The Psychological Mediators in the Relationship Between Disease Activity and Psychological Distress and Quality of Life in Inflammatory Bowel Disease

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Dedication

This thesis is dedicated to my wife Laura and my son Jacob, for their love, patience, understanding, and belief in my ability to complete this thesis. I could not have done this without you!

Acknowledgements

I would like to thank Dr Simon Knowles for his invaluable guidance and wisdom in supporting me to complete this thesis. I would also like to thank Simon for ingniting my interest in the area of gastroenterology. I would also like to thank Professor Michael Kyrios, whom was my intial associate supervisor, and who through the many years has been supportive and a mentor. I would also like to thank Dr Jason Skeus and Dr Serofino Mancuso for their assistance as well as Debra Osborne who as part of her honours thesis, helped post the surveys online. Finally, I would like to especially thank Dr Richard Moulding, whose friendship and help over the years has been unwaivering and limitless.

Abstract

Research indicates that inflammatory bowel disease (IBD) is associated with significant reductions in psychological wellbeing and quality of life (QoL). However, there is limited research into the factors that influence the relationship between disease activity and QoL. The aim of this study was to examine whether illness beliefs, coping styles, self-efficacy, and dispositional mindfulness mediate this relationship, as guided by the socio-cognitive common-sense model (CSM) by Leventhal et al. (1980). Using online and traditional survey collection methods, 261 individuals diagnosed with IBD completed a battery of questionnaires, which assessed: disease activity (Thia et al. 2011; Truelove & Witts, 1955); illness beliefs (Broadbent, Petrie, Main, & Weinman, 2006); coping styles (Carver, 1997); self-efficacy (Chen, Gully, & Eden, 2001); mindfulness (Brown & Ryan, 2003); psychological distress (Lovibond & Lovibond, 1995); and QoL (Guyatt et al., 1989). Utilising correlational analysis, support was found for the first hypnothesis whereby disease activity was associated with higher levels of psychological distress and reduced QoL. Support was also found for the second hypothesis, which found that greater disease activity was significantly correlated with greater engagement in maladaptive coping, and less engagement in adaptive coping. The remaining four hypotheses of this study were anaylsed using structural equation modelling. In accordance with the CSM, support was found for the third hypothesis whereby the effect of disease symptom severity on psychological distress and QoL would be fully mediated by other variables. Hypothesis four was also supported, with illness perceptions mediating the relationship between disease symptom severity and coping, self-efficacy, and mindfulness. Partial support was found for hypothesis five, whereby coping styles, self-efficacy, and mindfulness mediated the relationships between illness perceptions, and psychological distress and QoL. However, a direct relationship was also found between illness perceptions, psychological distress, and QoL. Finally, partial support was found for the sixth hypothesis, whereby a direct relationship between illness perceptions and QoL, and also an indirect pathway to QoL (mediated by psychological distress) was found. Overall, these results extend the research exploring the mediating factors that influence psychological distress and QoL in an IBD population.

Declaration

I declare that this dissertation, to the best of my knowledge does not in any way contain any material that has been previously submitted for any other degrees or diploma, nor contains any material previously written or published by another person, with the exception of due reference made in text.

I declare that ethical principles specified in the procedures and policies of Swinburne University Human Research Ethics Committee have been strictly adhered to in preparation of this dissertation.

Jim D. Kantidakis Date: May 2016

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1. Chapter 1: Introduction

1.1 Introduction

1.1.1 Inflammatory bowel disease.

Inflammatory bowel disease (IBD) is a collection of chronic gastrointestinal conditions, most commonly classified as either Crohn's disease (CD), ulcerative colitis (UC), or indeterminate colitis (IC) (Hugot, 2004). CD is characterised by patchy transmural inflammation that can affect the entire digestive tract from the mouth to the anus. CD involves inflammation across all the layers of the gastrointestinal tract and may be defined by its location (upper gastrointestinal, ileocolic, colonic or terminal ileum) or by the pattern of the disease (inflammatory, structuring or fistulating; Carter, Lobo, & Travis, 2004; Gasche et al., 2000; Sands, 2004). In contrast, UC is characterised by a diffuse mucosal inflammation that is confined to the large intestine and broadly divided into distal (proctitis or proctosigmoiditis) or more extensive disease (left sided colitis; up to slenic flexure or extensive colitis; up to hepatic flexure; Carter, Lobo & Travis, 2004; Gasche et al., 1998; Sands, 2004). IC is diagnosed in approximately 10% of IBD patients when there is an overlap between CD and UC, and when the disease is seen as continuous (i.e., there is no clear distinction between the two; Chandrasoma & Taylor, 1998; Hugot, 2004). Both CD and UC are characterised by episodes of symptom exacerbation and remission (Papadakis & Targan, 1999). Further details regarding differences between IBD subtypes are found in section 1.2 (p.6).

1.1.2 Incidence and prevalence of IBD

In a systematic review to determine changes in the incidence and prevalence of CD and UC around the world, Molodecky et al. (2012) found the highest annual incidence of CD was 12.7 per 100,000 persons-years in Europe, 5.0 persons per year in Middle East and Asia, and 20.2 per 100,000 persons-years in North America. With respect to UC, the highest annual incidence was 24.3 per 100,000 persons-years in Europe, 6.3 per 100,000 persons-years in the Middle East and Asia and 19.2 per 100,000 persons-years in North America. Europe was found to have the highest prevalence of IBD (CD, 322 per 100,000 persons; UC, 505 per 100,000 persons), followed by North America (CD, 319 per 100,000 persons; UC, 249 per 100,000 persons). Molodecky et al. (2012) suggest that these findings indicate the incidence and prevalence of IBD are not only increasing over time, but also across different regions around the world, especially developing countries like Asia.

In the first Australian prospective population-based IBD incidence study investigating at-risk groups, Wilson et al. (2010) found crude incidence rates of 29.3 per 100,000 persons (95% confidence interval [CI] 23.5-36.7 per 100, 000) for IBD overall; 17.4 per 100,000 persons for CD; 11.2 per 100,000 persons for UC; and 0.8 per 100,000 persons for IC. An overall IBD incidence rate of 29.6 per 100,000 persons were found when age was directly standardised to the World Health Organisation standard population. The study also found 76 new cases of IBD diagnosed between 1 April 2007 and 31 March 2008 in the Geelong region. Of these, 45 were CD, 29 UC, and two were IC. The study also found 43 were females, and the age of diagnosis ranged from 9 to 76 years.

In 2013, the Australian Crohn's and Colitis Association (ACCA), in collaboration with Pricewaterhouse Coopers Australia (PwC, 2013), estimated that between 68,058 and 83,666 Australians (*M* = 74,955) have been diagnosed with IBD, with a prevalence rate of 0.33%. These findings suggest an increase in the number of individuals diagnosed with IBD over time when compared to suggested estimates by the ACCA of 43,000 people diagnosed with IBD in Australia and a prevalence rate of 0.21%. However, based on a "best estimates" analysis carried out by Access Economics Pty Ltd (2006) for the ACCA, it was estimated that approximately 61,000 individuals have been diagnosed with IBD. The most recent report (PwC, 2013), however, does not elaborate on the differences between CD and UC. According to Access Economics Pty Ltd (2006), the estimated prevalence in Australia was 28,000 people with CD and 33,000 with UC. Based on these estimates, the prevalence rate for Australia for CD was 0.15% and 0.06% for UC.

1.1.3 Demographics.

Loftus (2004) suggests the presence of a slight gender-related difference in IBD incidence, with a predominance of CD in females. In certain low incidence areas, however, a male predominance of CD exists. According to Loftus, the higher incidence rates among women, especially among late adolescence and early adulthood, may be due to the influence hormones have on disease expression. Loftus (2004; Loftus et al., 2000) also suggests a slight predominance of UC in males with an increase in incidence over time, as compared to females who demonstrate a decrease in incidence.

Based on a multicentre study in Europe that included 2,201 IBD patients (1,379 UC and 706 CD), Binder (2004) found that women aged 25 to 34 years demonstrated a peak in UC incidence, with a rapid fall in incidence with age thereafter. Men also experienced a peak at this age, although it was not as great as was found in women (see Figure 1.1). In CD, both males and females showed a peak in incidence in the 15-24 years group, which was followed by a decline with increasing age (see Figure 1.1).

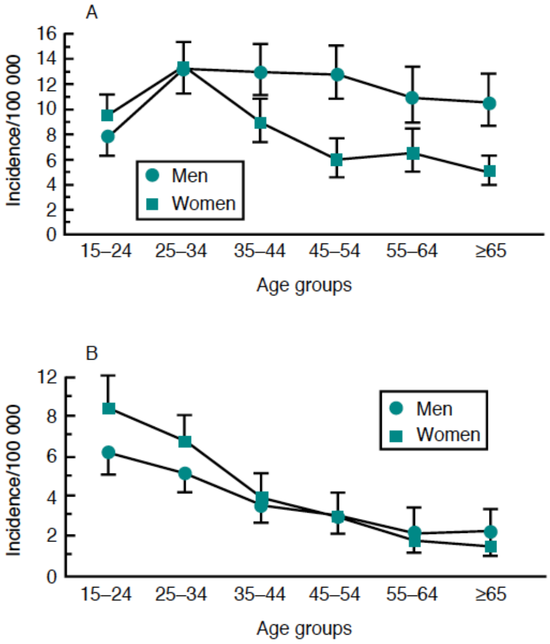


Figure 1.1. Age-specific incidence rates per 100,000 persons for UC (A) and CD (B) in the 20 centres included in the EC-IBD study (Binder, 2004).

The predominance rates of UC cases found were male:female ratios of 1.2:1.5, respectively, for centres in the north and south of Europe. However, more women than men were found to have CD; the male:female ratio being 0.8 in the northern centres and 1.0 in the south (Binder, 2004). In contrast to the United States and Europe, more men than women are diagnosed with CD in China (Szeto et al., 2007).

Using age and gender specific prevalence rates from Canada and New Zealand, of the 28,000 Australian individuals diagnosed with CD, approximately 59% were females and 41% males. The highest prevalence group was between 30 to 39 years of age (approximately 2,800 males and 4,300 females). The gender distribution for UC in Australia was reported to be 52% males and 48% females, with the highest prevalence found in those aged over the 60 years, consisting of 5,500 males and 4,200 females. In summary, whereas the prevalence of

CD peaks in individuals aged between 30 and 39, the prevalence of UC appeared to increase with age (Access Economics Pty Ltd., 2006).

