded pathway that represents all stakeholders in IBD care.

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Appendices

Appendix A: Systematic Review

A-1: Detailed Search Strategy by Database

EMBASE via Elsevier	
1.	exp inflammatory bowel disease/
2.	exp Enterocolitis/
3.	exp Proctitis/
4.	exp Ileitis/
5.	crohn*.ot,tw.
6.	(ulcer* adj5 colit*).tw,ot.
7.	(ulzer* adj5 kolit*).ot.
8.	(regional* adj2 enter*).tw,ot.
9.	ileitis.ot,tw.
10.	(enterocolit* or entero-colit*).tw. or (enterokolit* or entero-kolit*).ot.
11.	(proktiti* or proktokolit* or prokto-kolit*).ot.
12.	(proctiti* or proctocolit* or procto-colit*).tw,ot.
13.	(inflamm* adj5 bowel* adj5 disease*).tw.
14.	entzundliche* darm*.ot.
15.	ibd.mp.
16.	exp Crohn disease/ or "crohn* disease".mp.
17.	ulcerative colitis.mp. or exp ulcerative colitis/
18.	inflammatory bowel disease*.mp.
19.	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
20.	online.tw.
21.	on-line.tw.
22.	internet.tw.
23.	telehealth.mp.
24.	tele-health.mp.
25.	tele-medicine.mp.
26.	telemedicine.mp. or exp Telemedicine/
27.	video*.tw.
28.	videoconferenc*.tw.
29.	virtual*.tw.
30.	remote.mp.
31.	ehealth.tw.
32.	e-health.tw.
33.	web-based.tw.
34.	exp Videoconferencing/
35.	computer*.tw.
36.	communication*.tw. or exp Communication/ or exp medical information/
37.	communication*.tw. or exp Communication/ or exp medical information/
38.	"computer assisted instruction*".tw. or exp teaching/
39.	(telenursing or tele-nursing).mp. or exp Telenursing/
40.	exp teleconsultation/
41.	exp Telecommunication/ or telecommunication*.tw.

EMBASE via Elsevier

42.	(Zoom or skype or facetime or WebEx or "Microsoft Team*" or "Go To Meeting*" or "Google Meet*").mp.
43.	exp Mobile Application/ or "mobile app*".mp.
44.	20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43
45.	exp Mindfulness/
46.	mindful*.mp.
47.	mind ful*.mp.
48.	mbct.mp.
49.	mbsr.mp.
50.	exp Meditation/ or exp mindfulness meditation/ or meditat*.mp.
51.	yoga.mp. or exp Yoga/
52.	relax*.mp.
53.	exp Relaxation training/
54.	exp alternative medicine/
55.	(mind body or mind-body).mp.
56.	exp spiritual healing/
57.	exp Patient Education/ or patient education.mp.
58.	exp Psychotherapy/
59.	psychotherap*.mp.
60.	(psycholog* adj intervent*).tw.
61.	exp e-counseling/ or exp counseling/
62.	(psycho-educat* or psychoeducat*).mp.
63.	counsel*.mp.
64.	psychiat*.mp.
65.	exp Health Education/
66.	(cognitive adj4 therap*).mp.
67.	(stress adj4 manag*).mp.
68.	(manag* adj2 (anxiet* or depres*)).mp.
69.	((behavior* or behaviour*) adj4 (modify* or modificat* or therap* or chang*)).mp.
70.	exp Cognitive Behavioral Therapy/ or CBT.mp.
71.	cognitive behavio* therap*.mp.
72.	(cope* or coping).tw,ot.
73.	(group adj (therap* or treatment* or intervention*)).tw.
74.	(Acceptance adj2 Commitment).tw.
75.	"Acceptance and Commitment Therapy".mp. or exp "acceptance and commitment therapy"/
76.	(supporti* adj3 (therap* or care or treat* or intervent*)).tw.
77.	hypnotherap*.mp.
78.	(goal* adj3 setting).mp.
79.	dialectical behavio* therap*.mp.
80.	45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79
81.	19 and 44 and 80

MEDLINE via Ovid	
1.	exp Inflammatory Bowel Diseases/
2.	exp Enterocolitis/
3.	exp Proctitis/
4.	exp Ileitis/
5.	crohn*.tw,ot.
6.	(ulcer* adj5 colit*).tw,ot.
7.	(ulzer* adj5 kolit*).ot.
8.	(regional* adj2 enter*).tw,ot.
9.	ileitis.tw,ot.
10.	(enterocolit* or entero-colit*).tw. or (enterokolit* or entero-kolit*).ot.
11.	(proktiti* or proktokolit* or prokto-kolit*).ot.
12.	(proctiti* or proctocolit* or procto-colit*).tw,ot.
13.	(inflamm* adj5 bowel* adj5 disease*).tw.
14.	entzundliche* darm*.ot.
15.	ibd.mp.
16.	exp Crohn Disease/ or crohn* disease.mp.
17.	ulcerative colitis.mp. or exp Colitis, Ulcerative/
18.	inflammatory bowel disease*.mp.
19.	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
20.	online.ti,ab.
21.	on-line.ti,ab.
22.	internet.ti,ab.
23.	telehealth.mp.
24.	tele-health.mp.
25.	tele-medicine.mp.
26.	telemedicine.mp. or exp Telemedicine/
27.	video*.ti,ab.
28.	videoconferenc*.ti,ab.
29.	virtual*.ti,ab.
30.	remote.mp.
31.	ehealth.ti,ab.
32.	e-health.ti,ab.
33.	web-based.ti,ab.
34.	exp Videoconferencing/
35.	computer*.ti,ab.
36.	communication*.ti,ab. or exp Communication/ or exp Health Communication/
37.	computer assisted instruction*.ti,ab. or exp Computer-Assisted Instruction/
38.	(telenursing or tele-nursing).mp. or exp Telenursing/
39.	exp Remote Consultation/
40.	exp Telecommunications/ or telecommunication*.ti,ab.
41.	(Zoom or skype or facetime or WebEx or Microsoft Team* or Go To Meeting* or Google Meet*).mp.
42.	exp Mobile Applications/ or mobile app*.mp.
43.	20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or37 or 38 or 39 or 40 or 41 or 42
44.	exp Mindfulness/
45.	mindful*.mp.
46.	mind ful*.mp.

MEDLINE via Ovid

47.	mbct.mp.
48.	mbsr.mp.
49.	exp Meditation/ or meditat*.mp.
50.	yoga.mp. or exp Yoga/
51.	relax*.mp.
52.	exp Relaxation Therapy/
53.	exp Mind-Body Therapies/
54.	(mind body or mind-body).mp.
55.	exp spiritual therapies/
56.	exp Patient Education/ or patient education.mp.
57.	exp Psychotherapy/
58.	psychotherap*.mp.
59.	(psycholog* adj intervent*).tw.
60.	exp Counseling/
61.	(psycho-educat* or psychoeducat*).mp.
62.	counsel*.mp.
63.	psychiat*.mp.
64.	Health Education/
65.	(stress adj4 manag*).mp.
66.	(manag* adj2 (anxiet* or depres*)).mp.
67.	((behavior* or behaviour*) adj4 (modify* or modificat* or therap* or chang*)).mp.
68.	exp Cognitive Behavioral Therapy/ or CBT.mp.
69.	cognitive behavio* therap*.mp.
70.	(cognitive adj4 therap*).mp.
71.	(cope* or coping).tw,ot.
72.	(group adj (therap* or treatment* or intervention*)).tw.
73.	(Acceptance adj2 Commitment).tw.
74.	"acceptance and commitment therapy".mp. or exp "Acceptance and Commitment Therapy"/
75.	(supporti* adj3 (therap* or care or treat* or intervent*)).tw.
76.	hypnotherap*.mp.
77.	(goal* adj3 setting).mp.
78.	dialectical behavio* therap*.mp.
79.	44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78
80.	19 and 43 and 79

PSYCHInfo

1.	exp Colon Disorders/
2.	enterocolit*.mp.
3.	proctiti*.mp.
4.	ileitis.mp.
5.	crohn*.ti,ab.
6.	ulcer* colit*.ti,ab.
7.	regional* enter*.ti,ab.
8.	inflamm* bowel* disease*.mp.
9.	ibd.mp.
10.	crohn* disease.mp.

PSYCHInfo

11.	ulcerative colitis.mp. or exp Ulcerative Colitis/
12.	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
13.	online.ti,ab.
14.	on-line.ti,ab.
15.	internet.ti,ab.
16.	telehealth.mp.
17.	tele-health.mp.
18.	tele-medicine.mp.
19.	telemedicine.mp. or exp Telemedicine/
20.	video*.ti,ab.
21.	videoconferenc*.ti,ab.
22.	virtual*.ti,ab.
23.	remote.mp.
24.	ehealth.ti,ab.
25.	e-health.ti,ab.
26.	web-based.ti,ab.
27.	exp Videoconferencing/
28.	computer*.ti,ab.
29.	communication*.ti,ab. or exp Communication/ or exp health education/ or exp health information/
30.	computer assisted instruction*.ti,ab. or exp Computer Assisted Instruction/
31.	(telenursing or tele-nursing).mp.
32.	exp Telepsychiatry/
33.	exp Telecommunications Media/ or telecommunication*.ti,ab. or exp "Information and Communication Technology"/
34.	(Zoom or skype or facetime or WebEx or "Microsoft Team*" or "Go To Meeting*" or "Google Meet*").mp.
35.	exp Mobile Applications/ or mobile app*.mp.
36.	13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35
37.	exp Mindfulness/ or exp Mindfulness-Based Interventions/
38.	mindful*.mp.
39.	mind ful*.mp.
40.	mbct.mp.
41.	mbsr.mp.
42.	exp Meditation/ or meditat*.mp.
43.	yoga.mp. or exp Yoga/
44.	relax*.mp.
45.	exp Relaxation Therapy/
46.	exp Mind Body Therapy/ or exp Dualism/
47.	(mind body or mind-body).mp.
48.	exp Faith Healing/ or exp Spirituality/
49.	exp Client Education/ or patient education.mp.
50.	exp Psychotherapy/
51.	psychotherap*.mp.
52.	(psycholog* adj intervent*).ti,ab.
53.	exp Counseling/
54.	(psycho-educat* or psychoeducat*).mp.
55.	counsel*.mp.

