

**The role of spirituality and disease acceptance in
predicting psychological well being in a group of
individuals with Inflammatory Bowel Disease**

Volume 1

Submitted to the University of Hertfordshire in partial fulfilment of
the requirements of the degree of Doctorate in Clinical Psychology

Hasina Sarwari

Student number: 14116827

June 2018

Acknowledgements

Thank you to all the people who have been with me along my journey throughout this course. I have been privileged to work with an extremely supportive supervisory team who have helped me develop beyond my expectations.

In no particular order, my sincere appreciations to Dr Saskia Keville for the unwavering dedication, kindness and time you offered. Your feedback turnaround on my numerous drafts was remarkably efficient. Dr Keith Sullivan, your commended statistical expertise and pragmatism helped me believe it was all manageable. My thanks go to Dr Greg Wood and Dr David Wellsted, who both helped to shape this research in invaluable ways.

My earnest gratitude goes to all the participants who made this study possible.

Lastly and crucially, my friends and family have been an indescribable source of solace. I am forever grateful for each of you and hope to be able to return the generosity and kindness I have received from you all, especially my loving parents.

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Abstract

Background: Inflammatory Bowel Disease (IBD) is a long term health condition, characterised by the complex interplay between physical and psychosocial health. In the absence of a cure, psychological interventions that help with adjustment to IBD may be vital for effective disease management. Acceptance and spirituality are well-known coping strategies in chronic health conditions and both are considered to be linked to adjustment. Third wave Cognitive Behavioural Therapy (CBT) interventions draw upon features of spirituality through their utility in mindful acceptance and values, offering a framework in which, potentially valuable, coping strategies for IBD can be harnessed. However, the dearth of literature in this area limits the extent to which clinical recommendations can be made for third wave CBT's. The current study aims to elucidate whether acceptance and spirituality are valuable components to psychological wellbeing in IBD. In doing so, offering preliminary evidence for an intervention study.

Methods: A total of 120 participants were recruited from an online, web-based survey. This constituted an IBD group and a general population group. Predictor variables included anxiety, depression, spirituality, acceptance and disease severity. A cross-sectional, quantitative, exploratory design was undertaken. Analyses included correlations, followed by a series of regression analyses to examine predictors of psychological wellbeing.

Results: Disease severity was linked to psychological wellbeing and social support. Compared to the general population, acceptance was the most significant predictor of psychological wellbeing in IBD. To smaller degrees, spirituality and social support were also significant contributors of anxiety or depression between IBD and the general population. Associations were not found between spirituality and acceptance in any group. Additional qualitative reports

indicated beneficial effects of using complementary and alternative therapies, although quantitatively these findings were not supported.

Discussion: This is the first study to explore the potential for acceptance and spirituality to assist psychological wellbeing in a UK based IBD population. Disease severity and acceptance were unequivocally the most important factors contributing to psychological wellbeing. Spirituality may be protective of anxiety while social support appears to be a mediator of depression. The implementation of a pilot acceptance based intervention, such as an Acceptance and Commitment Therapy (ACT) group, for IBD is warranted.

Chapter 1: Introduction & Literature Review

1.1 Overview

This study sets out to explore several topics and it is, therefore, not within the scope of this project to investigate the full potential of the literature pertaining to the topic areas. As such, the introduction is organised to provide the reader with an overview of a broad range of areas related to the study, including inflammatory bowel disease (IBD), the psychological impact of IBD, the role of acceptance in adjusting to IBD and spirituality. A systematic literature review follows, linking empirical research to theoretical understandings of the key themes being studied. Finally, the rationale for this study, its clinical relevance, aims and hypotheses are outlined.

1.2 Epistemological Position and Personal Interest ¹

1.2.1 Epistemological position

Although in recent years there has been a proliferation in qualitative research in the field of clinical psychology, I have adopted a quantitative methodology and believe my epistemological position is akin to that of a post-positivist. In maintaining that a “truth” exists, I, however, believe it is singlehandedly unobtainable. Instead, for this research, I subscribe to the idea that research and science are positioned to uncover as best as possible, parts of this truth. Moreover, I am acutely aware of the fallibility and imperfection of each individual’s account and relationship with any perceived truth. Essentially, I hold that our interpretation of the world is influenced by inescapable personal lenses we view the world with. However the

¹ These sections will be written in first person to convey the personal motivations of the research. Throughout the thesis, first person may be used when reintroducing the epistemological position as well as the ending reflections. The remainder of the thesis is consistent with traditional writing in third person.

existence of an absolute truth is not prevented by this. With this account, I believe researchers can attempt to strive towards measuring degrees of this perceived or posited truth.

By collecting information from others through scientific methods of enquiry, a phenomenon may become crystallised (Kaplan, 2004) and through acknowledging the researcher's personal lens, greater clarity of the sought-after truth can be achieved. Science offers a useful means to converge established views, yet the contamination of human subjectivity may render truth unreachable. Essentially, my standpoint is one that respects a scientific method of inquiry to explore phenomena yet acknowledging the limitation of scientific methodologies when extrapolating onto multi-faceted human beings. Consequently, embracing this lens of viewing the world led me to utilise a quantitative methodology, with the intention of testing hypotheses based on previous, albeit scant, research and determining whether a difference or association exists between the variables I have chosen to study. This data would enable some preliminary comparisons and generalisations to be made.

I am indeed aware of the shortcomings inherent to empirical approaches when addressing questions related to rich, subjective human experiences. Therefore, it is important to state that I believe both quantitative and qualitative research offer equally valuable insight to the notion of a real truth. Albeit from different angles, each approach helps to bridge a gap in our understanding of reality from a focused lens of an individual or the amalgamated views of many, to determine a pattern. Although a qualitative approach would be helpful in exploring a phenomenon that little is known about, such as the role of spirituality in IBD, the vastly subjective experience and interpretation of the concept of spirituality would limit any generalisation that qualitative methods would allow to the larger population, thus, limiting the potential application of the findings of spirituality as a whole, in IBD. Furthermore, it is not

uncommon to use quantitative methods to study the phenomenon of acceptance and spirituality in the context of IBD and health related research (Cotton et al., 2009).

This led me to decide that quantitative methods were more practically useful, at this time. Furthermore, my choice to pursue quantitative research was partly influenced by the dissonance I experienced between a social constructionist philosophy and the NHS context. Specifically, a predominantly outcome driven system (payment by results) and evidence-based practice (Sackett, 1996) has augmented the use of quantitative research methodologies for research (Ponterotto, 2005). Associated with this paradigm is the quantification of human experiences for services to evidence their case to commissioners. This led to my desire to offer research that could be fostered within the organizational framework of the NHS. Ideally, with the luxury of time, the use of diverse and mixed methodologies would result in a stronger study.

In this vein, I acknowledge the predominance of qualitative researchers on the Hertfordshire Doctorate in Clinical Psychology course and deeply value the social constructionism and post-modernist theoretical principles covered by the course. My position as a developing clinical psychologist is to remain cautious of becoming dogmatically attached to an epistemological position. For example, a social constructionism epistemological position could have been adopted as an alternative. Fundamentally, subscribing to the idea that meaning and experience is relationally constructed through language (Burr, 2015). Furthermore, that 'knowledge' and reality is culturally, socially and historically dependent (Gergen, 1985), thereby, an objective observation of reality, or an absolute truth does not exist (Burr, 2015). This does not suppose that a physical reality is non-existent, rather, how an individual or group defines reality is context dependent and may not necessarily transpire in other sociocultural contexts.

However, an important consideration in social constructionism is the discrepancy within the framework about there being a distinction between ‘institutional facts’, which are based on social convention such as the money, and ‘brute facts’ that are independent of social agreement such as, natural disasters, quantum physics and bacteria (Searle, 1995). A pure social constructionist approach would maintain that all knowledge is socially constructed. In contrast, loose social constructionism refutes many of these claims, on the basis that some scientific concepts, such as evolution, may surpass cultural boundaries. Therefore, it was felt that due to IBD being a physically detectable condition through its biomarkers, an epistemological position that honoured this would be better suited. In line with these beliefs, throughout this study, I will use language in accordance with a positivist paradigm, whilst also making reference to the way my personal views may have impacted the research. This format aims to convey the complex interplay subscribing to an ultimate truth and the falsifiability of scientific research which will be displayed in the conflicting literature. Furthermore, taking moments to recognise how my personal lens may have affected this research will underline the various ways it can be understood.

Additionally, taking into account my hope to disseminate the outcomes of this study, I believe that speaking in a language the audience is able to understand and relate to, is helpful. The audience I hope to speak to are the people involved in decision making and commissioning of services, often embedded in a positivist culture. This research approach will help situate readers in the context and direction of the research in order to fully grasp the key messages of the study. Consequently, rather than approaching the subject in a very different way, such as a qualitative method alone, I hope to “respect the sameness” (Anderson 1987, p416).

The underpinning epistemological differences between quantitative and qualitative methodologies are too vast to cover in this document and too disparate for most readers to consider while also taking into account the clinical applications I endeavour to communicate.

1.2.3 Note on language use

The use of language throughout this study may be of some incongruence with the author's desire to challenge the current unidimensional approach of treating health difficulties. However, as alluded to in the author's epistemological stance, for the purpose of this research being digestible to people who may be in positions to drive change in physical health settings, the language use may appear to match that of readers accustomed to medical terminology and those working with patients.

The limitations of this are acknowledged, in view of the need for a paradigm shift in disease-based frameworks, in order to change the way systems and healthcare practices are delivered. However, throughout the study, the importance of psychosocial aspects of health are explicitly conveyed.

1.3 Context of Inflammatory Bowel Disease (IBD)

1.3.1 Overview of IBD

The focus of this study is on IBD. This is a chronic and relapsing inflammatory condition affecting the mucosal surface of the gastrointestinal (GI) tract. There are two main subtypes of IBD, namely, Crohn's disease (CD) and Ulcerative colitis (UC) both of which share a vaguely understood pathology and shared symptomatology (Stein, Hartmann, & Dignass, 2010). However, in UC inflammation is localised to the colon while CD can occur anywhere from the mouth to the anus (see Appendix A). Typically, gut inflammation leads to a host of chronic symptoms such as diarrhoea, abdominal bleeding, faecal urgency and abdominal pain (Lakhan & Kirchgessner, 2010). Not surprisingly, people with IBD can face considerable physical and psychosocial challenges resulting in reduced quality of life (QoL) a measure of psychological wellbeing (Graff et al., 2006). Demographically, the usual age of onset for IBD is between 15 and 30 years, and epidemiological reports generally show that gender is equally affected (Brant & Nguyen, 2008).

Nuances in GI diseases are often not well discerned by the lay person. However, it is important to appreciate some categorical differences. One of the primary ways that IBD is distinguished from other, non-inflammatory, gastrointestinal difficulties, such as irritable bowel syndrome (IBS) is the detection of faecal biomarkers, including calprotectin² in IBD (NICE, 2017). Furthermore, due to the ongoing discrepancies in its pathogenesis, IBD is non-curable and treatment is focused on symptom reduction and management of associated comorbidities, which will be expanded upon in section 1.5. The epidemiological aspects of IBD will be explored in the next section to enable the reader to further understand this condition.

² A protein biomarker detected in faecal samples in the presence of intestinal inflammation.

1.3.2 Current epidemiological concerns

IBD became a global disease at the turn of the 21st century. A recent systematic review of the worldwide prevalence of IBD revealed the highest epidemiology of IBD was in industrialised countries including Europe (CD 322 per 100,000 in Germany; UC 505 per 100,000 in Norway) and North America (CD 319 per 100 000 in Canada; UC 286 per 100,000 in the USA) (Ng et al., 2017). According to the most recent NICE guidelines report (2016), there are currently a minimum of 115,000 individuals with Crohn's disease in the UK (Crohn's disease NICE guideline CG152, 2012). However, the most common type of IBD is UC, with a reported UK prevalence of approximately 146,000 (Ulcerative colitis NICE guideline CG166, 2013). Attention is required, however, to the accelerating incidence that has been noted (M'Koma, 2013), particularly as the healthcare burden of IBD is growing and justifies the need for both disease prevention and more innovative approaches in the management of IBD. The following sections will endeavour to direct the reader to a better understanding of the current pathogenesis of IBD and alternative approaches to managing the disease.

1.3.3 Understanding how IBD develops: A biopsychosocial perspective

IBD remains an idiopathic disease. This means that even though it is considered to be triggered by a combination of difficulties based on immune responses to environmental factors in those with a genetic vulnerability, the exact cause of onset is highly complex and yet to be fully understood. Several genetic components to IBD have been identified in recent advances in genome mapping research. For instance, effective bacterial clearance and digestion processes are associated with the same genomes that lead to compromised immune responses, which may lead to intestinal inflammation found in IBD (Podolsky, 2002).

Although a genetic predisposition is considered to play a key role in the susceptibility of developing IBD, genetic underpinnings alone do not satisfy the risk of IBD onset as demonstrated in studies of identical twins and the predominantly Northern developed geographical spread of IBD (Husain & Triadafilopoulos, 2004). In general, a wide range of environmental risk factors such as diet, stress, smoking and drug use have been found to be related to IBD in conjunction with genetic variants ("Crohn's disease: management | Guidance and guidelines | NICE", 2017; Danese, Sans & Fiocchi, 2004).

Specifically, smoking is reported to have an adverse effect on CD, while having a protective effect in UC. To date, explanatory theories for this relationship are inconclusive (Mahid et al., 2006). Tentative theories propose that chemical interactions of nicotine and carbon monoxide in the gut play a role in gut bacteria and immune response (Quezada, Langenberg & Cross, 2016). Similarly, the role of dietary factors in the course of IBD is yet to be established, due to difficulties in obtaining accurate dietary habits for research. However, it has been suggested that a predominantly Western based diet such as a diet low in fruits and vegetables while high in fatty acids and refined sugars, may be linked to higher risk of developing IBD. Such a diet is believed to alter the gut bacterial composition resulting in greater gut permeability, hence, increasing susceptibility to inflammation (Amre et al., 2007).

Likewise, Andersen et al. (2012) propose that a diet high in processed animal protein may be linked to higher risk of IBD and flare-ups, predominantly due to the high content of saturated fat. This link is compelling given the rise in IBD in Western parts of the world and the emerging rise in IBD in low-incidence countries where Western diets are increasingly being introduced, for example, China and Puerto Rico (Hou et al., 2011). Several popular diets, including the low-FODMAP diet and the IBD-AID, appear to be reasonably helpful in reducing the exacerbation of IBD symptoms by limiting intake of foods that are thought to perpetuate the growth of gut bacteria involved in inflammation. Given the uncertainty in aetiological and

maintaining factors, caution must be taken in application of these findings as more rigorous research is required on the precise role of dietary interventions for IBD management (Knight-Sepulveda et al., 2015).

It is concerning that one of the treatments for IBD may be a factor increasing symptoms. For example, non-steroidal anti-inflammatory agents (NSAIDs) used to manage IBD are thought to be involved in the pathogenesis and long-term disease progression as a result of directly destroying the intestinal wall (Habib et al., 2014). Furthermore, psychological stress is considered to play a role in initiating and perpetuating both UC and CD. In fact, in a recent review, components of mood, including depression and anxiety, are found to be more common in individuals with IBD, influencing the deterioration of IBD symptoms (Graff, Walker & Bernstein, 2009). Clearly, the psychosocial impact of IBD is important yet unfortunately can be undervalued if physical aspects of the disease are the primary focus. In line with the desire to bring the psychosocial implications of incurable diseases to the forefront, subsequent sections will begin to elaborate on literature pertaining to psychological wellbeing of chronic health conditions such as IBD.

1.3.4 Bridging the gap between the mind and the body

The diathesis-stress model is commonly put forward as an explanatory hypothesis for diseases with an unknown cause. Simply put, factors related to an individual's genetic, immune and environment may account for causation. Therefore, a person may have a genetic predisposition which, in the face of environmental factors, may trigger an immune dysfunction leading to the development of IBD (Neuman, 2007). The idea that stress could interact with genetic and physiological factors to compromise an individual's ability to resist the onset of a disease, such as IBD, is not novel and has been researched extensively in the initiation and progression of

many chronic diseases (Baum & Posluszny, 1999). This is partly due to the brain-gut axis involvement, which relates to a wide series of neurally composed interactions, including 1) the central nervous system, 2) the autonomic nervous system, 3) the arousal system, 4) the modulation of the cortisol system and 5) the gastrointestinal response. Not surprisingly, many researchers consider that a complex, psycho-neuro-endocrine-immune modulation, via the brain-gut axis, may contribute to the pathogenesis of IBD. For example, a study by Hisamatsu et al. (2007) revealed that 75% of IBD patients believe that a disposition towards a tendency to be anxious or stressed played a role in the onset of IBD, and at least 90% hold that it affects disease activity (Kirsner et al., 2004).

In addition, some researchers believe that the experience of anxiety and depression may be predisposed by personality traits and not solely state dependent (Spielberger, 2013). However, there is no evidence of directionality for the relationship between psychological stress and IBD. Thus, the role of stress in disease onset is empirically inconclusive. These findings preliminarily indicate the influence a person's mental health may have on physical health and the need to be alert to the mind-body interplay in clinical practice.

A growing body of evidence exists supporting the notion that psychological factors can influence the disease course of IBD and individuals' coping behaviours (Sajadinejad et al., 2012). A well-documented study used animal models to demonstrate that low mood may trigger inflammation and worsen IBD activity (Ghia et al., 2009). Even though decades of research have been published on the gut-brain interaction, revealing crucial information about the bi-directional neural signalling pathways, until recently, these discoveries were perplexingly under-valued by the vast majority of medical and mental health professionals

(Mayer et al., 2014). Partly accountable for this is the evolution of gastrointestinal difficulties and how they have been situated in the context of medical history, which is briefly described in the following section.

1.4 A Focus on the Psychological Impact

1.4.1 Historical context of IBD in relation to psychological wellbeing

In the 1930's, gastroenterologists and psychiatrists first believed that significant life events and emotional experiences were linked to exacerbated bowel symptoms (Keefer, Keshavarzian & Mutlu, 2008). During this era, IBD was firmly viewed as a somatoform disease for both physicians and researchers. It was some decades later where this conceptualisation was questioned due to poor research methodologies, giving rise to the classification of IBD as an organic disease, with little or no regards to psychological influences. Today, there is an emphasis on the likely adverse effects of psychological factors on the course of IBD, as suggested in review articles (Camara et al., 2009; Mikocka-Walus et al., 2007). Current research points towards the triggering and exacerbating role of psychological factors on the course and severity of IBD (Kirsner et al, 2004; Hisamatsu et al., 2007), and some advocate the view that distress is implicated in disease relapse (Bitton, 2003). Nevertheless, directionality is yet to be determined, if at all, as demonstrated by what appears to be theoretical progression and regression. The deeper gastrointestinal difficulties are explored, the more one can appreciate the importance of understanding the neurobiology of the gut. Due to the vast depth of this topic, a brief overview will be covered in relation to IBD, in the next section.

1.4.2 Considering the bidirectional relationship between IBD and psychological wellbeing

The biochemical makeup of the gut is an important consideration of the mind-body link. Due to numerous overlapping pathways, any relationship between mood and IBD is complex and dynamic. Indeed, approximately 95% of the neurotransmitter, serotonin, also known as 5-hydroxytryptamin (5-HT), is located and produced in the gut. Coates et al. (2017) concludes that inflammation may significantly impact all aspects of gut 5-HT signalling, implicated in a wide range of functioning. Considering the numerous stressors people with IBD may already be experiencing, this appears to suggest that there may be a twofold, bidirectional impact of gut modulation, such as depression fuelling inflammation and inflammation fuelling depression (Keefer et al., 2017).

Furthermore, there is rapidly growing appreciation of epigenetics, that is, the role of the social environment modifying gene expression, thus affecting psychological health (Toyokawa et al., 2012). Although stress is known to have a considerable impact on gut functioning (Mawdsley, 2005), recent empirical advances suggest that gut bacteria can also contribute to epigenetic modification (Stilling, Dinan & Cryan, 2013). Such insights have the potential to raise clinician's awareness of the full scope of the bidirectional relationships in IBD, thus, inspiring IBD care teams to include gastroenterologists, psychologists, nurses and dietitians. In addition, given the high proportion of under-diagnosis or delayed diagnosis in IBD (Cantoro et al., 2017), this may facilitate earlier detection and diagnosis, which may lead to better prognosis, both psychologically and physically.

1.4.2.1 Psychological trajectory of IBD

This section will focus more specifically on the psychosocial impact of IBD. Undoubtedly, a high degree of interpersonal and psychological concerns may arise in people with IBD, from the levels of uncertainty, unpredictability and chronicity of the disease. Psychological implications of IBD range from fatigue, feeling dirty, embarrassment and social isolation due to loss of bowel control, and changes in body image (Kiebles, Doerfler & Keefer, 2010). As such, it is plausible that these concerns alongside the relapsing nature and incurability of IBD, alongside patients' fears of developing cancer or requiring complex surgery, are all likely to increase the risk for anxiety and depression (Graff, Walker & Bernstein, 2009).

A considerable body of research has elucidated the psychological impact of living with IBD (Hisamatsu et al., 2007; Sajadinejad et al., 2012). In particular, Graff et al. (2009), show that QoL may be the most important feature for individuals regardless of the severity or disease activity. In contrast, studies suggest that QoL is more related to disease activity, thus, individuals with quiescent IBD report better QoL than those with active disease (Larsson et al., 2008). Graff et al. (2006) for example, found that psychosocial outcomes are typically worse during active disease periods compared to inactive ones. Numerous studies have reported that anxiety and depression among people with IBD is substantially higher than in the general population ranging between 25-30% in prevalence for IBD compared to 13% for the general population (Walker et al., 2008; Mittermaier et al., 2004).

Anxiety is thought to be underrepresented, as it is considered to be unrecognised regardless of disease severity (Keefer et al., 2015). Furthermore, some believe that disease subtype may influence the variation in psychological outcomes within IBD. However, the recent literature maintains that the main driver in the relationship between diminished QoL and psychological

wellbeing is disease activity (Casellas et al., 2005). In contrast, Guthrie et al. (2002) argue that psychological symptoms and disease activity in IBD patients are independently implicated with QoL. Notwithstanding, previous research highlights that people with IBD and a comorbid psychological difficulty are more likely to experience complications and higher levels of disease activity (Mardini, Ki & Wilson, 2004). Furthermore, in recent studies, symptoms of anxiety and depression were associated with IBD severity (Chan et al., 2017). It is unclear why, but clearly worthy of further exploration.

The most recent comprehensive systemic review examining the rates of depression and anxiety in IBD reports that in total, 35% of IBD individuals have symptoms of depression which is greater than the general population incidence worldwide. Similar, disproportionately high prevalence rates were found for anxiety (20%) and symptoms of anxiety (35%) in IBD individuals compared with the general population worldwide (Neuendorf et al., 2016).

Nevertheless, the magnitude of psychological difficulties in IBD suggests a high disease burden as global research confirms the leading cause of disease burden comes from depression and anxiety (Ferrari et al., 2013). Likewise, evidence suggests that people with a chronic illness and a comorbid depressive disorder are more likely to experience greater physical symptoms resulting in higher medical care (Katon & Ciechanowski, 2002). In light of this, it is important to draw attention to the current treatment approaches recommended for IBD, both from an individual and national healthcare standpoint. Understanding this provides greater clarity on whether the healthcare as we currently know it sufficiently addresses the scope of patient needs.

1.5 Current context of treatment for IBD

1.5.1 Self-management

Indeed, due to the long-standing nature of IBD and its associated demands, disease self-management is important and necessary. According to Keefer & Kane (2017), IBD patients must simultaneously engage in three core self-management tasks. Firstly, medical management such as medication adherence and communication with the healthcare team; secondly, developing or strengthening meaningful activities and adjustment to disease-specific challenges; and thirdly, recognising and addressing the psychological and emotional impact of IBD (Lorig & Holman, 2003).

Accordingly, mood disorders such as depression, when comorbid with IBD, can lead to deleterious self-management and is likely to lead to more clinical appointments, both for physical and psychological difficulties (Drossman et al., 1991). Depression in IBD is also linked to higher risk of hospitalisation within 90 days (Allegretti et al., 2015), multiple unnecessary scans and colonoscopies, as well as greater risk of surgery (Ananthakrishnan et al., 2013). Therefore, ensuring that a person with IBD is maintaining the key features of self-management is a useful indicator of how well they are coping. The following section relates to the established medical treatment guidelines for IBD.

1.5.2 Clinical treatment in the UK

To date, there is no known cure for IBD. The biomedical approach currently remains the main focus of treatment in the UK. Medication attempts to target and reduce what is considered the primary culprit of the disease, inflammation. For example, a range of immunosuppressant's and steroids are available and offer patients some remission or symptom reduction. Where these medications are ineffective at symptom management, patients commonly undergo surgery (NHS Choices-IBD, 2016). Failing these approaches, biological drugs can be offered which enable mucosal regeneration and disease remission ("Biologic drugs in IBD | Crohn's &

Colitis UK", 2018; Podolsky, 2002). While some may benefit, surgery and medication side effects can lead to an array of complexities affecting the individual's QoL.

1.5.2.1 NICE recommendations

The most recent NICE guidelines for IBD (NICE, 2013) emphasises symptom reduction through pharmacological or surgical procedures and improvement of QoL. However, given the diverse effects of IBD including psychological, emotional, and social difficulties, the need for psychological intervention to enable individuals to adjust and cope better with the chronicity of IBD, appears to lack attention in the guidelines yet may be an equally important feature of disease management. Appropriately, a NICE (2014) quality standards and indicators briefing document, points to the inadequacy of psychological support levels in IBD and the need for these to be prioritised.

Indeed, the NICE guidelines recommend a stepped care approach for the treatment of depression in chronic physical health conditions in general, with the aim of promoting QoL. However, it is questionable to what extent psychological health is assessed and adequately treated in the routine care of IBD patients considering the lack of specific reference to psychological assessment or treatment in the NICE guidelines for IBD. Adding to this, since IBD is recognised as a physical health condition, a greater emphasis on the psychological impact of IBD may be required for healthcare professionals to include this as part of routine care. This is important as individuals with IBD are faced with huge psychosocial challenges of which may go undetected if clinical assessment procedures fail to address these. Equally, recognising these difficulties will require adept treatment approaches that are currently lacking in the research, which this study will usefully contribute towards.

Not surprisingly, perhaps driven by the mixed or disappointing outcomes experienced by patients in the healthcare provision for IBD, there appears to be a growing interest in alternative therapies. It is not clear whether this is due to the hope offered by alternative therapies or whether an under-researched therapeutic mechanism exists. Alternative interventions will now be explored.

1.5.3 Beyond the medical approach

Complementary and alternative medicines (CAM) can be defined as an unorthodox, unconventional set of practices and products sought by individuals as an adjunct to conventional healthcare approaches (Jamison et al., 2006). Due to the evolving nature of CAM, the parameters of what can be considered CAM are debatable (Opheim et al., 2012) and vary considerably between parts of Europe and North America (Langhorst et al. 2014). While it is beyond the scope of the current research to explore the many different types of CAM, they can be classified broadly under the following: Mind-body approaches which includes spiritual and meditation techniques; Alternative medicines such as acupuncture and homeopathy; Body-based approaches such as massage, osteopathy and chiropractic; Nutritional medicine which include herbal supplements (Jamison et al., 2006).

At least 30% of the Western population are thought to access CAM for their health (Langmead & Rampton 2006). Undoubtedly, people with IBD are increasingly seeking CAM for disease management with frequencies ranging from 21-60% (Hilsden et al., 2011; Joos et al., 2006). From these, one of the most common CAM approaches used included mind-body interventions (Langmead et al., 2006; Opheim et al., 2011). According to Langhorst et al., (2008), the primary reasons for seeking CAM includes unsuccessful conventional healthcare and a desire

for a holistic therapeutic approach. Although the literature in this area pertaining to IBD, is still developing empirical rigour, there are several studies highlighting the benefits.