1.1.4 Financial cost.

IBD has a high financial impact on the individuals it affects. According to research conducted by Access Economics (2006), the total financial cost of IBD in Australia in 2005 was approximately $500 million, including $239 million for CD and $258 million for UC. This cost was attributed to multiple factors, including the disruption to education and employment caused by the early age of onset of IBD resulting in loss of productivity. According to a more recent Australian study by PwC (2013), the total hospital cost of IBD in Australia is approximately $100 million per annum. The study also found a significant loss to work productivity totalling approximately $361,499,232 per annum. In total, the financial and economic cost in 2012 of IBD, which included: deadweight losses; informal care; funeral costs; out of pocket expenditure; welfare payment; and burden of disease, was estimated to be over $2.7 billion.

1.1.5 Diagnosis.

The diagnosis of IBD is based on several information sources, including clinical symptoms, endoscopic, histological, and radiological findings (Bernstein et al., 2010; McFarland, 2008). Due to the variance in frequency, symptom types and lack of structural abnormalities observed using endoscopic examination, the diagnosis of IBD can be delayed for as long as one year (McFarland, 2008). UC diagnosis can also be made with mucosal biopsies, which can assist in differentiating cases of UC from cases of CD, which present with inflammation (eiptheloid granulomas). Sequential testing strategy with F-calprotectin to test for biological inflammatory markers has also been an effective way of helping to diagnose IBD, thereby reducing the demand for colonoscopies (Mindemark & Larsson, 2012).

1.2 Types of IBD

1.2.1 Crohn’s disease.

CD is a transmural inflammatory disease of the mucosa that is characterised by episodic progression. It commonly affects the ileum (most commonly the terminal ileum), however, it has the potential to affect any part of the gastrointestinal (GI) tract, from the mouth to the anus (Orchard, Willimas, Tekkis, Goldin, & Goldin, 2011). It is characterised by noncaseating eiptheloid cell granulomas, transmural (full thickness) inflammation of the affected parts, and involves typical discontinuous segments or intestinal skip lesions (Chandrasoma & Taylor, 1998; Orchard, Willimas, Tekkis, Goldin, & Goldin, 2011; Figure 1.2). CD has also been called granulomatous colitis, with 75% of cases resulting in perineal complications, including fistulas, skin tags, and abscesses. CD is characterised by its gross appearance, with normal and affected intestine sharply demarcated from each other (Chandrasoma & Taylor, 1998).

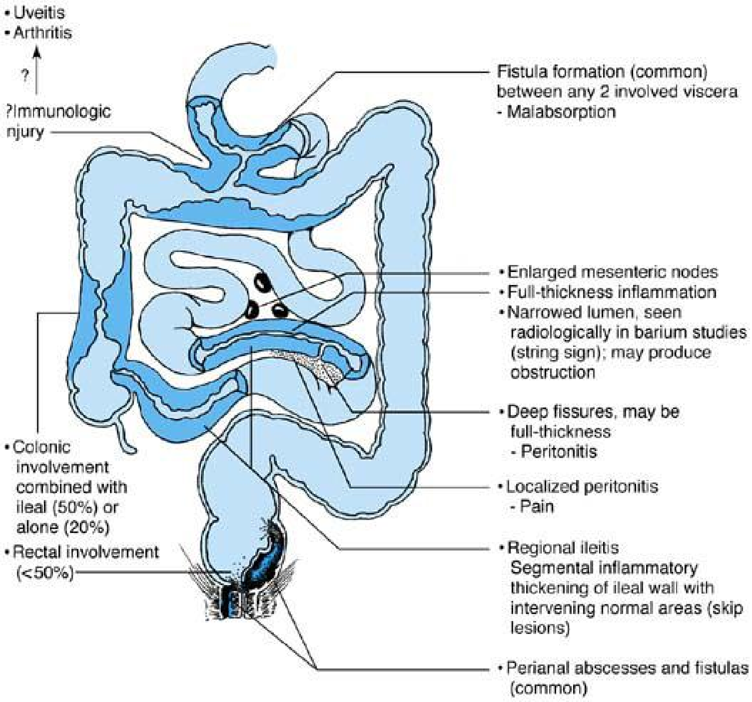


Figure 1.2. Pathogenic features of CD (Image taken from Chandrasoma & Taylor, 1998).

During the active phase of CD, the inflammation results in the intestine becoming swollen and reddened. The mucosa has shallow aphthous ulceration and diffuse hyperaemia. During the chronic phase of the disease, the affected segment of the GI tract is greatly thickened and is rigid, such that it resembles a garden hose or lead pipe (Figure 1.3). Intestinal obstruction is common, caused by marked fibrosis resulting in luminal narrowing (Bernstein, Fried, et al., 2010).

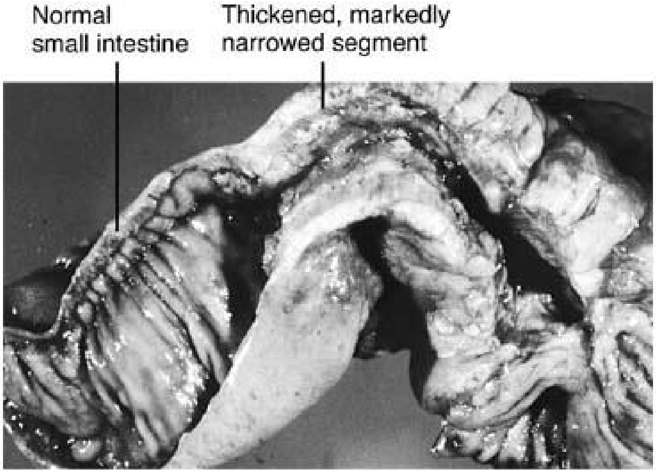


Figure 1.3. Intestinal obstruction (Image taken from Chandrasoma & Taylor, 1998).

1.2.2 Clinical features of CD.

The clinical features of CD depend on its localisation and may range from low-grade fever, diarrhoea, abdominal pain, malaise, weight loss, anaemia, non-bloody diarrhea, post pradial bloating, cramping in the lower right quadrant, and a tender mass in the lower abdomen (Bernstein, Fried et al., 2010).

1.2.3 Complications in CD.

Intraintestinal complications (i.e., complications occurring as a result of the direct influence the disease has on the GI tract) in CD include: intestinal obstruction; fistula formation between involved loops of bowel and adjacent viscera; fistulas between the ileum and colon, resulting in malabsorption; fistulas between the bowel and the urinary tract (enterovesical fistulas), resulting in urinary tract infections from the mixing of gas and faeces with urine; and enterovaginal fistulas that produce faecal and vaginal discharge (Bernstein, Fried et al., 2010). Malabsorption of vitamin B12 and bile acids, resulting in megalobalstic anaemia and fat malabsorption, occurs when the disease affects the terminal ileum. Loss of protein absorption (protein losing enteropathy) from inflamed mucosa, and chronic occult bleeding may also result in deficiency anaemia. Although much less common in CD than in UC, there is also a slight increased risk of developing carcinoma of the colon (Laukoetter et al., 2011; Jess et al., 2006).

Complications due to IBD involving organs other than the GI tract are termed extraintestinal symptoms. Extraintestinal symptoms may not always coincide with the underlying bowel disease, and can involve almost every organ system, including the eyes, skin, lungs, and bilary tract (Ott & Schölmerich, 2013). CD has also been found to be associated with oral lesions, pancreatitis, gallstones, amyloidosis, uveitis, arthritis (Ott & Schölmerich, 2013), and nephrolithiasis, whereas skin and eye problems are seen equally in CD and UC (Rothfuss et al., 2006).

According to Rothfuss et al. (2006), several factors may be responsible for extrainstestinal organ involvement, with difficulties at times differentiating the true extraintestinal manifestations of the disease (primary system affection by the disease itself), from secondary extraintestinal complications of the disease (for example, caused by malnutrition, side effects of therapy, and chronic inflammation). IBD is also associated with an increased risk of vascular complications, including arterial and venus thromboembolism, which is a significant cause of morbidity and mortality in IBD patients (Koutroubakis, 2005), and renal and urologic complications (Pardi, Tremaine, Sandborn, & McCarthy, 1998). A summary of extraintestinal manifestations and complications is shown in Table 1.1.

1.2.4 Ulcerative colitis.

Whereas CD can manifest anywhere in the GI tract, UC is a disease involving the colon and rectum, and extends continuously without skip areas (Figure 1.4). In UC, the mucosa of the colon is edematours and red, with the presence of pseudoplyps, resulting in a a cobblestone appareance (Orchard, Willimas, Tekkis, Goldin, & Goldin, 2011; Twedell, 2008).

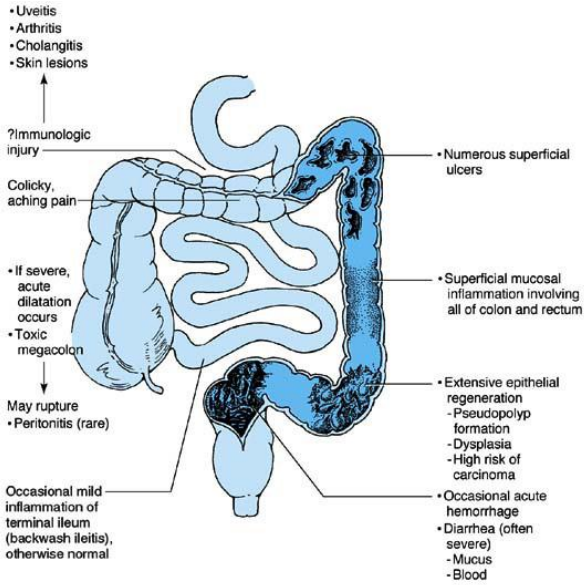


Figure 1.4. Pathogenic features of UC (Image taken from Chandrasoma & Taylor, 1998).

UC mainly involves the mucosa of the colon, with numerous superficial ulcerations on the mucosal surface during the acute phase of the disease (Ordas, Eckman, Talamini, Baumgart, & Sandborn, 2012). In contrast to CD, there is rarely any thickening in the bowel wall, with toxic dilation or megacolon only occurring in very rare cases. During chronic remission phases of UC, the mucosal surface appears flat and atrophic due to the re-epithelialisation of the ulcers (Ordas et al., 2012).

1.2.5 Clinical features of UC.

In UC, the patient may experience fever, leucocytosis (increase in number of white cells in blood), diarrhoea with blood and mucus in stools, and lower abdominal pain during the acute phase of the disease. UC is also characterised by remissions and exacerbations during the chronic phase of the disease (Chandrasoma & Taylor, 1998).

1.2.6 Complications of UC.

During the active phase of UC, complications can arise including, severe bleeding of the bowel, toxic megacolon, functional obstruction, and rarely, perforation (Meier & Sturm, 2011). UC may also require emergency colectomy (Samuel et al., 2013).