PSYCHInfo

56.	psychiat*.mp.
57.	Health Education/
58.	(cognitive adj4 therap*).mp.
59.	(stress adj4 manag*).mp.
60.	(manag* adj2 (anxiet* or depres*)).mp.
61.	((behavior* or behaviour*) adj4 (modify* or modificat* or therap* or chang*)).mp.
62.	exp Cognitive Behavior Therapy/ or CBT.mp.
63.	cognitive behavio* therap*.mp.
64.	(cope* or coping).ti,ab.
65.	(group adj (therap* or treatment* or intervention*)).ti,ab.
66.	(Acceptance adj2 Commitment).ti,ab.
67.	"Acceptance and Commitment Therapy".mp. or exp "Acceptance and Commitment Therapy"/
68.	(supporti* adj3 (therap* or care or treat* or intervent*)).ti,ab.
69.	hypnotherap*.mp.
70.	(goal* adj3 setting).mp.
71.	dialectical behavio* therap*.mp.
72.	37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71
73.	12 and 36 and 72

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#	Query
S76	S15 AND S39 AND S75
S75	S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74
S74	dialectical behavio* therap*
S73	(goal* N3 setting)
S72	hypnotherap*
S71	((TI supporti* OR AB supporti*) N3 ((TI therap* OR AB therap*) OR (TI care OR AB care) OR (TI treat* OR AB treat*) OR (TI intervent* OR AB intervent*)))
S70	"acceptance and commitment therapy" OR (MH "Acceptance and Commitment Therapy")
S69	((TI Acceptance OR AB Acceptance) N2 (TI Commitment OR AB Commitment))
S68	((TI group OR AB group) N1 ((TI therap* OR AB therap*) OR (TI treatment* OR AB treatment*) OR (TI intervention* OR AB intervention*)))
S67	((TI cope* OR AB cope*) OR (TI coping OR AB coping))
S66	"cognitive behavio* therap*"
S65	(MH "Cognitive Therapy+") OR CBT
S64	((behavior* OR behaviour*) N4 (modify* OR modificat* OR therap* OR chang*))
S63	(manag* N2 (anxiet* OR depres*))
S62	(stress N4 manag*)
S61	(cognitive N4 therap*)
S60	(MH "Health Education+")
S59	psychiat*
S58	counsel*

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S57	(psycho-educat* OR psychoeducat*)
S56	(MH Counseling+)
S55	((TI psycholog* OR AB psycholog*) N1 (TI intervent* OR AB intervent*))
S54	psychotherap*
S53	(MH Psychotherapy+)
S52	(MH "Patient Education+") OR "patient education"
S51	"spiritual therap*"
S50	"mind body" OR "mind-body"
S49	(MH "Mind Body Techniques+")
S48	(MH "Psychological Comfort Promotion (Iowa NIC)+")
S47	relax*
S46	yoga OR (MH Yoga+)
S45	(MH Meditation+) OR meditat*
S44	mbsr
S43	mbct
S42	"mind ful*"
S41	mindful*
S40	(MH Mindfulness+)
S39	S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38
S38	(MH "Mobile Applications") OR "mobile app*"
S37	(Zoom OR skype OR facetime OR WebEx OR "Microsoft Team*" OR "Go To Meeting*" OR "Google Meet*")
S36	(MH Telecommunications+) OR (TI telecommunication* OR AB telecommunication*)
S35	(MH "Remote Consultation")
S34	(telenursing OR tele-nursing) OR (MH Telenursing+)
S33	(TI "computer assisted instruction*" OR AB "computer assisted instruction*") OR (MH "Programmed Instruction+")
S32	(TI communication* OR AB communication*) OR (MH Communication+)
S31	(TI computer* OR AB computer*)
S30	(MH Videoconferencing+)
S29	(TI web-based OR AB web-based)
S28	(TI ehealth OR AB ehealth)
S27	(TI ehealth OR AB ehealth)
S26	remote
S25	(TI virtual* OR AB virtual*)
S24	(TI videoconferenc* OR AB videoconferenc*)
S23	(TI video* OR AB video*)
S22	telemedicine OR (MH "Telemedicine+") OR (MH "Telepsychiatry") OR (MH "Telehealth+")
S21	telemedicine
S20	telehealth
S19	telehealth
S18	(TI internet OR AB internet)
S17	(TI on-line OR AB on-line)
S16	(TI online OR AB online)

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S15	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14
S14	"inflammatory bowel disease*"
S13	"ulcerative colitis" OR (MH "Colitis, Ulcerative")
S12	(MH "Crohn Disease") OR "crohn* disease"
S11	ibd
S10	((TI inflamm* OR AB inflamm*) N5 (TI bowel* OR AB bowel*) N5 (TI disease* OR AB disease*))
S9	((TI proctiti* OR AB proctiti*) OR (TI proctocolit* OR AB proctocolit*) OR (TI procto-colit* OR AB procto-colit*))
S8	((TI enterocolit* OR AB enterocolit*) OR (TI entero-colit* OR AB entero-colit*))
S7	(TI ileitis OR AB ileitis)
S6	((TI regional* OR AB regional*) N2 (TI enter* OR AB enter*))
S5	((TI ulcer* OR AB ulcer*) N5 (TI colit* OR AB colit*))
S4	(TI crohn* OR AB crohn*)
S3	(MH Ileitis+)
S2	(MH Enterocolitis+)
S1	(MH "Inflammatory Bowel Diseases+")

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(TITLE-ABS-KEY (mindful*) OR TITLE-ABS-KEY ("mind ful*") OR TITLE-ABS-KEY (mbct) OR TITLE-ABS-KEY (mbsr) OR TITLE-ABS-KEY (meditat*) OR TITLE-ABS-KEY (yoga) OR TITLE-ABS-KEY (relax*) OR TITLE-ABS-KEY ("mind body" OR "mind-body") OR TITLE-ABS-KEY ("spiritual therap*") OR TITLE-ABS-KEY ("patient education") OR TITLE-ABS-KEY (psychotherap*) OR TITLE-ABS (psycholog* W/1 intervent*) OR TITLE-ABS-KEY (psycho-educat* OR psychoeducat*) OR TITLE-ABS-KEY (counsel*) OR TITLE-ABS-KEY (psychiat*) OR TITLE-ABS-KEY ("Health Education") OR TITLE-ABS-KEY (cognitive W/4 therap*) OR TITLE-ABS-KEY (stress W/4 manag*) OR TITLE-ABS-KEY (manag* W/2 (anxiet* OR depres*)) OR TITLE-ABS-KEY ((behavior* OR behaviour*) W/4 (modify* OR modificat* OR therap* OR c hang*)) OR TITLE-ABS-KEY (cbt) OR TITLE-ABS-KEY ("cognitive behavio* therap*") OR TITLE-ABS (cope* OR coping) OR TITLE-ABS (group W/1 (therap* OR treatment* OR intervention*)) OR TITLE-ABS (acceptance W/2 commitment) OR TITLE-ABS-KEY ("acceptance and commitment therapy") OR TITLE-ABS (supporti* W/3 (therap* OR care OR treat* OR intervent*)) OR TITLE-ABS-KEY (hypnotherap*) OR TITLE-ABS-KEY (goal* W/3 setting) OR TITLE-ABS-KEY ("dialectical behavio* therap*")) AND (TITLE-ABS (online) OR TITLE-ABS (on-line) OR TITLE-ABS (internet) OR TITLE-ABS-KEY (telehealth) OR TITLE-ABS-KEY (tele-health) OR TITLE-ABS-KEY (tele-medicine) OR TITLE-ABS-KEY (telemedicine) OR TITLE-ABS (video*) OR TITLE-ABS-KEY (videoconferenc*) OR TITLE-ABS (virtual*) OR TITLE-ABS-KEY (remote) OR TITLE-ABS (ehealth) OR TITLE-ABS (e-health) OR TITLE-ABS (web-based) OR TITLE-ABS (computer*) OR TITLE-ABS (communication*) OR TITLE-ABS ("computer

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assisted instruction*") OR TITLE-ABS ("computer-assisted instruction*") OR TITLE-ABS-KEY (telenursing OR tele-nursing) OR TITLE-ABS-KEY ("Remote Consultation*") OR TITLE-ABS (telecommunication*) OR TITLE-ABS-KEY (zoom OR skype OR facetime OR webex OR "Microsoft Team*" OR "Go To Meeting*" OR "Google Meet*") OR TITLE-ABS-KEY ("mobile app*")) AND (TITLE-ABS-KEY ("Inflammatory Bowel Disease*") OR TITLE-ABS (crohn*) OR TITLE-ABS (ulcer* W/5 colit*) OR TITLE (ulzer* W/5 kolit*) OR TITLE-ABS (regional* W/2 enter*) OR TITLE-ABS (ileitis) OR TITLE-ABS (enterocolit* OR entero-colit*) OR TITLE (enterokolit* OR entero-kolit*) OR TITLE (proktiti* OR proktokolit* OR prokto-kolit*) OR TITLE-ABS (proctiti* OR proctocolit* OR procto-colit*) OR TITLE-ABS (inflamm* W/5 bowel* W/5 disease*) OR TITLE ("entzundliche* darm*") OR TITLE-ABS-KEY (ibd) OR TITLE-ABS-KEY ("crohn* disease") OR TITLE-ABS-KEY ("ulcerative colitis"))

Appendix B: Methods

B-1: Recruitment One Page

Mind-IBD Quick Notes

Kaitlyn Chappell, MSc Student | ConnectCare: Kaitlyn D Chappell
kaitlyn.chappell@albertahealthservices.ca | kchappel@ualberta.ca

What Is Expected of Patients

- Complete a screening questionnaire and interview with a psychiatrist
- Complete a series of surveys
- Attend MBSR (8-weeks; 2.5-hour session every week + one full day on a weekend)
- Optional focus group

Inclusion Criteria	Exclusion Criteria
a. Have a known diagnosis of IBD	a. History of or current psychotic symptoms
b. Ability to communicate and write in English	b. History of dissociative symptoms, severe active untreated drug use, severe non-suicidal self-injury behaviour, acute or chronic suicidal ideation
c. Ability to give informed consent	c. History of cognitive impairment
d. Adult (aged 18-65)	d. Deemed unsuitable for participation by qualified psychiatrist
e. Ability to commit to attend the 8 weekly sessions and daily home practice	e. Have recently been prescribed or on corticosteroids
g. Physician/Self-identified anxiety and/or depressive symptoms	f. Have undergone surgery within 6 weeks of MBSR start date
h. Stable IBD medication for at least 2 months	
i. Stable psychiatric medication for at least 6 weeks	

How To Refer

- Referral using ConnectCare chat function is best
- Refer to Kaitlyn D Chappell
- For privacy reasons, you must send me the patient's name and contact info - you should NOT simply send me the chart
- You can also refer a patient to my UofA email (kchappel@ualberta.ca) or AHS email (kaitlyn.chappell@albertahealthservices.ca)