For example, one study suggests compassion meditation lowers inflammatory reactions to a laboratory stressor (Pace et al., 2009). Other findings reveal the beneficial effects of short-term meditation (Tang et al., 2009) and mind-body interventions such as Tai Chi (Motivala et al., 2006) and yoga practice (Brown & Gerbarg, 2005) on various measures of physiological responses related to IBD. Based on the long standing literature, these approaches are considered as CAM (Cramer et al., 2014), yet some would argue that a denominator of meditation and particularly Indo-Tibetan yoga is the spiritual component (Brown & Gerbarg, 2009). Nevertheless, it is unclear how these interventions lead to these outcomes in IBD, and it is unclear how those who received the benefits of CAM perceive their spirituality. These are potentially useful areas to explore to ameliorate such a debilitating and chronic condition. The next section will outline the current evidence base for psychological therapies in IBD.

1.5.4 Evolving from traditional Cognitive Behavioural Therapy (CBT)

Due to its empirical evidence base, the main psychological therapy offered to individuals with IBD is CBT. However, the conceptual framework of the application of CBT within the context of long term health conditions has its shortcomings. Specifically, CBT relies on challenging, seemingly, maladaptive cognitions as well as behavioural strategies targeting disease management alone, such as medication adherence. Efficacy findings indicate modest but consistent improvement in coping skills when receiving CBT. In contrast, inconsistent outcomes for the physical symptoms of IBD were found (Knowles, Monshat & Castle, 2013).

In addition, it has been reported that CBT may be relatively ineffective for more chronic, longer term presentations particularly seen in health settings (Fournier et al., 2008). Therefore, CBT for IBD does not reliably lead to amelioration of disease activity, although this does not rule out its usefulness in the presence of psychological comorbidity. Further, the rising demand from clinicians and patients for the treatment of the psychological aspects of IBD is, therefore, unsurprising and requires proactive strategies (Kiebles, Doerfler & Keefer, 2010). In recent times, the role of psychology in long term conditions has evolved. The drive towards better adjustment to the impact of a condition appears to be a pragmatic approach in the current absence of a cure. This will be explored in the subsequent sections.

1.5.5 Adjustment as a crucial ingredient to IBD management

Psychological adjustment in the context of chronic disease is a multidimensional construct which can be described as one's willingness to make the necessary behavioural adaptations to cope with disease-related burdens, in order to preserve QoL and psychological wellbeing (Stanton, Revenson & Tennen, 2007). This has been a key focus in the subject of rheumatoid diseases, cancer, cardiovascular disease and multiple sclerosis. Less investigated is psychological adjustment to IBD, yet, given its chronicity, this is a much needed feature of managing IBD. For example, poor QoL linked to IBD may lead to poor adherence to management and treatment of the disease (Walker et al., 2008). Based on established research, the impact of poor adjustment on predicting poor outcome performance such as demand on medical services and QoL, is notable (McCracken et al., 2004). This indicates the importance in adjustment to lifestyle that may indeed be significant, long term and all-encompassing.

Some clinicians agree that IBD patients undergo a natural process of psychological adjustment in a relatively brief period of time following receipt of the diagnosis. For instance, following an emotional response such as distress, grief, and anxiety; individuals may experience a behavioural response such as strengthening existing or developing new coping strategies to manage stress, seeking social support, altering diet and taking new medication. Without doubt, adjusting to a chronic health condition, like IBD, is an ongoing, complex and dynamic process and often challenging due to the relapsing, complicated and unpredictable course of the disease (Dorrian, 2009).

According to the theory of learned helplessness (Seligman, 2002), chronic health conditions of an uncertain and incurable nature impacts individual's perceptions of self-efficacy and personal control leading to helplessness, a risk factor for depression (Kiebles, Doerfler & Keefer, 2010). Adjustment enables one to counteract this process by adopting an empowering position through accepting the challenges without giving up on alternative ways of living a meaningful life. Therefore, acceptance plays a key role in the trajectory of chronic health conditions as explained next.

In connection with the above, acceptance typically goes hand-in-hand with adjustment as it is seen as an illness coping moderator. Poor acceptance in the context of chronic health conditions is the denial of the reality of a patient's illness as well as refusal to contemplate the illness. As described in previous sections, this is linked to poor disease-management, which can develop into substantial psychological distress and adjustment difficulties. Although research in this area is under-developed, it is likely that a large proportion of patients who are regularly seen by the NHS, also known as "frequent flyers", are indeed undergoing poor adjustment to their physical and psychological health as a result of poor coping strategies, which will be explored

in the literature review. Knowing this provides a strong rationale for more adjustment based treatment approaches.

1.5.6 A new wave: Towards a model of acceptance

Fortunately, the development of CBT into its ‘third wave’ may adequately address the shortcomings of traditional CBT. For example, ACT (Hayes, 2006) extends CBT through its use of mindfulness and acceptance techniques to assist people to cope with challenging experiences. Furthermore, ACT promotes refocusing one's energy and attention on personally meaningful, value-congruent thoughts and actions (Eifert et al., 2009). Acceptance and a willingness to experience difficulties rather than avoiding them is an important feature of acceptance based therapies. Arguably, acceptance in the face of a chronic health condition is difficult and denial is a common response in these contexts, which is considered to be a strong component of psychological distress (Hayes et al., 2003). Thereby, ACT is a relatively novel approach. Accordingly, studies on the efficacy of ACT for long term conditions are emerging; a recent review in this area evaluated 18 ACT intervention-based studies. Although the study qualities were deemed low due to the lack of RCT's, the outcome of the review indicated promising evidence supporting the application of ACT for psychological flexibility and disease self-management (Graham et al., 2016). Considering that a pertinent feature of acceptance based therapies appears to be spirituality, the following section will delve into the role of spirituality within the themes explored so far.

1.6 Coping with IBD through spirituality

1.6.1 Spirituality as distinguished from Religion

Religious and spiritual beliefs are ubiquitous and exist across socio-ecological, family and individual contexts. Spirituality and religion are often confused as one and the same as both are considered to be unique human experiences concerning a higher power, and both are universally recognised for providing meaning and purpose to life (Verghese, 2008). However, the primary components that appear to differentiate religion from spirituality is that spirituality relates to one's existentiality and a personal relationship with a transcendent, or higher, existence. In comparison, according to the Fetzer Institute (1992, p.2) "Religiousness has specific behavioural, social, doctrinal and denominational characteristics because it involves a system of worship and doctrine that is shared within a group". In other words, individuals practicing religion participate in an institutionalised set of beliefs and organised practices and rules of worshipping that are shared by a community (Hill et al., 2000; Hodge & Derezotes, 2008; Koenig, King & Carson, 2012).

1.6.1.1 Defining spirituality as applied in this study

Given the conceptual overlap and largely inconclusive scholarly consensus of the definition, the section below will necessarily establish the definition of spirituality that will be adopted in this study.

Spirituality is best understood as a multidimensional construct. According to Sullivan (1993), spirituality is a subjective feature that connects the individual to the universe, others and to nature, with or without belief in a God. Another author defines spirituality as a means to uncover purpose and meaning in life by linking inner experiences with the sacred (that is, a

higher metaphysical power that may or may not be a God) (Koenig et al. 2012; Puchalski, 2012). Furthermore, connectedness is a fundamental component of spirituality as shown in multiple conceptual analyses (Cook 2004; Chiu et al. 2004) and qualitative research (Gomez & Fisher, 2003).

The present study defines spirituality as a relational experience with the self, others, higher consciousness, and nature; independent of religious affiliation or worship of God(s). Importantly, the definition of spirituality within this study reflects the current context of the West, with the rise in diversity and secularism. Such context has led to a greater shift wherein individuals' increasingly value a unique search for connection with a higher meaning in life, independent of external rules and expectations (Heelas, 2015). This definition will constitute the parameters of the term spirituality as used in this study. Consequently, this study will focus on research that identifies spirituality as a separate construct. This will ensure clarity remains in the concept of spirituality within this current study attempting to ensure comparability (through similar definitions) to other research in this area. However, it must be noted that due to the vast majority of authors referring to religion and spirituality interchangeably in the literature, occasionally, religion may have to be considered.

In line with the post-positivist epistemological position of this study, this definition reflects the process of getting closer to an absolute truth that we may not fully understand. As seen in the rise in secularity, which perhaps reflects individual's quest for aspects of an ultimate truth through universal experiences such as spirituality.

1.6.2 Positioning spirituality in the current healthcare context

Dating back to the earliest records in history, incorporating spiritual beliefs in the process of healing and healthcare are familiar practices among all population groups (Koenig, King &

Carson, 2012). While still practiced in most developing countries, only recently has the interconnection between spirituality and physical healing become separate, in Western, highly developed countries. In the current health context, spirituality is considered to be a resource for coping with life stress, instilling hope and strengthening one's resilience, especially in people with a chronic health condition (Stefanek et al. 2005). Contrastingly, despite several positive correlations, some research has shed light on the unhelpful features of spirituality, such as attributing illness to a punishment from God, and spiritual doubts (Pargament et al., 1998). In the presence of these, higher rates of anxiety and depression are likely (Stratta et al. 2012).

Despite the emerging view that the relationship between spirituality and health outcomes is similar to that of religiosity, it is comparatively less researched (Carmody et al., 2008; Thoresen & Harris, 2002). Methodologically, both qualitative (Chiu et al., 2004) and quantitative (Thoresen, 1999) studies have reported a robust link between spirituality and positive health outcomes, including mental health (Koenig et al., 2012; Sawatzky et al. 2005), with the strongest association in people facing life-altering disease (Smith et al. 2003).

Specifically, numerous randomised clinical trials have shown that both religious and spiritual based interventions improve psychological wellbeing which, in turn, positively influences physical health (Smith et al., 2003). It is thought they enable coping and imbue adverse life events with meaning and purpose - which are both associated with better psychological wellbeing. By comparing spiritual and non-spiritual forms of meditation, Wachholtz & Pargament (2005) researched whether spirituality was a crucial ingredient of meditation. They found a significant reduction in anxiety and mood as well as higher pain tolerance in the

spiritual intervention group compared to other groups. Indeed, suggesting a beneficial role for spirituality in healthcare. This finding has clinical implications worthy of further investigation.

However, although healthcare professionals may encourage those they see to re-connect with religious or spiritual practices (Miller & Thoresen, 2003), spirituality is seldom included in standard clinical sessions (Curlin et al., 2007). Therefore, while clinicians may acknowledge spirituality as a useful resource, it is concerning that there seems minimal evidence of its integration in routine assessments in physical health care settings. Similarly, and of equal importance, is the role of spirituality in mental health, thus, the following section focuses on the link between spirituality and specific psychological interventions.

1.6.2.1 Spirituality and psychological interventions: A potential link

As mentioned, spirituality is associated with better health outcomes; yet the extent to which spirituality is related to Third Wave CBT such as ACT, Mindfulness-Based Cognitive Therapy (MBCT) and Dialectical Behaviour Therapy (DBT) remains poorly investigated, in the literature (Rosmarin et al., 2013). Virtually all third wave therapies incorporate principles stemming from spirituality and Eastern mystic traditions, such as acceptance, mindfulness and values (Follette, 2016; Hayes, 2002; 2004; Santiago & Gall, 2016). In addition, some research has shown that acceptance based approaches have heightened spiritual wellbeing (Carmody et al., 2008). The underlying mechanism is unclear however, this will be discussed in greater detail in section 1.11

Folkman (1997) introduced the idea of meaning-based coping, whereby cognitive efforts are employed to activate spiritual beliefs and imbue challenging life events with positive meaning. It is thought that the use of meaning-based coping strategies such as those central to ACT, could lead to better emotional wellbeing (Folkman & Greer, 2000). The extent to which individuals who self-identify as spiritual draw upon mindfulness-based strategies compared to individuals who do not self-identify as spiritual is unclear. Furthermore, there is scope to explore the extent to which spirituality is related to acceptance in IBD.

Findings from a recent meta-analysis revealed significantly lower anxiety and reduced symptoms of depression following spiritual interventions when compared with control groups (Gonçalves et al., 2015). In their study, spirituality could be incorporated in psychotherapy as well as meditation techniques such as Mindfulness-based stress reduction (MBSR). Several researchers (Abbott et al. 2014; Carmody et al., 2008; Chan & Larson, 2015), have found a significant association between MBSR and improvements in mindfulness and spirituality, which in turn, was linked to improved physical and mental health outcomes. Although they report that they were examining psychological, not spiritual, interventions, many of the authors acknowledge the origins of meditation and mindfulness from Eastern spirituality (Wallace & Shapiro, 2006).

1.6.3 Linking with IBD

Taking into account the mind-body link described in previous sections, alongside the role of meaning and purpose, it can be reasoned that psychological pathways are plausible means through which spirituality influences physical and psychosocial health. At least, this is an area worthy of further research. Regrettably, despite the sizeable literature indicting the potential

role of psychological distress in the deterioration and relapse of IBD, most individuals with IBD undertake minimal psychological interventions (Bennebroek Evertsz' et al., 2012). The exact reason for this is unclear and may be due to the lack of awareness of the psychological impact or the lack of resources available, rendering psychology a luxury rather than a potential necessity.

1.6.4 Bringing spirituality and acceptance together

For many people who develop IBD, adaptive adjustment can occur through disease acceptance. This is particularly important for individuals whose attempts to control or reduce IBD symptoms via medication or surgical procedures prove unsuccessful, and can overshadow other potential goals (Thompson & McCracken, 2011). However, where acceptance is prevented by resistance, poor coping strategies and poor social support, an individual may feel low, socially isolated and hopeless (Petрак et al., 2001). In addition, some mechanistic features of adjustment and spirituality that enable individuals to cope better with a chronic illness appear to be shared via acceptance. However, since research into the relationship between spirituality and acceptance is sparse, this may be a useful relationship to elucidate. Investigating this would potentially identify individuals that would benefit from acceptance based psychological therapies for IBD in an NHS setting. Also, this may indicate a need for the assessment and inclusion of spirituality as part of a holistic approach. A final aspect of the introduction relates more specifically to the role of social support, alluded to in previous sections.

1.7 Social support as a moderator

It is argued that social support may moderate the religion/spirituality-health relationship (George, Ellison & Larson, 2002). Consistent with this view, the strongest positive correlations

identified in a review by Koenig et al. (2012) were social support, meaning and purpose of life as well as hope as moderators in this relationship. Many believe that the role of religious and spiritual interventions are in adapting an individual's thoughts, encouraging greater disease acceptance and promoting social support (Rosendahl et al. 2009). It is therefore important to consider the role of social support in people with IBD and the extent to which this may be contributing to their health outcomes.

Furthermore, Rogala et al., (2008), suggests that the quality of social support received by patients with IBD is related to how well the individual has managed to adjust. Similarly, better social support available to IBD patients was found to alleviate psychological distress, and, ultimately improve health outcomes, possibly resulting from better adjustment to IBD (Sewitch et al., 2001). Therefore, examining the potentially under-valued role of social support could shed light on more nuanced aspects of disease management. Particularly, given the literature indicates a high likelihood of social constraints in this population (Joachim, 2002), and this being associated with greater health complications, unhelpful coping strategies and psychological distress, as is found in studies with other chronic health conditions (Zakowski et al., 2004).

1.8 An integration and summary of key themes from the introductory chapter

On top of the numerous physical symptoms of IBD, this patient group experiences markedly reduced psychological wellbeing (Petрак et al., 2001). Multidisciplinary, mind-body approaches are increasingly recognised as valuable and clinically relevant approaches to treating most GI diseases. One possibility for this trend may be the mounting empirical research supporting the multifaceted, biopsychosocial aetiology and pathophysiology of GI conditions.

Due to the pervasive, yet poorly addressed, psychosocial impact of IBD on the individual's QoL, addressing these difficulties can help develop more effective disease management options (von Wietersheim & Kessler, 2006).

At present, the inclusion of non-medical interventions for patients with IBD, within public and private hospitals, are rare. While conventional medication may induce remission, albeit at the cost of other negative side effects, there is currently no curative treatment for IBD. Not surprisingly, the use of complimentary therapies has been rapidly growing in recent decades and has gained much interest particularly with chronic health conditions. Evidently, individuals with IBD are seeking ways to substitute or supplement their standard care (Hilsden, et al., 2011; Opheim et al., 2012).

Moreover, the use of spirituality as a complementary form of care and as a coping strategy in chronic health conditions is gaining recognition following recent clinical trials. For instance, spiritual based interventions may lead to reduced clinical symptoms and disease activity (Gonçalves et al., 2015). This has been transferred into the use of psychological interventions which incorporate elements more commonly used in spiritual contexts such as mindfulness and acceptance. Furthermore, spirituality and social support appear to be interrelated as both may buffer against psychological difficulties in chronic health, facilitating coping.

All in all, the evidence base points towards individual's preference for a holistic approach to care, valuing 'Parity of Esteem' between mental health and physical health (Royal College of Psychiatrists, 2013). However, researchers must invest in the, currently unknown, impact of such interventions in the management of IBD (Jedel, Hankin, Voigt & Keshavarzian, 2012).

1.9 Systematic Literature Review

1.9.1 Overview of systematic literature Review

In order to conduct research on the predictors of psychological wellbeing in IBD, a comprehensive literature review was undertaken. This provides an in-depth overview of the current understanding and will highlight gaps in the evidence base for consideration. The section below will, therefore, outline the search strategy used, followed by a critical evaluation of the methodology and findings from the articles found, illustrating key considerations from previous research. The chapter will end with the rationale for this doctoral thesis, including the research aims, questions and hypotheses to be addressed within this study.

1.9.2 Search strategy

A comprehensive literature review was carried out using the databases, Pub Med, SCOPUS, Google Scholar and PSYCHinfo for a three month period up to 17th January 2018. Although the review was initially carried out for studies related to IBD, due to the lack of articles that emerged from this search term (3 in total) a decision was made to broaden the search criteria. A comprehensive list of the search terms used can be found in Appendix B, which illustrates the range and variation of search terms used to overcome the scarcity of articles being returned. Table 1.1 shows the main terms included were, spirituality, adjustment, acceptance, psychological wellbeing and chronic health conditions, rather than IBD alone. The literature search contained articles from 1999 onward as this was the year a key article on ACT was published, resulting in the rise of publications, articles and books in ACT. This would ensure to capture any ACT-related interventions conducted.

The role of adjustment following a chronic health condition is considered a buffer for the mood difficulties that occur following the all-encompassing changes an individual may face. Similarly, there is a close interplay between adjustment and acceptance in the ACT model. Therefore, an equal emphasis will be placed in the literature review on acceptance and adjustment to IBD due to this close overlap, and to ensure that the full scope of the acceptance theme is captured.

The Boolean terms 'OR' and 'AND' were used to combine search terms that would search for articles which relate to spirituality and adjustment and psychological wellbeing or mental health. A full breakdown of the review process can be found in Figure 1.1. In total, 296 articles were produced from these search terms. The inclusion criteria outlined in Table 1.2 was applied to the initial search, which led to the removal of 126 articles due to not meeting the criteria or being duplicates. Remaining from this was 170 unique articles. Next, article titles were screened to decide if they met inclusion criteria, resulting in 28 articles suitable for reading of abstracts for clarity, of which 15 were selected for full-text reading. Following full reading, 9 articles met the inclusion criteria, which are included in this review.

Table 1.1: Key search terms used for systematic review

<i>Key terms:</i>	Spirituality
	Chronic
	Psychological
	Adjustment
	Acceptance

Table 1.2: Inclusion criteria adopted in the literature review

Inclusion criteria
Sample does not include children or young people under 16.
Where a therapeutic intervention was used, must exclusively use an ACT or spirituality based intervention
Primary focus of research must be on individuals with a chronic health condition
A focus on patients not carers or family members
A focus on spirituality not religion
Peer-reviewed literature

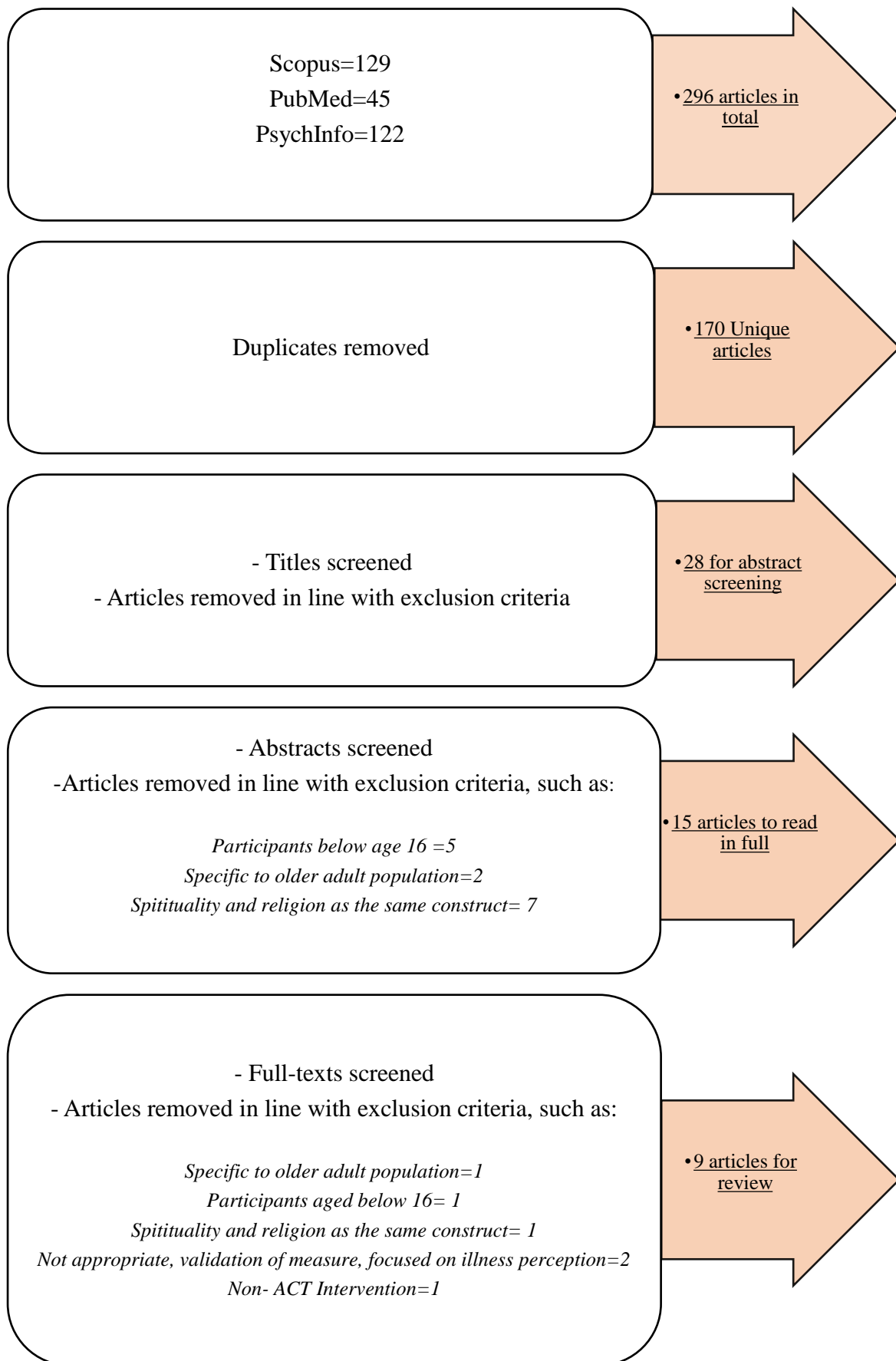


Figure 1.1: Flowchart of search process

1.9.3 Quality assessment of the Literature under review

The quality of the literature reviewed in this study was rated using the Effective Public Health Practice Project (EPHPP) criteria (see Appendix C). Overall, there was an equal mix of weak and moderate global ratings on the quality of the studies. It is beyond the scope of this review to cover each of these criteria in detail for all of the studies identified, however, this quality appraisal process can be found in Appendix D.

1.9.3.1 Issues Relating to the Literature

Following a thorough literature search, there were no articles that met the search criteria specifically related to the present study. Extending the search to chronic health conditions identified a number of studies each with varying degrees of relevance to the current study. Given the sparsity of the literature, these studies will also be evaluated in this review.

Despite the growing interest, the approaches used to quantify spirituality and psychological wellbeing lacked standardisation. The articles selected for this review reflect this variation, therefore impacting comparability with one another as well as its application to the current study. Overall, sample sizes used in the studies were mixed (Riley, 1998, n=261; Reynolds et al., 2014, n=128; Davison & Jhangri, 2013, n=253; Cotton et al., 2009, n=155; McCombie et al., 2015, n=54; Larsson et al., 2016, n=15; Faust et al., 2012 n=80). Only one study (Reynolds et al., 2014) reported sufficient power (>.90) with a sample of 128 participants. Other studies did not report on the sufficiency of their data gathering to ensure adequate power analysis. It is likely that these studies were underpowered, thus, limiting the generalisability of their findings to larger populations and their ability to detect significant findings.

Furthermore, a handful of articles were excluded due to not adequately distinguishing between spirituality and religion. Again, due to the paucity of data, the search criteria had to be compromised for two articles (Cotton et al., 2009; Reynolds et al., 2014) which used adolescent samples. These studies will be included in the current literature review due to the articles meeting the majority of the search criteria and their relevance to the current study.

1.9.4 Overview and Critical Evaluation of Papers

The section below is an overview of the literature derived from the systematic review process outlined above. A summary table of the key points of the studies in this review can be found in Appendix E, including the strengths and limitations of each study.

1.9.4.1 Articles related to the factors impacting psychological wellbeing

The first paper is a review article that provides a useful overview in the literature of the psychological correlates of adjustment outcomes in adults with IBD. Jordan et al. (2016) propose a bidirectional relationship between adjustment outcomes and disease severity, suggesting that while disease severity is a likely hindrance to adjustment, developing effective strategies for adjustment may improve the severity of IBD. Understandably then, the authors found that emotion-focused coping strategies, described as coping aimed at avoiding distress, were most consistently associated to diminished psychological wellbeing (Jordan et al., 2016). Positive adjustment is therefore considered important to cope with the disease; and predictors of good adjustment were found to be disease acceptance, symptom tolerance and engaging in meaningful activity. It was theorised that this would enable the individual to better manage and appraise IBD. This suggests that acceptance would be one way in which the psychological components of IBD could be managed, in turn, leading to better coping of the physical and

psychological impact. However, the review contained no intervention studies and disease acceptance was only exclusively examined in one study, indicating a gap for future research. In addition, due to the overall low power and, therefore, low quality of studies comprising the review, the conclusions from this article should be considered with caution until further research is carried out.

Another study by McCombie, Mulder, Geary (2015) used a longitudinal design to explore the association between coping strategies, QoL, anxiety, and depression in individuals with IBD over the first six months following diagnosis. Similarly, this study revealed that only unhelpful coping styles including, avoidance and psychological inflexibility were associated with lower QoL and higher rates of depression, anxiety and increased IBD symptomatology. Surprisingly, no associations were found between adaptive coping styles and outcomes although the study was contaminated with a number of methodological limitations, which are elaborated on later in this systematic review. In another article, Faust et al., (2012) revealed inconsistent findings related to different coping styles. However, they conclude a link between disengaged coping styles and psychological difficulties. Theoretically, they argued, an active disease state may lead some individuals with IBD to reduce their usual activities, increasing their susceptibility to psychological difficulties and, in turn, making it more likely they would turn to unhelpful, short term coping. With a small sample (n=80), however, little generalisability can be achieved.