During the active phase of UC, there is approximately a 2.4-fold risk of developing colon rectal carcinoma (Jess, Rungoe, & Peyrin–Biroulet, 2012), with a cumulative risk of 2% after 10 years of diagnosis, 8% after 20 years and 18% after 30 years of diagnosis (Ordas et al., 2012). Arthritis, uveitis (inflammation of the middle layer of the eye), and skin lesions, including pyoderma gangrenosum, are few of the extraintestinal manifestations of UC. Overall, more extraintestinal manifestations occur in UC compared to CD (Rothfuss et al., 2006). The clinical similarities and differences between CD and UC can be seen in Table 1.1

Table 1.1

Main Differences Between CD and UC (Orchard, Willimas, Tekkis, Goldin, & Goldin, 2011).

Crohn's Disease		**Ulcerative colitis**	
Location		*Location*	
Any part of the alimentary tract affected		Only Large Bowel (thiough possibility of 'backwash ileitis'):	
	Cases (%)		Cases (%)
Ileocolonic	45	Proctitis	25
Colitis only	25	Left sided (to splenic flexure)	45
Terminal ileum only	20	Extensive/pancolitis	30
Extensive small bowel	5		
Anorectal only	3		
Other (gastroduodenal, oral)	2		
Clinical		*Clinical*	
Diarrhea +/- rectal bleeding		Diarrhoea	
Weight loss		Rectal bleeding	
Abdominal pain			
Constitutional symptoms			
Perianal disease			
Histology		*Histology*	
Deep, transmural inflammation		Mucosal inflammation	
Patchy		Continuous	
Non-caseating granulomata characteristic		Granulomata rare	
Lymoid aggregates ++		Lymphoid aggregates rare	
Cryptitis and crypt abscesses +		Cryptitis and crypt abscesses ++	
Complications		*Complications*	
Fistula formation		No fistula	
Stricturing disease of small bowel		No small bowel involvement	
Abscess formation		Abcesses not a feature	
Vitamin B12 deficiency (ileal involvement;		Vitamin B12 defiency rare	
Less than UC		Increased risk of coloinic carcinoma	

1.3 Aetiology of IBD

IBD, including CD and UC, have been classified as complex genetic disorders of unknown etiology (Hugot, 2004). The limited understanding of the disease etiology places the diagnosing clinician in a difficult position of negating alternative diagnoses in order to make an accurate diagnosis of IBD (Korzenik, 2005). It is necessary to first eliminate all other possible alternative aetiologies from other very rare disorders, which means that diagnosing IBD is a drawn out process. The result is often a provisional diagnosis of IBD with patients being classified according to the clinical presentation of their disease (Hugot, 2004).

McFarland (2008) suggests the pathogenesis of IBD may involve four major causes: immunologically mediated pathology; pathology due to microbial dysbiosis; pathology triggered by environmental factors; and genetic predisposed pathology. An altered immune response can be found in both UC and CD, in the form of proinflammatory cytokines that are produced during IBD active phases. Seksik et al. (2006) suggest that microbial dysbiosis (microbial imbalance) of has been documented in IBD patients. Thompson-Chagoyán Maldonado, and Gil (2005) also suggest it is probable that IBD involves a combined etiology of genetic predisposition and environmental factors. However, Thompson-Chagoyán, et al. further suggest that these factors are channelled through an abnormality in the gut-barrier function, with the loss of antigen tolerance.

Many potential causes have been linked to IBD, including genetic (Ek, D'Amato, & Halfvarson, 2014; Hugot et al., 2001), environmental (Loftus, 2004), immunologically mediated pathology (Khor, Gardet, & Xavier, 2011), and microbial dysbiosis (Cantorna, McDaniel, Bora, Chen, & James, 2014). In 2001, Hugot et al. were the first to identify two genes that influenced the etiology of IBD; the nucleotide-binding oligomerisation domain containing 2 gene (NOD2) and the caspase-activating recruitment domain 15 gene (CARD 15). Since then, the genetic puzzle has become more complicated, with the findings of at least 163 risk genes/loci being linked to IBD aetiology (Ek et al., 2014). According to Ek et al. (2014), other immune-mediated disease like mycobacterial disease and immune-deficiencies are also shared with a large proportion of the IBD risk loci. Wang and Achkar (2015) argued that it is probable that IBD involves a combined aetiology of genetic predisposition and environmental factors. These environmental causes include: hygiene (Delcò & Sonnenberg, 1998); microbial exposure (Amre et al., 2006); diet (Danese, Sans, & Fiocchi, 2004); gastrointestinal infection (Mann, Saeed, & Shehzad, (2012); cigarette smoking for CD (Cosnes, 2004); infectious agents (Mann & Saeed, 2012); oral contraceptives (Khalili et al., 2012); perinatal and childhood factors (Roberts, Wotton, Williams, Griffith, & Goldacre, 2011); vaccination (Thompson, Pounder, Wakefield, & Montgomery, 1995); and psychogenic factors (Fiocchi, 1998).

Earlier research suggested psychological distress played a role in IBD onset and exacerbation (Maunder et al. 2006). In their review, Maunder et al. (2006) suggested that the reasons for the lack of support in the role of stress in IBD is due to historical exclusions of a number of studies due to inadequate methodological testing. According to Maunder et al. (2006), despite the necessary “pruning” of these flawed studies, eight of 15 controlled studies showed a positive association. In conclusion to their review, Maunder et al. (2006) suggested that there is support for the role of psychological stress in the course of UC, and for depression in the course of CD, even though results remain inconsistent. Levenstein et al. (2000) studied patients with known UC while in clinical remission. These patient’s perceived stress, stressful life events and depressive symptoms, along with potential confounders were followed up for up to 45 months, with exacerbation status monitored for up to 68 months. The 27 patients who had experienced an exacerbation were compared to those who were in remission. Both groups were assessed on their stress, depressive symptoms, and stressful life events. According to Levenstein et al. (2000), their findings suggested that long-term perceived stress increases the likelihood of exacerbation in UC (over a period of months to years), however, short-term stress does not. It is beyond the scope of the present study to explore these causative environmental factors in detail.

1.4 Treatments and Surgery

The goal of IBD treatment is to induce and maintain remission (Pithadia & Jain, 2011). Effective treatment of IBD is challenging, given there is no clear understanding of the aetiologies of the disease (Bernstein, Fried et al., 2010). As a result of an overactive immune response, standard treatment has incorporated the use of immunomodulators and immunosuppressive medications (McFarland, 2008). Traditional treatments using corticosteroids and 5-aminosicylates (5-ASA) are not without complications. Prolonged use of these drugs can lead to adverse side effects, including reactivation of tuberculosis, increases in serious infections, and the development of demyelinating disease or lymphoma (Stein & Hanauer, 2000).

According to Shergill and Terdiman (2008), the course of treatment for CD is as follows: following diagnosis, a patient is medicated based on their presenting symptoms and symptom severity. Mild-to-moderate symptoms are initially treated using medications such as antibiotics or 5-ASA. Mesalamine, though limited to being effective only with UC, are administered due to their minimal toxicity and good safety profile. Corticosteriods are initiated for patients with greater severity, due to their ability to effectively reduce inflammation and in turn, symptoms (Pithadia & Jain, 2011). Corticosteroid use is aimed at achieving symptomatic remission quickly, in order to stop its use before the development of long-term steroid-related complications. If the patient fails to improve with the corticosteroids, he or she is then prescribed immunomodulators, methotrexate or azthioprine (AZA), or biological agents such as adalimumab, infliximab, abatacept, and golimumab (Mozaffari, Nikfar, Abdolghaffari, & Abdollahi, 2014; Clark et al., 2007; Lichtenstein, Abreu, Cohen, & Tremaine, 2006). If standard treatment fails and remission is not achieved or the individual develops serious complications, surgery is usually the only other available option to the patient. For CD patients, the lifetime risk for surgery is 70-80%, and for UC patients 20-30% (Roberts, Williams, Yeates, & Goldacre, 2007).

According to a review by Bernstein, Fried et al. (2010), 70-75% of CD patients require surgery at some point, whether this may be due to the failure of drug treatment or for correction of complications. Despite the potential for surgery to provide long lasting remission, it is rarely curative. With UC, surgery occurs in 20-30% of patients if treatment is unsuccessful or if dysplasia is present. In contrast to CD, surgical resection can be considered curative (Bernstein Fried, et al., 2010). A total proctocolectomy is also an option, with the patient being given a permanent ileostomy or ileoanal anastomosis. Medication can still be included in treatment even post-surgery.

1.5 Morbidity and Mortality

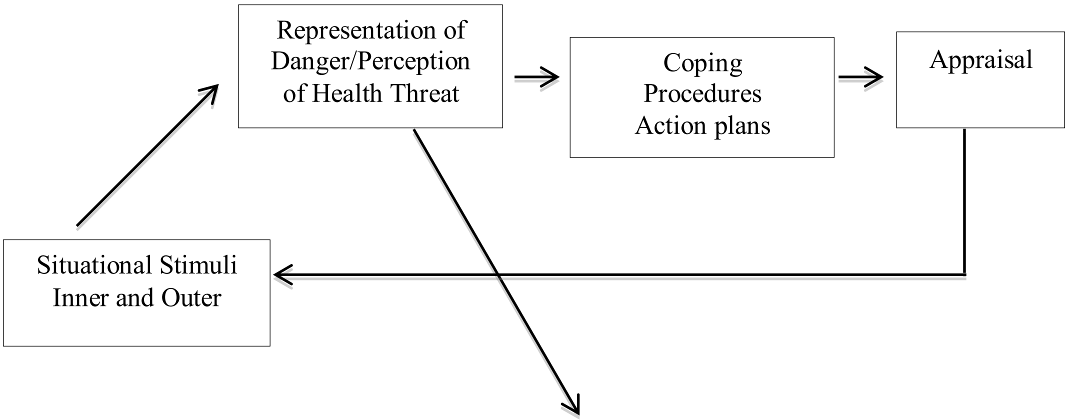
CD and UC may directly result in morbidity, however, rarely mortality (Selinger & Leong, 2012). Mortality that does occur tends to result from complications such as toxic megacolon, sepsis due to penetrating disease or colorectal cancer, and thromboembolism (Jess, Gamborg, Munkholm, & Sørensen, 2007; Mowat et al., 2011; Selinger & Leong, 2012). According to Selinger et al. (2013) and data collected from the northern hemisphere, patients with UC have similar survival rates as the general population, however, with CD, mortality rates are increased by up to 50%. In their study exploring an Australian cohort of patients with IBD, Selinger et al. (2013) found similar survival rates to the general population. Selinger and colleagues also found that IBD caused direct mortality in 17% of the 816 cases, with biliary and colorectal cancers being significant contributors of death. On the other hand, physical, social, and psychological morbidity can negatively impact upon a sufferer’s quality of life. The remaining sections of this chapter aim to focus on each of the psychological, social, and emotional factors affecting individuals diagnosed with CD and UC.