B-2: Poster Advertisement

MINDFULNESS-BASED STRESS REDUCTION THERAPY FOR ADULTS WITH INFLAMMATORY BOWEL DISEASE (MIND-IBD) (Pro00108955)

- **Do you have Inflammatory Bowel Disease and are suffering from stress, anxiety, depression and/or physical pain?**
- **Learn effective life long-tools that will help you to manage pain, stress and illness and live a healthier and happier life.**

Participate in the 8-week MIND-IBD online or in-person sessions

- **The aim of this study is to understand the effect of mindfulness based stress reduction therapy on anxiety and/or depression in individuals living with Inflammatory Bowel Disease**

You may be eligible to take part if you:

- **Are 18-65 years old**
- **Have a known diagnosis of IBD**
- **Are able to attend a 45 minutes online (zoom and telephone) and commit to attend all MBSR sessions (2.5 hours/week and a 7-hour all day weekend)**
- **Are able to commit to do home practices of 30-45 minutes per day**
- **Self identify as anxious and/or depressed**

What do you need:

- **Smart device or computer with internet access**
- **Email address**

Scan me

For more information and to refer a potential participant, please email or call: ibdpaths@ualberta.ca; 780-248-1037

'Mindfulness means paying attention in a particular way on purpose, in the present moment, and nonjudgmentally -Jon Kabat-Zinn

B-3: Trial Recruitment Script

Hello, [name of referred participant], my name is Kaitlyn Chappell, and I am a graduate student at the University of Alberta, under the supervision of one of the gastroenterologists, Dr. Karen Kroeker. I am calling today because you indicated you might be interested my current stress-reduction therapy study. I know it might have been a while since your doctor mentioned it, but I hope it sounds somewhat familiar. Are you still interested in hearing about it? Ok, is now a good time? My little information speech will take about 10 minutes?

So, before we start, I'll just make sure that you understand that your participation in any study, including this one, is voluntary, and declining to participate for whatever reason, will not change your treatment with your gastroenterologist. Does that make sense?

Alright, so the study I'm conducting is a part of my Master's thesis, and it focuses on trying to improve stress management and other mental health resources for Edmonton people living with IBD. To do this, I'm offering a group-based program called mindfulness-based stress reduction, or MBSR. MBSR has been around for about 30 years now and has gained some popularity recently in treating people with chronic disease. It's been shown to reduce people's feelings of stress, anxiety, and even some of the physical symptoms of disease like abdominal pain. Like I said, it's been widely tested already, but my goal is to see if IBD patients in Edmonton see it as a suitable option.

So, like I said, it's group based, meaning you attend the program in groups of about 8-16 people. You do have some small discussions within your groups, but you won't be expected to reveal anything personal about yourself or your struggles to the other people in the group. Our group will be online, so you'll attend the group through Zoom, and wouldn't be expected to make any extra trips to the hospital. It's delivered by psychiatrists, so medical doctors, who practice here at the UofA and have some extra training in the delivery of MBSR. My next group starts Sept 7 and lasts 8 weeks. During those 8 weeks it is a bit of a commitment, so I won't be upset if it's not for you. Every week you attend one group session from 5:30 in the evening to 8:00. On the days that you don't have group, you have some home practice related things that they ask you to do. Usually it's about 45 minutes, and in general it will be a little journaling as well as doing some guided meditation. Although they ask for 45 minutes, the group I just ran only did about 20-25 minutes a day. There's also a one-time Saturday session between week 6-7 that you attend. It's similar to your other group sessions, and it involves much of the same things. So taken all together, it's a bit intensive for those 8 weeks, but after the 8 weeks, the goal is that you have all of the tools that you need to better handle stress and anxious feelings, and so it's a bit of an investment – it does require some work, but most people do end up getting a lot out of it.

I'll break here if you have any questions. If it's not something you're interested in that's ok, you can let me know now – otherwise I can tell you a little more about what I'll be measuring for the study aspect.

Not interested? No worries! Did you want to stay on my contact list for future groups? Again – you can say no, it doesn't change your treatment with your doctor.

So, whatever happens in the group is private, I don't attend the sessions, and nothing you discuss is recorded. I'm really only interested in measuring your attendance and then also your levels of stress before and after treatment. So basically, I'll have you fill out about 10 minutes worth of surveys before you start the group, and then you'll fill out those same surveys after completing the group and then 6-months after completing the group. So, like I said the group is all yours and then I'll just gather some info from you before and after. I will also, be requiring access to a very limited portion of your medical chart. I'll be looking at your lab results and medications, and basically the point of that is to see if after the therapy we see any decrease in gut inflammation. None of your other medical information will be accessed.

Does that part make sense?

Before you can start the group you also have to do 2 things, but they're both quite simple. The first is you have to complete a questionnaire that evaluates your stress levels. It takes about 2 minutes and to be eligible you have to score at least a 5, which would indicate mild stress (I haven't had anyone not qualify, so usually it's not a problem). If that all goes well, then you have to meet with one of our psychiatrists for about 30-45 minutes. This is just a one-time interview, and really they just want to make sure they feel you're good to participate in the group.

That's pretty much all I have left information wise – I can go over the data storage part with you basically just what I do with the data I collect, and then I'll run you through the exclusion criteria.

So, I am collecting some data from you for the study. This would be the questionnaires and the medical chart info. Any data that I do collect from you is de-identified, which basically just means that after I collect it I remove your name and health number from it. So what I see is just a bunch of numbers, I can't see who it's from. If I publish any of the findings, your name won't appear anywhere, again it will be just the data. And the only people that will know you ever participated are me and then my supervisor. I do also usually send a letter to your gastro enterologist to let them know that you started the therapy.

We are a bit of a ways from the group start, but I will let you know that in order to participate you have to have been on stable medication for 6 weeks before the group starts, and you also can't be on any steroids. So, again, we're farther than 6 weeks from the groups start, but it is something to keep in mind. If you're interested and for some reason you change medications right before the group starts, I can get you enrolled in the next available group.

If it's still something you're interested in, I'll just grab your e-mail and I'll send you a consent form which has all of the info I just discussed. Once you complete the consent, it will prompt you to complete the brief stress questionnaire I talked about. Once I see the score of that I'd call you to arrange your interview and then you'd be good to go.

Can I grab your e-mail? Alright, well thank you so much for listening to me today, if you have any questions about the consent form or if you change your mind, please just shoot me an e-mail! My e-mail is attached to the consent form. Otherwise, the next time we talk would be to arrange an interview. Have a great day!

B-4: Trial Consent Form

Title of study: Mindfulness-based stress reduction therapy for adults with Inflammatory Bowel Disease (MIND-IBD) (Pro00108955)
Principal Investigator: Dr. Karen Kroeker (780-492-4873)
Research/Study Coordinator: Kaitlyn Chappell (780-248-1037)

Why am I being asked to take part in this research study?

You are being invited to participate in this research study because

(1) you have inflammatory bowel disease (IBD),

(2) you are between the ages of 18-65 and

(3) you have self-identified or have been referred by an Adult Gastroenterologist for anxiety and/or depression.

(Before you make a decision one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records).

What is the reason for doing the study?

Research shows that people who are living with Inflammatory Bowel Disease are more likely to have depression or anxiety illnesses. During active disease, IBD can be stressful and cause anxiety. It can be difficult to access mental health and psychiatric care as adults in Canada. The provincial healthcare plan only covers psychiatric and not psychological care. The Mindfulness-based stress reduction (MBSR) program can help you learn new ways to deal with the stress of living with IBD as well as other areas of your life. We hope that this study can allow psychiatrists and IBD specialists to work together to help people living with IBD who are stressed, anxious, or depressed.

What will I be asked to do?

You will be asked to

(1) Signed this informed consent form

(2) Complete of patient health questionnaire (PHQ-SADS). It takes about 3 minutes to complete this.

(3) Attend an online (zoom or telephone) screening interview with a psychiatrist to ensure you are eligible for the program. This will take approximately 45 minutes to 1 hour.

(4) Complete online questionnaires at the beginning of the study, at week 8 or 9 after completing the MBSR session, and 6-month post group therapy. You will be asked questions about mindfulness, adverse childhood experiences, quality of life, self-compassion, anxiety, and depression. The questionnaires take about 6-10 minutes to complete the questionnaires.

(5) Participate in an 8-week MBSR program* on Zoom. The MBSR session requires your commitment to 8 weekly sessions of 2.5 hours duration per week and a 7-hour all-day weekend session between week 6&7. The MBSR sessions are group sessions and there are 6-10 participants together in each session. You will be assigned to a group in the order of enrollment.

*NOTE: you may be asked to wait for a short period of time before starting the MBSR program.

(6) Complete home practice of 30-45 minutes per day over the 8 weeks of the program.

The team will review your medical chart to obtain laboratory value data, monitor disease activity, and medication history. This will help us to understand if the effect of the session is affected by any of these factors.

What are the risks and discomforts?

The time commitment to the session and home practices may be inconvenient. The time required to fill out the questionnaires may be a minor inconvenience to some people. The questions asked about your disease may make you uncomfortable. If you are uncomfortable answering a question, you do not have to answer it. It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?

We hope that this program will relieve the anxiety or stress related to your illness. However, you may not get any benefit directly from being in this research study.

Do I have to take part in the study?

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the care that you are entitled to. You do not have to answer any question that you are not comfortable with. Should you choose to leave the study, your data can be withdrawn at any time up until the start of data analysis.

Will I be paid to be in the research?

There is no reimbursement for participating in this study. There are no special visits to the hospital expected during this study.

Will my information be kept private?

During the study, we will be collecting data about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

Please be advised that although the researchers will take every precaution to maintain the confidentiality of the data, the nature of group sessions prevents the researchers from guaranteeing confidentiality. The researchers would like to remind participants to respect the privacy of their fellow participants.

The study doctor/study staff may need to look at your personal health records held at the study doctor's office, and/or kept by other health care providers that you may have seen in the past (i.e. your family doctor). Any personal health information that we get from these records will be only what is needed for the study.

During research studies, it is important that the data we get is accurate. For this reason, your health data including your name may be looked at by people from the University of Alberta auditors and members of the Research Ethics Board or Health Canada. By signing this consent form, you are giving permission for the study doctor/staff to collect, use and disclose information about you as described above.

After the study is done, we will still need to securely store the data that was collected as part of the study. At the University of Alberta, we keep data stored for 5 years after the end of the study.