In another article, Reynolds et al. (2014), argue that depression may put adolescents with IBD at risk of drawing on unhelpful coping strategies. This is concerning due to the elevated rates of depression in people with IBD compared to the general population. Within a bidirectional hypothesis, these results suggest that individuals engaging in poor coping and difficulties

accepting IBD lead to the exacerbation of psychological distress. These studies contribute to a growing evidence base for the usefulness and need to identify psychological difficulties as early as possible, in order to prevent individuals from turning to unhelpful coping strategies that may serve to perpetuate the multiple challenges of IBD. Problematically, little attention has been given to the potential for psychological interventions to harness many of the underlying processes of positive adjustment, such as acceptance.

1.9.4.2 Articles related to the mitigators of psychological distress

Remaining articles constituting this systematic review relate to the additional factors considered to be protective of the long-term physical and psychological difficulties in IBD. Faust et al. (2012) not only concur the importance of considering coping styles in IBD, but found high, coexisting, symptoms of anxiety, social constraint and depression (68%, 49% and 26% respectively). Social constraint, that is, considering oneself to be unsupported or withdrawn from a social network, was found to be linked to diminished QoL, psychological wellbeing and disease activity (Faust et al., 2012). Due to the marked social isolation in this population, the degree to which this contributes to IBD health outcomes needs to be considered as a way in which individuals with IBD, again, could be supported. Unfortunately, the small sample size (n=80) and the study's cross-sectional design are limiting, thus, urging further exploration. Selection bias is a notable limitation of this study as the majority of participants (60%) had moderate-severe disease activity, recruited from a tertiary referral centre. Also, the absence of a control group in this research compensates the quality of this study.

Five studies (Cotton et al., 2009; Davison & Jhangri, 2013; Gonçalves et al., 2017; Reynolds et al., 2014; Riley et al., 1999) propose that spirituality may enhance psychosocial outcomes in

chronic, physical health conditions. Although it is unclear exactly how, the process of better adjustment, via spirituality, is thought to be the mechanism by which anxiety and depression is decreased, resulting in better QoL outcomes and reduction of physical symptoms. Interestingly, Davison & Jhangri (2013) found that spirituality was a predictor of improved health outcomes regardless of the individual's psychosocial adjustment, suggesting there is potential for both to be adaptive coping strategies. However, although a relatively large sample was recruited in their study (n=253), the sample consisted of individuals with chronic kidney disease, preventing the extent it can be generalised. Extending this to an IBD sample would give rise to information about the usefulness of spirituality as an adaptive coping strategy within this chronic health condition.

In an adolescent sample, Reynolds et al. (2014) found that positive spiritual coping, prospectively, predicted reduced symptoms of depression, over two years. Concordantly, Cotton et al. (2009), found that after accounting for religion and belief in God, existential wellbeing, a primary component of spirituality, was associated to depression and health risk behaviours in an adolescent sample with IBD. The authors consider the role of meaning and purpose as a plausible explanation for the health and spirituality relationship.

In Gonçalves and colleagues (2017) systematic review, spirituality was based on individuals coping with disease through spiritual values such as a higher power which offered peace, acceptance, meaning and connection with others. However, due to the broad diversity of approaches in the delivery of spiritual intervention in this area, adequate comparison of methodologies were not possible. Considering their definition of spirituality comprised of

multiple facets, future research may wish to invest in elucidating the mechanistic processes involved in the usefulness of spirituality in chronic health.

Following on from Cotton et al. (2009) study, it would be useful to explore the extent to which these findings transpire in an adult sample. In addition, the role of spirituality may be comparable to that of social support as both may be resources for psychological wellbeing. To date, no known study has examined which of the two are more likely to facilitate psychological wellbeing, in IBD. In addition, the definition of spirituality adopted in Reynold et al. (2014) study is questionable due to the reference to a God, as well as the overall indistinguishable features of religion and spirituality. Limitations of note include the high attrition rate (n=41).

1.9.4.3 A qualitative perspective on coping strategies in IBD

A recent qualitative article set out to examine disease related distress, social and emotional coping strategies in patients with IBD (Larsson et al., 2016). Primary stressors were found to be psychosocial in nature, regardless of their disease duration. For example, a significant struggle was the fear of losing bowel control in public and subsequent feelings of shame and embarrassment. These difficulties are likely to endure, thus, require adjustment to, an area that psychological interventions can help facilitate.

Larsson et al. (2016), found that coping strategies of importance were a combination of social, behavioural and emotional. Acceptance as a coping strategy was deemed an important factor in the psychological wellbeing of individuals with IBD. Again, this implies that interventions must go beyond the medical approach alone to facilitate effective management of IBD. Advances in IBD healthcare, both from a clinical and economical point of view, therefore, may benefit from the inclusion of acceptance based strategies within services, as a potentially

valuable option towards increasing patient's ability to adjust, cope or live alongside the challenges of IBD

Contrary to these findings, the longitudinal study described above by McCombie et al. (2013) postulates that acceptance is not associated to psychological wellbeing in a sample of IBD patients. This finding appears to be counterintuitive given the evidence base. However, due to the small sample (baseline- n= 54, follow up- n=45), the study may be underpowered to detect an important difference. In addition, the sample consisted entirely of newly diagnosed IBD patients, thus, suggesting acceptance may be most difficult at this stage and it is unknown whether the same results would be produced in individuals with longer disease duration. In addition, an observational study limits causal inferences, indicating scope for much needed further study.

A strength of Larsson et al., (2016) study is the exploratory, qualitative approach, offering rich experimental data, among the predominantly quantitative studies retrieved for this review. Unfortunately, Larsson et al. (2016) did not examine the efficacy of the coping strategies reported in their study, by nature of the study's design. It is, therefore, not possible to know if coping strategies, such as acceptance, significantly influenced psychological wellbeing in any way. Clearly, there is some heterogeneity in the literature related to the impact of acceptance on wellbeing and more data is needed to confirm a pattern.

1.10 Non-UK based research

All the studies in this literature review were conducted outside the UK. Although the process of determining an IBD diagnosis is likely to be similar, the social and cultural context of coping with disease and how it is managed may be nuanced. Thus, disease severity, psychological

wellbeing and adjustment may differ. In line with post-positivism, aspects of the truth are perhaps obtained, however, these are limited and require corroboration through further investigation. Equally, the predominance of religion and spirituality hugely varies, geographically. Therefore, non-UK based studies are likely to be unrepresentative of the context this study aims to address.

1.11 Appropriateness of measures used to examine constructs

The majority of articles in this literature review are quantitative and, therefore, employ a range of outcome measures. Specifically, most studies exploring spirituality used The Spiritual Wellbeing Scale (SWS; Ellison & Paloutzian, 1982; Cotton et al., 2009; Davison & Jhangri, 2013; Riley, 1998). This encompasses both a religious and an existential wellbeing scale, however, only Cotton et al. (2009) adapted the religious wellbeing scale to replace God with Higher Power, in keeping with the current study's definition of spirituality.

One study (Reynolds et al., 2014), used the RCOPE, a validated measure of religious/ spiritual coping strategies in both adult and paediatric samples. Similarly, this scale does not adequately capture spiritual coping due to the presumption of a monotheistic orientation. Although these studies state that they are examining spirituality, the measures appear to be contaminated with statements that draw upon religious assumptions, breaching the current study's focus. Even though the definition of spirituality is often intertwined with religious concepts, this study endeavours to discriminate between religiousness and spirituality as separate constructs.

Furthermore, the only measure of psychological wellbeing examined by Reynolds et al. (2014) was depression. Still, depression was measured using a scale from the Behavioural Assessment System for Children (Reynolds & Kamphaus, 2004), an inappropriate measure for an adolescent sample. Anxiety is known to be a salient experience associated to IBD, indicating scope to extend this study to a more representative construct of psychological wellbeing.

1.12 An important gap in the literature

A prominent issue in the literature was found to be the absence of intervention studies and the dearth of RCT's available to inform causal relationships between acceptance and IBD outcomes. Equally, a recent systematic review examining the impact of spiritual interventions on physical health indicated a lack of RCT's in the literature (Gonçalves et al., 2017). However, due to the complexity, RCT's in this context may lack external validity, thus, longitudinal cohort studies may be a more robust way of evaluating the potential usefulness of alternative approaches to treating IBD. While there were several longitudinal studies in Gonçalves et al. (2017) systemic review, none involved an intervention study examining the usefulness of a spirituality based intervention in an IBD population, highlighting a sizeable gap in the peer-reviewed literature. The section below will briefly summarise the key themes identified in the literature review and implications for future research.

1.13 Summary of findings

This review has provided an overview and critique of studies published over the last few decades that explore the factors influencing psychological wellbeing in chronic health conditions, predominantly IBD. Pertinently, the studies reveal that the psychosocial difficulties in IBD are common and among some of the most challenging aspects of IBD to cope with,

despite primarily being known for its physical impact. A key focus was adjustment, which emphasises acceptance strategies as a useful and potentially reliable indicator of good adjustment.

Spirituality was considered an important factor in long term adjustment to chronic health conditions, including reduced symptoms of depression, over time. The role of meaning and purpose may be a mediator in the health and spirituality relationship. The role of acceptance and spirituality as potential predictors of psychological wellbeing suggest they may be helpful adjustment strategies in IBD. However, the paucity of the study quality and low generalisability of findings, call for more robust research methodologies.

As reported by several studies within this review, poor disease management is associated to deteriorated psychological wellbeing and amplified IBD disease activity. These findings also indicate that symptoms of anxiety and depression, as well as lack of social support, are associated with disease severity. The review appears to lean towards the usefulness of acceptance based coping strategies to counteract potential maladaptive coping strategies that may be maintaining the psychosocial difficulties reported in IBD. Although one study found that adaptive coping styles such as disease acceptance was not associated to psychological wellbeing whereas maladaptive coping negatively impacted outcomes, this was based on a very small sample. The coexistence of psychological difficulties and social constraints experienced by people with IBD as well as the potential for acceptance to impact on wellbeing, requires further study.

This literature review lends itself to consider the potential for acceptance based interventions as appropriate tools to facilitate psychological adjustment to IBD. Furthermore, features of

acceptance based interventions such as finding meaning and purpose via making value-congruent life choices, are consistent with aspects of spirituality. Considering the health and spirituality relationship, as shown in the literature review, individuals who identify as spiritual may find acceptance based interventions a useful approach in managing IBD.

Shortcomings of the existing literature include the misleading definitions of spirituality contaminated by the construct of religion, thereby, obscuring research related to spirituality. Due to the overall poor quality of the evidence and the lack of interventional studies, strong conclusions about directionality are prevented.

1.14 Rationale, Aim, Research Questions, Hypotheses and Relevance for Clinical Practice

1.14.1 Rationale

This chapter has demonstrated the paucity of research conducted on the role of acceptance in psychological wellbeing, thus, it's potential to facilitate better adjustment to IBD. Considering the limited literature, there remains a gap in the evidence base related to alternative, effective coping strategies, particularly for those who may be receptive to positive adjustment approaches. Therefore, this study will be the first to examine the potential for acceptance and spirituality to predict psychological wellbeing in IBD compared to the general population.

1.14.2 Research aim

This study sets out to fill this gap in the literature and to offer a novel perspective on the role of spirituality and acceptance as helpful forms of adapting, in the lives of individuals with IBD, forming a rationale for an intervention study in the future.

The aim of the research is to investigate whether a relationship exists between individuals who self-identify as spiritual and how accepting they are of their life circumstances as a strategy for living with the difficulties of IBD. Due to the potential moderating effect of social support in the relationships being explored, social support will be examined. Due to the evidence of the impact of disease severity, this variable will also be explored as a potential predictor of psychological wellbeing. This research will be a fundamental starting point in highlighting a relationship between themes that are interrelated but collectively under-researched.

This understanding will then enable further exploration of how participant's psychological wellbeing differs in respect to acceptance, spirituality and the extent to which social support, if at all, contributes to psychological wellbeing in people with IBD. This study has the potential to highlight underlying relationship between spirituality, psychological wellbeing and acceptance which may develop the impetus for researching causality between the elements described above to inform alternative therapeutic approaches to run concurrently with medical management for chronic gastrointestinal diseases. Ultimately, this should not only reduce the impact of IBD, thus, improving long-term QoL, but should also lower the reliance on clinical services to achieve this.

1.14.3 Research questions

This question will be explored through the following, specific research questions:

- (i) Is psychological wellbeing related to acceptance and spirituality?
- (ii) Does social support moderate psychological wellbeing and disease activity?
- (iii) Does disease severity predict psychological wellbeing?
- (iv) Is there a relationship between disease acceptance and spirituality?

1.4.3 Hypotheses

- Hypothesis 1** Social support will be a predictor of *disease activity* in IBD participants
- Hypothesis 2** Disease severity will be a significant predictor of *psychological wellbeing*
- Hypothesis 3** Acceptance will be a significant predictor of *psychological wellbeing*
- Hypothesis 4** Spirituality will be a significant predictor of *psychological wellbeing*
- Hypothesis 5** Social support will be a moderating factor of *psychological wellbeing*
- Hypothesis 6** There will be an association between *spirituality* and *acceptance*

Chapter 2: Methods

2.1 Outline of Methods Section

This section will discuss the study design and the epistemological position in relation to the design, followed by a description of measures used, recruitment of participants, service user involvement consultation and an outline of the procedure. Ethical issues related to the design will be considered, followed by a description of the data analysis.

2.2 Design

This research study utilised a cross-sectional, web-based survey, quantitative design. The study adopted a non-experimental, correlational design to investigate whether spirituality and disease acceptance predicts psychological wellbeing in a sample of individuals with IBD. A web-based survey approach was used to gather data for variables including, demographics, spirituality, acceptance (also known as psychological flexibility), psychological wellbeing as measured by depression and anxiety, IBD disease severity and social support. Standardised, self-report measures were used where possible, as outlined below. All participants were assessed for these measures except for disease severity which was only assessed in the IBD group.

Participants were asked to complete an online survey, taking between 10-15 minutes. The survey was published on an online survey-building programme Qualtrics (Qualtrics, 2015) which provides flexibility and user-friendly for participant use on a range of electronic devices including phones. Data collection was carried out anonymously through a password secure account. Furthermore, the data was held securely on Qualtrics servers, and only the principal researcher had access to the data.

2.2.1 Rationale for Study Design

Considering the potential that individuals with IBD may be experiencing a myriad of challenges that may influence their time and energy to participate in this research, it was believed that to facilitate recruitment and minimise attrition, the survey delivery should be kept as brief as possible. In fulfilling this, the briefest, validated and reliable questionnaires available were used as measures. To further aid this, closed questions were used throughout most of the survey to enable participants to respond quickly and with ease. Moreover, numerous studies have employed questionnaires to assess for spirituality and psychological wellbeing in chronic health populations as described in the previous chapter (see section 1.9.4).

Also, the use of web-based surveys in psychological research has received increasing attention over the last few decades for good reasons. They enable quick, large-scale data collection from wide geographical areas both cost-effectively and efficiently (e.g., Kongsved et al., 2007; Lefever, Dal, & Matthíasdóttir, 2007; Vallejo et al., 2007). This feature is particularly important to acquire large samples to negate the potential small effect sizes anticipated.

In keeping with the epistemological position that has been adopted throughout this research, the use of quantitative or empirical research methods are typically underpinned by positivist and post-positivist theoretical perspectives, in a search for an ultimate truth wherein measurement can be attempted through science and research. As such, quantitative research can be viewed like the onion layers of the onion bulb and through a series of direct or indirect observations and hypotheses testing, knowledge can be crystallised and corroborated to provide insight to aspects of the truth which can be generalised to larger populations. In the case of this

study, the findings may usefully bring us closer to delivering more effective and suitable interventions to individuals with IBD.

2.4 Measures

A series of self-report measures were administered to aid with measuring the constructs of interest within this study.

2.4.1 Action and Acceptance Questionnaire-2 (AAQ-II)

The AAQ-II (Bond et al, 2011) (Appendix F), is a measure developed by a team of ACT researchers and therapists and is frequently used to measure experiential avoidance, psychological inflexibility and acceptance, considered to be underlying processes of ACT. In congruence with ACT principles, the AAQ-II is the current measure of acceptance (Costa & Pinto-Gouveia, 2010), that is, the ability to accept difficult internal and aversive experiences and to live according to one's values. Over the past 16 years, psychological inflexibility and acceptance have been of growing interest as supported by a review conducted by Chawla & Ostafin (2007), revealing significant association's between psychological inflexibility in the maintenance of physical and psychological distress.

Although the current study is not an ACT intervention, the AAQ-II offers good validity and reliability in measuring acceptance, a primary measure within this study. Specifically, test-retest reliability at 3 and 12 months is .81 and .79, respectively, and good internal consistency with a mean alpha coefficient of .84 (.78–.88). Furthermore, it has shown sufficient construct validity (Bond et al., 2011). The AAQ-II has better psychometric consistency than its previous version, AAQ (Hayes et al., 2008).

Psychometric properties of this measure were further studied in a chronic pain sample (McCracken & Zhao-O'Brien, 2010) which revealed good internal consistency (Cronbach's .89) as well as construct validity. Results from McCracken and Zhao-O'Brien (2010) and Karkla and Panayiotoua (2011) show that AAQ-II has good incremental validity for the prediction of the participants general mindfulness and psychological distress above and beyond several coping strategies (e.g., emotional support, active coping). Collectively, these studies offer strong support for the psychometric qualities of the AAQ-II.

Furthermore, although the AAQ-II is commonly used as an outcome measure for ACT interventions in multiple contexts such as chronic pain (McCracken, Vowles, & Eccleston, 2004) and other health conditions (Lillis & Hayes, 2007), broadening the use of this measure to wider contexts could lead to useful findings. For example, by using the AAQ-II to measure ACT based processes such as acceptance, may enable the identification of physical diagnoses that have not yet been recognised to benefit from ACT, thus, building a rationale for the use of ACT interventions for those conditions. The AAQ-II is a 7-item measure and the total score is calculated by summing scores for each item, resulting in a minimum score of 7 and maximum of 49. Higher scores show greater psychological inflexibility, suggesting greater difficulty with acceptance (Bond et al, 2011).

2.4.2 The Spirituality Scale

Currently, there is no "gold standard" measure to operationalise spirituality. Thus, reviews indicate that most instruments of spirituality commonly focused on the religious domains of spirituality, hampering a reliable understanding of the construct and role of spirituality in the evidence base (George et al., 2000; Monod et al., 2011). While many measures of spirituality have been developed over time, the most commonly used, as discussed in the review chapter,

is the Spiritual WellBeing Scale (Paloutzian & Ellison, 1982). This scale is composed of the metaphysical/existential and religious domains of spirituality and is evidenced to have reliability and validity. However, despite its popularity, Fulton and Carson (1995) highlight that a major limitation of the scale is the Judeo-Christian bias. This scale may be suitable for certain parts of the world such as North America where reports indicate 83% of residents consider a monotheist God as important (Carballo, 1999). This may be unsuitable for inhabitants from Western Europe wherein the majority (51%) do not believe in God nor consider God as very important in their lives, although most people are interested in Spirituality. This is reflected in the exponential growth in publications on yoga and meditation practices. While it is considered that not everyone is religious, both religious and non-religious people can have spiritual experiences (Carballo, 1999).

The definition in which the Spirituality Scale (SS; Delaney, 2005) (Appendix G) is based is that spirituality is "...universally experienced and encompasses a personal, interpersonal, and transpersonal context consisting of four interrelated domains: (a) higher power—that may or may not include formal religious practices; (b) self-discovery—the spiritual journey begins with inner reflection and a search for meaning and purpose (c) relationships and (d) eco-awareness—an integral connection to nature based on a deep respect and reverence for the environment" (Delaney, 2005, p.4). Table 2.1 provides examples of the items used in the SS and how these map onto three factors of spirituality, self-discovery, relationships, and eco-awareness.

Psychometric analyses of the SS provided strong support of the reliability and validity of the measure. For example, the SS has good internal consistency with a Cronbach's alpha

coefficient of .94. Although the SS has not been used as widely as the Spiritual Wellbeing Scale, it has gained recognition over the years and has been used in clinical research (Caldwell-Harris et al., 2010). The SS was chosen for the current study due to the definitional congruence of spirituality underpinning the development of the scale. Furthermore, this appears to be the only scale of a reasonable length (23 items) and which does not refer to religiosity.

In addition to the spirituality scale, due to the broad definitional inconsistencies and overlap of spirituality and religiosity, this study used a closed-ended question to measure individual's subjective perception of how spiritual and religious they consider themselves to be, based on their own interpretation of the terms. Participants were asked a 5-point Likert scale ranging, from "Definitely Yes" to "Definitely No", was also incorporated in the survey to ascertain whether individuals considered themselves to be religious and/or spiritual. Responses could therefore be correlated with their scores on the spirituality scale.

Table 2.1: Example items from spirituality Scale

Items from the Spirituality Scale	Tenets of spirituality
-I find meaning in my life experiences -I have a sense of purpose	Self-Discovery
-I value maintaining and nurturing my relationships with others -I meditate to gain access to my inner spirit	Relationships
-I believe in a Higher Power -I believe there is a connection between all things that I cannot see but can sense. -I believe nature should be respected	Eco-Awareness

2.4.3 Psychological wellbeing

The Patient Health Questionnaire-9 and Generalised Anxiety Disorder Questionnaire-7 in this study were employed to operationalise psychological wellbeing.

2.4.3.1 Patient Health Questionnaire-9 (PHQ-9)

The PHQ-9 (Appendix H) is a brief 9-item self-administered screening and diagnostic measure widely used to assess symptoms of depression. The total score is calculated by summing scores of each item. Total scores on the PHQ-9 can range from 0-27, with higher scores indicative of greater levels of depression. The following scores indicate incremental levels of depression: 0-4 (none), 5-9 (mild), 10-14 (moderate), 15-19 (moderately severe), 20-27 (severe). The PHQ-9 has been found to have robust psychometric properties with diagnostic validity being established in a number of studies (Kroenke, Spitzer & Williams, 2001). The PHQ-9 is quick to administer and has excellent internal reliability, with a Cronbach's alpha of .89 as well as excellent test-retest reliability. Furthermore, this measure is a valid and reliable tool to measure depression severity (Kroeneke et al., 2001).

2.4.3.2 Generalised Anxiety Disorder Questionnaire-7 (GAD-7)

The GAD-7 (Spitzer, Kroenke & Williams, 2006) (Appendix I) is a self-administered, 7-item screening tool used to assess the presence and severity of symptoms of generalised anxiety disorder. The GAD-7 is scored from 0-3, with a maximum score of 21. A total score is obtained by summing the scores of individual items, with higher scores indicative of greater levels of anxiety. Cut-off scores for this measure are 5 for mild, 10 for moderate and 15 for severe anxiety. Research shows the GAD-7 offers excellent internal consistency ($\alpha = .92$) (Spitzer, Kroenke & Williams, 2006), good test-retest reliability (intraclass correlation = 0.83) and strong criterion validity (Lowe et al., 2008; Spitzer et al., 2006).

2.4.4 Brief-Social Support Questionnaire

An extensive evidence base suggests that perceived social support has an influential role in the prevention of mental and physical health difficulties (Holt-Lunstad et al., 2010). Not surprisingly, many assessment tools have been developed to measure social support. However, the majority of these scales are lengthy and time-consuming (e.g. Social Support Questionnaire; Sarason et al., 1983), have poor validity and reliability (e.g., Oslo Social Support Scale; Van Lente, 2011) among other evaluative issues identified (Moser et al. 2012). The only existing scale that offered a solution to the abovementioned issues is the Brief Social Support Questionnaire (Kliem et al., 2015; F-SozU K-6) (Appendix K). This scale is a shorter version of the well-established Social Support Questionnaire (F-SozU) developed by Fydrich et al. (1999) and is highly correlated. Additionally, the F-SozU K-6 has been used in a study with an IBD group (Sewitch et al., 2001), and has shown very good validity and reliability (Kliem et al., 2015).

The scale comprises of a 5-point Likert Scale, ranging from “Strongly Disagree” to “Strongly Agree”. Three key characteristics of social support are measured: practical support, emotional support, and social integration. A total score is obtained by summing the individual scores, with higher scores indicating better social support. Although the sample was based on a German, representative sample, the authors conclude that based on demographic characteristics, comparisons can appropriately be made with Western European samples.

2.4.5 Demographic variables

Demographic variables such as age, gender, ethnicity, and personal characteristics are reported to have significant influences in the manifestation and development of human spirituality

(Delaney, 2005). Furthermore, research described in the previous chapter suggests some demographics may be more associated with IBD. Thus, the survey includes a series of questions related to the client's demographics including disease type, current disease activity, IBD medication, co-morbidities and alternative therapies/treatment currently being used.

2.4.6 IBD Disability Index (Adapted)

The impact of IBD on functioning is often measured using the IBD disability index (IBD-DI; Peyrin-Biroulet et al., 2011). The IBD-DI contains a total 28 questions related to the patient's psychological, social, familial and physical health and has been correlated with disease activity and severity (see Appendix L; Yoon et al., 2017). Since IBD is characterised by episodes of relapse and remission, measuring the individual's functional limitations and disease burden is important in determining the extent to which this affects the relationships with other variables.

Answers are given on a 5-point Likert scale (1, no to 5, extreme), with high scores indicating higher disease disability and activity. The first question relates to the patient's general health, followed by questions about mood, sleep, energy, pain and body image, as these are found to be the most frequently reported difficulties among this population (Graff et al., 2009; Ranjbaran et al., 2007; Van Langenberg & Gibson, 2010). Crucially, the index incorporates questions pertaining to the individual's environment to account for the availability and access to healthcare resources which vary across the world, and which would inevitably influence the level of disability. Furthermore, family support constitutes an environmental factor, as social support and caregivers input are considered to impact disease severity.

Many studies show that IBD-DI has validity and reliability including excellent inter-rater reliability, good internal consistency, and strong construct validity as reported from a recent systematic review and meta-analysis by Lo et al. (2017). The authors conclude there is a significant association between disease activity, treatment received and disability.

In the current study, the IBD-DI was adapted to a slightly shorter version of the original scale, with 20 items instead of 28. Table 2.2 is a breakdown summary of the adaptations made. Adaptations include removal of items pertaining to biological measures of IBD such as the presence of blood in stool and number of liquid or soft stool per week and adapting the language of items related to defecation. The work and education domain was adapted to encompass a broader construct of work and activities. The IBD-DI contains positive and negative items to measure whether environmental factors alleviated or worsened difficulties. These questions were adapted to ask how their difficulties were impacted by environmental stimuli, thus, reducing the number of questions being asked.

Further, respondents were asked to respond to all items on the adapted IBD-DI based on the last month rather than the last week. It was thought a one month period would be more representative of the individuals functioning, circumventing responses based on recent flare-ups or recent anomalous quiescence; further, changes in disease activity based on the last week may be unlikely to impact spirituality or disease acceptance.