1.6 Illness Perception

Illness perceptions or cognitive representations are important to an individual's ability to cope and manage stressful situations (Leventhal, Nerenz, & Steele, 1984; Petrie & Weinman, 2006). Illness perceptions refer to the organised cognitive representations or beliefs an individual holds about their illness or disease (Petrie, Jago, & Devcich, 2007). Illness perceptions have been shown to determine behaviour such as treatment adherence and influences functional recovery (Leventhal et al., 1997; Weinman & Petrie, 1997). When individuals are faced with new health threats - based on a symptom or diagnosis - they create cognitive models (or representations) of the threats which in turn determines how individuals respond (Lau & Hartman, 1983; Leventhal et al., 1984; Petrie & Weinman, 1997). These representations or perceptions, explained below, are based upon an individual's personal experience and from their interpretation of others' experiences with similar symptoms and/or diagnoses (Broadbent et al., 2006; Leventhal et al., 1980; Petrie & Weinman, 2006; Weinman & Petrie, 1997).

Once an individual notices a symptom, there is pressure for them to find a label they can assign to that symptom in order to help explain their ill health (Petrie & Weinman, 2006). The opposite, however, can also occur; when a patient is given a diagnosis, the patient will then search for symptoms they see relevant to their diagnosis, even if the disease is asymptomatic. This can be further complicated by an individual's poor knowledge regarding their own body (Petrie & Weinman, 2006).

Once these perceptions are made, they then guide the individual to behave in a way that reduces the danger of the illness or threat. Simultaneously, the individual will develop coping strategies to reduce the emotional response to the threat (Leventhal et al., 1984; Petrie & Weinman, 2006). The final stage of the model results in the individual incorporating a continuous feedback loop, where the outcomes of the appraisal process are incorporated back into the formation of the illness perception, resulting in the adoption of coping responses (Broadbent et al., 2006); see Figure 1.5 and refer to section 1.12 for full explanation of the common sense model (CSM).



IDENTITY	TIMELINE (duration)	CONSEQUENCES (expected outcomes)	CAUSE	CONTROL (yes/no)
Symptoms	Perceived time	Physical Disability	Lack of sleep Contact with sick individual	Treatments effective?

Figure 1.5. The five domains of illness representations within the CSM (Leventhal, Brissette, & Leventhal, 2003).

According to Leventhal et al. (1984), five inter-related components are involved in patients formulating views or representations of their illness. These include: identity, timeline, consequences, cause, and cure or control. It is these different perceptions that contribute to patients with the same illness experiencing that illness differently, ultimately, resulting in different psychological and illness trajectories (Petrie & Weinman, 2006).

Illness identity involves the label used by the individual to describe their illness and symptoms they perceive to be a part of their illness (Broadbent et al., 2006). It is not uncommon for the identity of the illness to be misattributed and different to that of medical staff treating the condition (Petrie & Weinman, 2006). Once an individual is diagnosed with an illness, they quickly formulate causal beliefs as to how they developed the illness, commonly attributing it to stress or environmental pollution (Petrie & Wessely, 2002).

Timeline beliefs occur when an individual with an illness adopts a timeline to their disease, ranging from acute to chronic. This also includes their belief of how long they believe it will last, which also influences whether they will adhere to their medications. For example, individuals with acute conditions are more likely to abandon treatment, compared to individuals with more chronic perceptions (Petrie & Weinman, 2006).

The consequences component refers to the consequences of the illness upon the patient's QoL, including their family, work, finances, and lifestyle (Petrie & Weinman, 2006). Consequence is influenced by the subjectively perceived severity of the condition, with little relation to the actual objective clinical markers for the disease and its severity (Petrie & Weinman, 2006).

Causal beliefs influences the behavioural changes individuals will undertake in order to control their illness. An example would be of an individual who has suffered a heart attack, and who may believe that their poor diet and smoking contributed to this, therefore highlighting the need to change (Weinman, Petrie, Sharpe, & Walker, 2000). Influence on emotions can also be strongly attributed to causal beliefs. This may be seen in individuals diagnosed with diseases of unknown aetiology, including cancer or a sexually transmitted disease, where the individual blames themselves for the onset of the illness (Petrie & Weinman, 2006).

Control/cure perception suggests the level of control an individual perceives they have over their illness. According to Petrie and Weinman (2006), causal beliefs and timeline are closely associated with control or cure of illness. This is evident when individuals feel they have control over their illness, therefore reducing the perceived timeline of their illness.

According to Leventhal, Brissette, and Leventhal (2003), each of these five domains contains both perceptual and semantic information about the particular illness threat, with each variable in the domain being both concrete and abstract. An example by Nemeroff and Rozin (1994) explains the causal concept of contagion as involving both the concrete (i.e., the concept of germs), and abstract (i.e., exposure through contact with an infected person). Another example using the domain timeline is when the illness is represented abstractly (e.g., “How long will this flu last?”) and experientially (e.g., “It has taken forever to overcome this flu”; Nemeroff & Rozin, 1994).

1.6.1 Illness perception and chronic illness.

Previous studies on individuals diagnosed with a disease have found illness beliefs to be associated with more negative outcomes, including slow recovery and future disability independent of the initial medical severity of the condition (Petrie et al., 2007). Examples of these diseases include: coronary obstructive pulmonary disease (COPD; e.g., Borge et al., 2014); diabetes (e.g., Eiser, Riazi, Eiser, Hammersley, & Tooke, 2001; Paschalides et al., 2004); breast cancer (e.g., McCorry et al., 2013); arthritis (e.g., Zyrianova, Kelly, Sheehan, McCarthy, & Dinan, 2011); asthma and renal disease (e.g., Broadbent et al., 2006); chronic fatigue (e.g., Moss-Morris, Petrie, & Weinman, 1996); myocardial infarction (e.g., Alsén, Brink, Persson, Brändström, & Karlson, 2010; Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009); and chronic repetitive strain injury (e.g., Sluiter & Frings-Dresen, 2008).

Using the Illness Perceptions Questionnaire-Revised (IPQ-R; Moss-Morris et al., 2002), Cancer Coping Questionnaire (Moorey, Frampton, & Greer, 2003) and the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), McCorry et al. (2013) examined the extent to which illness perceptions and coping explained psychological distress in patients diagnosed with breast cancer. Ninety breast cancer patients were tested at the time of diagnosis and at six-month follow-up. Using cluster analysis, McCorry and colleagues found illness perception membership and positive (adaptive) focus type coping to be important predictors of lower psychological distress, both at the time of diagnosis and at six-month follow-up. The authors also reported women diagnosed with breast cancer experience lower levels of distress when they believe that: their cancer will not be cyclical; do not have strong beliefs about the cause of their cancer; will not have serious consequences; and treatment will be effective such that the cancer will not last a long time. These findings suggest that, unless this population is subjected to direct interventions aimed at modifying perceptions, breast cancer patients' illness perceptions are resistant to change (McCorry et al., 2013).

Chronic pulmonary disease (COPD) is a chronic disease affecting the respiratory system and is characterised by respiratory symptoms including cough, primary dyspnoea, sputum production, and a decline in lung function over time (Rycroft, Heyes, Lanza, & Becker, 2012). Consequently, COPD is associated with psychological distress (Blakemore et al., 2014) resulting from hospitalisations, work absences, economic burden, and disability (Rycroft et al., 2012). Borge et al. (2014) explored illness perceptions and QoL in 154 individuals diagnosed with COPD. Using the Brief Illness Perceptions Questionnaire (BIPQ; Broadbent et al., 2006), the Respiratory QoL Questionnaire (Stavem, Erikssen, & Boe, 1999), Short Form-12 Health Survey (Ware, Kosinski, & Keller, 1996), and the QoL Scale (QOLS; Burckhardt, Woods, Schultz, & Ziebarth, 1989), Borge et al. (2014) found that higher scores on the illness perception dimensions identity, consequences, and concerns were associated with impaired physical health, and consequences. Higher scores on the emotional representation and identity dimensions were associated with impaired mental health. Higher scores on the illness perception dimensions of identity, consequences, coherence, and emotional representation were associated with impaired global QoL. Finally, high scores on the dimensions of identity, concern, consequences, and emotional representation were also associated with increased physiological changes; for example, increased breathlessness.

Paschalides et al. (2004) explored the association of illness perceptions with anxiety, depression, and QoL in 184 individuals diagnosed with Type 2 diabetes. Utilising the IPQ (Weinman, Petrie, Moss-Morris, & Horne, 1996), and measures for psychological wellbeing (Wellbeing Scale [WBQ]; Bradley, 1994) and QoL (SF-36; Ware & Sherbourne, 1992), Paschalides et al. found that depression was correlated with perceived lack of control ($r = .28$, $p < .01$) and higher symptom load ($r = .48$, $p < .01$). Illness perceptions relating to symptom load and perceived consequences were associated with the QoL physical functioning domain, while depression and anxiety, together with illness perceptions of control, were independently associated with the QoL mental function score. Contrary to their hypothesis, Paschalides et al. did not find either IPQ or WBQ scores to be associated with glycosylated haemoglobin (HbA1c) levels, despite previous findings by Hampson, Glasgow, and Strycker (2000).

Additional evidence for the influence of illness perception on disease has also been found in studies aiming to improve patients' QoL and their adherence to treatment (Broadbent et al., 2006; Frostholm et al., 2005; Keogh et al., 2007; Petrie, Cameron, Ellis, Buick, & Weinman, 2002). For example, Broadbent et al. (2009) conducted a randomised controlled trial in order to develop and test a brief in-hospital illness perception intervention program, which was completed by 103 individuals with acute myocardial infarction (MI). Patients were randomised into the intervention group or standard care group. The intervention groups consisted of three half-hour patient sessions and one half-hour patient and spouse sessions. Broadbent et al. (2009) found that a brief in-hospital intervention was successful in changing a patient's perception of their MI, resulting in a more optimistic outlook towards the future, a quicker return to work, and less rates of reporting angina symptoms as compared to the control group. This was likely a result of patients not worrying or excessively checking their symptoms whilst being more actively involved in rehabilitation programs (Broadbent et al., 2009).

In summary, a number of studies highlight the importance that illness perceptions have on chronic illness, specifically, psychological wellbeing and QoL (Borge et al., 2014; McCorry et al., 2013; Paschalides et al., 2004). Studies also suggest the importance illness perceptions play in treatment compliance programs (Broadbent et al., 2006; Frostholm et al., 2005; Keogh et al., 2007; Petrie, Cameron, Ellis, Buick, & Weinman, 2002) and interventions aimed at improving therapeutic outcomes, including QoL (Broadbent et al., 2009).