If you leave the study, we will not collect new information about you. You can request the withdrawal of your information collected during the study. If you would like to request the withdrawal of your data, please let your study staff know.

De-identified information collected during the research study will be entered into a secure, password-protected and encrypted database housed at the University of Alberta Hospital in Edmonton.

REDCap is a web-based software for designing and capturing data for research studies, allowing researchers to build and manage online surveys and research databases quickly and securely. Of note, your email address, which may contain identifying information such as your name, will be stored in the REDCap database and linked to the questionnaire data collected from you for the research study. It is necessary to store your email address to be able to use the survey function of the REDCap software to facilitate send-out and track completion of questionnaires.

What if I have questions?

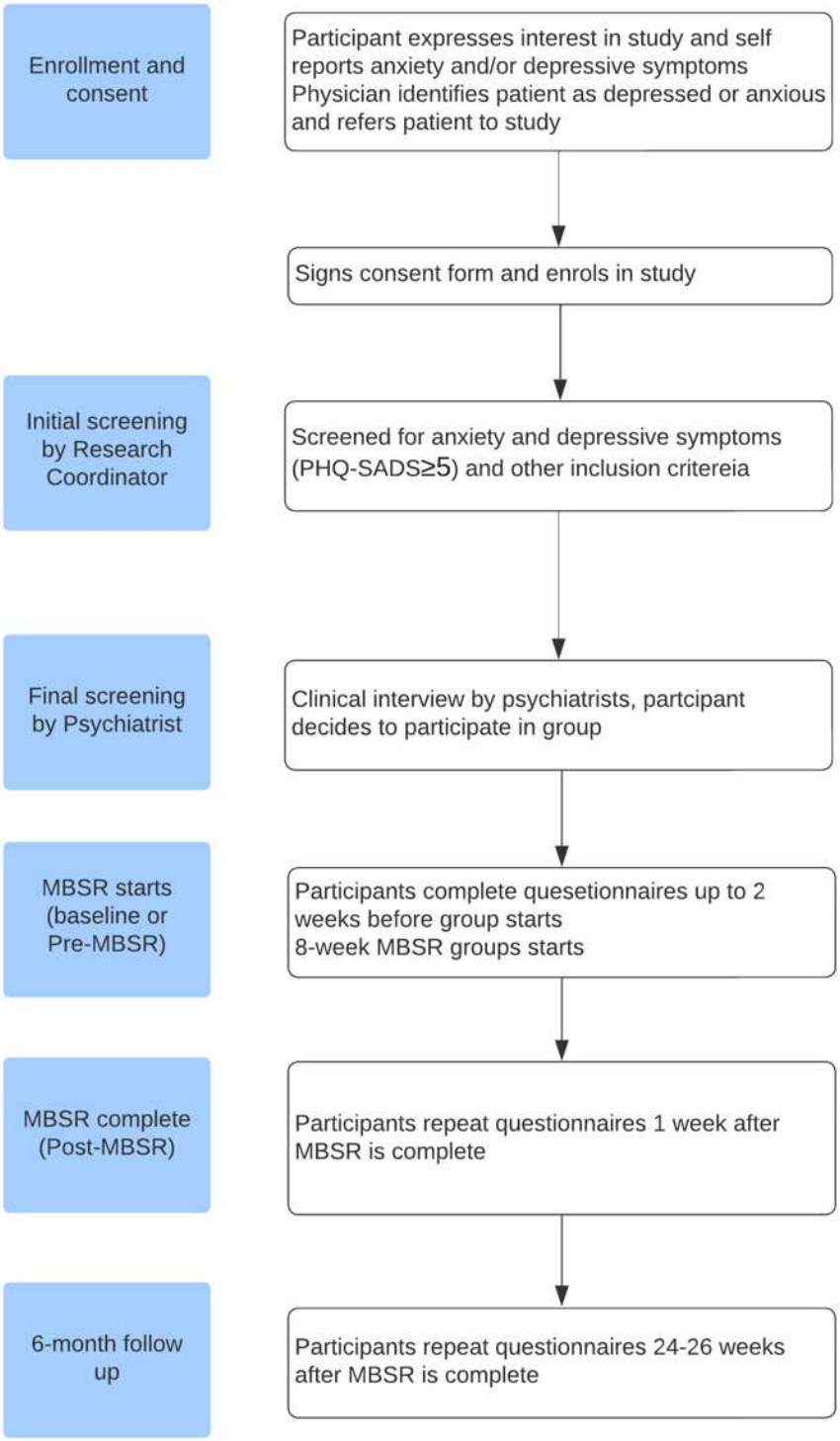
If you have any questions about the research now or later, please contact (780-492-4873 or 780-248-1037).

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

Electronic consent: Please answer the questions below and select your choice below.
Clicking on the "agree" button below indicates that:
- You have read the above information
- You voluntarily agree to participate
- you are at least 18 years of age

Do you understand that you have been asked to be in a research study?	◯ Yes ◯ No
Have you read and received a copy of the attached information sheet?	◯ Yes ◯ No
Do you understand the benefit and risks involved in taking part in this research study?	◯ Yes ◯ No
Have you had an opportunity to ask questions and discuss this study?	◯ Yes ◯ No
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your care?	◯ Yes ◯ No
Has the issue of confidentiality been explained to you?	◯ Yes ◯ No
Do you understand who will have access to your study records?	◯ Yes ◯ No
Electronic Consent	◯ Agree ◯ Disagree
First Name	_____
Last Name	_____

B-5: Participant Flow



B-6: Study Enrollment Notice

[GI Name]
[GI Address]

[Date]

Dear Dr. _____

This letter is to inform you that your patient, [patient name], has enrolled in a study. The study is being conducted with the Division of Gastroenterology at the University of Alberta. Ethics approval was obtained from the University of Alberta (Pro00108955).

The study is piloting Mindfulness-Based Stress Reduction (MBSR). Over the course of the program, which lasts eight weeks, your patient will have access to the MBSR program delivered by psychiatrists at the University of Alberta Hospital. The program is designed to provide participants with training in integrating mindfulness and mindful movement into one's daily life. It has been previously shown to reduce symptoms of anxiety, depression, stress, and chronic pain. Your patient was screened before entering the trial and was deemed suitable to participate by our psychiatrists.

The intervention begins on [intervention start date] and the expected end date is [intervention end date]

If you have any questions regarding the study, please contact me at 780-248-1037.

Kind Regards,

Kaitlyn Chappell (she/her)
MSc Student
Department of Gastroenterology
780-248-1037 | kchappel@ualberta.ca

B-7: Interview Guide

Interview guide code:
Underlined: notes/guidance for interviewer
Italicized: specific prompt questions

Before Beginning:

- Remind them of the aims of the current study.
  - The two phases: Perspectives about 1. MBSR and 2. overall wellness
- Assure them about confidentiality, data storage, and anonymity.
- Duration: around 30-45 minutes.

Background:

- Can you tell me a little bit about yourself?
  - Cover: age, type of IBD, employment status, relationship/children, living situation

MBSR:

Primary goal: identify patient perspectives on MBSR and the barriers and benefits associated with it.

* Three categories of people: completed MBSR, partially completed, did not participate in MBSR*

Completed/Partially Completed

- What were your expectations with regards to MBSR?
  - Did you know anything about it before participating? Had you ever heard of it?
  - Was there anything part you found particularly interesting or that you thought might be difficult?
- Were your expectations met or not met?
  - In what ways?
  - Was your experience positive or negative?
- What would you consider some of the benefits of the program?
- What would you consider some of the barriers to complete the program?
  - If there are multiple: ask to identify which ones were the most difficult and which ones were less difficult.
  - If time is a barrier:
    - What does a usual week look like for you?
      - How many nights a week are you home? What do you do in the evening?
- Would you recommend the program?

Did Not Participate:

- Did you know anything about MBSR before hearing about the study?
- What was the main reason you declined to participate?
    - If more than one reason stated, have them define the most prominent one
    - If time is a barrier:
        - What does a usual week look like for you?
            - How many nights a week are you home? What do you do in the evening?
- Were there other factors that contributed to your decision to decline?

Wellness:

Primary goal: investigate how participants define wellness and their experience trying to improve their wellness in the past.

- Remind participant that they were referred to this study because they or their doctor identified them as wanting help dealing with stress/anxiety/depression.
- Keeping that in mind, how do you define wellness?
    - If definition is focused on physical or generally narrow: *Would your definition include elements of social, emotional, or spiritual wellness?* Only give them the definitions if they ask.
        - Social: encompasses the quality and extent of interaction with others and the interdependence between the individual, others, the community, and nature
        - Emotional: awareness and control of feelings, as well as a realistic, positive, and developmental view of the self, conflict, and life circumstances
        - Physical: the active and continuous effort to maintain the optimum level of physical activity and focus on nutrition, as well as self-care and maintaining healthy lifestyle choices
        - Spiritual: innate and continual process of finding meaning and purpose in life, while accepting and transcending one's place in the complex and interrelated universe
        - Thinking about your definition of wellness, how much do you feel like your IBD impacts to your wellness?
        - Are you currently doing, or have you previously done, anything to improve your well-being?
    - If participant **completed MBSR**: were your reasons for trying MBSR similar to your reasons for trying other wellness improvements?
        - Why did you specifically try MBSR and not something else?
    - If participant **partially completed MBSR**: keeping in mind that you've attempted other wellness improvements, what were your reasons for not completing MBSR?

- What was it about other wellness improvements that you preferred?

- If participant **declined MBSR**: keeping in mind that you've attempted other wellness improvements, what were your reasons for not trying MBSR?
  - What was it about other wellness improvements that you preferred?

Wrap-up:

- Is there anything else related to MBSR or wellness that you want to add?
- Thank them for their time.
- Remind them one last time about data storage.
- Remind them they will be sent a list of resources that they can use if they feel anxious or depressed.