Table 2.2 : The amendments made to the IBD-DI questions used in the current study compared to those used by Peyrin-Biroulet et al. (2011)

Domain	IBD-DI (Peyrin-Biroulet et al., 2011)	Adapted IBD-DI
Sleep and Energy	-	No changes to content of items
Affect	-	One additional item added: <i>Overall in the last month, how much difficulty have you had managing anger?</i>
Body Image	-	No changes to content of items
Pain	-	No changes to content of items
Regulating defecation	Original item: Overall, in the last week, how much difficulty did you have coordinating managing defecation including choosing and getting to an appropriate place for defecation and cleaning oneself after defecation?	Adapted item: <i>Overall in the last month, how much difficulty did you have coordinating and managing getting to the toilet?</i> One additional item added: <i>Overall in the last month, how much difficulty did you have with passing excess gas?</i>
Looking after one's health?	-	No changes to content of items
Interpersonal activities	-	No changes to content of items
Work and education	-	<i>Overall in the last month, how much difficulty did you have doing leisure or sport activities due to bowel difficulties?</i>
Environmental and social support	Original items: -Overall in the last week, did the medication the patient take alleviate her/his problems and difficulties? -Overall in the last week, did the food the patient take alleviate her/his problems and difficulties? -Overall in the last week, did the medication the patient's family alleviate her/his problems and difficulties? -Overall in the last week, did health professionals alleviate her/his problems and difficulties?	Adapted items: <i>Overall in the last month, how much did the medication help alleviate the difficulties you experienced?</i> <i>Overall in the last month, how much did the food you ate alleviate the difficulties you experienced?</i> <i>Overall in the last month, how much did your family help alleviate the difficulties you experienced?</i> <i>Overall in the last month, how much did health professions help alleviate the difficulties you experienced?</i>

2.5 Recruitment

Data collection occurred between the 30th November 2017, and the 22nd February 2018. Due to the time constraints, it was not feasible to continue data collection beyond this date. Two groups of participants were recruited: individuals with a diagnosis of IBD and a control group from the general population. The two groups were distinguished based on whether the participant confirmed or disconfirmed a diagnosis of IBD on the web-based survey. Participants were recruited using a purposive, snowball sampling method, using social media sites including Facebook, Twitter and Instagram, researcher contacts and charity organisations including Mind and the Crohns and Colitis UK research page. Other forms of recruitment included word of mouth, email contacts and University of Hertfordshire email dissemination of participant recruitment information.

Furthermore, on social media sites, personal contacts catalysed participation by actively distributing the research link to individual contacts of their own or by re-posting the link on their own social media page to encourage and promote participation. Specific details of recruitment methods employed can be viewed in Table 2.3. The origin of participant recruitment is often helpful in determining how representative the sample is. The wide range of methods employed in this study indicates a representative sample and Table 2.3 can be used to ascertain this judgment. To ensure confidentiality, participants' recruitment source was not tracked, hence specific information related to the number of participants from each recruitment channel is not available. The table has been colour-coded based on where the researcher feels the distribution of participant recruitment is spread, based on the timing of responses received.

In terms of sample selection, the IBD sample was not actively recruited based on severity or IBD subtype. It is suspected that the majority of participants recruited for the IBD group via the Crohns and Colitis UK support organisation were individuals with an active interest in IBD research and, arguably, not newly diagnosed. Individuals recruited from the general population were likely to be a combination of those interested in IBD as well as students with an interest in contributing to research.

At the start of the survey, an information sheet (see Appendix M) was presented with the aims of the research, what participation entails and why they were being asked to take part along with contact information for physical and mental health resources, should participants require. Following this, informed consent (Appendix N) for the research was sought. Participants were informed about their right to withdraw consent for the research at any time.

Table 2.3: Key code and table of methods by which the participant groups were targeted**Key:**Green suspected **high** recruitment via this methodOrange suspected **average** recruitment using this methodGrey suspected **low** recruitment using this method

Recruitment Method:	Participant groups	
	IBD Participants	General population
Personal Facebook page	✓	✓
@IBD_Research Twitter account	✓	N/A
IBD Instagram page	✓	✓
Personal contacts and their contacts	✓	✓
Mind charity	✓	✓
Crohns and Colitis UK Research Page	✓	N/A
University of Hertfordshire research link circulation	✓	✓

2.6 Inclusion and exclusion criteria

As it was expected that all individuals accessing this research would meet criteria for either IBD group or general population, no exclusion criteria was created in this regard. The first exclusion criteria is participants below the age of 16 years old. It was thought that inclusion of young participants in this study could make the findings more generalisable and, therefore, more clinically significant. Furthermore, previous research focussing on adolescents revealed useful findings (Cotton et al., 2009). In slightly broadening the age range, this study lends itself to more widely applicable conclusions. To minimise the confounding variable inherent in

participants with multiple comorbidities the second exclusion criteria was participants with two or more chronic health conditions. To ensure the sample size was not limited and retained ecological validity, it was decided there would be no exclusion of those who had reported accessing CAM within the last month.

2.7 Participants

2.7.1 Sample size and effect size

Commonly underreported in research, a vital part of quantitative research is effect size, a measure of the magnitude of the phenomenon under scrutiny. Unlike effect size, significance values are contingent on sample size yet they do not offer any information about the size of the difference between means, merely the probability of observing such a difference considering the null hypothesis (Cohen, 1990). Cohen (1988) emphasised the importance of effect sizes and recommended the Cohen's *d* values to determine small (0.2) medium (0.5) and large (0.8) effect sizes. Holding this in mind, the study's effect size was accounted for when designing the study as well as post-analysis.

2.7.2 Power analysis.

Initial power calculations were conducted using G*Power software (Version 3.1.9.2) (Buchner et al., 2009). In this, the alpha level was always set at 5% and Table 2.4 was produced when considering study powers of 70%, 80% and 90%. This was an "*a priori*" power calculation undertaken specifically for the study's multiple regression analysis. Table 2.4 displays the study power, the number of participant's required (sample size) to attain the necessary power at various levels of Cohens *d* (0.15, 0.10, 0.05) (Cohen's *d*; Cohen, 1988). From this, it was felt that a 10% clinical difference, at an 80% power, would be appropriate for this study.

Therefore, the projected study sample size was 100, allowing for 10% loss to follow up. The final projected sample size was 110. In fact, 120 participants were finally recruited in the study, as specified in the next section.

Table 2.4. Sample sizes needed to achieve at least either 15%, 10% or 5% clinical difference

Clinical difference/ Effect size (Cohen's d)	Power		
	70%	80%	90%
15%	55	70	90
10%	80	100	130
5%	160	200	260

2.7.3 Drop out

In total, 155 participants were recruited. Due to the time constraints of the project, recruitment was ended at this point. Of this total, 16 provided no information in the survey whatsoever; it is assumed a percentage of these were gatekeepers of recruitment sources such as Crohns and Colitis Research Team and senior staff at Mind, seeking to verify the research link and survey before disseminating it further. A further 8 did not respond beyond the consent form. Of the remaining participants, 11 did not continue to the end or did not complete answers to questions at the end of the survey, leaving a total of 120 who completed the full survey; a dropout rate of 10% for those who began the main survey and 12% for those who did not provide any information beyond consent. It was, therefore, deemed that attrition was low.

2.8 Patient Participant Involvement

In developing the survey, a patient representative was consulted and contributed to the overall survey delivery. The initial list of measures of interest were presented to the representative for screening and assessment of appropriateness and feasibility. The main suggestion was using an online survey due to accessibility and convenience; ensuring that the survey required minimal time and effort to discourage drop-out; finally making the research available via several platforms of recruitment.

Due to the initial number of suggested measures being considered too long, potentially discouraging participants, some measures were removed. This included, The Hope scale (Snyder et al., 1996) and The Brief Illness Perception Questionnaire (Broadbent et al., 2006). In addition, collaboratively, the wording of some measures deemed too complicated to process were adapted, hence adaptations to the original IBD-DI. Furthermore, the original choice of some measures were considered too lengthy (The Social Support Scale) which led to the search for briefer, validated versions (see 2.4.4). Finally, some questions specific to IBD were added or adapted as necessary, and the ordering of measures were amended following feedback.

2.9 Procedure

This was a web-based study involving participants completing a series of measures as described above. No face to face contact was involved. Charity organisations such as Crohn's and Colitis UK, social media forums and university administrators (see Table 2.2 for details of forums contacted) were contacted with a proposal of the research along with confirmation of ethical approval. For the majority of these organisations, the research link was disseminated from that point. For Crohns and Colitis UK, a request was made to publish the research link

on their take part in research page (Appendix O). Once approval was received, a brief advert was posted on their research page containing a Qualtrics link to the research.

Participants accessing the research link were presented with an information sheet outlining the study. Participants were then asked to confirm their informed consent for participation. The survey then led to two standardised presentation of measures depending on whether the participant had a diagnosis of IBD or not. For participants who confirmed they have IBD, additional questions related to IBD were automatically presented. For example, they were asked to specify the type of IBD they have, any IBD medications currently being taken and any alternative therapies accessed for IBD including a brief description of the outcome. The order of presentation of measures within this study is illustrated in Figure 2.1.

All questions were presented in one block with response scales visible at the top, which was aimed to ensure answers could be viewed easily. Furthermore, this way of presenting questions appeared to result in quicker responses as participants became accustomed to the same response options. Due to the numerous measures involved, participants were presented with notes throughout the survey to offer encouragement and reduce attrition. A debriefing procedure followed once the participant completed the surveys. Screenshots illustrating the online presentation of the measures as viewed on Qualtrics can be seen in Appendix P.

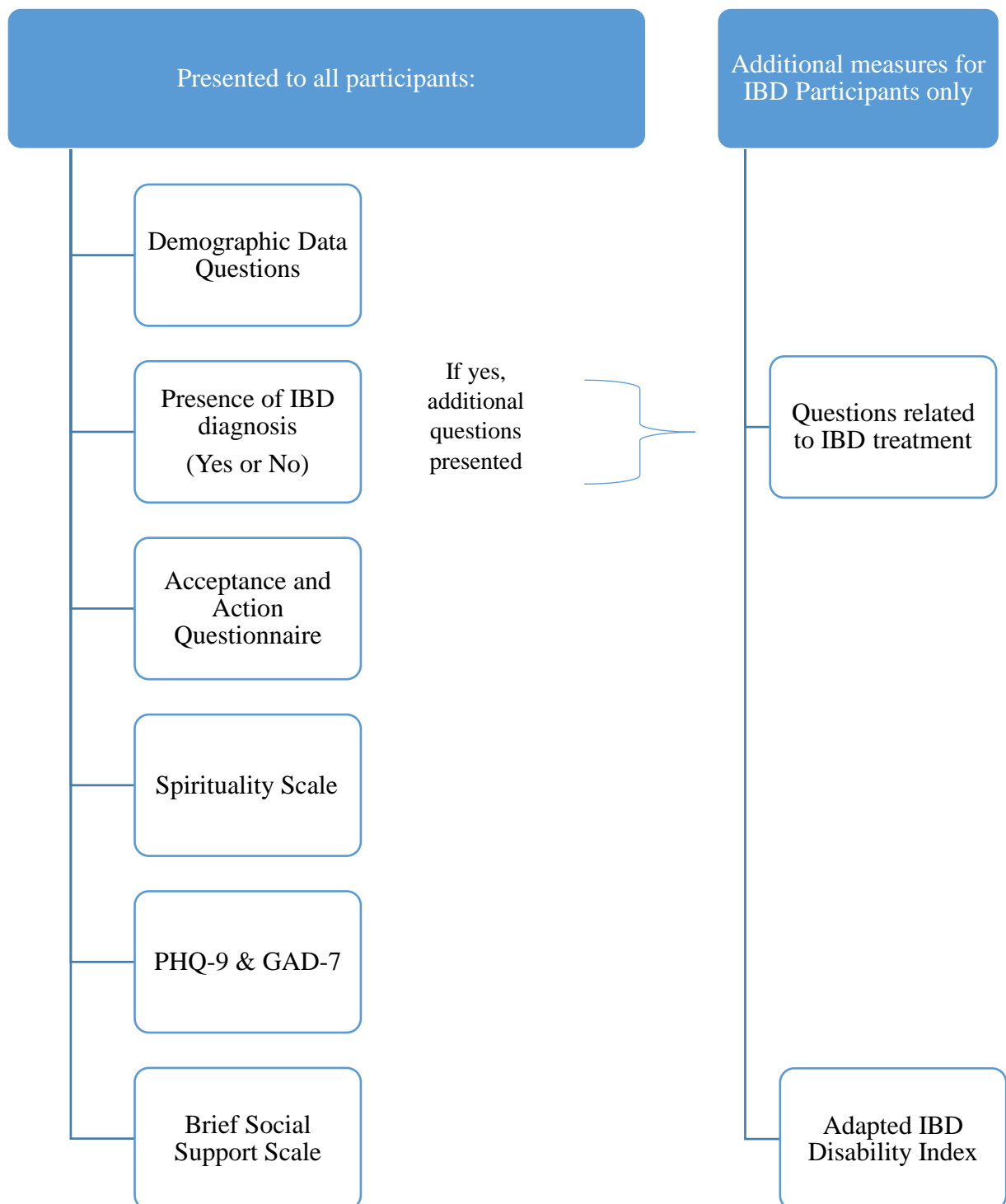


Figure 2.1: Diagram illustrating the presentation order of measures, including the items and measures exclusive to the IBD group.

2.10 Data Analysis

All statistical analyses were conducted using the computer package, Statistical Package for the Social Sciences (SPSS), Macintosh Version 22 (IBM Corp.). Distribution of data was explored using a Levene's test and an independent samples t-test was used to compare demographic differences between the IBD group and the general population. Parametric and non-parametric correlations were carried out to identify relationships between variables. Initially, a hypothesis driven, fixed multiple regression analysis was carried out. Subsequently, to identify the most powerful contributors of the dependent variables, forward stepwise multiple regression analyses were performed. Further detail of the analysis will be discussed in the following chapter.

2.10.1 Missing data

Of the 120 who completed the survey, 92% (n=110) answered all questions asked of them, therefore missing data was considered to be low. Of participants who did not complete the entire survey, missing data on variables ranged from 0.8% - 6.7%, thus the vast majority of data was complete. As missing data on all variables was below 10%, it was deemed low and therefore not excluded from analysis. Imputations for missing data were not undertaken as these were not felt necessary.

2.11 Ethics

Ethical approval was granted by the University of Hertfordshire Research Ethics Committee (Reference: LMS/PGR/UH/02928; Appendix Q). Before commencing the online survey, participants were provided with an information sheet which communicated the research objectives and benefits, confidentiality, their right to withdraw from the study at any point and any potential harm that may be involved. In this section, information was included about where

participants can seek help should they become distressed. A range of contact details were listed that could offer both immediate and long-term support if required. Following this, informed consent was obtained online.

At the end of the survey, in the event that participants became distressed or upset while completing the online survey, a debrief sheet (Appendix R) was presented with all the contact details of support services that were listed in the information sheet. Participants were once again informed of their right to withdraw and the protection and confidentiality of their data at the end of the survey.

In line with the National Research Ethics Service guidelines, confidentiality was ensured as data extracted from Qualtrics was stored electronically on a password-protected laptop. All participant data was anonymised, and participants informed that their identity would be anonymised through a number on the database.

Chapter 3: Results

3.1 Outline of Results Section

This section will discuss in full, the quantitative data analysis. Analyses include all 120 participants with available data, unless analyses are performed on the IBD group (N=55), therefore some analyses may vary and this will be made clear.

Firstly, a description of the overall sociodemographic information will be presented. Following this, in order to assess the variability of the data, statistical analyses will be conducted to determine if it meets the assumptions of parametric testing as well as investigating the presence of particular demographics that may affect subsequent analyses. Where concerns arose related to the data meeting criteria for parametric testing, non-parametric, equally robust analyses were conducted instead such as a Spearman's rho correlation. Following these, appropriate analyses will be carried out to address the research questions which comprises of some primary component analyses, followed by presenting the results from an initial, fixed hypothesis testing regression analysis, before considering a series of stepwise multiple regression analyses using the forward selection procedure.

This combination of analyses were used due to the limitations of a fixed hypothesis testing, in that SPSS undertakes each variable entered into the regression via sequence of inclusion. The forward stepwise regression analysis was used to supplement the hypothesis testing regression analysis as it identifies the most powerful contributor to be the dependent variable while adding subsequent variables to the model to determine their contribution to the dependent variable. This allowed the most statistically significant variables to be taken as the strongest model, and successive statistically significant variables are taken, constituting weaker models. Within the

regression analyses, all variables were entered into the model as predictors to address the hypotheses and to control for confounding demographic variables.

Furthermore, to examine whether spirituality and acceptance can predict psychological wellbeing, multiple regression analyses were conducted. Multiple regression analysis was also used to explore the presence of a relationship between disease severity and the principle variables under research. Finally, chi-square associations were performed to determine any relationship between acceptance and spirituality. All analyses were conducted using SPSS 24 (IBM Corp.)

3.2 Demographics

Table 3.1 shows frequencies and percentages of demographic data for the whole sample and each group, which show that demographic variables are broadly alike. It can be seen that there were more female (n=95, 79%) than male (n=24, 20%), or transgender participants (n=1, 1%). Similar numbers of participants existed in each of the IBD (n=55) and general population (n=65) groups, with the majority of participants employed full time in both IBD and the general population (69% and 79%; respectively) group. All participants were aged 16 or over. Furthermore, the majority of participants were of White British origin in both IBD and general population groups (91% and 83%; respectively) with the second largest ethnicity group in the total sample being Asian, Asian Other (n=10, 8%).

Overall, the majority of participants were single (60%). Of this, almost half of the IBD group were single (51%) with a relatively high proportion married (38%). The general population

was similar in that most were single (69%) with almost one third married (29%). In terms of education, the majority of participants were educated with at least a Bachelor's degree and beyond (75%). For the majority of participants in both groups, the highest education level reported was a Bachelor's degree (IBD= 36%; general population=32%) followed by a Master's degree (IBD=23%, general population=32%). Within the IBD group, there was a relatively fair mix of participants with Crohn's (55%) and Colitis (45%).

Table 3.1: Frequencies and percentages of demographics for the overall sample and each group

	Total (N=120)	IBD (N=55)	General population (N=65)
Gender (%)			
Male	24 (20)	14 (25%)	10 (15%)
Female	95 (79)	41 (75%)	54 (84%)
Transgender	1 (1)		1 (1%)
Ethnicity (%)			
White/ White British	104 (87%)	50 (91%)	54 (83%)
Asian/ Asian British	10 (8%)	3 (6%)	7 (11%)
Other	6 (5%)	2 (4%)	4 (6%)
Marital Status (%)			
Single	72 (60%)	28 (51%)	44 (68%)
Married	40 (33%)	21 (38%)	19 (29%)
Divorce	7 (6%)	6 (11%)	1 (1.5%)
Employment Status (%)			
Employed full time	88 (73%)	38 (69%)	50 (79%)
Employed part time	18 (15%)	11 (20%)	7 (11%)
Unemployed looking for work	4 (3%)	2 (4%)	2 (3%)
Unemployed not looking for work	2 (2%)	2 (4%)	0
Student	8 (7%)	2 (4%)	6 (9%)
Education (%)			
		<i>(Missing data , N=4)</i>	<i>(Missing data , N=2)</i>
A Levels	5 (4%)	2 (4%)	3 (5%)
Bachelor's degree	41 (32.8%)	20 (36%)	21 (32%)
Diploma	11 (8.8%)	9 (16%)	2 (3%)
Doctoral degree	9 (7.2%)	0	9 (14%)
High School	4 (3%)	3 (5%)	1 (1.5%)
Masters	35 (28%)	13 (23%)	22 (32%)
PhD	9 (7%)	3 (5%)	6 (11%)
IBD Diagnosis			
Crohn's Disease	30 (55%)	30 (55%)	-
Ulcerative Colitis	25 (45%)	25 (45%)	-
IBD Medication			
Yes	38 (69%)	38 (69%)	-
No	17 (31%)	17 (31%)	-

3.3 Descriptives

The data was explored to check for skewness and outliers, the distribution of scores were assessed for the whole sample. This also allowed for a decision to be made about whether to employ parametric or non-parametric analyses. The central assumptions for parametric testing as theorised by authors such as Field (2005), include:

- Normality: Normal distribution of data
- Linearity: Interval level data with a linear relationship
- Homogeneity of variances: Similar variance in data among multiple groups
- Independence: Independent of other data

The significance level for this study is defined as $p < 0.05$, however, borderline significance will also be considered ($0.05 < p < 0.10$). All the data, except for social support, were normally distributed, therefore independent samples t-tests were conducted to establish the effect of the groups on the variables of interest. Table 3.2 shows the results from a Levene's test, including t-tests where equal variance is both assumed and not assumed. As can be seen in Table 3.1, both groups were not significantly different on either acceptance or spirituality. However, there was a significant difference between the IBD and control group for psychological wellbeing measures including a strong significance in depression $t(118) = -3.01, p = .003$, and a moderate significance between groups in anxiety, $t(118) = -1.87, p = .06$. Therefore, there appears to be a significant effect of group on psychological wellbeing.

Due to the data from social support being heavily skewed, assumptions of non-normality were tested for this variable. Therefore, a Mann Whitney U test was conducted which revealed that there was a borderline significant difference in social support between the IBD group (Mdn=66.50) and the control group (Mdn=55.42) $U=1457.50$, $p=.081$ two-tailed. Due to the significance level falling within the $0.05 < p < 0.10$ range, it is expected that these results would have higher significance given larger numbers of participants.

Table 3.2: Results of an independent samples t-tests for differences between groups when equal variances are assumed and are not assumed

Group	Acceptance	Spirituality	Anxiety	Depression
IBD	20.8 (7.26)	87.78 (22.03)	13.30 (5.22)	16.14 (4.46)
Control	20.15 (7.26)	87.68 (17.42)	11.60 (4.80)	13.57 (5.22)
<i>Equal variances not assumed</i>	$t(107)=-0.46$, $p=.64$	$t(102)=-0.03$, $p=.98$	$t(111)=-1.85$, $p=.07$	$t(117)=-3.03$, $p<.005^*$

3.3.1 Religiousness and spirituality

Data related to participants views of how religious and spiritual they consider themselves to be can be found in Table 3.3. For both IBD and control group, more than half the participants considered themselves to be either definitely not or probably not religious ($n=35$, 29% and $n=28$, 23% respectively) and it can be seen that more individuals from the IBD believed to be spiritual. No association was found between religion and group ($p=.86$). However, a significant association was found between spirituality and group ($\chi^2(1,120)=19.93$, $p < 0.001$), which indicates that a relationship exists between how spiritual people with IBD consider themselves to be compared to the general population.

Table 3.3: Frequencies and percentages of how spiritual and religious participants consider themselves to be in both IBD and control group.

	IBD (N=55)		General population (N=65)	
	Religious (%)	Spiritual (%)	Religious (%)	Spiritual (%)
Definitely yes	6(11)	13(24)	4(6)	10(15)
Probably yes	9(16)	20(36)	9(14)	17(26)
Unsure	5(9)	12(22)	5(8)	12(19)
Probably not	14(26)	2(4)	19(29)	22(34)
Definitely not	21(38)	8(15)	28(43)	4(6)

3.4 Correlation Analyses

3.4.1 Correlation analyses between groups

Correlational analyses were conducted as an initial analysis to assess the strength of any relationships between the main variables measured in this study. Due to the normal distribution of the majority of the data, a Pearson's correlation analysis was conducted for all variables for both the total sample (see Appendix S) and for individual groups. In addition, a Spearman's rho correlation was also performed on both groups for Social Support, which is more suitable due to the unequal distribution of data, as described above.

Table 3.4 shows that there was a significant positive correlation between the measure of acceptance and anxiety and depression in both IBD ($r = .51, p = < .001$ and $r = .49, p = < .001$; respectively) and control group ($r = .60, p = < .001$ and $r = .48$; respectively). This indicates that the higher individuals scored in psychological inflexibility, or difficulty with acceptance, the higher their scores on anxiety and/or depression. No significant correlations were identified for any variable within this Spearman's rho correlation for social support.

3.4.2 Correlations with IBD severity

Correlations were conducted on the IBD group for IBD severity as can be seen in Table 3.4. A positive correlation was also found between difficulty with acceptance and IBD severity $r = .46, p = < .001$. This indicates that disease activity may be related to acceptance. In addition, a significant positive relationship was found between spirituality and IBD severity $r = .33, p = < .01$. Both measures of psychological wellbeing, that is anxiety and depression, were positively correlated with IBD severity, $r = .63, p = < .001$ and $r = .57, p = < .001$ (respectively). No significant correlation was found for social support and IBD severity. ($p=.18$) when Spearman's rho correlations were performed. These findings show that IBD severity is linked to the majority of key variables examined. It is important to clarify that due to the nature of the design of the current study, these findings do not imply any causal relationships and solely indicate potential associations between variables.

Table 3.4: Correlation matrix for all variables assessed by parametric correlations for IBD group and control group (including non-parametric correlation for social support)

		Acceptance		Spirituality		Anxiety		Depression		IBD Severity
		IBD group	Control group	IBD group	Control group	IBD group	Control group	IBD group	Control group	IBD group
Acceptance	Pearson	1	1							
	Correlation									
	Sig. (2-tailed)									
Spirituality	N	54	65							
	Pearson	-.252	-.032	1	1					
	Correlation									
Anxiety	Sig. (2-tailed)	.067	.800							
	N	54	65	55	65					
	Pearson	.511**	.598**	.147	.091	1	1			
Depression	Correlation									
	Sig. (2-tailed)	.000	.000	.283	.470					
	N	54	65	55	65	55	65			
IBD Severity	Pearson	.485**	.480**	-.006	.167	.649**	.772**	1	1	
	Correlation									
	Sig. (2-tailed)	<.005	<.005	.968	.184	<.005	<.005			
Social Support	N	54	65	55	65	55	65	55	65	
	Pearson	.459**	-	.326*	-	.631**	-	.574**	-	1
	Correlation									
Non-parametric correlation using Spearman's rho for Social support	Sig. (2-tailed)	.001	-	.016	-	<.005	-	<.005	-	
	N	53	-	54	-	54	-	54	-	54

Non-parametric correlation using Spearman's rho for Social support

		IBD group	Control group	IBD group	Control group	IBD group	Control group	IBD group	Control group	IBD group
Social Support	Correlation	.118	-.157	-.001	.073	-.024	.015	.117	.072	.187
	Coefficient									
	Sig. (2-tailed)	.395	.212	.992	.562	.863	.908	.397	.570	.176
Non-parametric correlation using Spearman's rho for Social support	N	54	65	55	65	55	65	55	65	54

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed)

3.5 Regression analyses

3.5.1 Predictors of disease activity

Following the correlation analyses, it was felt that a regression model would be developed to explore the unique contribution of all independent, predictor variables (spirituality, acceptance, social support and group) of psychological wellbeing. Separate analyses were conducted for each measure of psychological wellbeing in this study namely, depression and anxiety, and IBD severity as dependent variables.

In accordance with Field (2013), the data was explored for suitability for regression analyses using standard procedures. Cooks' distances, standardised residuals, diagnostic statistics and multicollinearity were examined. The data were not affected by these.

Two types of multiple regression analyses were performed. Initially, a fixed, hypothesis driven regression analysis was conducted wherein all variables including demographic variables were factored into the model. This analysis was performed for anxiety (Appendix T), depression (Appendix U). The findings from this identified a number of variables that did not reach significance and were therefore immediately excluded from the model. These included, gender, marital status, education and employment. However, within the model, ethnicity reached borderline significance as a predictor of depression, $F_{7,110}=9.36$, $p=.073$. Similarly, marital status yielded borderline significance as a predictor of anxiety $F_{7,110}=10.98$, $p=.10$. Following this method of analysis, it was thought that a model building regression analysis should be employed to establish the degree of strength of each predictor in order to identify the best predictor model. This will be outlined in detail in the following section.

3.5.2 Disease severity in IBD

The first research question considered the psychosocial parameters as predictors of IBD severity. On average, disease severity in the IBD group was moderate ($M=26.4$, $SD=8.9$). Since it is not feasible to ascertain the directionality of the relationships that are found and considering that evidence suggests a bidirectional relationship between disease severity and psychological wellbeing outcomes (see Graff et al., 2009; Larsson et al., 2008), the predictors of disease severity in IBD were explored as a separate model and considered necessary in order to ensure that potential relationships are not missed. These can be found in Table 3.5. The findings show that anxiety contributed the largest in the model ($Beta=.59$), followed by social support. Adding social support to the model was found to account for 44% (Adjusted $R^2= .440$) of the variance with a significant model, $F_{2,50}= 21.39$, $p=.02$.