1.6.2 Illness perception in IBD.

Few studies have specifically explored the relationship between illness perceptions, and psychological morbidity and QoL in individuals living with IBD (Daniel, 2002; Han et al., 2005; Kiebles, Doerfler, & Keefer, 2010). Han et al. (2005) explored the role of illness perceptions and demographic factors in predicting QoL. One hundred and eleven UC in-patients and out-patients completed a number of measures, including: the Inflammatory Bowel Disease Questionnaire (IBDQ; Guyatt et al., 1989); 36-item Short-Form Health Survey (SF-36; Ware, 1992); IPQ (Weinman, Petrie, Moss-Morris, & Horne, 1996); demographic questions (e.g., age, gender, living circumstances, marital status, and socioeconomic status including income level); disease activity measures, including the Colitis Activity Index (CAI; Lichtiger et al., 1994); and biological markers, including erythrocyte sedimentation rate (ESR) levels. Using bivariate analysis and multivariate regression, Han et al. found illness perception to be a relatively weak predictor of QoL, with a stronger relationship being found between disease activity and QoL. The authors also reported no significant differences between demographic variables or biological indicators that significantly predicted QoL. According to the authors, reducing symptoms is more important than reducing illness perceptions when looking to improve QoL. Although the study utilised a reasonable sample size of 111 UC participants, it was limited in its exploration of other important factors; for example, not including or comparing findings with a CD cohort or including other measures to test for psychological distress, coping or self-efficacy (Han et al., 2005).

In a sample of 38 individuals diagnosed with CD (45%) and UC (55%), Kiebles, Doerfler, and Keefer (2010) assessed illness perceptions (IPQ-R; Moss-Morris et al., 1996), emotional functioning (Brief Symptom Inventory; Derogatis & Melisaratos, 1983), stress (Perceived Stress Questionnaire; Levenstein et al., 1993), coping strategies (Brief Cope; Carver, 1997), disease acceptance (Digestive Diseases Acceptance Questionnaire; Zinke & Keefer, 2008), disease impact (Beckman et al. 2008), and QoL (IBDQ; Guyatt et al., 1989). Using correlational analysis and independent samples *t*-tests, Kiebles et al. (2010) found increased disease activity, psychological distress, and reduced QoL to be associated with poorer illness perceptions. Although the authors reported robust results, their sample size was still relatively small. Kiebles et al. also reported only using the impact on life, chronicity, and beliefs about control components the IPQR despite the IPQR also including the components of cause of illness and identity. The results nonetheless indicate illness perceptions influence psychological distress.

The study by Hans et al (2005) highlights some inconsistencies in the literutre regarding the importance of illness perceptions on QoL, however the majority of studies reinforce past chronic illness studies discussed in section 1.4.2. There is an obvious limit to the small number of studies specifically exploring illness perceptions in IBD (i.e., two), both of which featured methodological limitations, including: small sample sizes (Kiebles et al., 2010); only testing one type of IBD (Han et al., 2005); and only recruiting newly diagnosed participants within a specific setting (Kiebles et al., 2010). Nevertheless, both studies found that poorer illness perceptions (i.e., greater illness identity; beliefs about the long-term course and adverse effects of the illness; greater beliefs that a specific cause contributed to the illness; and stronger beliefs that control or cure is not possible) contribute to higher psychological distress and reduced QoL.

An expanding area of IBD oriented research is extending the illness perception literature within the context of the CSM (Dorrian, Dempster, & Adair, 2009; Knowles, Cook, & Tribbick, 2013; Knowles, Gass, & Macrae, 2013; Knowles et al., 2011; Rochelle & Fidler, 2013; van der Have et al., 2013). The CSM involves the generation of a cognitive and emotional representation of an illness/threat that influences the development of a behavioural representation. These behavioural regulations are aimed at reducing the threat and regulating the emotions (Leventhal, H., Meyer, D., & Nerenz, D., 1980). These studies, and how illness perceptions interact with other psychological constructs and outcomes, will be discussed in greater detail later in section 1.12.

1.7 Coping

According to the CSM (discussed in section 1.12), once an illness perception has been formulated, an individual will then either actively or passively attempt to reduce the threat by regulating emotion with coping strategies (Llewellyn et al., 2007). Coping or adaptation processes are considered ways in which an individual manages and deals with stress (Lazarus & Folkman, 1984) and dates back to Sigmund Freud and his concept of defence as a set of psychological mechanisms by which individuals distort reality to manage distressing feelings (Somerfield & McCrae, 2000). This was further expanded upon in Anna Freud’s work where she introduced the notion that individuals have preferred styles or ways of managing stress (Somerfield & McCrae, 2000).

These psychoanalytical approaches were later criticised by Lazarus and Folkman (Folkman & Lazarus, 1985; Lazarus & Folkman, 1984) as coping was evaluated along a single dimension. According to Steed (1998), these approaches underestimated the variability and complexity of actual coping efforts. In a review of the coping measurement literarure, Steed (1998) argued that these psychoanalytical approaches do not provide information as to how or whether the person copes nor helps to identify any changes in coping behaviour during an encounter.

Lazarus and Folkman (1984) define coping as thoughts and behaviours people use to manage internally and externally demanding situations that they perceived as stressful. The aim of coping is therefore to reduce the physical, emotional and psychological burden of events the individual experiences as stressful (Snyder, 1999). Lazarus and Folkman (1984) described coping as an unfolding process in the context of a condition or situation that is appraised as personally significant or exceeding the coping resources of the individual. This suggestes coping is process-orientated instead of trait-orientated (Steed, 1989). The process initially involves the individual appraising whether their important goals are being threatened, harmed or lost. Because coping responses are initiated in an emotional environment, the appraisals are often characterised by negative intense emotions. As a result, one of the initial coping tasks is to reduce negative emotions that are deemed as stressful or interfere with the form of coping (Folkman & Moskowitz, 2004).

Lazarus and Folkman (1984) proposed two major theory-based functions of coping: problem-focused coping and emotion focused coping. Problem-focused coping primarily involves addressing the problem causing the distress by making a plan of action. Emotion-focused coping, on the other hand, aims to ameliorate negative emotion that is associated with the problem by employing distracting activities, including using alcohol or drugs, or seeking emotional support. This distinction has provided a useful framework for conceptualising coping (e.g., Calsbeek, Rijken, Bekkers, Van Berge Henegouwen, & Dekker, 2006; Dorrian et al., 2009; Drossman et al., 2000; Folkman & Moskowitz, 2004; Graff, Walker, & Bernstein, 2009; Knowles et al., 2011; Larsson, Lööf, Rönnblom, & Nordin, 2008;

Lazarus & Folkman, 1984; McCombie, Mulder, & Gearry, 2013; Mussell, Böcker, Nagel, & Singer, 2004; Pellissier, Dantzer, Canini, Mathieu, & Bonaz, 2010; Petrak et al., 2001; Raffle & Bush, 2009; Rhodes, 2007; Seres et al., 2008; Tanaka & Kazuma, 2005; Thomsen et al., 2002; Voth & Sirois, 2009). Folkman and Moskowitz (2004) explain coping as a complex multidimensional process. The first process is the environment, which includes demands and resources, and the second process includes the personality dispositions that influence the appraisal of stress and resources for coping.

Felton and Revenson (1984) state that the effectiveness of coping strategies is dependent on the type of stress being faced. Folkman and Lazarus (1980) found that emotion-focused coping was more likely to be utilised compared to problem-focused coping when confronted with health problems that were appraised as uncontrollable. Felton and Revenson (1984) amongst others (Baum, Singer, & Baum, 1981; Lazarus & Folkman, 1984) suggested that controllability is a critical property of stressors, which determine what strategy will be employed to either address the problem directly or alleviate the emotional distress that arises from the situation or problem. If the problem is deemed uncontrollable, then the coping strategies are limited.

Although Lazarus and Folkman (1984) initially separate coping into problem-focused and emotion-focused, Folkman (1992) argued that this might be too restrictive. Cox and Ferguson (1991) also argued that restricting coping in this way not only demonstrates weak predictive power, but also masks the rich variety of coping strategies. On the other hand, Folkman (1992) argued that subscales like those found in the A-COPE (Patterson & McCubbin, 1987) and COPE (Carver, Scheier & Weintraub, 1989,) create an unwieldy number of combinations of coping.

There are over 400 individual coping methods suggested in the literature (Skinner, Edge, Altman, & Sherwood, 2003). Of the coping strategies, problem-focused coping has the greatest conceptual clarity, emerging as a distinct factor following factor analysis of coping inventories (Steed, 1998). Problem-focused coping was also found to be consistent with Lazarus and Folkman's (1984) original two major theory-based functions of coping. Emotion-focused coping on the other hand needs clarification, as it can be construed as emotion-focused or problem-focused according to the person and situation (Steed, 1998).

Folkman and Moskowitz (2004) also suggest certain kinds of coping strategies are associated with either negative or positive outcomes. Negative outcomes arise from certain escapist coping strategies, whereas coping strategies involving problem–focusing and social support-seeking behaviours are associated with sometimes negative outcomes, sometimes positive outcomes, and sometimes neither, depending on the individual's appraisal of the stressful situation. According to Folkman and Lazarus (1980), people employ both forms of coping to some degree in managing distress, adjusting strategies according to their individual preferences and within the context of the situation.

Although the the problem- versus emotion-focused coping dichotomy is the most common characterisation of coping (McCombie et al., 2013), Carver et al. (1989) argued against the early developments of the coping scales using a grounded theory approach, and went on to develop a multidimensional coping scale, the "COPE" (Carver et al., 1989) using a hypothetical-deductive or theory based approach. The Carver model of coping therefore appears to address the above problems and confusion by clarifying coping into adaptive and maladaptive (Carver et al., 1989).

The COPE assesses the different ways people cope by utilising five scales, each comprising four items. Adaptive coping is associated with a positive outcome and takes into account problem-focused coping and emotion-focused coping, while maladaptive coping also takes into account emotion-focused coping that is associated with negative outcomes (Carver et al., 1989; Steed, 1998). Avoidant behaviour can be interpreted as emotion or maladaptive coping strategies (Carver et al., 1989). According to Carver et al. (1989), adaptive or problem-focused coping involves planning, active coping, restraint coping, seeking instrumental support, and suppression of competing activities. Adaptive emotion-focused coping involves positive reinterpretation, seeking emotional support, denial, acceptance, and turning to religion. Maladaptive (often labelled as emotion-focused) or less useful coping styles are primarily used to suppress thinking about the problem, and can be viewed as distancing (Lazarus & Folkman, 1984). Emotion focused coping (maladaptive) is measured using three scales; behavioural disengagement, mental disengagement, and focusing on and venting of emotions (Carver et al., 1989).