B-8: Audit Trail for Interview Guide

Original Guide:

- Developed for a qualitative research class
- Received guidance and advice from Dr. Kate Storey as well as psychiatrists, Dr. Diana Meakins and Dr. Melanie Marsh Joyal.
    - Suggestions from psychiatrists: brought up the fact that previous research indicates that social supports tend to have an influence on if/how much people choose to take help offered to them

Revision: July 27

- Large revisions made. Meant to shorten the guide, and narrow down the portion on wellness, as it was bloated before.
- Removed a question from the background section about what a typical week looks like and moved it to a prompt if the participant identifies time as a barrier later on
    - The intent of this question was to get an idea of how a person's schedule might influence the time the want to dedicate to psychological help
    - After consultation with Dr. Kroeker, we figured this was better asked only if time was considered a barrier, and fit more naturally in that section
- Added a prompt at the beginning of the wellness section reminding the participant of the intent of the program they participated in
    - This was added after consultation with Dr. Kroeker. After discussion, we thought it would be a good preface to the section in general, just so they didn't feel like wellness had to be positive and that it could be a work in progress.
- Added the first question about their definition as wellness. This ties in to the prompt from before and hopefully generates a definition that ties into their experience in MBSR or at least builds on it.
- Added definitions of different types of wellness.
- Amended the question about IBDs impact on wellness to include their previously stated definition.
- Removed questions about the importance of wellness.
- Removed questions about experiences talking to doctor about wellness
- Added a question about current methods they are using to improve wellness and the benefits and barriers of them.

Revision: August 2

- Added the goals of the interview to the guide
- Added a prompt asking them to rank the barriers if they identify multiple.
- Removed the reading of the wellness definitions.

    - Amended, so that the wellness definitions will only be given if they are really struggling and ask for an example.
    - Amended so that if their definition is narrow, could prompt with these definitions and ask if they would consider any of these other aspects of wellness.
- Added a follow-up to the part of what they are currently doing to improve their wellness and that considers if the participant participated or no
    - Asks their reason for completing/not completing/declining MBSR and what aspects they preferred about MBSR (if they picked it) or other wellness improvements (if they didn't pick MBSR)
    - This section is meant to work on identifying the barriers/benefits to other wellness improvements and how they compare to MBSR
    - Also meant to shorten the interview
- Added a question that allows the participant to add anything else that they feel is relevant if it wasn't already covered
- Added a section for the interviewer that goes over confidentiality one more time.

<u>Revision: August 6</u>

- Added a section where the interviewer will go over the goals and agenda at the beginning.
- Revised the goals of each section to ask "what" (more PICO focused)
- Added a reminder for interviewer to offer the participant a list of debrief resources in case the interview made them feel anxious

<u>Post-Pilot Interview:</u>

- Piloted the interview with someone who has a chronic disease who had completed group therapy
- Interview took about 25 minutes which was an appropriate length
- Interviewee had no notes about wording and thought it was clear.
- No changes made.

B-9: Interview Recruitment Script

Hi ____, this is Kaitlyn, I'm a research coordinator with the division of gastroenterology at the University of Alberta. I talked to you over the summer about possibly participating in a short interview that would allow patients to talk about what they'd like to see out of stress management resources for people with IBD. Does that sound a little familiar? Is now a good time to talk? Ok, so I know its' been a while, but I conducted a small study that gave people access to a mindfulness course earlier in the year. I would have talked to you about participating, and now my goal is to get peoples opinions on how we can improve programs like it to better support those with IBD in Alberta. To do that, I'm conducting interviews over Zoom of about 15-20 minutes with people who didn't participate in the program. If that quick little description sounds like something you'd be willing to participate in, I can tell you a little more about the interview, although honestly, there isn't much more to say!

Hello, may I please speak with [name of referred participant]

If potential participant is not home, the researcher will ask if there is a better time to call or inform whoever they are speaking to that they will try again.
If potential participant is home, the conversation will continue.

Hello, [name of referred participant], my name is Kaitlyn Chappell, and I am a graduate student at the University of Alberta, under the supervision of one of the gastroenterologists, Dr. Karen Kroeker. I am calling today because you indicated you might be interested in being interviewed about your experience in MBSR and how you practice wellness, is now a good time to talk?

If participant participated in the feasibility trial, they would already be very familiar with the study coordinator, Kaitlyn, and so the introduction may be less formal

If no, the researcher will ask when a better time to call is.
If yes, conversation continues.

So before we start, I'll just make sure that you understand that your participation in any study, including this one, is voluntary, and declining to participate for whatever reason, will not change your treatment with your gastroenterologist. Does that make sense?

If no, reexplain that they do not have to participate in the study and that they are free to decline.
If yes, continue.

The study I'm conducting will focus on interviewing IBD patients and exploring what they thought about the MBSR group as well as what other kinds of wellness practices they complete. The goal of the study is to understand a little more about participant experience in the MBSR group, as well as what some of the benefits and barriers were associated with not only MBSR but other wellness practices as well. When I talk about wellness, I'm talking about any practices you do to be "well". This could be eating a certain diet, going on daily walks, or anything you do with the goal of benefiting your physical or mental wellness.

The only thing required of you for this study is participation in the interview and consent to view certain parts of your medical chart. The interview should last around 30-45 minutes and you can choose to either meet virtually, or in person. If you choose a virtual interview, we'll conduct the interview over Zoom. If you choose an in-person interview, you will meet with a research coordinator at the Ziedler Ledcor Building of the University of Alberta. All in-person interviews will be conducted with COVID-19 guidelines in mind, and current AHS and UofA guidelines will be respected. The medical chart review is the other part of the study. This part doesn't require any active participation on your part, but it's important to know that certain sections of your chart will be reviewed. The only thing I'm interested in are your age of diagnosis, your type of IBD, as well as your most recent medication list and lab results. Anything else is your medical chart will not be looked at. The goal of me collecting that information is to add some more context to the type of wellness practices IBD patients seek out.

Does this study sound like something you would be interested in?

If no, thank them for their time and say goodbye.
If yes, continue.

Alright, I'll email you an information sheet and a consent form for you to have a look at. They will both describe in a little more detail why we are doing the study as well as what we are looking to do with the data we collect. I'll explain what kind of data we will be collecting next, but I just want you to know that everything I discuss will also be written in the information sheet.

So, the interviews will be recorded. The virtual interviews will be recorded using the Zoom feature and the in-person interviews will be recorded using an audio recording device. The goal of recording the interviews is for me to be able to transcribe everything that was said so that I can look for themes and sort through the information. Once I transcribe the interviews, the recordings will be deleted. The transcriptions won't include any personal information (I'll redact any names or identifying information) and after the initial interview, all of the data will

be unassociated from your name. During the interview, you can choose to not answer a question, with no consequences. You can also stop the interview at any point and ask that the recording be turned off. Until 4 weeks after the interview, you can still request any part of your interview or your whole interview be excluded from any further analysis. After 4 weeks has passed, the data from the interview will have been analyzed and therefore will no longer be able to be removed from the study.

Does the confidentiality aspect of the study make sense?

If no, re-explain until everything is clear.
If yes, continue.

Once again, I know this can be a lot of information to take in at once, so I will send you an information sheet with all of this written down. Can I get an e-mail address from you so I can do this?

Record e-mail.

Would you like to set-up a time now for you interview or would you like to look over the information sheet before doing so?

If now…
Confirm if virtual or in-person interview is preferred. Confirm e-mail for Zoom invitation. Get preferred date and time.

If later…
I'll have that information sheet sent to you right away, and I'll follow up on [give date approx. 3 business days from now] to touch base about a date and time.

If you are going through the information sheet and have any questions or you don't understand anything, please feel free to contact me. My contact information is listed on the bottom of the information sheet. If you change your mind about participating, it's no worries at all, just let me know at any time. Before I let you go, I just want to make sure I have a good phone number in case I need to reach you again. Is the current phone number an okay contact for you?

If no, get a better number.
If yes continue.

Thank you for your time today. Again, please reach out if you have any questions or if I can clarify something for you. I hope you have a great day. Goodbye.

B-10: Interview Consent Form

Consent Form

Thank you for your interest in the study!

Follow this link to access the consent form. If you have any questions please do not hesitate to contact the study coordinator, Kaitlyn Chappell, at ibdpaths@ualberta.ca or by calling 780-248-1037

Thank you for your interest in the study! Please read the consent form carefully and sign below. If you have any questions please contact the study coordinator, Kaitlyn Chappell, using the e-mail or phone number listed below.

Introduction

You have the option to take part in a research study. The goals of this form are to give you information about what will happen in the study if you choose to take part and to help you decide if you want to be in the study.

You are being invited to participate in this research study because you have inflammatory bowel disease (IBD) and you were approached to participate a previous study about mindfulness. This form provides a summary of the information the research team will discuss with you. If you decide to take part in this study, you will sign this form to confirm your decision. If you sign this form, you will receive a signed copy for your records.

Before agreeing to participate, it is important for you to understand all the information related to this optional research study. You are encouraged to ask questions if you feel anything needs to be made clearer.

Why are we doing this study?

Crohn's disease and ulcerative colitis (known as inflammatory bowel disease or IBD) are chronic illnesses with symptoms including diarrhea, rectal bleeding, abdominal pain and weight loss. Medications are used to both get and keep patients well since there is no cure. The rates of depression and anxiety related illness are higher in IBD patients than the general population. Further, the uncertainty of active disease can be stressful and cause anxiety for individuals living with IBD. Access to mental health and psychiatric care is challenging for adults in Canada as provincial healthcare plans only cover psychiatry and not psychology. Practicing mindfulness can reduce stress, anxiety and improve quality of life for IBD patients.

As a follow-up to an on-going feasibility trail piloting MBSR for patients with IBD, this study is designed to explore Edmonton-area IBD patient perspectives and experiences in the eight-week MBSR program and their pursuit of physical and emotional wellness outside of it. These two aspects of wellness explored will be physical wellness and emotional wellness. The interview will focus on the benefits and barriers related to both MBSR and physical and emotional wellness.

Who will participate in this study?

Approximately 15 patients who were approached about the MBSR study take part in this study.

What does the study invovle?

If you agree to take part in this study, you will be asked to complete a 30–45-minute interview with the study coordinator. This interview can be scheduled to take place virtually, over zoom, or in person and the interview will be recorded. The interview will discuss benefits and barriers of MBSR as well as how IBD effects emotional and physical wellness.

Access to your medical history is also a part of the study. If you participated in the MBSR study, then no additional information will be accessed; although, the data collected from you in the MBSR study will be accessed. If you did not participate in the MBSR study, access to certain parts of your medical chart is involved. Specifically, we will be looking at your age of diagnosis, the type of diagnosis, and an up-to-date medication and lab list. The goal of collecting this information is to look for similarities and differences between the wellness practices of IBD patients.

What are the possible harms and discomforts?

If you choose to be interviewed virtually you will not be required to make any extra visits to the hospital or any extra procedures.

If you choose to interview in person, you will be required to visit the Ziedler Ledcor Center at the University of Alberta. In-person interviews will be conducted respecting the most updated University of Alberta and Alberta Health Services guidelines. The interview area will be sanitized before and after the interview and social distancing will be respected.