Furthermore, to address the second research hypothesis, regression analyses exploring the predictors of psychological wellbeing in the IBD group alone revealed that IBD severity was the strongest predictor for both depression (Table 3.6) and anxiety (Table 3.7) followed by acceptance. The extent to which this varies when entering group as a predictor variable will be reported in the next section.

3.5.3 Predicting psychological wellbeing between IBD group and general population

The remaining analyses included both IBD group and the general population group. In order to address the third and fourth hypotheses, related to whether spirituality and acceptance can predict psychological wellbeing, a series of forward stepwise multiple regression analyses were performed, where $n=120$. The findings from the regression analysis can be seen in Table 3.8 and 3.9. Variables were excluded from the model based on the F value set between 0.10-

0.15. Only variables that added statistical significance to the overall R^2 were computed in the model.

After entering all variables into the model, the strongest incremental predictor of psychological wellbeing for both depression and anxiety was acceptance which uniquely explained 30% (Adjusted $R^2 = .300$) of the variation for anxiety and 21.7% (Adjusted $R^2 = .217$) in depression, and both significantly contributed to their unique regression models, $F_{1,117} = 51.45$, $p < .001$ (for anxiety), and $F_{1,117} = 33.70$, $p < .001$ (for depression). Introducing spirituality contributed an additional 33.6% (Adjusted $R^2 = .336$) of the variance in anxiety, at a significant level, $F_{2,116} = 30.86$, $p = .007$, while social support did not meet significance for anxiety. However, spirituality was no longer a significant predictor of depression and only acceptance and social support remained as the best fitting model, explaining 31.4% of the variance, wherein all predictors significantly contributed, $F_{2,116} = 27.95$, $p < .001$. Finally, the addition of group in both depression and anxiety regression models explained a variance of 35.1% (Adjusted $R^2 = .351$) in anxiety with borderline significance, $F_{1,115} = 22.27$, $p = .058$ and 34.5% (Adjusted $R^2 = .345$) in depression, resulting in a significant model $F_{1,115} = 21.75$, $p = .01$. However, as the third variable in the model, this model would be considered the least best fit.

3.5.4 Predicting value of social support in psychological wellbeing

The fourth research question sought to identify whether social support is a moderator of psychological wellbeing in the IBD group in line with research suggesting the benefit of social support in health outcomes for individuals with IBD (Sewitch et al., 2001). For this, a forward stepwise multiple regression analyses was performed, with $n=54$ as presented in Tables 3.6

and 3.7. Depression and anxiety remained as dependent variables, and all predictor variables were entered into this model as well as social support and IBD severity.

The findings reveal that IBD severity made the largest contribution to psychological wellbeing in participants with IBD. Specifically, IBD severity accounted for 38.6% (Adjusted $R^2 = .386$) of the variance in anxiety with a highly significant model, $F_{1,51} = 33.73$, $p < 0.001$. For depression, IBD severity accounted for 31% (Adjusted $R^2 = .310$) of the variance, also producing a highly significant model, $F_{1,51} = 24.37$, $p < 0.001$. Building upon the model, acceptance was found to be a significant predictor in anxiety, $F_{2,50} = 21.26$, $P = 0.021$, while contributing to an additional 43.8% (Adjusted $R^2 = .438$) of the variance. Acceptance was also a significant predictor for depression, $F_{2,50} = 15.50$, $p = .03$.

Lastly, introducing social support was an insignificant predictor variable of anxiety, yet a significant predictor of depression in the IBD group as a third variable, $F_{3,49} = 13.18$, $p = .02$. In the regression model for depression, social support contributed to 41.3% (Adjusted $R^2 = .413$) of the variance. All other variables were removed from the regression model as they did not reach significance and therefore could not make a unique contribution. Nunnally and Bernstein (1994) noted that due to the interlink between variables in the social sciences, variables contributing to a regression analysis as a third variable is expected to have smaller effects compared to other variables. Therefore, the fact that social support reached significance in this model suggests it is not the strongest model.

Table 3.5: Coefficients variables resulting from multiple linear regression analysis for Dependant variable (IBD Severity) in IBD group, Confidence Interval and Standard error

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	R ²	Adjusted R ²	F	B 95% CI	
		B	Std. Error	Beta						Lower Bound	Upper Bound
1	(Constant)	12.297	2.635		4.667	<.0005				7.007	17.587
	Anxiety	1.070	.184	.631**	5.807	<.0005	.398	.386	33.73	.700	1.440
2	(Constant)	-.304	5.788		-.053	.958				-11.929	11.320
	Anxiety	.997	.179	.588**	5.582	<.0005				.638	1.356
	Social support	.244	.101	.255*	2.418	.019	.461	.440	21.39	.041	.447

** p<.001, *p>.05

Table 3.6: Coefficients variables resulting from multiple forward stepwise regression analysis for Dependant variable (Anxiety) in IBD group Confidence Interval and Standard error

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	R ²	Adjusted R ²	F	B 95% CI	
		B	Std. Error	Beta						Lower Bound	Upper Bound
1	(Constant)	3.432	1.793		1.914	.061	.			-.168	7.031
	IBD Severity	.372	.064	.631**	5.807	<.0005	.398	.386	33.73	.243	.501
2	(Constant)	1.673	1.867		.896	.374				-2.077	5.424
	IBD Severity	.297	.069	.503**	4.298	<.0005				.158	.435
	Acceptance	.182	.076	.279*	2.385	.021	.460	.438	21.26	.029	.335

** p<.001, *p>.05

Table 3.7: Coefficients variables resulting from multiple linear regression analysis for Dependant variable (Depression) in IBD group, Confidence Interval and Standard error

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	R ²	Adjusted R ²	F	B 95% CI	
		B	Std. Error	Beta						Lower Bound	Upper Bound
1	(Constant)	8.653	1.602		5.401	.0005				5.437	11.870
	IBD Severity	.283	.057	.569**	4.937	<.0005	.323	.310	24.37	.168	.398
2	(Constant)	7.197	1.682		4.279	<.0005				3.818	10.576
	IBD Severity	.220	.062	.443**	3.541	.001				.095	.345
	Acceptance	.151	.069	.274*	2.193	.033	.383	.358	15.50	.013	.289
3	(Constant)	1.085	3.033		.358	.722				-5.010	7.179
	IBD Severity	.165	.064	.331**	2.578	.013				.036	.293
	Acceptance	.169	.066	.308**	2.555	.014	.447			.036	.302
	Social Support	.130	.055	.272*	2.378	.021		.413	13.18	.020	.239

*** p<.001, **p>.01, *p>.05

Table 3.8: Coefficients variables resulting from a forward stepwise multiple regression analysis for Dependant variable (Anxiety), Confidence Interval and Standard error

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	R ²	Adjusted R ²	F	B 95% CI	
		B	Std. Error	Beta						Lower Bound	Upper Bound
1	(Constant)	4.883	1.116		4.374	<.0005				2.672	7.093
	Acceptance	.367	.051	.553**	7.173	<.0005	.305	.300	51.45	.266	.468
2	(Constant)	-.278	2.182		-.127	.899				-4.600	4.045
	Acceptance	.387	.050	.583**	7.691	<.0005				.288	.487
	Spirituality	.054	.020	.207*	2.726	.007	.347	.336	30.86	.015	.093
3	(Constant)	-2.208	2.381		-.927	.356				-6.923	2.508
	Acceptance	.383	.050	.577*	7.682	<.0005				.284	.482
	Spirituality	.053	.020	.203*	2.711	.008				.014	.092
	Group	1.444	.753	.142	1.918	.058	.368	.351	22.27	-.047	2.936

** p<.001, *p<.0

Table 3.9: Coefficients variables resulting from a forward stepwise multiple regression analysis for Dependant variable (Depression), Confidence Interval and Standard error (p<.001, *p<.01)**

Model		Unstandardized Coefficients		Standardized Coefficients	T	Sig.	R ²	Adjusted R ²	F	B 95% CI	
		B	Std. Error	Beta						Lower Bound	Upper Bound
1	(Constant)	8.635	1.128		7.655	<.0005				6.401	10.869
	Acceptance	.300	.052	.473**	5.805	<.0005	.224	.217	33.70	.198	.402
2	(Constant)	1.741	1.959		.888	.376				-2.140	5.621
	Acceptance	.336	.049	.529**	6.830	<.0005				.238	.433
	Social Support	.117	.028	.324**	4.178	<.0005	.325	.314	27.95	.061	.172
3	(Constant)	-.044	2.035		-.022	.983				-4.075	3.986
	Acceptance	.326	.048	.513**	6.767	<.0005				.230	.421
	Social Support	.102	.028	.283**	3.657	<.0005				.047	.157
	Group	1.904	.739	.196**	2.578	.011	.362	.345	21.75	.441	3.367

3.6 Associations between acceptance and spirituality

The first research question examined the presence of a relationship between acceptance and spirituality in IBD compared to the general population. This question was investigated through a chi-square analysis. An initial investigation using the whole sample revealed no significant association between association and spirituality, regardless of analyses conducted using a high-low method. Further exploration of this research question can be seen in Table 3.10, which shows that when re-grouping acceptance as well as spirituality, and cross tabulating against group, no significant association was found between spirituality and acceptance in people with IBD compared to the general population. This shows that people with high spirituality are not necessarily more likely to be better at acceptance.

Table 3.10: Crosstabulations of Acceptance and Spirituality between IBD and control group

Group			Acceptance		Total
			Low	High	
Control	Spirituality	High	36 (55.38%)	29 (44.62%)	65
	Total		36 (55.38%)	29 (44.62%)	65
IBD	Spirituality	Low	1 (100%)	0 (0%)	1
		High	29 (54.72%)	24 (45.28%)	53
	Total		30 (55.56%)	24 (44.44%)	54
Total	Spirituality	Low	1 (100%)	0 (0%)	1
		High	65 (55.08%)	53 (44.95)	118
	Total		66 (55.46%)	53 (44.54%)	119

3.6.1 Stratified analyses

Due to the chi-square analyses showing that spirituality and acceptance are non-significant, it was felt that further associations may be uncovered. A pragmatic decision was, therefore, made to conduct a series of stratified chi-square analyses to determine additional findings of interest between demographic variables.

Firstly, the findings in Appendix W indicate that there were no associations between gender and group ($p=.18$). Following a chi-square analysis, a significant difference was found between marital status and group ($\chi^2 (1,120) = 6.59, p < 0.04$). However, upon stratified analysis to establish a more specific association as can be seen in Table 3.11, it was found that the significant difference only exists for males ($\chi^2 (1,120)= 5.90, p < 0.02$). Furthermore, crosstabulations as can be seen in Table 3.12 reveal that across both groups, females are significantly more spiritual than men ($\chi^2 (1,120)= 14.48, p < 0.006$). This highlights a number of relationships that exist between groups and demographics.

Table 3.11: Crosstabulations of gender, Spirituality and group

Gender			Do you consider yourself to be spiritual?					Total
			Definitely yes	Probably yes	Unsure	Probably not	Definitely not	
Male	Group	Control	2 (20%)	2 (20%)	1 (10%)	3 (30%)	2 (20%)	10 (100%)
		IBD	3 (21%)	6(43%)	3 (21%)	0	2 (14%)	14 (100%)
	Total		5(41%)	8(63%)	4(31%)	3(30%)	4(34%)	24 (100%)
Female	Group	Control	8(15%)	15(27%)	11(20%)	19(35%)	2(3%)	55 (100%)
		IBD	10(24%)	14(34%)	9(22%)	2(4%)	6(15%)	41 (100%)
	Total		18(19%)	29(30%)	20(21%)	21(22%)	8(8%)	96 (100%)
Total	Group	Control	10(15%)	17(26%)	12(18%)	22(34%)	4(6%)	65 (100%)
		IBD	13(24%)	20(36%)	12(22%)	2(4%)	8(15%)	55 (100%)
	Total		23(39%)	37(62%)	24(40%)	24(38%)	12(21%)	120 (100%)

Table 3.12: Crosstabulations between group, gender and marital status

Gender			Marital Status			Total
			Single	Married	Divorced	
Male	Group	Control	9 (90%)	1 (10%)	0 (0%)	10 (100%)
		IBD	6 (42.86%)	4 (28.57%)	4 (28.57%)	14 (100%)
	Total		15 (62.50%)	5 (20.83%)	4 (16.67%)	24 (100%)
Female	Group	Control	35 (64.81%)	18 (33.33%)	1 (1.85%)	54 (100%)
		IBD	22 (53.66%)	17 (41.46%)	2 (4.88%)	41 (100%)
	Total		57 (60.00%)	35 (36.84%)	3 (3.16%)	95 (100%)
Total	Group	Control	44 (68.75%)	19 (29.69%)	1 (1.56%)	64 (100%)
		IBD	28 (50.91%)	21 (38.18%)	6 (10.91%)	55 (100%)
	Total		72	40	7	

3.7 Additional findings of interest

3.7.1 Comorbidities

Of the 55 participants in the IBD group, 18 (33%), reported a comorbid health condition, of which a full breakdown can be found in Appendix X. Although these individuals were not further analysed, it is useful to report that nearly half (n=7, 39%) of the comorbidities in the IBD group were asthma. Other diagnoses ranged from single reports of HIV, Pulmonary Stenosis, Osteopenia, chronic fatigue, Usher Syndrome Type II, Coeliac disease and several reports of psychological difficulties (n=3, 17%).

3.7.2 Use of CAM

Participants were given an opportunity to report any CAM they currently or previously accessed for IBD management (Appendix Y). The findings revealed that a quarter (25%) of the IBD sample reported using complementary and alternative therapies for IBD, as shown in Figure 3.1. This is consistent with research suggesting at least 26% of an IBD population used CAM (Langmead et al., 2006). Participants CAM use ranged from mind-body interventions such as meditation and hypnotherapy to biologically based alternative therapies such as herbalism, dietary manipulation and acupuncture. A non-parametric independent samples t-test was therefore performed on all variables, to examine whether participants differed in scores based on CAM access. The t-test in Appendix Z indicated that there were no significant differences, on any variable, between individuals who accessed CAM compared to those who did not report accessing CAM.

Although the majority of individuals did not report on the outcome of the CAM they used, in general, there appeared to be positive reports of CAM for those who did. For instance, one person reported receiving CBT and psychotherapy “with good effect”, another participant found massage therapy “very helpful with overall stress”. For those who practiced meditation, positive effects were reported such as, “I found that it did help especially with sleeping at night which was affected by the Crohn’s, but I did give it up”. Hypnotherapy was also reported to have “positive outcomes”. In terms of dietary control, a paleo diet led to, “some relief from symptoms” and according to one report, nutrition control resulted in, “no symptoms for the past 6 years”. Interestingly, functional medicine was reported to have “made symptoms worse”.

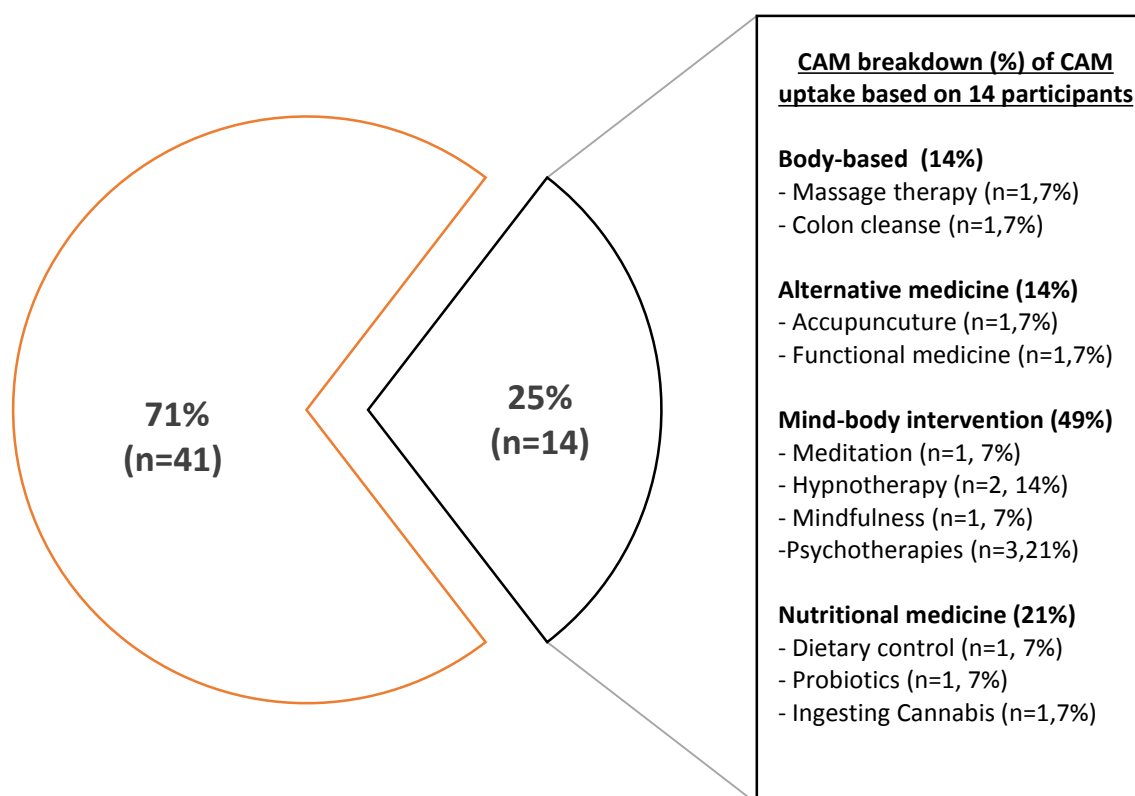


Figure 3.1: Pie chart illustrating the percentage CAM usage in the IBD group with breakdown of treatments for participants who accessed CAM

3.8 Summary of the results

Hypothesis 1- Social support will be a predictor of IBD *disease activity*

A regression analysis was performed to determine the predictors of disease activity in the IBD group alone. After entering all variables, anxiety was the largest predictor of disease severity, followed by social support.

Hypothesis 2 - Disease severity will be a significant predictor of *psychological wellbeing*

Disease severity was found to be the most significant predictor of psychological wellbeing when examining the IBD group alone. This indicates that anxiety and depression increases when participants have more active disease states.

Hypothesis 3 - Acceptance will be a significant predictor of *psychological wellbeing*

Excluding disease severity, the regression analyses confirmed that acceptance was the strongest predictor of psychological wellbeing. Compared to the general population, having a diagnosis of IBD was also a significant predictor, albeit with the least powerful model.

Hypothesis 4- Spirituality will be a significant predictor of *psychological wellbeing*

The regression analysis revealed that spirituality was a significant predictor of anxiety but not depression. A third model indicated that group also influenced the power of spirituality predicting anxiety, although this was not the strongest regression model.

Hypothesis 5- Social support will be a moderating factor of psychological wellbeing in IBD participants

Social support was found to be a significant predictor of depression but not anxiety. Social support appears to be a moderating factor.

Hypothesis 6- There will be an association between spirituality and acceptance

No associations were found between spirituality and acceptance, regardless of IBD group or general population, stratification or high-low methods of analysis.

- Additional findings of interest

Almost one third of participants reported using CAM for IBD. A t-test revealed no significant differences, on any variable, between individuals who accessed CAM compared to those who did not report accessing CAM. However, qualitative reports provided by individuals who accessed CAM consistently revealed positive benefits of CAM on the physical and psychological impact of IBD

Chapter 4: Discussion

4.1 Overview of discussion

The final chapter of this study will begin with reintroducing the research question and hypotheses. Then, the key findings will be discussed, in relation to the hypotheses and how these map onto existing psychological theory and literature. A discussion on the clinical application and external validity of the study findings will follow. Consideration is then given to the quality of this study and important strengths and limitations of the research will be reflected on. Following this, recommendations and suggestions for future research will be highlighted. Finally, a concluding summary will be provided before ending with a personal reflection.

4.1.1 Recap of research questions and hypotheses

The main research question this study aimed to address was:

The role of disease acceptance and spirituality in predicting psychological wellbeing in a group of individuals with IBD.

The following hypotheses set out to explore this:

- Hypothesis 1** Social support will be a predictor of *disease activity* in IBD participants
- Hypothesis 2** Disease severity will be a significant predictor of *psychological wellbeing*
- Hypothesis 3** Acceptance will be a significant predictor of *psychological wellbeing*
- Hypothesis 4** Spirituality will be a significant predictor of *psychological wellbeing*
- Hypothesis 5** Social support will be a moderating factor of *psychological wellbeing*
- Hypothesis 6** There will be an association between *spirituality* and *acceptance*

4.2 Discussion of main findings

A range of quantitative analytical methods were performed including chi-square associations, correlational analyses and multiple regression analyses to investigate predictive relationships between key study variables. Regression models examined the predictors of psychological wellbeing and IBD severity. Analyses were also performed for demographic variables which provide additional patterns of interest.

Studies exploring the contribution of spirituality and acceptance to psychological wellbeing are meagre, and those carried out on individuals with IBD are rarer still. This is the first study to examine the role of acceptance and spirituality as predictors of psychological wellbeing in a group of people with IBD, in the UK. In summary, the findings revealed that psychological wellbeing and social support are implicated in IBD. Predictors of psychological wellbeing were primarily disease severity and acceptance, followed by spirituality and social support, indicating that disease acceptance can be a pivotal aspect of psychological adjustment to IBD.

The discussion will begin with exploring the factors related to disease severity before going on to psychological wellbeing. Therefore, findings related to the IBD group alone will be discussed first before comparisons against the general population are introduced. As it is beyond the scope of this thesis to discuss each finding in equal depth, some findings may be integrated as part of a broader discussion.

4.2.1 Most important contributors of IBD severity

Although there are some differences between IBD subtypes such as, the well-documented negative effect of smoking on CD yet protective qualities in UC (Quezada, Langenberg & Cross, 2016), the sample consisted of more or less equal proportions of CD (55%) and UC (45%) participants. Therefore the subtype of IBD was not considered to significantly impact the outcomes in this study and separate analyses were not conducted in the current study.

IBD severity is typically a measure of the degree of difficulty caused by the physical symptoms of IBD, such as abdominal pain and diarrhoea. Regression modelling performed on the IBD sample revealed that anxiety was the most important psychological predictor of IBD severity. This is unsurprising as it underscores the likely impact an acute flare up may have on wellbeing in the here and now. Consistent with previous reports (Chan et al., 2017), anxiety was found to be the strongest psychological predictor of IBD severity. This was reported on a Singaporean sample, which was thought to differ to findings from a UK sample, due to cultural differences. However, this study identifies similar issues indicating this is concordant with the experience of IBD rather than this being dependent on cultural context. Moreover, it is likely that this finding reflects the wider literature related to the impact of uncertainty and unpredictability associated with IBD (Graff et al., 2009), as well as the embarrassment associated with loss of bowel control (Kiebles, Doerfler & Keefer, 2010; Larsson et al., 2016). This may, understandably, elicit constant anxiety, possibly explaining the finding that anxiety is the main predictor of disease severity.

Recent literature shows that anxiety may be under-recognised in IBD (Keefer et al., 2015), which appears to fit with the slightly surprising salience of anxiety alone in predicting disease

activity. Another recent study has identified that anxiety may be associated to poor adjustment outcomes (Sajadinejad et al., 2017). This study, therefore, indicates that focusing on ways of managing emotions may be an important factor in the trajectory of the psychological impact of IBD, consistent with findings from Jordan et al. (2016) systematic review. Practically, these findings suggest that a plausible means in which anxiety should be explored is during physical assessments related to IBD, following which individuals can be provided with options to manage this offshoot of IBD.

4.2.2 Identifying whether social support makes a difference to disease severity

Social support also revealed a significant model in predicting IBD severity, thus, the first hypothesis can be accepted. This shows that while anxiety plays an important role in disease severity, low social support also has the potential to influence disease severity. Indeed, those with more social support may feel less isolated and may have greater access to physical care, reducing the subjective and objective impact of the disease. Although Faust et al. (2012) documented a negative correlation between social constraints and QoL, they found that social constraint did not appear to moderate QoL. Therefore, the findings in the current study differ in this respect and have important implications. The ability for individuals to access and maintain social support may be impacted by wider factors, thus, an understanding of obstacles to accessing and engaging social relationships may be necessary in promoting better physical health outcomes. Due to the complex interplay between biopsychosocial factors in this study, predictors of psychological wellbeing can enhance our understanding of the key factors impinging on IBD, hence, the following section shifts focus to the factors related to psychological wellbeing.

4.2.3 Disease severity as a predictor of psychological wellbeing in IBD

Regression modelling was performed exclusively on the IBD group, first, to determine whether disease severity predicts psychological wellbeing in IBD. All variables were entered into the regression model, which revealed that IBD severity indeed made the largest contribution to psychological wellbeing, consistent with the second hypothesis. Due to the unclear directionality, and largely mixed, controversial reports in the literature related to the role of disease activity on psychological wellbeing (Graff et al., 2006; Guthrie et al., 2002), it was uncertain whether this relationship would exist in the present study. However, these findings add to the growing empirical weight for the notion that disease activity is detrimental to psychological wellbeing (Casellas et al., 2005; Keefer et al., 2017; Mikocka-Walus et al., 2007), explaining the significant relationship found with anxiety. For example, psychological factors are believed to modulate the experience of IBD with the potential to either exacerbate, relapse (see Hisamatsu et al., 2007) or sustain remission of IBD (see Bitton, 2003).

Furthermore, from a biological perspective, it is well known that the gut neuro-bio-chemistry is implicated in psychological health via the, bi-directional, gut-brain axis (Figure 4.1). This postulates a communicatory pathway between gut function (such as microbiota³, peripheral serotonin and intestinal immune system) and the CNS, therein influencing psychological function (see Appendix AA). While the precise mechanism of communication remains unestablished, it is well-documented that disease activity and flare ups in IBD lead to gut inflammation and broadly alters neural, metabolic and immune pathways in the gut (Coates et

³ Microbiota in humans refers to multi-trillion microorganisms contained in the gut, including highly complex bacteria (composed of over 3 million genes, that is, over 100 times more than human genes), fungi, viruses and archaea contained in the gut.

al., 2017; Moloney et al., 2014). Clearly, this has the potential to compound psychological difficulty on top of the expected psychological stressors individuals may be facing.

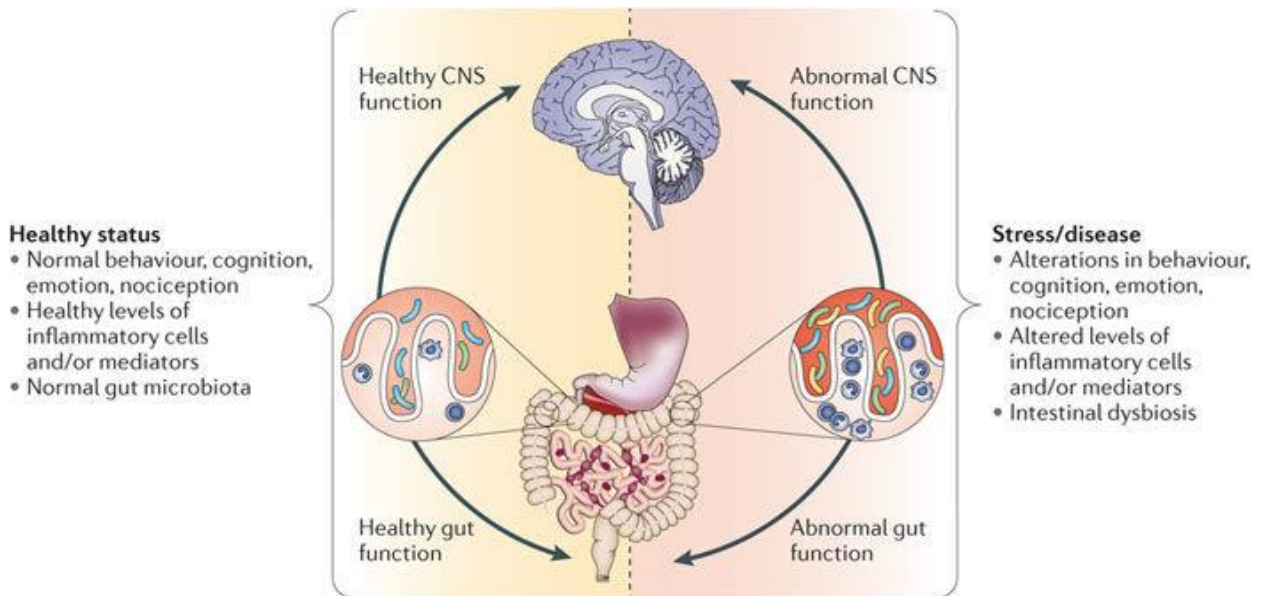


Figure 4.1: Image of Gut-Brain Axis as impacted by Microbiota (Cryan & Dinan, 2012)

Therefore, this supports the consensus that the physical and psychological components of IBD may be interrelated, thereby, each with the potential to be points of target.