It is beyond the scope of this study to explore, in depth, the similarities and differences among the various coping contructs. For the puporse of the present study, and in order to simplify discussion involving the coping contruct, a two-factor conceptualisation will be used (e.g., Carver et al., 1989). Therefore, when relating to a positive outcome, the coping strategy will be identified as adaptive (both problem-focused and positve emotion-focused) and when relating to a negative outcome, the strategy will be considered a maladaptive (negative) coping strategy.

1.7.1 Coping and chronic illness.

Chronic illness affects an individual’s physical, psychological, social, and vocational functioning (Livneh & Antonak, 1997). An individual’s selection of coping strategies is based upon the type and nature of stress they are facing (e.g., long term, short term, physical or psychological stress; Lazarus, 1980).

Chronic illness can be considered as both internally and externally demanding (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984), which negatively impacts upon an individual’s QoL (Ambriz Murillo, Menor Almagro, Campos-González, & Cardiel, 2015; Devy, Lehert, Varlan, Genty, & Edan, 2014; Norris et al., 2011; Sikdar, Wang, MacDonald,

& Gadag, 2010; Singh & Bradley, 2006). In order to mitigate the physical and/or emotional threat, an individual with a chronic illness is likely to employ coping strategies.

There have been several studies exploring the coping strategies employed by individuals experiencing chronic illness. These studies include a diverse number of chronic conditions, such as COPD (e.g., Hundt et al., 2013), Type 1 diabetes (e.g., Jaser & White, 2011), heart failure (e.g., Allman, Berry, & Nasir, 2009), alopecia (e.g., Cartwright, Endean & Porter, 2009), breast cancer (e.g., Bigatti, Steiner, & Miller, 2012; De Vries, Den Oudsten, Jacobs, & Roukema, 2014), Fibromyalgia (e.g., Alok et al., 2014), rheumatoid arthritis (e.g., Englbrecht et al., 2012), osteoarthritis (e.g., Golightly, Allen, Stechuchak, Coffman & Keefe, 2015), and for patients undergoing haemodyalysis (e.g., Lindqvist, Carlsson, & Sjödén ,1998).

Hundt et al. (2013) utilised Lazarus and Folkman’s (1984) problem- and emotion-focused coping dichotomy in 227 veterans with COPD or congestive heart failure (CHF). Using the Medical Research Council Dyspnea Score (MRC; Fletcher et al., 1959) to measure the extent of participants’ disease severity and shortness of breath, the Brief COPE (Carver, 1997), and the Multidimensional Health Locus of Contol, Form C (Wallston, Stein & Smith,1994), the authors found illness intrusiveness to be related to avoidant emotion-focused coping (maladative), being younger, and greater symptom severity. Maladaptive, but not adaptive, coping was found to mediate the relationship between disease severity and illness intrusiveness, suggesting that people are more likely to employ avoidant emotion-focused coping under greater disease severity.

In a review of the literature exploring heart disease, coping and depression, Allman et al. (2009) found that problem-focused strategies such as planning problem solving and seeking social support had a direct negative relationship with depression, while emotion-focused (maladaptive) coping strategies such as wishful thinking had a positive and direct relationship. A similar relationship was found by Bigatti, Steiner, and Miller (2012), who utilised the Ways of Coping Questionnaire (Folkman & Lazarus, 1988) in a sample of 65 women with breast cancer. Using path analysis and a depression measure (CES-D; Radloff, 1977), the authors found that greater use of escape avoidance coping predicted greater depressive outcomes.

However, not all studies clearly define coping according to the dichotomous model of problem-focused (adaptive coping) and emotion-focused (maladaptive coping), as proposed by Lazarus and Folman (1984) or Carver et al. (1989). For example, Felton and Reverson (1984) utilised a similar two-pronged structure of coping; however, they used different terms. Exploring the effects coping had in a sample of 151 middle aged and older adults diagnosed with hypertension, diabetes, arthritis or cancer, Felton and Reverson termed information seeking as problem-focused coping, and termed wish-fulfilling fantasy as emotion-focused coping. Felton and Revenson sought to determine which of these coping strategies would be utilised among people with illnesses that offer few opportunities for control (e.g., cancer and RA) compared to people with illnesses that are more responsive to medical and individual control (e.g., diabetes and hypertension). Felton and Revenson found information (problem-focused) seeking to have beneficial effects on psychological distress and emotion-focused wish-fulfilling fantasy to have deleterious consequences, regardless of the controllability of the participants’ illness.

Lindqvist, Carlsson, and Sjödén (1998) used the Jaloweic Coping Scale (Jalowiec, 1991), which is comprised of eight factors that could be separated into adaptive and maladaptive coping styles. In their qualitative focus group study exploring QoL and coping in 30 Scandinavian haemodialysis patients, and compared to patients on a continuous ambulatory dialysis, Lindqvist and colleagues utilised the Jaloweic Coping Scale, (Jaloweic, 1991) that is made up of four problem focused (adaptive) coping styles (optimistic, supportive, self-reliant and confrontational), and 4 maladaptive coping styles (palliative, evasive, fatalistic and emotive). Lindqvist, Carlsson, and Sjödén found optimistic coping style (adaptive coping), to be the most widely adopted coping style in dealing with stressful aspects of treatment when undergoing dialysis. This supported previous studies that found dialysis patients were more likely to use problem-focused coping than emotion-focused coping methods (Gurklis & Menke, 1988; Powers, Baldree, & Murphy, 1982).

Englbrecht et al. (2012) also adopted a separate two-pronged structure of coping by distinguishing adaptive and maladaptive coping strategies as active (e.g., functioning despite pain) and passive (e.g., engaging in wish-fulfilling thoughts). Utilising a sample of 434 RA patients, and a coping measure (C-RAQ; Englbrecht et al., 2012) created via previous studies that utilised the problem- versus emotion-focused dichotomy, Englbrecht and colleagues found problem-focused coping (represented by the scales of active problem-solving and cognitive reframing), were found to be positively associated with better coping effectiveness. Emotional expression was related to helplessness.

Lazarus (1980) suggested that, when confronted with health problems that are deemed uncontrollable, coping stratgeies are limited and the individual is more likley to utilise an emotion-focused (maladaptive) coping style. Following this suggestion, Hundt et al. (2013) found that patients with no support and severe COPD or heart disease were more likely to use avoidant/emotion-focused coping (e.g. self-blame or denial) due to their inability to engage in active problem-focused coping strategies that may involve physical exertion (e.g. seeking social support or distraction using hobbies).

However, Lindqvist, Carlsson, and Sjödén (1998) did not find support for such suggestions. They found that patients with HD or COPD adopted a more optimistic adaptive style of coping. This may be the result of the knowledge that their condition is controllable through treatment. Another possible explaination of the findings may include the type of scale utilised in the study. Lindqvist and colleagues (1998) used the Jaloweic Coping Scale (Jaloweic, 1991), which assessed the maladaptive coping strategies of fatalistic, confrontational, evasive and palliative coping. Given the nature and controllability of HD and CAPD, as was diagnosed in Lindqvist and colleague's study, the participants may not have identified with these subscales. Interestingly, Fenton and Revenson (1984) found illness controllability not be influential in the coping sytle used.

De Vries, Den Oudsten, Jacobs, and Roukema (2014) reported gender differences in the coping style used; specifically, they found that 80% of women diagnosed with reoccurring breast cancer utilsed emotion-focused coping. According to De Vries et al., avoidance is a valuable form of coping when situations are deemed uncontrollable or threatening. Englbrecht et al. (2012) also suggested that the type of coping strategy used may depend on gender and age According to the authors, distancing was the most utilised coping strategy, followed by active problem solving and cognitive reframing. Females were found to use emotional expression (related to helplessness), cognitive reframing, and active problem solving more often than did males with RA, despite women experiencing more hopelessness. Englebrecht et al. explained that this may be due to females reporting more openly about their emotions compared to males who may be conditioned to deny any feelings of helplessness.

In summary, challenges present in the coping/chronic illness literature due to the complexity of the coping construct (Skinner, Edge, Altman, & Sherwood, 2003). Several studies within the chronic illness literature have either utilised Lazarus and Folkman's (1984) dichotomous construct of problem- and emotion-focused coping (Allman et al., 2009), while others have reclassified the dichotomy as active versus passive coping (Englbrecht et al., 2012); adaptive versus maladaptive coping (Hundt et al., 2013). Alternatively, others have relabelled the sub-measures according to more specific attributes, like cognitive restructuring for active coping and wish-fulfilling, and fantasy or avoidance as passive coping (Englbrecht et al., 2012). Other studies have used specific coping measures, like the eight-item Emotional Approach Coping Scale (Smalls et al., 2012), which utilises specific subgroups of emotional coping; for example, emotional expression (EE), emotional process (EP), and self-care behaviours. Despite these challenges, and regardless of the terms given to the dichotomous construct of coping originally created by Lazarus and Folkman (1984), the findings support the benefits of active, adaptive or problem-focused coping on psychological wellbeing and QoL compared to emotional, passive or maladaptive coping. Also, individuals are more likely to adopt maladaptive coping strategies when confronted with an illness they perceive as threatening and little control over.

1.7.2 Coping and IBD.

Consistent with the other chronic illnesses discussed previously, the coping literature involving IBD cohorts would also be expected to show adaptive problem-focused coping to be related to improved psychological wellbeing and QoL, while emotion-focused or maladaptive, passive coping to be related to increased psychological distress and reduced QoL. Maladaptive coping would also be expected to be the most commonly utilised coping strategy due to the high levels of psychological distress and poorer illness perceptions found within the IBD population.

Pellissier, Dantzer, Cannini, Mathieu, and Bonaz (2010) explored coping styles and psychological outcomes in 26 CD and 22 UC patients utilising a number of measures including the State-Trait Anxiety Inventory (STAI; Spielberger, 1983), Center for Epidemiologic Studies-Depression Scale (CES-D; Fuhrer & Rouillon, 1989; Radloff, 1977), Perceived Stress Scale (PSS; S. Cohen, Kamarck, & Mermelstein, 1983), and the Coping Checklist Revised (WCC-R; Vitaliano et al., 1985). Using a principle component analysis, Pellissier et al. found that positive affective adjustment in individuals with both CD and UC was associated with problem-focused coping strategies, and a negative affect with emotion-focused (maladaptive) coping.

Similar results were found by Knowles, Cook, et al. (2013), who explored coping and psychological distress with 83 IBD stoma patients. Utilising the Brief COPE (Carver,1997), HADS (Zigmond & Snaith, 1983), Brief IPQ (Broadbent, Petrie Main & Weinman, 2006) and current health status, Knowles, Cook et al. (2013) found maladapitve coping to be associated with increased depression and anxiety by using structural equation modelling.