The time commitment to the session may be a minor inconvenience to some people. The questions ask about disease may make some participants uncomfortable. If you are uncomfortable answering a question, you do not have to answer it.

What are the potential benefits?

You may not benefit directly from participating in this study. We hope that the information learned from this study can be used in the future to benefit other people with similar disease.

Do I have to participate in this study?

Being in this study is your choice. If you decide to be in the study, you can change your mind and withdraw from the study at any time. This will in no way affect the care or treatment that you are entitled to.

Would I be paid to join this study?

There is no reimbursement for participating in this study. There are no special visits to the hospital expected during this study.

If I join the study can I stop?

You may withdraw from the study at any time. During the interviews, you may ask the recording to be stopped at any time, if you no longer wish to participate. If you are completing your interview via Zoom, you may ask to be interviews with your camera off. You may request (verbally or in writing) that any data that has not yet been analyzed be destroyed. Data analysis will occur 4 weeks after participation, and after this point, the information cannot be removed from the study. If a paper has been published about the study, your information cannot be removed because the paper cannot be retracted (however, at no time would data be presented in a way that your identity would be known). You may withdraw your permission for participation at any time by contacting the study staff.

Will my information be kept private?

During the study we will be collecting data about you. During the study we will need to collect some additional information about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the study doctor's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

The interviews, whether in-person or virtual, will be recoded. Zoom video recordings will be downloaded and stored on a local device at the University of Alberta, so that it can be transcribed by the research coordinator. After the interview has been transcribed, the video file will be deleted. Interviews that occur in person, will be recorded using an audio recording device. The audio recording will be downloaded and stored on a local device at the University of Alberta immediately after the interview has been completed. The recording will be kept for 5 years, after which it will be deleted.

This consent form will be sent to you using a software called RedCAP. RedCAP is a secure software that allows consent forms to be filled out through e-mail. An e-mail will be sent to you from RedCAP that will include a secure link. This link is encrypted and cannot be forwarded. Once you click on the link you will be able to read the consent form and submit an e-signature on the bottom. The use of RedCAP to deliver the consent form will ensure your personal health information and your participation in the study are kept confidential. Only the study coordinator will be able to access the signed consent form.

The study coordinator may need to look at your personal health records held at the study doctor's office, and/or kept by other health care providers that you may have seen in the past (i.e. your family doctor). To do this, we will collect your personal health number. Any personal health information that we get from these records will be only what is needed for the study. Specifically, we will be looking at the age of diagnosis, the type of diagnosis, and an up-to-date medication list. The goal of collecting this information is to look for similarities and differences between the wellness practices of IBD patients. By signing this consent form you are saying it is okay for the study team to collect, use and disclose information about you from your personal health records as described above.

During research studies it is important that the data we get is accurate. For this reason, your health data including name, may be looked at by people from the University of Alberta auditors and members of the Research Ethics Board. By signing this consent form, you are giving permission for the study doctor/staff to collect, use and disclose information about you as described above.

After the study is done, we will still need to securely store the data that was collected as part of the study. At the University of Alberta, we keep data stored for 5 years after the end of the study.

If you leave the study, we will not collect new information about you. You can request the withdrawal of your information collected during the study. If you would like to request the withdrawal of your data, please let your study staff know.

De-identified information collected during the research study will be entered into a secure, password protected and encrypted database housed at the University of Alberta Hospital in Edmonton.

Who do I contact if I have questions or concerns?

If you have any questions about the research now or later, please contact the investigator or the study coordinators. If you feel that you have suffered a research related injury – please contact the Investigator at this number as well.

Dr. Karen Kroeker T: (780) 492 4873 |E: karen.kroeker@ualberta.ca
Kaitlyn Chappell T: (780) 248-1037 |E: ibdpaths@ualberta.ca

If you have any questions regarding your rights as a research participant, you may contact the University of Alberta Research Ethics Office at reoffice@ualberta.ca and quote Ethics ID Pro00119852. This office is independent of the study investigators.

How do I indicate my agreement to be in this study?

By signing below, you understand:

• That you have read the above information and have had anything that you do not understand explained to you to your satisfaction.
• That you will be taking part in a research study.
• That you may freely leave the research study at any time.
• That you do not waive your legal rights by being in the study
• That the legal and professional obligations of the investigators and involved institutions are not changed by your taking part in this study.

Name of participant:

1) First name: _____

2) Last name: _____

3) Signature of study participant: _____

If you would like a copy of the consent form for your records you can download it here:

[Attachment: "Consent 160522.docx"]

B-11: Coding Audit Trail

Analysis of Interview Data

Overview

- Interviews being coded using methodology described in Graneheim & Lundman (2004)
- Starting by identifying condensed meaning units
  - Summary of what the participant is explaining
  - Meant to make code disputes easier, and to add an extra checkpoint for bias checking
  - Should be little interpretation in this, functions to summarize anecdotes or responses to questions
- Condensed meaning units (CMUs) are grouped into the interview sections
  - Example: Responses given to a question about expectations are all grouped together
- CMUs are then organized into codes based on what question they were responding to
- CMUs that talk about an experience that was not directly relevant to the question asked will be reorganized accordingly.
  - If they are relevant to a previous/future question they may be added to be considered in those codes
  - If they are not relevant to any of the questions asked, they will be dealt with and considered separately to see if other themes emerged that branched off of the goal of the interview

Coding Audit Trail

Codes: After CMUs Created For 3rd Interview

Code created: MBSR//Before Participating//Negative Expectations

- Will group CMU that describe negative expectations participants had before starting MBSR

Code created: MBSR//Before Participating//Motivations

- Will group CMU that describe what motivated participants to join

Code created: MBSR//Before Participating// Previous Experiences

- CMU that detail the experiences that participants had previously had with mindfulness

Code created: MBSR//Before Participating// Personal Experiences//Personal

- CMU that detail the experiences that participants had personally had with mindfulness in the past and had tried themselves

Code created: MBSR//Before Participating// Personal Experiences//Research

- CMU that detail the research participants did before participating

Code created: MBSR//After Participating// Benefits
- CMU that detail what participants considered the benefits of the program

Code created: MBSR//After Participating// Benefits// Techniques Learnt
- CMU that detail any specific benefits the participants took away from the techniques that they learnt

Code created: MBSR//After Participating// Positive Experiences
- CMU that details any positive experiences participants had in the group

Code created: MBSR//After Participating// Negative Experiences
- CMU that details any negative experiences participants had in the group

Code created: MBSR//After Participating// Barriers and Improvements
- CMU that details any barriers to participation or improvement participants think would be helpful

Code created: MBSR//After Participating// Recommendations
- CMU that details how participants feel about recommending the program or mindfulness in general

Code created: MBSR//Wellness// IBD and Wellness
- Any CMU that talks how IBD impacts wellness or what IBD changes about wellness

Code created: MBSR//Wellness// IBD and Wellness//Emotional and Mental
- Emotional and mental specific impacts of IBD

Code created: MBSR//Wellness// IBD and Wellness//Emotional and Mental//Fear & Anxiety
- Adds a more specific category of feelings

Code amended: MBSR//Wellness// IBD and Wellness//Emotional and Mental//Fear, Anxiety & Shame
- Broadens the category
- Rationale: feelings of shame also emerged, only a small amount of CMUs and did not warrant its own category, fits into fear and anxiety

Code created: MBSR//Wellness// IBD and Wellness//Physical and Disease Impacts
- Physical impacts of IBD on wellness including disease

Code created: MBSR//Wellness// IBD and Wellness//Interplay
- How physical and mental symptoms of disease influence each other or how one causes/exasperates the other

Code created: MBSR//Wellness// Definition
- How participants would define wellness

Code created: MBSR//Wellness// Definition//Mental
- Descriptions of wellness that focus on mental aspects

Code created: MBSR//Wellness// Definition//Physical
- Descriptions of wellness that focus on physical aspects

Code created: MBSR//Wellness// Practices
- Participants current or past wellness practices

Code created: MBSR//Wellness// Practices//Physical Health Related

- Wellness practices that relate to physical health including physical activity, general movement, or diet

Code created: MBSR//Wellness// Practices//Mental Health Related

- Wellness practices that relate to mental health including professional help, mindfulness, and social supports

Codes: After CMUs Created For 4th Interview

Code created: MBSR//Before Participating//Motivations//Learning

- CMU that detail what participants wanted to learn or what they hoped to get out of MBSR and how that was motivating

Code created: MBSR//Before Participating//Motivations//Others and Research

- CMU that detail how their own research or the encouragement of others motivated them to join MBSR

Code created: MBSR//After Participating// Benefits//Facilitators

- CMU that detail logistic elements that made participation easier

Code created: MBSR//After Participating// Neutral Experiences

- CMU that details any neutral experiences participants had in the group

Code created: MBSR//After Participating// Barriers and Improvements//Home Practice

- CMU that details any barriers that relate to home practice

Code created: MBSR//Wellness// Definition//Multifaceted

- Descriptions of wellness that describe the multifaceted nature of it

Code amended: MBSR//Wellness// Practices//Physical Health Related

- Wellness practices that relate to physical health including ~~physical activity~~, general movement, or diet
- Rationale: a specific category for physical activity is warranted

Code created: MBSR//Wellness// Practices//Physical Health Related//Physical Activity

- Relating specifically to physical activity

Code created: MBSR//After Participating// Positive Experiences//Group Itself

- Positive experiences that discuss specific aspects of the group or features of the group that were enjoyed or lead to a positive experience

Codes: After CMUs Created For 5th Interview

Code amended: MBSR//Before Participating//Negative or Limited Expectations

- Will group CMU that describe negative or limited expectations participants had before starting MBSR
- Rationale: multiple CMUs that discuss a lack of or limited expectations, grouping with negative expectations

Code created: MBSR//Before Participating//Negative or Limited Expectations//General Negative

- More specific category for general statements about negative expectations

Code created: MBSR//Before Participating//Negative or Limited Expectations//General Limited

- More specific category for general statements about lack of or limited expectations

Code created: MBSR//Before Participating//Negative or Limited Expectations//Group Specific

- Any negative or limited expectations that identify specific parts of the group as a reason for the expectation

Code created: MBSR//Before Participating//Motivations//Group Specifics

- CMU that detail how specific aspects of MBSR motivated them to join

Code created: MBSR//After Participating// Recommendations//Caveats

- Any CMU that talks about caveats participants would talk about when recommending the program

Code amended: MBSR//Wellness// IBD and Wellness//Physical ~~and Disease~~ Impacts

- Physical impacts of IBD on wellness
- Rationale: disease specific impacts such as flares warrant their own code