The following analysis will focus on demographic data, followed by analyses between the IBD and general population group.

4.2.4 Spirituality in the sample

The overall sample scored high on spirituality compared to religion. Higher rates of spirituality were found in the IBD group compared to the general population. Interestingly, there were no associations found, in either group, with religion, indicating the two were viewed as fundamentally different. The mechanism in which spirituality and health are linked

may be very different to that of traditional religious practices. This is reflected in the literature as individuals with IBD with significantly impacted psychosocial health, were shown to be more likely to turn to spirituality as a coping resource than the general population (Cotton et al., 2009). It is thought that living with unpredictable, adverse health circumstances instigates within an individual, a way to manage its implications, thus, enabling them to cope better. This finding enables more valid interpretations to be drawn in relation to the findings related to spirituality, to be discussed later in this chapter.

4.2.5 Gender

Although gender did not yield a significant contribution to either psychological wellbeing or IBD severity, gender appeared to be linked to spirituality. Specifically, females were found to be more spiritual than men in the present study. The existing literature base related to gender difference in spirituality is mixed (Park et al., 2011). As such, gender may play a role in the relationship between spirituality and health. However, according to Bryant (2007), gender differences found in religiosity are not considered to exist in spirituality, although men are thought to express spirituality based on community involvement rather than relationships (Bryant, 2007). This may explain the inconsistencies reported in the literature. Nonetheless, this finding may not be substantiated as a predominantly female sample was accessed in the current study (79%).

4.2.6 Predictors of psychological wellbeing- *comparing IBD with the general population*

Surprisingly, when examining both IBD and the general population groups, the regression model revealed that group was the least powerful predictor of psychological wellbeing as compared to other variables. This is interesting as it appears to indicate that the roles of

acceptance, spirituality and social support are overall important predictors of psychological wellbeing before the presence of IBD. The following sections focus on findings comparing the IBD group to the general population, which reveal new patterns than those previously discussed.

4.2.7 The role of acceptance

The third hypothesis is accepted as findings revealed that poor acceptance was a significantly strong predictor of increased depression and anxiety. The role of acceptance across both groups made considerable contributions to psychological wellbeing. Although some discrepancies were found in the literature in terms of the impact of acceptance on IBD outcomes (McCombie et al., 2013), the current findings are in keeping with the majority of the literature (Jordan et al., 2016; Larsson et al., 2013). It is thought that acceptance plays a significant part in helping individuals tolerate challenging symptoms, while behaviourally opting to engage in meaningful activity. Both considered integral to positive adjustment in IBD (Jordan et al, 2016).

Clearly, one of the principle components fostered in acceptance-based interventions, including but not limited to ACT is acceptance, or psychological flexibility (Hayes et al., 2004). For example, within the ACT model, acceptance is practiced through the awareness and active embracing of challenging personal circumstances, without attempting to change them (Hayes et al., 2006). Therefore, individuals with a chronic health condition are thought to benefit from developing acceptance skills, as an adaptive coping strategy in response to a long term, debilitating condition (Hayes et al., 2003). In order to gain clarity here, a feasibility intervention study employing an acceptance-based intervention is warranted to explore its potential to improve and manage psychological wellbeing.

4.2.8 Possible moderating predictors

Additional significant models yielded interesting, yet discrepant, contributions to psychological wellbeing. Specifically, acceptance, spirituality and the group variable all made significant and independent contributions, explaining 35% of the variance on anxiety. However, for depression, acceptance, social support and group, also significantly contributed to 35% of the variance. Therefore, the third and fourth hypotheses were partially supported in this study as spirituality only contributed to anxiety and social support only moderated depression.

While the findings indeed indicated strength in the parameter of acceptance, to smaller degrees, spirituality contributed to anxiety and similarly, social support was a predictor of depression. These results suggest that acceptance may have a notable impact on psychological wellbeing while spirituality may help to manage anxiety but may be moderated by social support for depression, consistent with previous research (George, Ellison & Larson, 2002). Contributions of social support and spirituality within this model will be explored in more detail in the following section.

4.2.8.1 Social support as a predictor of psychological wellbeing in IBD

At the start of this discussion, it was found that social support was a significant predictor of IBD severity, when examining the IBD group alone (section 4.2.2). When both groups were included in a regression analysis, social support only showed significance in predicting depression in IBD, while insignificant as a predictor of anxiety. Therefore, the fifth Hypothesis was partially supported. As described above, this is concordant with the literature related to the important role of social support in psychological wellbeing. However, specific

reports on the benefits of social support differing between depression and anxiety were not found in the IBD literature (Sewitch et al., 2001). Therefore, the present study offers potentially novel information in delineating the underlying processes that impact IBD as well as the ways in which psychological wellbeing is affected in IBD. Applying this knowledge to the development of tailored interventions would be useful to help individuals manage the psychological burden of IBD, especially for those that may already be experiencing difficulties with emotional experiences and managing life.

In addition, it can be argued that social support was only significant for depression when comparing the IBD sample with the general population. Perhaps this reflects the considerable impact of coping with IBD, a challenge that some individuals find they can no longer manage. A loss of interest in activities and a perpetual loss of motivation is a well-recognised symptom of depression (Kroenke, Spitzer & Williams, 2001). Therefore, it is plausible that social support is most pertinent to those experiencing low mood as social support may be necessary for encouraging activity, thus, lifting mood.

4.2.8.2 Influence of marital status

Most of the sample reported being single (60%), with a larger proportion of married participants in the IBD group compared to the control group. An association was found between marital status and group. Upon further analysis, gender was also linked to this relationship as only males were found to be associated to marital status and group. The data confirmed that more males in the IBD group were either married or divorced than males from the control group, a difference not identified in females. This suggests that males with IBD are more likely to seek marital support, although equally likely to be divorced, than female

participants. Additionally, marital status was an independent predictor of anxiety, albeit with borderline significance. One explanation accounting for this may be due to the theoretical link between social support and marital status, likening marital status to a buffer against anxiety, akin to the benefits of social support. It is curious that this link only applied to anxiety and not depression, suggesting that the presence of anxiety may elicit a drive to actively seek marital relationships to strengthen support and resilience while in the same vein, high anxiety may be detrimental to the marital status of individuals with IBD.

Given the link found between marital status and anxiety, it was surprising that social support as a predictor of anxiety was found to be insignificant, both in the IBD group (see section 4.2.8.1) and the general population. Social support and marital status, therefore, may not necessarily be linked as it is likely that social support is conceptualised to encompass a much broader range of contact, beyond that of a spouse. Furthermore, the fact that the findings revealed social support and spirituality may have been competing predictor variables, there is reason to believe that spirituality has the potential to compensate the usefulness of social support. Specifically, the aspect of spirituality related to the fundamental role of connectedness with the self, others and nature (Cook 2004; Chiu et al. 2004), may surpass the impact of social support. This will be explored further in the following section.

4.2.8.3 The role of Spirituality

In keeping with the literature, previous studies have shown that spirituality may enhance QoL and psychological wellbeing in people with chronic health conditions (Davison & Jhangri, 2013), and IBD (Koenig et al., 2012). Spirituality, therefore, is considered to be a resource for coping with an enduring health condition (Stefanek et al. 2005). It has been postulated that effective coping leads to better adjustment, which may be a vehicle by which psychological

wellbeing is achieved (Koenig et al., 1999). In keeping with this, Davison & Jhangri (2013), propose that spirituality plays a key role in helping individuals adjust to a medical condition by mediating the psychological impact of the condition. For instance, it is thought that psychological difficulties are a manifestation of spiritual suffering and often overlap with features of depression, such as worthlessness, hopelessness and meaninglessness of life.

Spirituality is likely to have substituted the role of social support in anxiety. For instance, although the precise reason for the effects of spirituality are unknown, previous research in chronic health conditions has associated the positive psychological effects of disease acceptance to meaning-based coping, (Folkman & Greer, 2000). A similar mechanism is thought to underlie the association between spirituality and improved psychological wellbeing outcomes, in that it may imbue adversities with meaning and purpose, which ultimately lead to better physical and mental health outcomes (Wachholtz & Pargament, 2005). Meaning and purpose is known to help people deal with the high levels of uncertainty and concerns about the future, a symptom of anxiety commonly experienced in chronic health condition, including IBD (Kiebles, Doerfler & Keefer, 2010; Spitzer, Kroenke & Williams, 2006). The findings suggest that psychological pathways may account for the way in which spirituality positively impacts physical and psychosocial health.

4.2.9 Psychological processes underlying the findings

The findings related to social support and spirituality have the potential to suggest that spirituality is more sought after for coping with the impact of anxiety-related symptoms than depression. The exact reason for this would be difficult to ascertain, however, qualitative differences between depression and anxiety may account for the differences in coping. For example, anxiety may be more common as an acute experience to symptoms, thus, making

individuals more willing to draw on self preservatory coping strategies that offer a sense of meaning in life, which spirituality may help to enable. In contrast, due to the incurable nature of IBD, depression may be a longer term impact as a consequence of learned helplessness (Seligman, 2002), which impacts individual's views of self-efficacy, appraisal of IBD and personal control, making it less likely that individuals will maintain a sense of purpose or hope (Cooper et al., 2010; Kiebles, Doerfler & Keefer, 2010). Furthermore, Reynolds et al. (2014), found that greater use of spiritual coping in an IBD sample was linked to reduced depression over a two-year follow up. In the current study, although spirituality was not a significant predictor of depression, the effects of spirituality may indeed be seen longitudinally. Therefore this requires prospective investigation.

4.2.10 Moving forwards

With an increasingly secular Western society and research indicating that more people are turning away from organised religion (Shafranske & Cummings, 2012), third wave CBT's (as discussed in section 1.6.2.1) may be one way in which people could access the benefits of spirituality (via acceptance) to facilitate better management of the psychological impact of IBD. One aspect of ACT is to promote psychological openness to the range of physical, cognitive, and emotional experience, often hampered by avoidance coping styles (Lorig & Holman, 2003). This acceptance is thought to be necessary for being able to live a value-congruent life.

Hayes (2004), reports that ACT draws from various spiritual traditions, such as Buddhism, which strive to cultivate acceptance, thereby allowing the individual to process their private internal experience, to achieve amelioration of experiences of suffering. Furthermore, as a value-based psychological intervention, ACT alludes to interconnectedness, transcendence and

expansiveness of consciousness (Hayes et al., 2006), which are aspects of spirituality (Santiago & Gall, 2016). Therefore, ACT may offer something unique in that it refrains from a rigid, rule-governed course of intervention towards a more flexible, value-orientated action approach. This may foster a greater sense of control over self-management, in a condition that potentially requires developing or re-introducing meaningful activities as part of adaptive adjustment. Perhaps it is time that the potential usefulness of an acceptance based intervention for IBD be known, and this requires serious consideration.

4.2.11 Summary of significance of psychological wellbeing

Research has shown that effective adjustment to a chronic health condition requires disease acceptance. Considering that acceptance was reliably linked to psychological wellbeing, and anxiety was the strongest predictor of IBD severity, suggests that psychological factors play an important role in the experience of having IBD. This study revealed that individuals with IBD were significantly more spiritual than the general population after accounting for religion. Spirituality, as with social support, were also important, although these seem to be one of the ways in which individuals cope with IBD, rather than a continuous factor in the psychological wellbeing trajectory. Therefore, in light of these findings, an acceptance based intervention group may provide a framework and a means to repeatedly access and harness acceptance and spirituality or social support, particularly for those with no religious denomination. This could be used as a rationale to explore whether such intervention could impact on the psychological wellbeing aspects of IBD. Given the nuanced findings between the roles of spirituality and acceptance in the trajectory of a chronic health condition, the extent to which they are associated will be explored in the next section.

4.2.12 Associations between spirituality and acceptance

A link between spirituality and acceptance was considered probable. For example, spirituality is concerned with one's personal journey involving connectedness with nature, others and oneself and several components of ACT such as acceptance and mindfulness are reported to be drawn from Spirituality and Eastern mystic traditions (Hayes, 2004).

Contrary to the final hypothesis, the chi-square analyses and further stratified analyses indicated that this association was not present in the current study. A correlational analysis further corroborated the absence of a relationship between spirituality and acceptance, independent of group. This finding was surprising due to a number of studies pointing out the overlapping elements between spirituality and acceptance (Carmody et al., 2008; Follette, 2016; Hayes, 2002; 2004). For example, research has found that acceptance based therapies have positively impacted spiritual wellbeing (Mull, 2015).

This finding suggests that acceptance and spirituality may be independent of one another. Reynolds et al. (2014), suggested that the relationship between spirituality and adjustment is likely to be bidirectional. Although the current study found higher spirituality among the IBD participants, no relationship was found with acceptance. However, an intervention was not carried out to truly determine the interplay of acceptance, which highlights a need for an experimental study involving an acceptance based intervention to discern whether acceptance could enable individuals to better manage the psychosocial impact of IBD.

Furthermore, another possibility for this incongruence is the measure used to assess acceptance. The AAQ-II (Bond et al, 2011) is typically used as an appropriate measure of psychological flexibility in ACT intervention studies (McCracken, Vowles, & Eccleston, 2004). While this is currently the most widely used and most reliable and valid tool to examine

acceptance (Costa & Pinto-Gouveia, 2011; Wheaton), it may be less sensitive for a non-experimental design. Secondly, the fact that the AAQ-II is not specific to IBD and does not directly relate questions to IBD, potentially limits the degree it captures IBD, symptom-specific acceptance.

Additionally, it can be taken for granted that spirituality denotes positive coping, thus expected to be linked to acceptance. However, negative spiritual coping, involving beliefs about karmic debt and deserving to suffer, is also experienced as reported by Reynolds et al. (2014), offering parallels with attribution theory (Peterson et al., 1982). In this case, individuals may struggle with acceptance. Indeed, this is complex and needs further exploration.

4.2.13 Additional findings of interest

4.2.13.1 Ethnicity

Of the total sample, the majority were from a White ethnic background (87%). Within the IBD group, ethnicity was found to be a predictor of depression. In contrast to the research indicating higher rates of spirituality in BME groups compared to non-BME populations (Park et al., 2011), no significant link was found between ethnicity and spirituality in this study. However, given the sample was predominantly White British, consistent with the epidemiology of IBD in the literature, the extent to which the finding would be replicated with a more equal mix of ethnic backgrounds is questionable until further investigated.

4.2.13.2 Complementary and Alternative Medicine (CAM)

A quarter of the IBD sample reported accessing CAM for IBD. Intriguingly, a t-test revealed no benefits in any variable for those who accessed CAM. In contrast, further examining this

with participant's qualitative reports, showed the majority of individuals reported positive outcomes. Several reasons may account for this discrepancy. Akin to a type II error, the small IBD sample size may lend itself to undetectable significant findings in this area. Furthermore, there is no clear information available pertaining to whether participants were reporting on present or past CAM use. Additionally, all measures asked questions based on up to the last month, hence, potentially invalidating any data analysis comparing current context to factors that helped in the past.

While individual differences would influence IBD relapse triggers, several participants reported on the benefit of dietary control ranging from, "*some relief from symptoms*" to, "*no symptoms for the past 6 years*". This is in keeping with the mixed reports in the literature on the role of food in IBD. Indeed, as an environmental trigger, dietary factors may be understated as Western diets, known for its high fatty acids and refined sugars intake, may adversely affect gut microbiota, thus, increasing susceptibility to inflammation (Amre et al., 2017). Nonetheless, the need for further studies are indicated.

Arguably, these findings are among the most interesting in this study as they suggest a number of possibilities. Firstly, individuals with IBD are clearly seeking options beyond medical treatment which may reflect the inadequacy of a unidimensional approach to treating chronic conditions such as IBD (possibly due to the psychological impact of the condition). Secondly, the effects of CAM are subjectively reported as beneficial. The most commonly sought categories of CAM in this sample were mind-body approaches (49%), such as meditation, and nutritional medicine (21%), such as dietary control. This point towards a desire for more holistic treatment which encapsulates the mind and body interplay. Furthermore this suggests

that therapies similar to third wave CBT's are already being sought by some individuals, adding to the argument for introducing these therapies within the NHS, in pursuit of equity of access. Consistent with Opheim et al. (2011), mind-body interventions were the most sought after for IBD. Further, this urges clinicians to recognise the psychological impact of the condition at a time where standard medical approaches may need to incorporate broader treatment options to adequately manage IBD, or even prevent it. Longitudinally researching the effects of CAM may lead to interesting and more generalisable results.

Although an overview of the key findings from this research were provided, the extent to which each finding can be explored in detail is beyond the scope of the study. However, the findings form the basis for, at least, considering an acceptance based intervention study for IBD, and at best, obtaining/commissioning resources to pilot the efficacy of such interventions within a UK based clinical setting.

4.3 Clinical implications

Numerous studies have described the immense difficulties faced by people with chronic health conditions in adjusting to their diagnosis. This includes impact on the psychological, social and physical health (Graff, Walker & Bernstein, 2009). As such, the nature of the patient's adjustment to a disease is perhaps as important as their physical health status. Further development in integrative therapies to include addressing the biopsychosocial, and spiritual, may have the potential to reduce the chronicity, exacerbation and ultimately long term medical costs of treating individuals with IBD.

Medical conceptions of physical disease and subjective meanings are complementary and both important for individual's sense of control and adjustment to chronic health difficulties (Bury, 1982). Considerations should not only be made for the individual but also the familial and wider contextual level. In doing so, this may broaden clinicians lens to the ways in which patients can be supported psychologically, and systemically which may include a spiritual based resource or linking in with social support groups if not a psychological group based intervention. This may widen coping strategies, thus, contribute to better adjustment. Furthermore, reports indicate that spirituality is seldom inquired about by clinicians (Curlin et al., 2007), when in fact, this may be an appropriate resource to draw on, maximising the self-management options for individuals with IBD alongside their routine medical care (Keefer & Kane, 2017). Some practical considerations regarding the active inclusion of acceptance and spirituality in clinical settings will be discussed next.

4.3.1 Intervention

Currently, the largest driving force in IBD treatment is the development of pharmacological interventions. However, these come with many adverse side effects and are limited in effectiveness (Khan, 2013). Due to its empirical evidence base psychological interventions, predominantly CBT, are sometimes offered, yet with mixed or counterproductive outcomes (Knowles, Monshat & Castle, 2013). For example, it is likely that teaching individuals to alter their 'faulty' thinking, encouraged in traditional CBT, can inadvertently instil a sense of fault, blame and invalidation in people with IBD. Moreover, it is plausible that individuals who do not benefit from CBT continue to experience difficulties if the underlying processes perpetuating the distress, such as psychological inflexibility, remain poorly addressed.

The findings in this study add to the value of acceptance in helping to improve psychological wellbeing, thus, having the potential to enable individuals to better cope with the impact of IBD. Although the results from this study are not based on an intervention, offering interventions such as third-wave CBT's, including, but not limited to, MBSR (Carlson et al., 2001; Carmody et al. 2008) and ACT, may be conduits to targeting the valuable aspects revealed in this study. For instance, the results from this study point towards acceptance as a useful strategy to consider in psychological interventions for IBD. In helping to develop the individual's psychological flexibility, third wave CBT's such as ACT, encourage acceptance of difficult life experiences, thus, reducing the resistance to make the necessary adjustments to cope with the disease. Consequently, this frees up the cognitive space to focus on value-congruent thoughts and behaviours. This is more likely to reduce psychological distress, consistent with the link found between the psychological wellbeing outcomes and acceptance.

In clinical health settings, an evidence base exists for the use of ACT for a range of chronic health condition such as, chronic pain, diabetes, epilepsy, substance abuse, obesity and psychosis (McCracken et al., 2004; Gregg et al., 2007; Batten & Hayes, 2005; Lillis et al., 2009; Bach, 2013, respectively). Specifically, mediational analyses within studies highlight that on acceptance coping strategies contributed to the long term benefits of ACT in alleviating the cognitive and emotional difficulties experienced by patients in physical health settings (Gregg et al., 2007).

Unfortunately, due to a lack of studies, third-wave CBT's are not currently recommended in NICE guidelines for IBD (NICE, 2013), although a recent review has corroborated the efficacy of ACT in facilitating disease management (Graham et al., 2016). However, the findings from

this research, combined with the previous studies conducted in other chronic health conditions indicate that a feasibility study may help to evaluate the potential for an acceptance based intervention as an effective adjunct to IBD treatment. This may be crucial particularly for vulnerable groups who may already have psychological difficulties.

The use of MBSR programs in improving mindfulness and spirituality, leading to reduction in physical and psychological symptoms, is documented (Carmody et al., 2008). Another suggestion in ascertaining the potential usefulness of spiritual based interventions could be trialling MBSR groups in an IBD service. Due to NHS resource limitations, this approach would not only be cost-effective by enabling sizeable numbers of individuals to access this treatment, but may also, inadvertently, provide social support, which has shown to be useful for psychological wellbeing and disease severity in this study.

Although there is growing evidence supporting the incorporation of mind, body and spirit interventions for chronic health conditions (Gonçalves et al., 2015), the current implementation of this practice remains scarce in public, physical health services. Granted, it can be argued that valid challenges may account for the above, particularly in the current climate of the NHS, including whether doing so is financially feasible, model fidelity, limitations in clinician's knowledge and time constraints. However, such practice may in fact lead to a more cost effective service by reducing the time and resource intensiveness of a physical health dominated approach (Jedel, Hankin, Voigt & Keshavarzian, 2012).

Taking into account the socially isolating aspect of IBD (Kiebles, Doerfler & Keefer, 2010) and the fact that social support was found to play a pivotal role in the variables studied, social

support should be incorporated as part of routine assessment. For individuals who struggle with social support, it may be helpful for clinicians to encourage participation in social activities, perhaps via group based interventions, to prevent social isolation. Potentially, this may also tackle issues related to the stigma of accessing psychological therapy for those who struggle to consider the need to address these aspects of their health.

Epistemologically, considering we do not yet fully understand the whole truth about IBD, through further research, perhaps we may come close enough to establishing a more informed truth.

4.4 Suggestions for future research

Several directions for future studies are indicated by the findings of the current study. Primarily, the IBD literature would benefit from prospectively studying the relationship variables in this study, over multiple time points. New research should also consider broadening the scope of social, cognitive and behavioural factors related to QoL in IBD such as hope, illness perception, health related anxiety and other coping strategies drawn upon. In addition, a longitudinal design would better enable directionality and causality to be established. A larger sample size should be studied in order to ensure an adequately powered statistical analysis is conducted to detect the benefits of CAM for IBD management and in order to counterbalance attrition. In efforts to reduce selection bias and broaden generalisability, recruitment should include participants randomly selected from primary and secondary care, from multiple sites across the country.

More robust and valid methods of disease severity could be established through collecting information about IBD medication dosage and obtaining faecal biomarker results for analysis.

For example, it would be interesting to correlate psychological wellbeing with a subjective self-report measure such as, IBD-DI as well as objective data including:

- a) Active inflammatory markers in the blood – ESR⁴ + CRP⁵
- b) Active inflammatory markers in the stool – Calprotectin

Subsequently, multivariate analyses may then be used to assess the relationships between these factors alongside measures of psychological wellbeing, spirituality, social support and acceptance, thus, building a stronger biopsychosocial explanation of the interrelationships.

The findings from this study seem to suggest that ACT may be useful. However, there is a dearth of evidence to support the use of ACT in IBD contexts. Therefore, future studies may employ a mixed method design to assess tailored psychological interventions using an ACT model. Ideally, baseline and follow-up scores as well as qualitative reports on participant's experience of ACT would be evaluated in order to capture the true effect, if any, of ACT in an IBD population. Of importance, blinding participants to the intervention would help counteract some limitations such as demand characteristics. Overall, this study offers strong potential for both future research and clinical application. Important evaluations of the study will be outlined in the next section in order to appreciate the strengths and limitations.

⁴ ESR- erythrocyte sedimentation rate and

⁵ CRP- C-reactive protein, both used to detect inflammation in a blood sample.

4.5 Strengths

This is the first known study to examine the relationship between interrelated variables in an adult population with IBD, in the UK. Novel findings were therefore discovered. IBD is a substantially growing chronic health condition, only partly due to greater sensitivity of diagnostic tools in the detection of IBD. It is, therefore, concerning that it currently receives less attention than other chronic health conditions, with equally growing health cost burden. Consequently, this study contributes useful information to the literature base, which has the potential to inform the clinical application of acceptance based interventions for IBD.

In contrast to previous literature, a noteworthy strength of this study is the effort to exclusively focus on the construct of spirituality without the integration of religion, or a monotheistic God. This is important as the study aimed to reflect, as closely as possible, the increasingly secular and rising interest in spiritual ways of life in the West. The findings revealed that participants views on how spiritual they considered themselves to be was consistent with how they scored on The Spirituality Scale (Delaney et al., 2005). This suggests that analyses conducted using this scale, in subsequent sections of the discussion, is likely to reliably measure of how participants perceive their spirituality.

In the present study, no association was found between the IBD group or the general population in terms of religion, indicating that religiosity was not a significant feature of the sample, thus, reducing the confound of religiosity on the construct of spirituality measured in this study. Understanding the role and impact of spirituality, can provide insight to its usefulness and potential clinical application in chronic illnesses such as IBD.

The use of a quantitative methodology in addressing the research questions, with an acceptable study power (80%), is considered another strength. Findings can potentially be generalised or at least can provide insight to the potentially neglected aspects of coping with IBD. Naturally, this offers scope for the development of alternative approaches fostering a biopsychosocial-spiritual approach, to support the treatment of IBD. At the very least, the findings provide a rationale for future research to explore the use of psychological interventions that assimilate features of acceptance and spirituality. In conducting an interventional study, causal relationships may be identified.

Lastly, a notable strength of this study is the use of a control group to compare the findings of the IBD group. The majority of findings were compared against a control group from the general population. This study, therefore, attempts to offer some insightful differences on how acceptance and spirituality can be useful to individuals with IBD, over and above what would be found in the general population. Although this was not a matched sample design, the participants in both groups did not vary significantly in demographics, strengthening the validity of the comparisons made.

4.5.1 Limitations

When interpreting the current findings, several limitations should be considered in this study. It is acknowledged that qualitative information was lacking, that may indeed substantiate the findings. For example, a qualitative study by Larsson et al. (2016), found that the main difficulties for individuals with IBD was the feeling of shame associated with loss of faecal control, concluding that healthcare professionals need to focus on reducing this symptom. This information would be difficult to derive from structured measures used in

quantitative research, resulting in constraints in the depth of the data. Similarly, useful information about the benefits of CAM, negated by statistical analysis, would have been missed if qualitative reporting were not made available to participants in the current study.