Kinash and colleagues (1993), in their study of 150 non-hospitalised adults with IBD, also found that participants who adopted emotion-focused (maladaptive) coping strategies experienced a lower QoL as compared to those who adopted problem-focused coping strategies. The findings have since been supported by more recent studies (e.g., Larsson et al., 2002, Petrak et al., 2001; Smolen & Topp, 1998). According to Jones, Wessinger and Crowell's (2006) study of 48 IBD patients, emotion-focused coping (maladaptive) was the dominant coping style in IBD patients compared to a control group, who were more likely to utilise problem-focused coping. As expected, IBD patients using emotion-focused coping styles were also found to experience greater psychological distress. No differences were found between participants with CD versus UC, or between patients with active disease or patients in remission. Interestingly, this was despite CD patients reporting greater reductions to QoL compared to UC patients, and the active disease participants reporting more reduced QoL compared to participants with an inactive disease. These inconsistencies, however, may be the result of small sample sizes and the coping measure used having a low to moderate Cronbach alpha scores of .6 to .8 (Jones et al.).

Iglesias-Rey et al. (2013) also found emotion-focused (maladaptive) coping to be the most common coping strategy in 875 IBD patients, with no difference between the two disease types of UC and CD. Using the COPE (Carver et al.. 1989), which defines adaptive coping as problem-focused, maladaptive coping as avoidance coping, and emotion focused-coping, the authors found that emotion-focused coping was associated with the highest anxiety scores, while the highest depression scores were associated with escape avoidance. Stress levels and coping type did not show any correlation. These findings are inconsistent with the Spanish study by Crespo and Cruzado (1997), who found problem-focused coping to be the most utilised coping style in the general population. Iglesias-Rey et al. also reported inconsistencies with the study by Jones, Wessinger, and Crowell (2006) and Moradkhani, Kerwin, Dudley-Brown, and Tabibian (2011), who found a predominance of escape-avoidance coping and active (adaptive-focused) coping, respectively. Moradkhani et al. (2011) also found that active coping (adaptive/problem-focused) was the predominant coping style used when IBD patients had more knowledge about their disease.

Coping and IBD were also explored by Van der Zaag-Loonen, Grootenhuis, Last, and Derkx (2002) in a sample of 65 adolescents (12-18 years old) diagnosed with IBD. Using measures including the Utrecht Coping List for Adolescents (UCL-A; Screurs et al., 1984), Cognitive Control Strategy Scale for Children (CCSs; Rothbaum et al., 1982), and the Impact-11 (a measure of QoL; Loonen et al., 2002), Van der Zaag-Loonen et al. found that adolescents with IBD were more likely to utilise avoidant (maladaptive) coping styles compared to their healthy peers, and that a more adaptive coping style (e.g. predictive coping) was associated with better QoL scores.

Based on the studies discussed above, emotion-focused (maladaptive) coping is associated with poorer psychological outcomes, and problem-focused coping is associated with reduced psychological distress. Although studies have found problem-focused coping strategies to lead to improved outcome (Cotrim & Pereira, 2008; Joachi & Milne, 1987; Mahjoubi et al., 2009; Maunder et al., 1999; Pellissier et al., 2010), it was not supported by Petrak et al. (2001), and Mussell, Bocker, Nagel, and Singer (2003); both of whom found active problem-focused coping to be associated with poorer outcomes. For example, contrary to their hypothesis, Petrak et al. found in their sample of 1,322 German IBD patients, that active coping had a negative influence on QoL during the active phase of the disease, however, not in patients experiencing remission. According to the authors, this suggests that patients in the active phase of their disease may not benefit from “wasting” energy through activism and would instead benefit more from following medical and psychological options. They did, however, conclude the importance of replicating their study before making generalised recommendations. Mussell, Bocker, Nagel, and Singer (2003) found emotion-focused coping to be associated with psychological distress and IBD-related concerns, however, active problem-focused coping was found to be associated with more somatic complaints and more intense concerns. Mussell et al., explained the possibility of these findings as being due to the IBD patients’ inability to successfully change the disease or distress they perceive as uncontrollable.

McCombie, Mulder, and Gearry (2012) conducted a systematic review of 39 IBD coping oriented studies. The authors concluded that, irrespective of the coping scale used, emotion-focused coping (maladaptive) was associated with poorer psychological outcomes in patients with IBD. McCombie e al’s (2012) review further supported the findings of previous studies investigating coping in a range of other chronic illnesses (e.g., Curtis, 2005; Dorrian et al., 2009; Drossman et al., 2000; Kinash, Fischer, Lukie, & Carr, 1993; Knowles et al., 2011; Mussell et al., 2004; Pellissier et al., 2010; Raffle & Bush, 2009; Seres et al., 2008; Smolen & Topp, 1998; Tanaka & Kazuma, 2005; Thomsen et al., 2002; Voth & Sirois, 2009). According to McCombie et al’s (2013) review however, adaptive or problem-focused coping and outcomes were not as clear-cut. The review of the literature found: (a) one study that showed a positive relationship between problem-focused coping and better outcomes (Pellissier, Dantzer, Canini, Mathieu, & Bonaz, 2010); (b) two studies that showed worse outcomes (Mussell et al., 2004, Petrak et al., 2011); (c) three studies that showed better outcomes, even though they reported small effect sizes; and (d) five studies that showed no relationship (Dorrian et al., 2009; Kinash et al., 1993; Smolen & Topp, 1998; Calsbeek et al., 2006). Possible limitations in these studies may have contributed to these inconsistencies. Limitations included: variability in coping measures and research design; small to modest sample sizes; mixed disease samples; limited generalisability of cohorts on the basis of gender bias and other demographic characteristics; and the limited number of studies examining coping longitudinally (McCombie et al.).

Like coping, self-efficacy has also been regarded an important attribute influencing psychological wellbeing and QoL in individuals experiencing chronic illness. This therefore warrants further exploration of the self-efficacy construct and its associated relationship with chronic illness, especially IBD.

1.8 Self-efficacy

Self-efficacy is another psychological construct that affects how an individual deals with stress and influences outcomes. Bandura’s self-efficacy construct was developed as part of social learning theory (Ashford & LeCroy, 2010), which later progressed into being a key component in social cognitive theory (Bandura, 1977; Levin, Culkin, & Perrotto, 2001). According to Redmond (2010), Bandura’s (1977) social cognitive theory resulted from his dissatisfaction with the principles of psychoanalysis and behaviourism, where the role of the situation and cognition in motivation are largely ignored. While there have been many definitions of self-efficacy since Bandura’s initial study (Bandura, 1977), Wood and Bandura (1989, p. 408) defined self-efficacy as “beliefs in one’s capabilities to mobilize the motivation, cognitive resources, and courses of action needed to meet given situational demands”. Initially, self-efficacy research primarily focused upon organisational research (Bandura, 1977; Stajkovic & Luthans, 1998), in which self-efficacy was found to predict several work related outcomes, including job performance (Stajkovic & Luthans, 1998), job attitudes (Saks, 1995), and training proficiency (Martocchio & Judge, 1997). More recently, self-efficacy research has expanded to predicting outcomes in a variety of spheres, including drug abstinence (Gwaltney, Shiffman, Balabanis, & Paty, 2005), academic self-efficacy (Gore Jr, 2006), and overcoming psychological trauma (Luszczynska, Benight, & Cieslak, 2009). Importantly, self-efficacy has become a prominent construct in studies of the psychology of health due to its ability to influence wellbeing (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008).

According to Bandura's (1977, 1986) social cognitive theory, self-efficacy beliefs vary on three dimensions: (1) magnitude, which is the level of task difficulty the person believes they can accomplish; (2) strength, which is the level of certainty the person has about their ability to successfully perform a particular task; and (3) generality, which is the extent to which strength and magnitude beliefs generalise across tasks and situations. More recently, other researchers have posited alternative definitions of self-efficacy, which may potentially have different implications for outcomes. Lorig and González (1992) refer to self-efficacy as a belief or confidence that a person can achieve a specific cognitive or behavioural state, whereas Kreitler, Peleg, and Ehrenfeld (2007) describe self-efficacy as a subjective experience of different stressors, with perceived stress as a personality disposition. Kreitler et al. (2007) suggest that self-efficacy is related to the effort, resilience and perseverance that will characterise a person's behaviour in adverse situations. It may then be expected that self-efficacy will affect the amount of stress and anxiety an individual experiences when engaging in a task and the degree of their accomplishments.

Chen et al. (2001), however, believe Bandura's restrictive description of self-efficacy as relating to "given situational demands" has resulted in a narrow focus of self-efficacy. They suggest that this has resulted in researchers narrowing the focus of their research to the strength and magnitude dimensions of self-efficacy, therefore conceptualising and studying self-efficacy as a state-trait construct or task-specific (Lee & Bobko, 1994). Researchers have expanded the concept of self-efficacy from a state to a more a trait-like generality of self-efficacy (Eden, 1988; Judge, Erez, & Bono, 1998; Judge, Locke, & Durham, 1997). In contrast, some researchers have focussed on wider views of self-efficacy. Eden (1988) defines General Self-Efficacy (GSE) as "one's belief in one's overall competence to effect requisite performances across a wide variety of achievement situations" (p. 63), whereas Judge et al. (1998) define it as an "individual's perception of their ability to perform across a variety of different situations" (p. 170). Chen et al. (2001) on the other hand, summarise GSE as capturing "differences among individuals in their tendency to view themselves as capable of meeting task demands in a broad array of contexts" (p.63).

Despite self-efficacy being viewed as a state (SSE) or trait (GSE) construct, both denote beliefs about an individuals ability to achieve desired outcomes (Eden, 1988). As such, both types of self-efficacy share similar antecedents (e.g., vicarious experience, actual experience, verbal persuasion, and psychological states); however, they differ in the scope of their constructs (i.e., generality or specificity; Bandura, 1977). Some researchers, however, have questioned the construct validity of GSE (Bandura, 1986; Stajkovic & Luthans, 1998; Stanley & Murphy, 1997), arguing there is little distinction from self-esteem (Brockner, 1988; Gardner & Pierce, 1998). As a result, Chen et al. (2001) questioned whether predictions made with the General Self-efficacy Scale (GSES; Sherer et al., 1982) were attributable to GSE or to other related constructs (e.g., self-esteem, persistence).

For these reasons, Chen et al. (2001) developed a new self-efficacy measure in order to deal with the limitations of the GSE, and which has somewhat better prediction and improved divergent validity. Chen et al. (2001) created the 8-item New General Self Efficacy scale (NGSE), which is uni-dimensional rather than multi-dimensional (GSE). The NGSE scale has higher construct validity, and relatively higher predictive validity compared to the GSE scale (Chen et al., 2001).