Code created: MBSR//Wellness// IBD and Wellness//Flares and Disease

- How flares or disease impact wellness

Codes combined: MBSR//After Participating// Negative and Neutral Experiences

- CMU that details any negative neutral experiences participants had in the group
- Rationale: Small number of codes in each category warrants combining

Code created: MBSR//After Participating// Positive Experiences//Group Itself//IBD Specific

- Positive experiences that discuss the fact that the group was IBD specific

Code created: MBSR//After Participating// Mindfulness Now and Going Forward

- Codes that details how participants are currently using mindfulness or their intent to continue to use mindfulness in the future or do more research into it

Code created: MBSR//After Participating// Benefits//Techniques//Stress and Anxiety Management

- Codes that talk about how techniques improved stress and anxiety management

Code created: MBSR//After Participating// Benefits//Techniques//Disease and Pain Management

- Codes that talk about how techniques improved disease and pain management

Code created: MBSR//After Participating// Benefits//Techniques//General Well-Being and Mindfulness

- Codes that talk about how techniques generally improved general well-being or mindfulness skills

Code created: MBSR//After Participating// Benefits//Changes to Perception and Attitude

- Discuss changes to outlook, perception of world, and attitude

Code amended: MBSR//After Participating// Positive Experiences//~~Group Itself//~~IBD Specific

- Describing how the group being IBD specific was helpful
- Rationale: merits its own code due to the fact that it came up in all interviews

Code amended: MBSR//After Participating// Positive Experiences//Group Itself

- Describes positive experiences that talk about features of the group or the group in general
- Rationale: changing the definition of this code, expanding to include any code that describe participants positives relating to the group and eliminating the IBD specific sub-category

Code amended: MBSR//Before Participating~~//Motivations//~~//Personal Experiences//Others and Research

- CMU that detail how their personal experience with mindfulness was attributed to their own research or the encouragement of others motivated them to join MBSR
- Rationale: moved to the personal experience category instead of the motivation category. The personal experience category already included a code about research, and this category doesn't require the past experience to be motivating, just for it to have been present.

Code created: MBSR//Wellness// IBD and Wellness//Emotional and Mental//Frustration

- Feelings of frustration

Code created: MBSR//Before Participating//Difficulty Finding Adequate Resources for Mental Health

- Discussion of difficulty talking about mental health with doctor or finding appropriate resources for mental health care

Code created: MBSR//Before Participating//Difficulty Finding Adequate Resources for Mental Health//Desire For More Mental Health Care Within IBD Care

- Mention of desire for interdisciplinary/holistic care or an integrated mental health component to care

Proposed Themes

- I think with what was generated it might be best to try and paint a common picture of those that completed the group and what commonalities they possess
    - I think this goes well with the idea that the group wasn't feasible for everyone, but maybe there is a certain type of IBD patient that the group would be best targeted for
- My proposed themes (maybe better described as a narrative) would be characterizing the participants before the group
    - Before: Recognize that physical and mental wellness are connected and both are influenced by IBD; had tried to improve both physical and mental wellness before, but struggled finding an appropriate resource for mental health
        - Other notes: participants didn't go in thinking the IBD specificity of the group would be a positive, but they did leave thinking this
            - Discussion: could the group be expanded to diseases where this cycle of stress and disease exist to make group more feasible?

- Before: Had experience with mindfulness and were interested in the techniques the program could teach them
- During and After: Were doubtful, but found there be to be positives (general experience and techniques learnt to reduce stress, anxiety, and help disease management)
  - Notes: Despite previous experiences with mindfulness, they remained doubtful of the group (not necessarily pessimistic though, were still more motivated to try it and learn)

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  - Discussion: maybe this is an important thing to look for when considering referring patients – do they have general interest in "mindfulness" and are they interested in learning some of the techniques they might have hears/read about
- After: Biggest struggle was the time, they had to give (mostly related to daily practice); some negative experiences existed although most of them went away as they became more comfortable with the group; would still recommend program to others (with some disclaimers) and will continue to practice mindfulness
  - Notes: Benefits outweighed the time commitment for these participants (expected since they completed)
    - Discussion: if doctors emphasized the idea that this is only 8 weeks to give time to and the benefits could be long-term would that help?

Critical Friend Discussion

Input from a critical friend is being used to ensure rigour in the interview data. On April 7, 2023, the Nvivo file was sent to Allison Bihari, who reviewed all of the CMUs, codes, and themes. A discussion about the data was organized on April 12, 2023. The main takeaways from the discussion are as follows:

- The data from the interviews will be used to support the quantitative data, and this is key when developing the themes.
- There are some relevant and interesting data/codes from the interviews that do not fit into the quantitative study, and so they should be published or presented separately.
- The best way to organize the data is as follows:
  - A set of themes that would support the "demographics" of the quantitative study
    - Would include their past experiences with mindfulness, their motivations to join, and previously struggles finding support
  - A set of themes that expands the "effectiveness"

        - Includes the barriers and facilitators, the participants experiences' in the group, and their perceived benefits
    - Maybe: a set of themes that offers more information on if the participants will continue to use it (could support the 6-month data)
        - Includes if they intend to keep practicing and if they would recommend
        - It is possible that this section could be combined with the previous one to elaborate on the overall positives of the participants experiences depending on the manuscript

Reorganization of Codes and Creation of Themes

- A section entitled "Participant-specific" was created
    - The goal of this section was to organize all themes that related to the participants in the study and could be used to support the participant characteristic data from the quantitative study
    - This section has 3 topics with themes:
        - Motivations to Engage in MBSR:
            - Group Specific Features: describes anything about the logistic or organization of the group that motivated participants to join
                - Codes included:
                    - IBD-Specific
                    - Taught By Others
            - Improvement of Quality of Life and Disease Management Through Learning: describes motivation that stems from wanting to learn how to improve their quality of life or learn how to better manage their disease
                - Codes included:
                    - Motivation//Learning
            - Personal Experience with Mindfulness: describes any personal experience participants had with mindfulness in the past and the idea that this was motivating and encouraging
                - Codes included:
                    - Personal Experience//Mindfulness
            - Recommendation From Others: describes how suggestion and encouragement from others was motivating
                - Codes included:
                    - Others and Research (split this code)
                    - Others//From HCP Specifically
            - Personal Research: described how their own research about mindfulness motivated them to participate
                - Codes included:

- Others and Research (split this code)
- Expectations Before Participating
  - Limited and Negative: describes that participants expectations were generally negative or limited
    - Codes included:
      - Negative and Neutral Expectations//General Limited
      - Negative and Neutral Expectations//General Negative
      - Negative and Neutral Expectations//General Negative//Group Specific
- Previous Experiences with Wellness Improvements
  - Mental Health Related: describes previous efforts to improve mental health
  - Physical Health Related: describes previous efforts to improve physical health
  - Difficulty Finding Adequate Resources for Mental Health: describes previous struggles participants had finding mental health supports and programs

– A section titled "Program-specific" was created
  - The goal of this section was to organize everything related to participants experiences in the program
  - This section has 4 topics with themes:
    - Barriers & Facilitators
      - Barriers: describes barriers that participants feel made participation difficult
      - Facilitators: describes facilitators that participants feel made participation easier
    - Experiences in Program
      - Being with Others with IBD was Helpful: describes participants' feelings that being in a group with others with IBD was positive and helpful
        - Codes included:
          - Positive Experiences//IBD Specific
      - Changes to Perceptions and Attitudes: describes how the group changed participants perceptions and attitudes
      - General Positives: describes the positive experiences participants had in the group
    - Perceived Benefits

- Mindfulness and Focus Tools: describes any tools that participants feel like they developed in the group
  - Codes included:
    - General Well-Being and Mindfulness
- Coping Skills: Stress and Anxiety Management: describes how participants feel they are better able to handle stress and anxiety
  - Codes included:
    - Stress and Anxiety Management
- Disease Management: Symptoms and Pain: describes how participants feel they are better able to handle their disease and pain
  - Codes included:
    - Disease and Pain Management

- Endorsements and Future Directions
  - Positive Recommendations: describes that participants would recommend the program and why
    - Codes included:
      - Recommendations
  - Mindfulness Now and Going Forward: describes participants intentions to continue to practice mindfulness and how they may look to expand on it in the future

Appendix C: Results

C-1: Theme Table

Participant-Specific

Interview guide questions	*Were your reasons for trying MBSR similar to your reasons for trying other wellness improvements? Why did you specifically try MBSR and not something else?*						
Topic	Motivations to Engage in MBSR (n=5)						
Themes	**Previous Experience with Mindfulness (n=2)**	**Improvement of Quality of Life and Disease Management Through Learning (n=3)**	**Personal Research (n=3)**	**Group Features (n=2)**		**Recommendations from Others (n=3)**	
Sub-themes				*Taught By Others (n=2)*	*Other Particip-ants Have IBD (n=1)*		*From Health Care Practitioner (n=2)*
Quotes	"I started to look into mindfulness a little bit um in in terms of like, you know, gratitude journals… I think what I liked about that was that you were like taking a positive outlook on something that would seem mundane."	"What I really wanted to do was, um, to be able to manage my stress better because… stress causes inflammation in my body." "I was like excited to try, and get some new techniques to help myself."	"You read about like meditation and stuff, and they-I know they've done tons of studies about how it relieves pain… so I'm thinking like, well, if it works for them, why the hell can't it work for me."	"I thought it was really nice to have someone who could actually teach you to meditate instead of just telling you to meditate." "I learn better when, like someone can teach me."	"I thought it was really interesting that it was focused around like IBD patients."	"As I was talking about whether or not I wanted to take on the time commitment, my uncle told me that he does mindfulness, and so he was like 'yes, do it. You have to do it! It's the best thing!'"	"When my doctor, like, kind of called and she was like 'I know you have anxiety, like I know it impacts your health'…I was like, you know what, that sounds like awesome."

Interview guide questions	*What were your expectations with regards to MBSR? Did you know anything about it before participating? Had you ever heard of it? Was there anything part you found particularly interesting or that you thought might be difficult?*		
Topic	Expectations Before Starting MBSR (n=4)		
Themes	**Limited (n=4)**	**Negative (n=4)**	
Sub-theme			*Session-Length (n=3)*
Quotes	"I didn't really have like any expectations. I kind of just like was looking forward to like learning how to meditate, I guess." "I had never heard of it beforehand, so I didn't really think of anything. I didn't have the expectations."	"I was like a real Negative Nellie, like when I went into it. Like this isn't going to really work and it's taking up a lot of my time." "I thought it was…kind of like new age like I thought it was kind of, um, like a bit out there."	"When I first heard about it I was like, oh my, like that's a really long amount of time. So, I think that was like a bit intimidating like going into it I was like three hours, two hours, like I can't like focus for this long."