Confounding variables identified in this study should be acknowledged. While the use of self-report measures were not only practically convenient but also recognised as reliable and valid forms of assessing a variable, these are difficult to control. For example, the classification of disease severity may have been subject to response biases as individuals may provide spurious or emotionally driven responses about their disease activity, distorting the accuracy of the phenomenon being studied. Similarly, the researcher has no control over how much attention is being paid to the different parts of the survey.

In order to reduce the response burden to participants, brief measures were selected for this study. Arguably, a more comprehensive measure of acceptance, rather than an ACT intervention measure, specific to challenges faced by IBD participants may have led to a more robust assessment of this construct, enabling firmer conclusions. Furthermore, since acceptance is a coping strategy, the stage of disease trajectory may have influenced readiness for acceptance. This study did not account for the duration of diagnosis to assess whether this factor influenced acceptance. Disease stage is likely to play a role in participation as participants were not actively recruited based on different stages and severity of IBD, resulting in a skewed sample. Additionally, IBD duration, by means of length of impact, may differentially be associated to depression, thus, a potential confounding variable.

Research indicates that gender prevalence of IBD appears to vary slightly based on geographical location, although, in contrast to the present study, epidemiological studies

generally indicate an equal balance in gender (Bryant et al., 2008). Hence, further investigation of this finding with a more balanced gender ratio would allow firmer conclusions to be made about the findings and their generalisability. This would be important as such findings would inform the clinical implications of assessing spirituality and any adapted approaches required to ensure that men are not disregarded in accessing potentially useful, supplementary, interventions. Moreover, considering that females were a risk factor for high disease activity as cited in the development of the IBD-DI measure (Gower-Rousseau et al., 2017), the higher proportions of females in the current study may have produced a disproportionately higher incidence of disease activity, thus, impacting representability.

It is worth considering that a proportion of participants from the IBD (n=18) reported comorbidities that may have been confounding the study. The most common comorbidities in the IBD group was asthma, among other single reports of HIV, Pulmonary Stenosis, Osteopenia, chronic fatigue, Usher Syndrome Type II, Coeliac disease and several reports of psychological difficulties including anxiety and depression. Participants with comorbidities were included in the study in order to conserve power and retain ecological validity. Furthermore, the number of participants presenting with comorbidities, in the IBD group, were very small (n=18). When considering this number, as well as the time constraints of the study, it was felt that further analyses would not be practical on 14 participants. Nonetheless, it was agreed that this could be a useful area to explore for future research. Similarly, it is worth noting that, the majority of participants in the IBD group were on medication for IBD symptom management (69%). The impact of this could also be examined in future studies with larger samples.

Another limitation is the cross-sectional design, precluding examination of the prospective nature of relationships between the variables of interest. Thus, conclusions about casual relationships are not possible in the present study. Crucially, correlation does not imply causation. Therefore, another limitation is the risk of extrapolating a predictive model from a fixed correlation analysis, as correlations do not allow going beyond the data limits, hence conclusions must be treated with caution until further research is conducted.

A lack of randomised sampling procedures in this study meant that a biased sample was recruited. Given the scope and timescale of the present study, some limitations related to the sample were inevitable as a web-based survey. For example, the sample recruited for the general population, consisted of a larger proportion of higher educated participants. Granted this was a convenience sample, and partly accountable was perhaps the willingness of the recipients of the Doctoral college recruitment email circulations. Therefore, this may have impacted the generalisability of the findings, ethnic diversity of individuals and the extent to which the two groups can reliably be compared. An extended study may focus on targeting a broadly representative control group. Similarly, the confound of poor ethnic diversity applied to both sample groups. It is of note, however, that epidemiological reports indicate higher prevalence of IBD among European and North American populations (Ng et al. 2017), therefore this may simply reflect the prevalence of IBD in the UK.

Nonetheless, selection bias is likely to have impacted this study as the recruitment strategy was predominantly web-based mediums, requiring individuals to be actively accessing IBD forums as well as having computer access and literacy, and language competence, thus, potentially screening out the diversity that may be present in an NHS outpatient clinic. Again, given

additional time, the recruitment would have extended to GI specific services in hospitals and outpatient clinics, offering greater representation of the breadth of individuals affected by IBD.

Lastly, while disease severity was determined by individual's scores on the IBD-DI, some of the items on this scale, such as the sleep and energy domain, overlapped with a few items on the PHQ-9 scale. Therefore, it is possible that there is some, albeit limited association between these scales. However, since this is a novel area of research, no previous studies have investigated whether an association exists between these two scales.

4.6 Conclusions

To conclude, this study offers some novel insight to the factors that contribute to psychological wellbeing in IBD. As expected, individuals who reported highly on the physical symptomatology of their IBD, that is, more active disease states, predicted impaired psychological wellbeing. Acceptance appeared to be the main predictor variable of value to both anxiety and depression. This gives weight to the potential usefulness in evaluating acceptance based interventions as a promising adjunct for the treatment of IBD, which could help to facilitate adjustment.

In addition, this study suggests that both spirituality and social support offer value and some potential to improve psychological wellbeing in IBD, to varying degrees. While this may be somewhat expected, this is the first known study to investigate these pockets of under-researched resources within this clinical health population. Contrary to what was expected, acceptance and spirituality were not associated, yet, each appeared to play valuable roles in the lives of individuals with IBD. Ultimately, this research remains in its infancy until further, prospective, intervention studies are carried out on whether spirituality or acceptance can

causally impact psychological wellbeing in IBD. In addition, the contribution and value of the areas investigated demonstrate their potential to be explored at an individual level with people with IBD.

Positive, qualitative reports in the use of CAM for IBD, indicates a need for healthcare approaches to go beyond medical care. Thus, screening patients for psychological difficulties and promoting adjustment via acceptance based intervention groups may lead to an evidence base for novel and noteworthy clinical recommendations for IBD. Facilitating better adjustment in the absence of an IBD cure fits with the biopsychosocial approach individuals with IBD are likely to benefit most from. Furthermore, addressing the use of spirituality as a coping strategy, may enable the identification of patients who may benefit from interventions, such as ACT, which enable some features of spirituality to be harnessed (acceptance and mindfulness).

Providing these services in a GI service context could be cost effective in the long run by potentially decreasing individual's reliance on medical services for support. While advances in IBD treatment are still being developed, shifting credence to the psychosocial factors that exacerbate IBD, appear to be a promising direction towards more effective IBD management.

4.7 Personal Reflections

To end this thesis, I will now provide a summary reflective account. In writing the final chapter, I have been intrigued by the emotions that have been evoked from learning the outcome of this research. Firstly, I am appreciative of the results for its potential to, even minutely, positively contribute to the lives of people with IBD. I feel lucky that the study concludes with genuine scope to draw further attention to the psychological aspects exacerbating IBD, in a society that may be lagging with bridging physical and mental health.

In the research process I have become even more aware of my desire for a paradigm shift in the way that physical health is viewed and treated. On reflection, I wondered whether this drive was partly founded by my views on the pressing need to loosen the illness model constructs of mental health. In being quick to believe that physical health conditions should not be treated exclusively physically, I found myself up against some challenges. I realised that just as frustrating as it can be to find oneself, at times, trying to rescript a disease-saturated narrative of psychological difficulty, resistance to psychosocial ideas for physical health conditions may require more advocacy and greater awareness at multiple contexts in order to influence change. However, I hope that with momentum in putting clinical recommendations into practice, such as the ones from this study, the future of physical health care may be one that views psychosocial approaches on par. Undoubtedly, I find myself stimulated to further research in this area.

Going forward, I believe my interest in this area should be used to continue to benefit individuals with physical health conditions that are yet to realise the ameliorating effects of accessible psychological interventions, as the wait for a cure continues. Indeed, at times it has

felt as though quantitative research is given less merit than it deserves, or is viewed as an easier methodology. However, I feel that this view can be reductionist and frustrating. Instead, I believe that robust, quantitative analysis can offer meaningful and in-depth results, often unearthing extremely valuable information. I am excited about the prospects of my research and how, if at all, it may be received by the gatekeepers of high impact GI journals as well as IBD services in the NHS. In conducting research in an area that sparks my fundamental beliefs about healthcare, I feel committed and endeavour to publish my research for the best interest of individuals with IBD and as an ethical duty to the participants who contributed their time to the study.

Originally, I considered conducting my research on a psychosomatic difficulty, however, I challenged myself to research a health condition classified as biomedical. This was due to my, once, naïve view that physical health conditions could be a cause of psychosocial adversity in which they ought to be targeted with psychological interventions. I have learnt a great deal about the pathogenesis of physical health, in that, no single theory can be held accountable for its complexity. Thankfully, this development in understanding will stand me in good stead to work with individuals from this context.

I was surprised at the discovery that spirituality was not a constant theme in the findings of this research, rather, a variable one. An important personal development from this research was my reflexivity, born from my idealisation of the concept of spirituality. In recognising the healing value of spirituality, adopted commonly in the East, I was initially disappointed, but gradually humbled that this was not a strong consensus of the study, rather a personal

perspective. However, it was quite clear that the acknowledgement of these ideas are in their infancy in empirical research for Western health contexts yet not void of potential.

Admittedly, I was pleased that CAM use offered some intriguing data. However, I was filled with far more questions than I had fathomed. Deep down, I couldn't help but wonder whether so many potentially insightful pockets of research related to health conditions were being missed. Are holistic/ mind-body CAM approaches economically detrimental to pharmaceutical corporations, impacting their publication platforms? Are clinicians too afraid to explore beyond the remits of NICE guidelines? For example, are subjects such as energy therapy and spirituality taboo? On the basis of a lack of scientific support, perhaps so. However, given the fallibility of research and the constantly new emergence of it, I was reminded that the more I know, the more I realise I don't know.

I have been fortunate to spend my time researching an area that has helpfully unveiled the depth of the knowledge gap. I envisage that the skills I have acquired as a researcher will continue to be applied in my future as a clinical psychologist, as I seek ways to address some of the unanswered questions I have been inspired by. The innumerable seeds of curiosity that have been planted through clinical psychology training is one way in which my learning will continue, despite the journey coming to an end.

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6: Appendices

Appendix A

Diagram of the different parts of the gastrointestinal tract impacted by IBD

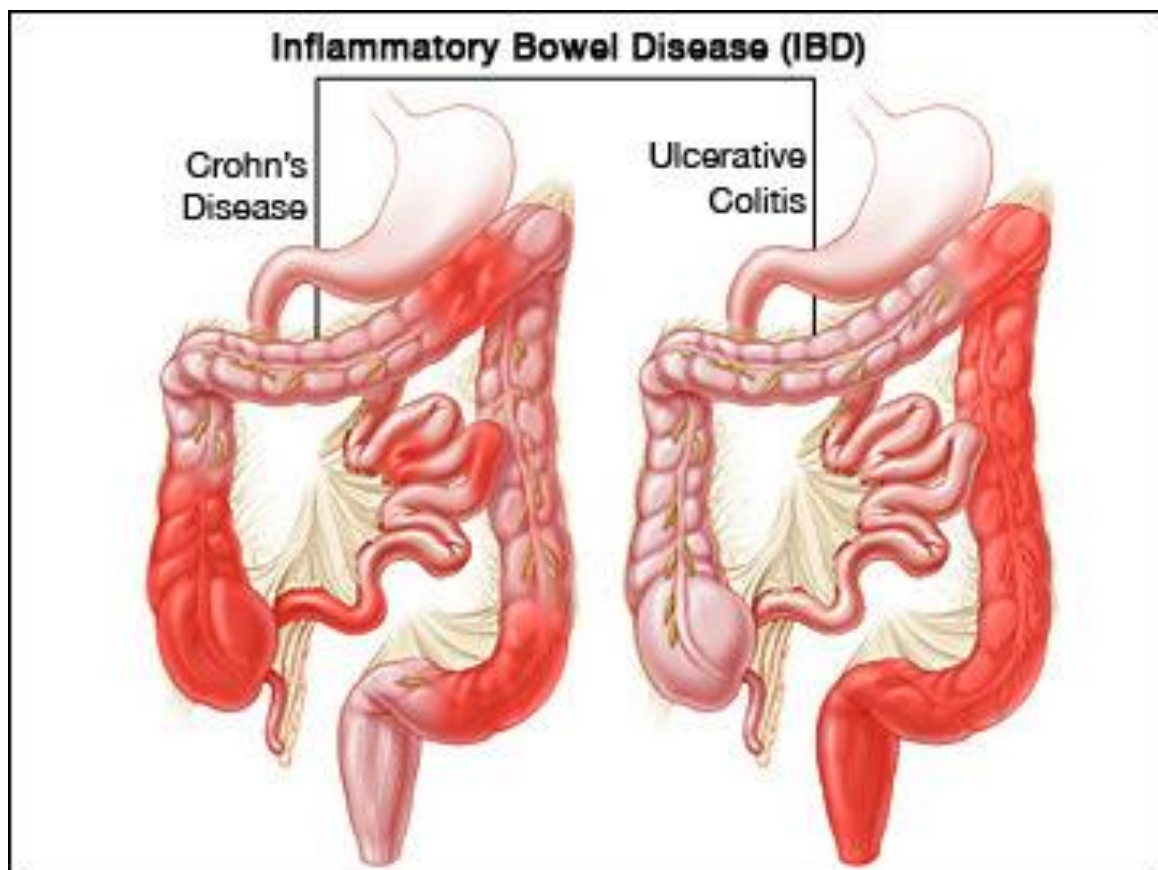


Diagram of the affect areas in IBD⁶ (iCons in medicine, 2011). In UC, disease is continuous and affects anywhere in the large colon only. In Crohn's inflammation is not continuous and can affect any area in the gastrointestinal tract.

⁶ Image obtained by conducting a google search for 'Inflammatory Bowel Disease' (Accessed May 2017).

Appendix B

Comprehensive search strategy used, including all search terms, from three databases

Various search terms entered	PUB MED	SCOPUS	PSYCHinfo/ ProQuest
spiritual OR spirituality AND chronic OR health OR long term OR inflammatory OR inflammatory bowel disease AND psychological OR adjustment OR adjust OR acceptance OR acceptance and commitment therapy	Initial return= 413 45 returned when refining to:	Initial return: 710 129 returned when refined to:	Initial return: 906 122 when refining search to:
(((spiritual[Title/Abstract]) AND chronic[Title/Abstract]) OR inflammatory bowel) AND psychological[Title/Abstract] OR mental[Title/Abstract]	humans NOT pharmacological AND refining publication date from 1999/01/01 to 2017/12/31	TO (subjarea , "medi") or limit- to (subjarea , "nurs") or limit- to (subjarea , "psyc") or limit- to (subjarea , "soci")) and (limit- to (subjarea , "medi") or limit- to (subjarea , "psyc") or limit- to (subjarea , "soci") or limit- to (subjarea , "heal") or limit- to (subjarea , "neur")) and (limit- to (subjarea , "nurs") or limit- to (subjarea , "bioc"))	Peer reviewed Scholarly Journals 1999 - 2018 Article religion OR culture OR philosophy OR christianity OR society OR spirituality OR mental disorders OR psychology OR illnesses OR islam OR quality of life OR theology OR medical research OR psychoanalysis OR chronic illnesses OR disease OR mental depression OR pain OR social conditions & trends OR traditions OR meditation OR philosophers OR questionnaires OR alternative medicine OR buddhism OR consciousness OR health OR psychiatry
(((spiritual[Title/Abstract]) AND chronic[Title/Abstract]) OR inflammatory bowel) AND psychological[Title/Abstract] OR mental[Title/Abstract]			
((spirituality) AND chronic health AND adjustment OR acceptance [Title/Abstract] NOT religion			

Appendix C**Quality Consideration Ratings for the Domains of the EPHPP Quality Assessment Tool**

Domain	Strong Rating (3)	Medium Rating (2)	Weak Rating (1)
Selection bias	Highly likely to be representative of the target population. At least 80% participation rate	Likely to be representative of target population. Between 60-79% participation rate	Not stated or below 60% participation rate
Study design	RCT's or other clinically controlled trial	Case control, cohort analytic, case control or interrupted time series	All other designs or unclear design/ not stated
Confounders	At least 80% of confounders controlled for	Controlled for approximately 60-79% of confounders	Confounders uncontrolled or not stated
Data collection methods	Measures used are valid and reliable	Measure is valid but not reliable (or vice versa)	Evidence of reliability and validity lacking or not stated
Withdrawal and drop out	Minimum 80% participant follow-up rate	Participants follow up rate between 60-79%	Participant follow up rate of less than 60% or no clear information about dropouts or withdrawals

Appendix D**The results of quality considerations of the articles in the systematic literature review**

Study	Selection Bias	Study Design	Confounders	Data Collection	Withdrawal & Dropout	Total Score	Global Rating
Cotton et al. (2009)	Weak	Medium	Weak	Strong	Strong	2	Moderate
Davison & Jhangri (2013)	Weak	Medium	Weak	Strong	Strong	2	Moderate
Faust et al. (2012)	Medium	Weak	Weak	Strong	Medium	1.8	Weak
Goncalves et al., 2017	Medium	Strong	Medium	Medium	Medium	2.2	Moderate
Jordan et al. (2016)	Strong	Medium	Strong	Weak	Medium	2.2	Moderate
Larsson et al., 2016	Weak	Strong	Weak	Medium	Medium	1.8	Weak
McCombie et al. (2015)	Medium	Strong	Weak	Medium	Weak	1.8	Weak
Reynolds et al. (2014)	Medium	Strong	Medium	Medium	Medium	2.2	Moderate
Riley et al. (1999)	Medium	Weak	Weak	Strong	Medium	1.8	Weak

Appendix E

Summary and Evaluation of Studies in the Systematic Literature Review

Authors, Title, Setting	Participants	Research methodology	Summary of study and key findings	Strengths and limitations
Cotton, Kudel, Roberts, Pallerla, Tsevat, Yim & Succop (2009) Spiritual Well-Being and Mental Health Outcomes in Adolescents With or Without Inflammatory Bowel Disease USA	N=155 adolescents between 11–19 years IBD group N=67 Healthy controls N=88 Recruited from children’s hospital and the university hospital in the area via telephone or flyers.	Quantitative study. Participants completed self-report questionnaires on spiritual well-being, depression and QoL Covariates in multivariable models included demographics, disease status, and interactions Children’s Depression Inventory–Short Form Adapted version of the Spiritual Well-Being Scale	Examining relationship between spiritual well-being and mental health in sample of adolescents with IBD compared to healthy controls. Both IBD group and control group scored high in their spirituality. However, IBD moderated relationship between spirituality and mental health. Existential well-being was associated to mental health than was religious well-being. Supports the role of meaning and purpose as possible mediator of health and spirituality relationship. Disease severity impacted the association between spirituality and mental health outcomes in IBD participants. Specifically,	Strengths: - Use of control group - Novel findings (first study to explore spirituality in an adolescent sample with IBD) Limitations: - Spirituality scale focusing on both existential domain and higher power, covering the spectrum of their definition of spirituality. - Skewed sample based on recruitment from hospitalised IBD patients therefore those with potentially higher disease severity - Disease duration and severity was not controlled for - Small/ unrepresentative sample

			positive correlation existed compared to healthy controls.	<ul style="list-style-type: none"> - Majority (82%) Caucasian sample - Cross-sectional design
Davison & Jhangri (2013)	N=253 dialysis patients and stage 4/ 5 chronic kidney disease recruited from Canadian, university renal-program	Quantitative study	Spirituality and adjustment independently predict HRQL.	Strengths
The Relationship Between Spirituality, Psychosocial Adjustment to Illness, and Health-Related Quality of Life in Patients With Advanced Chronic Kidney Disease.		Battery of self-report measures were completed including: the Spiritual Well-Being Scale, the Adjustment to Illness Scale, and Quality of Life Short Form.	Adjustment in terms of psychological distress seems to mediate some of the beneficial effects of existential well-being on HRQL.	Limitations
Canada.		Cross-sectional analysis.	However, spirituality, has a unique influence in HRQL, independent regardless of adjustment.	<ul style="list-style-type: none"> - Cohort study - Large sample (potentially high powered) - Not generalisable to ethnically diverse populations - Cross-sectional - Predominantly white sample - Lack of control group - Recruitment method limits generalisation
Faust, Leslie, Halpern & Cross (2012)	N=80 adults with IBD	Quantitative study	Examine predictors of coping and social constraints to IBD disease activity and QoL	Strengths
Psychosocial Factors Conibuting to IBD activity		Retrospective analysis design	Social constraint, negatively associated to QoL	<ul style="list-style-type: none"> - Adds useful findings to a sparse literature base - Appropriate statistical analyses
				Limitations
				<ul style="list-style-type: none"> - Predominantly Caucasian sample (78%)

and Health-Related Quality of Life	Disengaged coping styles positively correlated with disease activity. Regression analyses revealed disengagement was associated to increased likelihood of active disease	- Participants solely from a tertiary care service - Small sample and non-representative - Confounding variables were not controlled for and no control group	
USA	No association between engagement coping styles and disease activity.		
	Social support was not found to moderate disease activity but was correlated with QoL. Social support considered an important factor for clinicians to consider with IBD patients		
Gonçalves, Lucchetti & Vallada 2017 Complementary religious and spiritual interventions in physical health and quality of life: A systematic review of randomized controlled clinical trial	N=30 articles met criteria for the review A systematic review using the PRISMA guidelines	Examining whether religious and spiritual interventions (RSI's) improve QoL and physical health in chronic health conditions RSIs had some benefits, such as reducing pain, improved QoL and health behaviours, compared with other CAM therapies.	Strengths - Inclusion of some clinical trials - Randomisation method of articles adopted by CONSORT (Consolidated Standards of Reporting Trials) Limitations - No meta-analysis was conducted - Lack of RCT's/ good quality studies, limits the conclusions that can be

Italy	<p>More studies are required to understand the mechanisms of action underlying the benefits of RSIs in health care</p>	<p>drawn and generalisation that can be made from this review</p> <ul style="list-style-type: none"> - Studies were very diverse in their protocols which limits comparability of studies - Search was limited to English, Spanish and Portuguese 	
<p>Jordan, Sin, Fear & Chalder (2016) A systematic review of the psychological correlates of adjustment outcome in adults with IBD London, UK</p>	<p>N= 25 IBD related studies Systematic review. Studies were independently rated by two authors</p>	<p>Aimed to suggest evidence based targets that could be modified through psychological interventions</p> <p>Psychological variables covered include – personality traits, stress and coping, emotions, and IBD related cognitions.</p> <p>Most consistent relationship was found between emotion focused coping (such as acceptance) and IBD adjustment outcomes.</p> <p>Adjustment based interventions should focus on coping strategies, stress and IBD related cognitions</p>	<p>Strengths</p> <ul style="list-style-type: none"> - Rigorous and replicable method - First systematic review of psychosocial correlates of adjustment - Wide range of psychological factors were assessed - Studies were independently reviewed by a second authors <p>Limitation</p> <ul style="list-style-type: none"> - Qualitative studies were excluded - Unable to assess publication bias as studies were solely from peer reviewed journals

				<ul style="list-style-type: none"> - All but one study were cross-sectional, limiting conclusions about directionality - Overall low quality of studies in the review
<p>McCombie, Mulder, Gearry (2015)</p> <p>Coping Strategies and Psychological Outcomes of Patients with Inflammatory Bowel Disease in the First 6 Months After Diagnosis</p> <p>New Zealand</p>	<p>N=54 participants at baseline. 80% participant retention at 6 month follow up.</p>	<p>Quantitative study.</p> <p>Prospective observational study. Questionnaires administered at baseline and 6 months later post diagnosis.</p>	<p>Examining the association between coping strategies and QoL, anxiety, and depression.</p> <p>Over 6 months, maladaptive coping, and neuroticism were associated with lower QoL and greater anxiety and depression.</p> <p>No associations found with adaptive coping and better QoL and lower depression and anxiety suggesting adaptive coping was neutral and maladaptive coping had an impact on psychological well-being.</p>	<p>Strengths</p> <ul style="list-style-type: none"> - Comprehensive use of validated measures - Prospective study - Low drop out and high retention rate <p>Limitations</p> <ul style="list-style-type: none"> - Small sample and potentially low power. - Skewed sample due to newly diagnosed patients - Limited generalisability
<p>Reynolds et al., (2014)</p>	<p>N=128 participants.</p> <p>Age=(M)14</p>	<p>Quantitative study</p> <p>Participants completed spiritual coping measures and</p>	<p>Exploring relationships between spiritual coping and adjustment in adolescents with chronic illness.</p>	<p>Strengths</p> <ul style="list-style-type: none"> - Longitudinal - Power calculations report sufficient study power (>.90).

<p>Spiritual Coping and Adjustment in Adolescents With Chronic Illness: A 2-Year Prospective Study</p> <p>USA</p>	<p>adjustment at baseline and 2 years after.</p> <p>Analyses conducted using regression models</p>	<p>Positive spiritual coping predicted lower rates of depression and less negative spiritual coping in follow up. In contrast, negative spiritual coping predicted more positive spiritual coping.</p> <p>Depressive symptoms predicted higher levels of poor spiritual coping in follow up. Results were trans-diagnostically consistent.</p> <p>Positive spiritual coping may be protective of developing depression and unhelpful coping strategies in adolescents.</p> <p>Recommendations around addressing the role of spirituality and depressive symptoms in adolescents receiving healthcare.</p>	<p>-</p> <p>Limitations</p> <ul style="list-style-type: none"> - Adolescent sample - Poor generalisability - Lack of ethnic diversity - No control group - High rates of attrition - Role of religion was not assessed at both points therefore hard to determine the unique role of spiritual coping on adjustment. - Time between baseline and follow-up may have been too long to capture true effects of spiritual coping in adjustment. - Relatively small sample even though - 83% participants were Caucasian background 	
<p>Riley, Perna, Tate, Forchheimer, Luer (1998).</p>	<p>216 in-patients with chronic health diseases.</p>	<p>Quantitative study.</p>	<p>To identify different types of spirituality among individuals with physical health problems</p>	<p>Strengths</p> <ul style="list-style-type: none"> - Large sample

<p>Types of Spiritual Well-Being Among Persons With Chronic Illness: Their Relation to Various Forms of Quality of Life.</p> <p>Michigan, USA.</p>	<p>Cluster analyses used to develop a spiritual-wellbeing scale then assess the relationship between spiritual well-being, quality of life and health in chronic illnesses.</p> <p>Self-administered questionnaires at a hospital unit measuring various forms of spirituality and quality of life domains.</p>	<p>caused by chronic illness and whether different types of spiritual well-being differ in relation to QoL, health and life satisfaction.</p> <p>Three forms of spiritual wellbeing were identified, each of which differed in terms of QOL. Religious and existential group did not differ in QOL. However, non-spiritual participants had poorer QOL compared to religious an existential thus may be protective factors in chronic illnesses.</p> <p>Further research required to determine if type of spiritual well-being has a causal effect on treatment outcome or on the recovery process.</p>	<p>- cluster analysis (Riley et al., 1998)</p> <p>Limitations</p> <ul style="list-style-type: none"> - No information about participant's ethnicity. - Research not broadly generalisable - No studies related to IBD/ GI diseases

Appendix F**Measure used in online survey- Acceptance and Action Questionnaire- II**

AAQ-II

Below you will find a list of statements. Please rate the truth of each statement (for the agreed time period) in the column on the right, using the following scale:

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

1. My painful experiences and memories make it difficult for me to live a life that I would value
2. I'm afraid of my feelings
3. I worry about not being able to control my worries and feelings
4. My painful memories prevent me from having a fulfilling life
5. Emotions cause problems in my life
6. It seems like most people are handling their lives better than I am
7. Worries get in the way of my success

Total score =

Appendix G

Measure used in online survey- The spirituality Scale

Spirituality Scale

Please indicate your level of agreement to the following statements by circling the appropriate number that corresponds with the answer key.