Interview guide questions	*Are you currently doing, or have you previously done, anything to improve your well-being?*					
Topic	Past Experiences and Difficulties Trying to Improve Well-Being (n=5)					
Theme	**Attempts to Improve Physical Wellness (n=5)**		**Attempts to Improve Mental Wellness (n=5)**		**Struggles (n=4)**	
Sub-theme	*Diet & Lifestyle (n=3)*	*Exercise (n=4)*	*Social (n=3)*	*Psychiatric Help (n=2)*	*Lack of Discussions About Mental Health Management with IBD Specialist (n=4)*	*Mental Health Practitioner Lacks Understanding of IBD (n=1)*
Quotes	"Watching what I eat is very, very - it's been helpful." "I've always tried to eat healthy… nourish my body"	"I try and move my body, I find that that really helps." "Somethin g I've been doing is, I've been doing a lot of like classes, like activity classes."	"Surrounding myself with, like, the right people because that can really have an impact." "I've been trying to get out more… trying to reach out to more people and trying to talk to them"	"I take care of my mental health is by like seeing a psychiatrist and having the proper medications for that as well."	"[Referring to the link with stress] a lot of that discovery of management of disease has fallen on my plate." "When I first got diagnosed [the IBD specialist] just like rattled off like the usual, you know? … Make sure you got a good diet, exercise, stay healthy. And then that was it." "Having those conversations [about stress management] is really important, and I personally, I've never had that." "My first GI was, like, very dismissive about mental health. It wasn't something that he, like, focused on. He was kind of like, if you have questions, like, I'm not someone who can answer them for you."	"It can be difficult finding, like, mental health practitioner people that are like qualified and like understanding of the disease."

Program-Specific

Interview guide questions	*What would you consider some of the benefits of the program? What would you consider some of the barriers to complete the program?*		
Topic	Barriers & Facilitators (n=5)		
Theme	**Time is a Barriers (n=5)**		**Online Access was a Facilitators (n=1)**
Sub-theme	*Time Related to Home Practice (n=5)*	*Weekly Session Length (n=1)*	
Quotes	"The barrier for me was to be able to parcel out a bit of time for me every day." "Like 45 min a day was just completely infeasible like I tried, but I could never do it." "I just couldn't find time. Or, I just didn't want to find time." "It was only like the hour per day that was kind of like a lot. Especially, like 7 days a week."	"[referring to the weekly meeting] It was long. And you were just like okay, like we need to, we have other things to do, kind of thing."	"I actually really liked that it was online. Um, I think for me, it would have been a lot harder to commit to if I had to like go to an in-person location very week."

Interview guide questions	Would you recommend the program? Are you currently doing anything to improve your well-being?		
Topic	Endorsements and Future Intentions (n=5)		
Theme	**Recommendations (n=5)**	**Mindfulness Going Forward (n=3)**	
Sub-theme		*Intent to Continue Mindfulness Practice (n=3)*	*Sharing Learnings with Others (n=3)*
Quotes	"I would recommend it, but I feel like if you're going into the program you have to be, like, very, like, you have to want to learn. It's not just going to, like, come to you." "This would be beneficial for just about anybody, really, you know? Um, but, for Crohn's and Colitis patients, absolutely!" "I would recommend it because it helped with stress."	"I'm very pleased with, uh, how things turned out so far. I'm. I, I do, um, I do, I would like to continue more with it." "It's now part of a daily thing that I do." "I've been doing yeah, some form of meditation every day"	"I've been telling everyone that I know pretty much that I've been doing mindfulness." "My mom also has Crohn's. So, I suggested her to do it."

Interview guide questions	Were your expectations met or not met? In what ways? Was your experience positive or negative?		
Topic	Experiences in the Program (n=5)		
Theme	**General Positives (n=5)**	**Peers with IBD Contributed to Enjoyment (n=5)**	**Improved Perception and Attitude (n=2)**
Quotes	"I found myself, like, looking forward to the groups by the end because, like, it was very relaxing… I thought like the group was very supportive and everyone was super respectful." "Mentally I feel well. Um, and I feel better than when I first started the course, So that's awesome." "It seemed to go really fast, even though it was 2 hours… and I quite enjoyed it actually."	"It was helpful, like seeing other people kind of going through the same things." "I do think that it was like it was beneficial to hear everyone else, and knowing that they also had um IBD in whatever form…there's something in, and you know, being with your peers, if you will, that's pretty powerful." "I liked having everyone, have the same, not the same thing, but similar.	"I do think that it's been like life changing in the sense that you know I see the world differently." "And I feel, now it's been very empowering because for the longest time I felt trapped by those things." "I don't think like a complete three sixty is enough [referring to changes to attitude]. I feel like I did like so much more than that." "The small things. It really changed my perception of that… I think it changed my outlook."

Interview guide questions	*What would you consider some of the benefits of the program?*		
Topic	Perceived Benefits Related to Development of New Techniques (n=5)		
Theme	**Disease Management: Symptoms and Pain (n=4)**	**Coping Skills: Stress and Anxiety Management (n=5)**	**Mindfulness and Focus Tools (n=5)**
Quotes	"One of the big issues, like when my disease is active, is like, keeping yourself calm, so I think like those techniques, I definitely have them now if I ever need them." "I was actually able to take my pain level down to zero… and it actually stayed away for a long time, and then, um, I've been finding too, that when it gets pretty intense, I can lay back and… I can feel the switch." "The MBSR thing was so beneficial, because you know now I've got some-some tools now that are gonna help me take that pain level down if it gets to be too much." "It kind of helped me be more mindful about stuff…my body, my health."	"I just noticed that I'm not as stressed as much, and stress was a huge trigger for my disease … it was like I learned how to manage that better… it's wild how much it's changed." "There were a few techniques that I found like really beneficial in specific… I feel like that's really helpful for someone with anxiety, especially when your like anxiety impacts you physically. It's like nice to be able to calm yourself down." "When I feel like I'm starting to get stressed out, like, I take maybe 10 minutes, and it like, seems to really help me."	"I picked up like a lot of useful like techniques and stuff that I would have never really been able to discover on my own." "I remember at the beginning just how agitated I felt. Like my mind was still running, like, I gotta do this, I gotta do that after… but I think, what really helped me, start to focus, was when we started the exercises to focus on the breath." "The mindfulness aspect has allowed me to like, really start like amping up my physical activity, which has been awesome." "I do think that a lot of the techniques that I learned there, it was a really good base."

IBD Care & Wellness

Interview guide questions	*How do you define wellness? Thinking about your definition of wellness, how much do you feel like your IBD impacts to your wellness?*				
Topic	Defining Wellness and the Impact of IBD (n=5)				
Category	Wellness is Multifaceted (n=5)		IBD has a Negative Impact on Health and Wellness (n=5)		
Theme	**Physical, Mental, and Their Interplay (n=5)**	**Balance (n=2)**	**Physical Health (n=5)**	**Mental and Emotional Health (n=4)**	**All Aspects of Health (n=4)**
Quotes	"Wellness for me is like, if you're talking about mental and physical, like, at least one of them being strong at once." "You always have your physical wellness… for me, that aspect of my wellness, is like making sure I'm in remission, and, I'm taking care of my health, I'm following my medications and things like that. And then you have kind of like the mental wellness. Um, so, for me, that can be like, it can be a lot, it can be like stress, like my social battery, um, anxiety."	"The whole thing for me is balance. Like work-life, um, you know, your-your mental, physical, spiritual, has to be in balance. If there's something that's off, everything is gonna go off."	"For someone with a chronic illness, [physical wellness] can be very different than someone else." "Fatigue is really debilitating. Um, and I think some of the medications that doctors have prescribed over the years… they can be really rough on your sleep cycle." "I used to [before IBD diagnosis] be able to stay up super late and work… now, if I don't go to sleep at a reasonable time and sleep solidly, for you know at least 8 hours, I like, wake up sick like I can't or I can't function because I'm tired."	"Because after a while, you know, you start to get a little bit of PTSD constantly going in and out of the hospitals." "I felt like I was so messed up in my head. You know, like this disease really has taken a lot out of me emotionally."	"Both physically and mentally, it can be like very, it can have a very big impact, especially during the time where its like flaring." "When you have a digestive track issue, you realize just how important your digestive track is for everything that you do, like anything daily."

	"Wellness is making sure that whatever triggers are for you, for your disease, whether that's food, or whether that's you know environmental factors or you know stress at work, whatever the case is like, realizing that, what are the triggers and trying to address that."	"Wellness is that balance. So, recognizing that you'll always have stress… but then, recognizing that you need to sort of restart that stress cycle."	"It was only 2 years ago that I was diagnosed and before that I had no health problems, so like, yeah, like I don't know, I find that, like my body, I feel like in my head, my body is failing me."	"When I have a bad day it's just like my heads just like a great big fog, and-and trying to think-trying to think, or trying to figure out okay, how do I get it to settle down so that I can feel better and do things."	"When I'm flaring it impacts every aspect of my life. Because I can't leave my house. If I have any plans outside of the house I have to cancel them."

Interview guide questions	***There was no interview question that focused on this theme. Participants volunteered this information, or it emerged naturally in their dialogue. ***	
Topic	Mental Health Care Within IBD Care (n=5)	
Theme	**Increased Emphasis on Interdisciplinary Care and Training for IBD Specialists (n=5)**	**More Discussions About Mental Health (n=5)**
Quotes	"I really hope I don't have to wait another ten years to kind of see the gastroenterology industry really embrace this philosophy [of interdisciplinary care]." "Having, you know, mindfulness and MBSR really like pitched to patients alongside, um, you know, prescribing medication is - would be a game changer." "This should be automatically offered… if they can find a way to make it all work together, that would be cool." "We rely on [a doctor's] opinion substantially. And so, yeah, I would just love, would like absolutely love it if doctors would just, not even for myself, but just in general just embrace this." "I feel like [IBD specialists] should have like some training [in mental health] because it's like so interconnected with patients." "Wellness management is vital to our care, it's you know, like as you could throw a whole bunch of medications at us, and for some it'll work, and some it won't. But if you don't do the holistic part as well, then we're kind of we're not really, you know, taking a well-rounded approach to it."	"I do think that it should be, you know, something that is prescribed or discussed, at least with these specialists… there's so much more to [Crohn's disease] than just medication." "I think even just having that discussion with patients…having those conversations is really important."