Key:

1. Strongly Disagree
2. Disagree
3. Mostly disagree
4. Mostly agree
5. Agree
6. Strongly Agree

1. I find meaning in my life experiences.	1 2 3 4 5 6
2 I have a sense of purpose.	1 2 3 4 5 6
3. I am happy about the person I have become.	1 2 3 4 5 6
4. I see the sacredness in everyday life.	1 2 3 4 5 6
5. I meditate to gain access to my inner spirit	1 2 3 4 5 6
6. I live in harmony with nature.	1 2 3 4 5 6
7. I believe there is a connection between all things that I cannot see but can sense.	1 2 3 4 5 6
8. My life is a process of becoming.	1 2 3 4 5 6
9. I believe in a Higher Power/Universal Intelligence.	1 2 3 4 5 6
10. I believe that all living creatures deserve respect.	1 2 3 4 5 6
11. The earth is sacred.	1 2 3 4 5 6
12. I value maintaining and nurturing my relationships with others.	1 2 3 4 5 6
13. I use silence to get in touch with myself.	1 2 3 4 5 6
14. I believe that nature should be respected.	1 2 3 4 5 6
15. I have a relationship with a Higher Power/Universal Intelligence.	1 2 3 4 5 6
16. My spirituality gives me inner strength.	1 2 3 4 5 6
17. I am able to receive love from others.	1 2 3 4 5 6
18. My faith in a Higher Power/Universal Intelligence helps me cope during challenges in my life.	1 2 3 4 5 6

patterns/practices.	
20. I respect the diversity of people.	1 2 3 4 5 6
21. Prayer is an integral part of my spiritual nature.	1 2 3 4 5 6
22. At times, I feel at one with the universe.	1 2 3 4 5 6
23. I often take time to assess my life choices as a way of living	1 2 3 4 5 6

Appendix H**Measure used in online survey- GAD-7****GAD-7 Anxiety**

Over the <u>last 2 weeks</u>, how often have you been bothered by the following problems? (Use "✓" to indicate your answer"	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

Appendix I

Measure used in online survey- PHQ-9

PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?
(Use "✓" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING 0 + _____ + _____ + _____
=Total Score: _____

Appendix K**Measure used in online survey- Brief Social Support Scale**

The following questions are about social aspects of your life. Please select the most appropriate response for each question:

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
I receive a lot of understanding and security from others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is someone very close to me whose help I can always count on.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I need to, I can borrow something from friends or neighbors without any problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know several people with whom I like to do things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am sick, I can ask friends/relatives to handle important things for me without hesitation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I'm very depressed, I know who I can turn to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix L

Measure used in online survey- Original IBD-Disability Index

PLEASE READ ALOUD THIS INSTRUCTIONS TO THE PATIENT The first question is about the overall health of the patient, including both physical and mental health.						
ANSWERS: 1 = Very good; 2 = Good; 3 = Moderate; 4 = Bad; 5 = Very bad						
Overall Health	1	2	3	4	5	
1. In general, how would you rate your health today?						
PLEASE READ ALOUD THESE INSTRUCTIONS TO THE PATIENT Now I would like to review different functions of your body and activities of daily life. When answering these questions, I would like you to think about the last week, taking both good and bad days into account. When I ask about difficulty / problem, I would like you to consider how much difficulty / problem you have had, on an average, in the past week, while doing the activity in the way that you usually do it. By difficulty I mean that you require increased effort, that you have discomfort or pain, or that the activity is slower or that there are other changes in the way you do the activity. Please answer this question taking into account any assistance you have available. (Read and show scale to respondent).						
ANSWERS: 1 = None; 2 = Mild; 3 = Moderate; 4 = Severe; 5 = Extreme						
Sleep and Energy	1	2	3	4	5	
2. Overall in the last week, how much of a problem did you have with sleeping, such as falling asleep, waking up frequently during the night or waking up too early in the morning? (b134)						
3. In the last week, how much of a problem did you have due to not feeling rested and refreshed during the day (e.g. feeling tired, not having energy)? (b130)						
Affect						
4. Overall in the last week, how much of a problem did you have with feeling sad, low or depressed? (b152)						
5. Overall in the last week, how much of a problem did you have with worry or anxiety? (b152)						
Body Image						
6. Overall in the last week, how much of a problem did you have with the way your body or body parts looked? (b1801)						
Pain						
7. Overall in the last week, how much of stomach or abdomen aches or pains did you have? (b28012)						
ANSWERS: 1 = None; 2 = Mild; 3 = Moderate; 4 = Severe; 5 = Extreme or cannot do						
Regulating defecation	1	2	3	4	5	
8. Overall in the last week, how much difficulty did you have coordinating and managing defecation including choosing and getting to an appropriate place for defecation and cleaning oneself after defecation? (d5301)						
Looking after one's health						
9. Overall in the last week, how much difficulty did you have looking after your health, including maintaining a balanced diet? (d570)						
Interpersonal Activities						
10. Overall in the last week, how much difficulty did you have with personal relationships? (d7)						
11. Overall in the last week, how much difficulty did you have with participation in the community? (d920)						
Work and Education						
12. Overall in the last week, how much difficulty did you have with work or household activities? (d840-d859)						
13. Overall in the last week, how much difficulty did you have with school or studying activities? (d810-d899)						
(b525)	Number of liquid or very soft stools in the last week					
(b515)	Body mass index (BMI): <input type="text"/> kg/m ²					
(b515)	Do you feel that you have lost weight in the last week? <input type="checkbox"/> Yes <input type="checkbox"/> No					
(s540)	Blood in stool (weekly average): <input type="checkbox"/> None <input type="checkbox"/> Little <input type="checkbox"/> A lot					
(s770)	Is arthritis or arthralgia present? <input type="checkbox"/> Yes <input type="checkbox"/> No					
Please rate the extent to which the following aspects of the patient's environment positively or negatively influenced disease activity, body functions, and activities of daily life, which you have reviewed with the patient.						
ANSWERS: NA = Not applicable; 1 = No positive effect; 2 = Mild positive effect; 3 = Moderate positive effect; 4 = Severe positive effect; 5 = Extreme positive effect						
	NA	1	2	3	4	5
+14. Overall in the last week, did the medication the patient take <u>alleviate</u> her/his problems and difficulties? (e1100)						
+15. Overall in the last week, did the food the patient take <u>alleviate</u> her/his problems and difficulties? (e1101)						
+16. Overall in the last week, did the patient's family <u>alleviate</u> her/his problems and difficulties? (e310)						
+17. Overall in the last week, did health professionals <u>alleviate</u> the patient's problems and difficulties? (e355)						
ANSWERS: NA = Not applicable; 1 = No negative effect; 2 = Mild negative effect; 3 = Moderate negative effect; 4 = Severe negative effect; 5 = Extreme negative effect						
	NA	1	2	3	4	5
-14. Overall in the last week, did the medication the patient take <u>worsen</u> her/his problems and difficulties? (e1100)						
-15. Overall in the last week, did the food the patient take <u>worsen</u> her/his problems and difficulties? (e1101)						
-16. Overall in the last week, did the patient's family <u>worsen</u> her/his problems and difficulties? (e310)						
-17. Overall in the last week, did health professionals <u>worsen</u> the patient's problems and difficulties? (e355)						
ANSWERS: 1 = No; 2 = yes						
Social security and health services, systems and policies		1	2			
18. Does the patient benefit from the support he or she needs from the social security system? (e570)						
19. Does the patient receive the health care he or she needs? (e580)						

Appendix M

Information sheet presented to participants at the start of the online survey

INFORMATION SHEET

Title of research: Identifying the relationship between disease acceptance and spirituality in a sample of individuals with Inflammatory Bowel Disease. How does this impact on their psychological wellbeing?

Introduction

You are invited to take part in a study being conducted by Hasina Sarwari, a Trainee Clinical Psychologist from the University of Hertfordshire. This study is being supervised by Dr. Keith Sullivan who is an active researcher and lecturer at the University of Hertfordshire.

Aim of the study

The aim of this study is to investigate the relationship between disease acceptances, spirituality in people with a diagnosis of inflammatory bowel disease (IBD) including Crohn's and Colitis. In addition, I will also be exploring whether spirituality and disease acceptance has an impact on psychological wellbeing within individuals with IBD. For example, experiences such as anxiety, depression and quality of life will be measured, in order to understand how these may be different depending on the individual's spirituality.

What are the benefits of taking part?

By taking part you in this study you will help us to enhance our understanding of the relationship between spirituality, disease acceptance and psychological wellbeing. The information we get from this study will help us to think about ways we can support individuals with IBD by considering a range of other potential disease management approaches, beyond medical care.

What is involved?

If you agree to take part in this study, you will be asked to give your consent to completing an online survey. The survey will feature a range of questionnaires based on your spiritual views, experience of living with IBD and psychological wellbeing. There are no right or wrong answers. I am interested in your personal

experience and views. You will have the opportunity to ask any questions via the contact details provided at the end of this form.

What are the possible disadvantages of taking part?

There are no dangers involved in taking part, although as this is a personal and sensitive subject area being explored, it is possible that some of the questions related to your experience could be distressing and cause you some discomfort. If this occurs, you will be able to take a break at any time when completing the questionnaires or decide not to continue taking part. If you do find completing the surveys upsetting, there is a list of contact details of professional organisations that can offer you support if you experience any emotional distress or feel upset. Please could you take a note of any numbers or contact details now, should you decide to withdraw from the study, as there will be no means of providing these at that time. If you complete the study, you will be provided with further information of where you can get support from at the end of the study.

How long will my part in the study take?

If you decide to take part you will complete an online questionnaire at home or somewhere private which should take no longer than 20-30 minutes to complete.

Voluntary participation

Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason as participation in this study is completely voluntary. If you withdraw from the study, any data provided will not be used in the results.

Confidentiality

Any data you provide in this study will remain both confidential and anonymous and will be used only for the purposes outlined here. Your name will not be asked for in this study, therefore, any data provided will be entered into the database using numbers rather than names. Your data will only be available to myself as the researcher and my supervisor Dr. Keith Sullivan. All data will be kept on a password protected computer.

What will happen to the results of this study?

The data collected during this study will be used as part of a Doctoral Clinical Psychology project at the University of Hertfordshire. When the study is completed I will write up the findings as an academic thesis that will be submitted as part of the

requirements of the course. In addition, I will write up an article for publication in a journal. In the event that the results of the study are published, your identity will continue to be protected as we do not ask for your name.

Who has reviewed this study?

This study has been reviewed by The University of Hertfordshire Health and Human Sciences Ethics Committee with Delegated Authority. The UH protocol number is LMS/PGR/UH/02928.

Taking part in this study

If you wish to take part in this study, then please click next to proceed further. If you have decided that you would not like to take part in this study, then you may simply close your browser window.

Further Information

If you would like further information or would like to discuss any details personally, please get in touch with the researcher by email. Alternatively you can contact the research supervisor:

Principal researcher:

Hasina Sarwari

Trainee Clinical Psychologist

Email: h.sarwari@herts.ac.uk

Address: Dr Keith Sullivan, University of Hertfordshire, College Lane, Hatfield, Hertfordshire, AL10 9AB

Research supervisor:

Dr. Keith Sullivan

Researcher

Email: k.sullivan3@herts.ac.uk

Sources of Support

In the event of any concerns, emotional distress and discomfort experienced, you can contact the following organisations for support and guidance regarding any concerns or worries you have regarding your emotional and psychological wellbeing:

Your GP

Please consider contacting your GP if you are feeling low or anxious

Psychological therapies

If you think that you may benefit from engaging in a talking therapy (such as cognitive behavioural therapy), then you may wish to consider self-referring to your local psychological therapies service, or asking your GP to refer you.

To find your nearest service, you can search on the NHS choices webpage:
[http://www.nhs.uk/Service-Search/Psychological-therapies-\(IAPT\)/LocationSearch/10008](http://www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008)

Samaritans

This is a 24 hour a day, free and confidential helpline for anyone experiencing any emotional distress.

Freephone: 08457 90 90 90

Website: www.samaritans.org

NHS Direct

Website: www.nhsdirect.nhs.uk

Helpline: 0845 4647

Alternatively, you may wish to discuss any distress with a representative from **Crohns and Colitis UK**Support. This is a telephone, support service for anyone who needs a safe place to talk about living with IBD.

Telephone: 0121 737 9931

Available: Monday to Friday 1:00pm-3:30pm and 6:30pm-9:00pm,

These sources of support will be able to help you.

Appendix N**Consent form presented to participants on the web-based survey****CONSENT FORM**

Please read the following statements before you agree to take part in this study.

1) I confirm that I have read and understand the information sheet for the above study.

2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. If I withdraw from the study, the data that I have submitted will also be withdrawn at my request.

3) I understand that the information that I will submit will be confidential and anonymous, used only for the purpose of this study

4) I agree that research data gathered for the study may be published and if this occurs precautions will be taken to protect my anonymity.

5) Contact information has been provided should I wish to seek further information from the investigator at any time for purposes of clarification.

6) I agree to take part in the above study

Please confirm:

I agree with the above statements

I disagree with the above statements

Appendix O

Screenshot of research information as advertised/ posted on Crohn's & Colitis UK

The screenshot shows the Crohn's & Colitis UK website header with the logo and tagline 'FIGHTING INFLAMMATORY BOWEL DISEASE TOGETHER'. Navigation links include 'About Inflammatory Bowel Disease', 'Support for you', 'Get involved', 'Research', 'Improving health services', and 'Healthcare Professionals'. Action buttons for 'Questions & Answers', 'Donate', and 'Become a Member' are also visible. The main content area features a purple banner with the text 'DISEASE ACCEPTANCE AND SPIRITUALITY IN IBD' and the University of Hertfordshire logo.

Home > Research > Take part in research > Disease acceptance and spirituality in IBD

Researchers at the University of Hertfordshire are looking for patients to take part in a study investigating disease acceptance and spirituality, and its impact on psychological wellbeing.

This new study will investigate the relationship between disease acceptance and spirituality in people with a diagnosis of **Inflammatory Bowel Disease (IBD)**. As part of the research, individuals with IBD are invited to take part in filling out a set of online questionnaires. The research aims to explore whether spirituality and disease acceptance have an impact on psychological wellbeing. Therefore, some questions will ask about experiences related to anxiety, depression and quality of life. This information will help explore other ways individuals with IBD could be supported with disease management, beyond medical care.

To take part, you need to have a confirmed diagnosis of IBD, be able to read and write spoken English and be at least 16 years old.

Participation involves completing some questionnaire which would take approximately 20-30 minutes. If you are interested and would like more information about the study, please visit the [website](#) or contact Hasina Sarwari, Trainee Clinical Psychologist from the University of Hertfordshire by email: h.sarwari@herts.ac.uk. This study is being supervised by Dr. Keith Sullivan.

Appendix P

Example screenshots illustrating presentation of survey in web and mobile view

Please state what type of Inflammatory Bowel Disease you have:

Do you have any other formal diagnosis of a chronic health condition? If so, please state all diagnoses

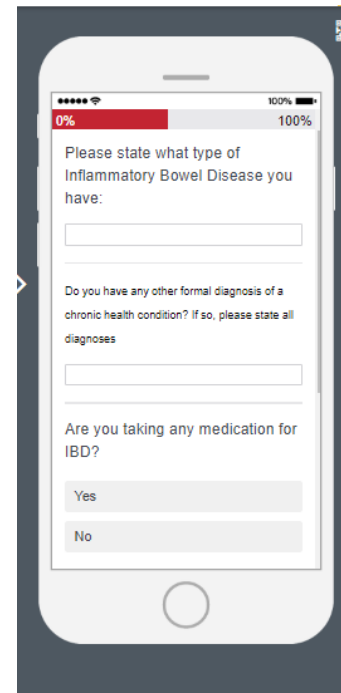
Are you taking any medication for IBD?

Yes

No

Please state any alternative therapies you have accessed for IBD: (Briefly describe the outcome if possible)

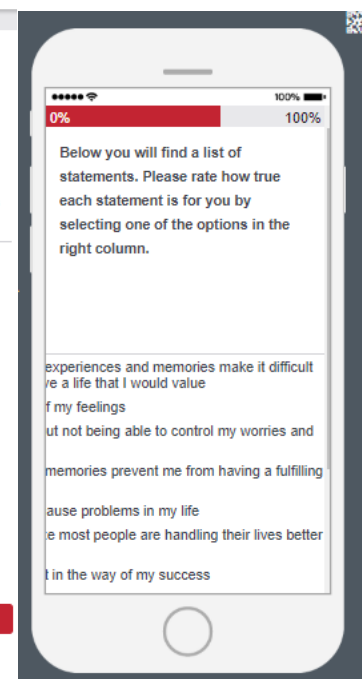
>>



Below you will find a list of statements. Please rate how true each statement is for you by selecting one of the options in the right column.

	Click to write Column 1						
	Never True	Very Seldom True	Seldom True	Sometimes True	Frequently True	Almost Always True	Always True
My painful experiences and memories make it difficult for me to live a life that I would value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm afraid of my feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about not being able to control my worries and feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My painful memories prevent me from having a fulfilling life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emotions cause problems in my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It seems like most people are handling their lives better than I am	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worries get in the way of my success	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

>>



Appendix Q

Ethical Approval Letter from the University of Hertfordshire School of Life and Medical Sciences Ethics Committee confirming permission to conduct this research after ethical issues were considered



HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO: Hasina Sarwari
 CC: Dr Keith Sullivan
 FROM: Dr Simon Trainis, Health, Sciences, Engineering & Technology ECDA Chair
 DATE: 3rd August 2017

Protocol number: LMS/PGR/UH/02928

Title of study: *Identifying the relationship between disease acceptance and spirituality in individuals with Inflammatory Bowel Disease (IBD) and Irritable Bowel Syndrome (IBS). How does this impact on the psychological wellbeing of individuals with IBD?*

Your application for ethics approval has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below.

This approval is valid:

From: 03/08/17

To: 31/10/18

Additional workers: no additional workers named

Please note:

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

Appendix R

Debrief information sheet presented at the end of the web survey

DEBRIEF SHEET

Thank you for giving your time to take part in this research project. Hopefully this research will help us develop ways we can support people with IBD.

The information that you have provided will be kept confidential and all data will be destroyed after the completion of the research. If you wish to withdraw your involvement in the research, you can do so at any time.

If participation in this research caused you any distress, discomfort or upsetting feeling, you may wish to contact immediate sources of support such as your family, friends, GP or a therapist.

Alternatively, you may wish to discuss any distress with a representative from **Crohns and Colitis UK** Support. This is a telephone, support service for anyone who needs a safe place to talk about living with IBD.

Telephone: 0121 737 9931

Available: Monday to Friday 1:00pm-3:30pm and 6:30pm-9:00pm,

If you would like further support, please find below the details of some organisations that may be useful. These sources of support will be able to help you regarding any concerns or worries you have regarding your emotional and psychological wellbeing.

Your GP

Please consider contacting your GP if you are feeling low or anxious

Psychological therapies

If you think that you may benefit from engaging in a talking therapy (such as cognitive behavioural therapy), then you may wish to consider self-referring to your local psychological therapies service, or asking your GP to refer you.

To find your nearest service, you can search on the NHS choices webpage:
[http://www.nhs.uk/Service-Search/Psychological-therapies-\(IAPT\)/LocationSearch/10008](http://www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008)

Samaritans

This is a 24 hour a day, free and confidential helpline for anyone experiencing any emotional distress.

Freephone: 08457 90 90 90

Website: www.samaritans.org

NHS Direct

Website: www.nhsdirect.nhs.uk

Helpline: 0845 4647

If you have any further questions, or would be interested in being informed in the outcome of this study, then please contact the researcher, Hasina Sarwari, by email (h.sarwari@herts.ac.uk).

If you have any complaints about the study, please contact Dr Keith Sullivan by email (k.sullivan3@herts.ac.uk).

Thank you again for your participation and support.

Appendix S**Table showing Pearson's correlation for overall sample with all variables and spearman's rho for social support**

		Acceptance	Spirituality	Anxiety	Depression	Social Support	IBD Severity
Acceptance	Pearson Correlation	1	-.149	.553**	.473**	-.173	.459**
	Sig. (2-tailed)		.106	.000	.0005	.059	.001
	N	119	119	119	119	119	53
Spirituality	Pearson Correlation	-.149	1	.120	.078	.176	.326*
	Sig. (2-tailed)	.106		.193	.395	.055	.016
	N	119	120	120	120	120	54
Anxiety	Pearson Correlation	.553**	.120	1	.723**	.059	.631**
	Sig. (2-tailed)	.005	.193		.0005	.522	.005
	N	119	120	120	120	120	54
Depression	Pearson Correlation	.473**	.078	.723**	1	.232*	.574**
	Sig. (2-tailed)	.005	.395	.005		.011	.005
	N	119	120	120	120	120	54
Social Support	Pearson Correlation	-.173	.176	.059	.232*	1	.357**
	Sig. (2-tailed)	.059	.055	.522	.011		.008
	N	119	120	120	120	120	54
IBD Severity	Pearson Correlation	.459**	.326*	.631**	.574**	.357**	1
	Sig. (2-tailed)	.001	.016	.005	.005	.008	
	N	53	54	54	54	54	54

Appendix T

Fixed regression model for dependent variable (Depression) and all independent variables

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	R ²	Adjusted R ²	F
		B	Std. Error	Beta					
1	(Constant)	2.798	2.921		.958	.340	.37	.33	9.36
	Gender	-.565	.895	-.048	-.632	.529			
	Ethnicity	-.956	.528	-.142	-1.808	.073			
	Marital Status	-.270	.611	-.035	-.442	.660			
	Employment status	.066	.280	.019	.236	.814			
	Acceptance	.347	.048	.563	7.279	.000			
	Spirituality	.013	.019	.054	.689	.493			
	Social Support	.119	.028	.340	4.215	.000			

*** p<.001, **p>.01, *p>.05

Appendix U

Fixed regression model for dependent variable (Anxiety) and all independent variables

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	R ²	Adjusted R ²	F
		B	Std. Error	Beta					
1	(Constant)	-1.790	2.974		-.602	.548	.41	.37	10.98
	Gender	1.132	.911	.092	1.242	.217			
	Ethnicity	-.717	.538	-.101	-1.331	.186			
	Marital Status	-1.038	.622	-.127	-1.667	.098			
	Employment status	-.182	.285	-.049	-.640	.524			
	Acceptance	.402	.049	.621	8.278	.000			
	Spirituality	.038	.020	.148	1.940	.055			
	Social Support	.063	.029	.172	2.195	.030			

Appendix V

Fixed regression analysis for depression in IBD group only (n=55)

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	R ²	Adjusted R ²	F
		B	Std. Error	Beta					
1	(Constant)	5.442	4.242		1.283	.206	.52	.45	6.00
	Gender	-.216	1.173	-.021	-.184	.855			
	Ethnicity	-1.345	.786	-.184	-1.711	.094			
	Marital Status	-.747	.707	-.115	-1.056	.297			
	Employment status	.278	.434	.071	.640	.526			
	Acceptance	.136	.074	.248	1.840	.073			
	Spirituality	-.030	.027	-.145	-1.087	.283			
	Social Support	.149	.057	.312	2.635	.012			
	IBD Severity	.186	.073	.375	2.540	.015			

*** p<.001, **p>.01, *p>.05

Appendix W

Fixed regression analysis for anxiety in IBD group (n=55)

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	R ²	Adjusted R ²	F
		B	Std. Error	Beta					
1	(Constant)	1.254	5.171		.243	.809	.50	.40	5.41
	Gender	.859	1.430	.070	.601	.551			
	Ethnicity	-.460	.958	-.053	-.480	.633			
	Marital Status	-1.039	.862	-.135	-1.205	.235			
	Employment status	-.152	.529	-.033	-.287	.775			
	Acceptance	.220	.090	.337	2.434	.019			
	Spirituality	.024	.033	.098	.716	.478			
	Social Support	-.010	.069	-.017	-.140	.890			
	IBD Severity	.259	.089	.439	2.894	.006			

Appendix X**Table of comorbidities reported in IBD group****Diagnosed health conditions in IBD group**

Psoriasis

HIV

IBS

PCOS (polycystic ovary syndrome)

IBS

IBS

Asthma

Asthma

Cancer in remission

Recent diagnosis of high cholesterol. To commence a statin for this.

multiple sclerosis, migraine

Ankle pain

Chronic fatigue syndrome and related pain

Infertility

Hyperthyroid

Hypothyroidism, PCOS

Hashimoto thyroid disease

Eczema

Appendix Y**Qualitative information related to CAM accessed for IBD and outcomes of CAM therapies**

CAM accessed for IBD	Outcome
-I have tried most herbal therapies, currently ingesting cannabis	
-Probiotics	
-Nutrition	no symptoms for the past 6 years
-Functional medicine.	Made symptoms worse
-Psychological therapy/ CBT	
-Massage Therapy/ Deep Tissue Massage	(very helpful with tight muscles and overall stress)
-I had ileostomy surgery in March this year, I no longer have a large intestine	
-Psychological therapy when first diagnosed	With good effect.
-Meditation	I found that it did help especially with sleeping at night which was affected by the Cohn's but I did give it up
-I was taking mesalazine, steroids, sulphasalazine, humira,	
-Acupuncture , paleo diet - Currently have a temporary ileostomy but still have flaring UC in rectum	Acupuncture - no outcome, Paleo diet - some relief from flare up
-Mindfulness	
-CBT for anxiety and stress	helped a bit with anxiety / stress levels
-Hypnotherapy	Positive outcome
-Colon clean	
-Hypnotherapy	

Appendix Z**Independent Samples T-test comparing differences in measures between CAM users and non-CAM users**

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
								Lower		Upper
Acceptance	Equal variances assumed	.592	.445	.805	52	.424	1.95724	2.43063	-2.92019	6.83466
	Equal variances not assumed			.768	25.593	.449	1.95724	2.54735	-3.28298	7.19745
Spirituality	Equal variances assumed	1.842	.181	-1.520	53	.134	-9.82692	6.46337	-22.79080	3.13695
	Equal variances not assumed			-1.354	22.417	.189	-9.82692	7.25683	-24.86046	5.20661
Anxiety	Equal variances assumed	.833	.366	.166	53	.869	.25962	1.56300	-2.87537	3.39460
	Equal variances not assumed			.184	35.552	.855	.25962	1.41033	-2.60192	3.12115
Depression	Equal variances assumed	2.109	.152	.485	53	.630	.64583	1.33278	-2.02738	3.31905
	Equal variances not assumed			.581	43.227	.564	.64583	1.11156	-1.59549	2.88716
Social Support	Equal variances assumed	.282	.598	-.671	53	.505	-1.84936	2.75765	-7.38050	3.68178
	Equal variances not assumed			-.856	49.453	.396	-1.84936	2.15939	-6.18782	2.48910
IBD Severity	Equal variances assumed	1.625	.208	-.313	52	.756	-.84211	2.69332	-6.24664	4.56243
	Equal variances not assumed			-.347	36.289	.730	-.84211	2.42523	-5.75935	4.07514

Appendix AA

Supplementary biological explanatory models of IBD

IBD may predominantly be a physical disease, yet, crucially interrelated with psychological distress, forming a vicious biopsychosocial cycle. One angle may be, acknowledging the role of biological factors can enable the development of therapeutics that tackle some of the complex interactions in the gut microflora. This may in turn assist with improving psychological wellbeing, a considerable unmet need.

While the serotonin hypothesis for mood is dubious and in some reviews has been considered no longer tenable due to being over-simplistic (Cowen, 2008), there is tentative indication that manipulation of serotonin in the gut, may impact the availability of its precursor, tryptophan, in the brain. However, this may or may not impact mood (Cowen, 2015). Conversely, growing evidence, predominantly from animal studies, postulate that psychological stressors can also alter the composition of gut microbes (De Palma et al., 2014; Moloney et al., 2013).