As noted by Judge, Erez, Bono, and Thoresen (2002), self-efficacy relates highly to other self-evaluative constructs, including locus of control, neuroticism, and self-esteem. In their attempt to investigate the common core of self-efficacy, self-esteem, locus of control, and neuroticism, the authors found a pattern of correlations emerging between self-efficacy and self-esteem, emotional stability and generalised self-efficacy, generalised self-efficacy and locus of control.

Judge et al. (2002) also found the possibility of a second-order latent factor potentially explaining the connection among the measures, which highlights that researchers should not abandon the study of these variables as isolated traits.

Conscientiousness and the need for achievement are other motivational traits that have been found to be positively related to GSE (Chen et al., 2001). There have also been a number of studies utilising related constructs, including perceived stigma (Corrigan, Watson, & Barr, 2006), patient empowerment (Aujoulat et al., 2008), and personal control (Cooper, Collier, James, & Hawkey, 2010), that influence cognitive, behavioural, and physiological outcomes or goals. The relationship between these constructs and self-efficacy is unfortunately under-studied, so it is unclear how relevant these findings are to the more general literature.

According to Cooper et al. (2010), self-efficacy beliefs are influenced by four sources of information. These include vicarious experience, performance accomplishments, verbal persuasion, and physiological and emotional feedback. Vicarious experience includes responses and actions modelled by others creating self-efficacy expectations. Performance accomplishments include past achievements and experiences that encourage future resilience and mastery. Verbal persuasion involves advice and instructions received from others, and physiological and emotional feedback involves feedback from bodily sensations (fatigue, urgency and pain), and physical and emotional arousal. These four factors result in an individual's sense of personal control.

The multiple definitions and complex understandings of the self-efficacy construct (Bandura, 1977; Chen et al., 2001; Cooper et al., 2010; Eden, 1988; Judge et al., 1998; Kreitler, Peleg, & Ehrenfeld, 2007; Lee & Bobko, 1994; Lorig & González, 1992; Wood & Bandura, 1989), together with its strong relationship with other psychological/self-evaluative constructs (e.g., self-esteem, personal control, patient empowerment, persistence, neuroticism, conscientiousness, perceived stigma, and locus of control) result in a diversified understanding of self-efficacy. This makes it difficult to define self-efficacy as a single, isolated factor. A complete evaluation of all these different constructs is beyond the scope of the present study. Despite the challenges listed above, self-efficacy can still be regarded according to Wood and Bandura's (1989) definition.

1.8.1 Self-efficacy and chronic illness.

Research has found that self-efficacy is a strong predictor of health outcomes in chronic illness. These illnesses include: rheumatoid arthritis, (e.g., Benka et al., 2014; Magklara, Burton, & Morrison, 2014; Sundén, Ekdahi, Magnusson, Johnsson, & Gyllensten, 103); stroke (e.g., French, Moore, Pohlig, & Reisman, 2015; Lewin, Jöbges & Werheid, 2013; Tang et al., 2015; Tao, Soh, Tam, Tan, & Thompson, 2012); cancer (e.g., Akin, Can, Durna, & Aydiner, 2008; Kreitler et al., 2007; Mystakidou et al., 2013 Phillips & McAuley, 2014); COPD (e.g., Andenæs, Bentsen, Hvinden, Fagermoen, & Lerdal, 2014; Larson, Covey, Kapella, Alex, & McAuley, 2014; Stellefson, Tennant, & Chaney, 2012); chronic kidney disease (e.g., Curtin et al., 2008); and diabetes (e.g., Al-Khawaldeh, Al-Hassan, & Froelicher, 2012; Chander et al., 2012; Iannotti et al., 2006; Sarkar, Fisher & Schillinger, 2006; Stupiansky, Hanna, Slaven, Weaver, & Fortenberry, 2013).

The self-efficacy construct has also been explored in various ways across the chronic illness literature. For example, the influence self-efficacy has on psychological distress in individuals with early RA (*n* = 102; disease duration of ≤ 4 years) and established RA (*n* = 146; disease duration of ≥ 12 years) was explored by Benka et al. (2014). Using correlation and hierarchical regression, with scales measuring neuroticism and extraversion (Eysenck's Personality Questionnaire revised short scale; Sanderman, Arrindel, Ranchor, Eysenck, & Eysenck, 2012), disease activity (Disease Activity Score-28; Van Gestel et al., 1996), functional disability (Groningen Activity Restriction Scale; Kempen & Suurmeijer, 1990), coping self-efficacy (Chesney, Neilands, Chambers, Taylor, & Folkman, 2006) and psychological distress (HADS; Zigmond & Snaith, 1983), Benka et al. found coping self-efficacy (problem-focused coping strategies) was negatively associated with psychological distress in both the early and well-established groups, irrespective of personality differences or disease-related variables. Patients with higher self-efficacy also carried out coping behaviour that contributed to reduced depression and anxiety. Interestingly, Benka et al. also found the strongest association lay between anxiety and the early RA group, suggesting a likely benefit of intervention programs aimed at increasing self-efficacy during the early phases of the disease.

Self-efficacy has also been shown to be associated with increased empowerment; a process focusing on helping individuals increase their knowledge about their condition and body in order to take control of the disease and treatment (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008; Keers et al., 2006), and self-management across self-care, partnership, communication, and medication adherence (Curtin et al., 2008). Self-efficacy has been posited by Bandura (1977) to be an intermediate step that enables self-management. Therefore, goal setting, problem solving, and education can provide individuals with chronic illnesses, such as kidney disease (e.g., Curtin et al., 2008), with the self-efficacy needed to enable self-management, and therefore, improved coping and positive outcomes.

Self-efficacy and self-management were explored by Curtin et al. (2008) in a study of 174 chronic kidney disease patients. Using a cross-sectional survey that included measures for self-efficacy (Perceived Efficacy in Patient-Physician Interaction Questionnaire; Maly, Frank, Marshall, DiMatteo, & Reuben, 1998), mental and physical functioning (Medical Outcomes Study 36-Item Short Form Health Survey questionnaire; Ware, Kosinski, & Keller, 1994), and self-management (e.g., partnership in care, self-care, communication with caregivers, self-advocacy and medication adherence; Curtin & Mapes, 2001; Curtin et al., 2004), Curtin et al. (2008) found that higher perceived self-efficacy scores were related to increased partnership, self-care, communication, and medical-adherence behaviours. In conclusion, the authors suggested that self-efficacy contributes more towards self-management than do demographic or health characteristics.

The mediating effects of self-efficacy have also been explored. Phillips and McAuley (2014) explored the mediating effects of self-efficacy and health status between physical activity and QoL in 1,527 breast cancer survivors. Participants were asked to complete measures assessing their self-efficacy (Exercise Self-Efficacy Scale; McAuley, 1993), physical activity (ActiGraph accelerometer; Bassett et al., 2000), health status (Functional Assessment of Cancer Therapy-General; Cella et al., 1993) and QoL (5-item Satisfaction with Life Scale; Diener, Emmons, Larsen & Griffin, 1985). Using a path analysis, Phillips and McAuley (2014) reported a good fit, where self-efficacy and health status mediated the relationship between physical activity and QoL.

Andenæs et al. (2014) sought to expand the self-efficacy literature by exploring the relationship between general self-efficacy and the physical and mental health components of QoL in patients diagnosed with COPD. In a sample of 97 participants with COPD involved in a pulmonary rehabilitation program, and using scales measuring general self-efficacy (GSE; Schwarzer & Jerusalem, 1995), QoL (SF-12 Health Survey, Ware, Kosinski, Turner-Bowker, & Gandek, 2005), a standardised measure testing regular time physical activity (Norweigian Nord- Trøndelag Health Survey; Drøyvold, Holmen, Midthjell, & Lydersen (2004), and socio-demographic variables (e.g, employment status), Andenæs et al. found general self-efficacy to have a differential relationship with the physical and mental health dimensions of QoL. The results indicated that better mental health was associated with having higher self-efficacy, being physically active, and living with a partner. The physical health dimension of QoL, however, was not significantly related to self-efficacy nor age, sex, marital status, education, physical activity or work status. The authors suggest that general self-efficacy, paid work, and physical activity are factors that need to be incorporated into pulmonary rehabilitation in order to improvethe QoL of patients suffering COPD.

Treatment compliance has repeatedly been indicated as vital to therapeutic outcomes and improved QoL across multiple studies (Broadbent et al., 2006; Friedman et al., 2014; Frostholm et al., 2005; Iannotti et al., 2006; Keogh et al., 2007; Petrie, Cameron, Ellis, Buick, & Weinman, 2002; Rosenzweig et al., 2007). Via self-management, self-efficacy has also been shown to have a positive association between treatment compliance in patients diagnosed with Type 1 diabetes. One hundred and sixty-eight adolescents with Type 1 diabetes and their parents were assessed utilising the modified version of the Diabetes Self-Management Profile (DSMP; Harris et al. 2000), while the youths with diabetes completed the diabetes-specific self-efficacy scale and outcome expectations measure (Iannotti et al., 2006). Glycaemic control was assessed by analysing the glycosylated haemoglobin (HbA_{1c}) assays. Iannotti et al. (2006) found that self-efficacy with expectations of positive outcome was significantly associated with glycaemic control and diabetes self-management. The authors also found that the effect of self-efficacy on treatment adherence was strongest when the adolescents had a greater belief in the beneficial outcomes of treatment adherence.

Chronic illnesses can significantly affect the social and emotional aspects of an individual's life. The presence of a stoma is one such situation that has been found to result in psychological distress, shame, embarrassment, body distortion, and a reduction in QoL (de Gouveia Santos, Chaves, & Kimura, 2006; Gooszen, Geelkerken, Hermans, Lagaay, & Gooszen, 2000; Silva, Ratnayake, & Deen, 2003). The role of self-efficacy in the psychosocial health and QoL in patients who have received a stoma following a bowel resection was explored by Wu, Pak-Chun Chau, and Twinn, (2007). Using a stoma self-efficacy scale (Bekkers, Van Knippenberg, Van Den Borne, & van Berge-Henegouwen, 1996), a short-form health survey (Ware, Snow, & Kosinski, 1993), the authors found a strong correlation between self-efficacy and QoL in a Chinese sample (n = 96; M_{age} = 64 years). Similar results were found in a Korean study by Kim et al. (2007). The study involved introducing 21 colostomy patients to a program aimed at increasing self-efficacy. The program was carried out over 10 months and involved increasing vicarious experience through a compact disk program, incorporating verbal persuasion via education and telephone coaching, and building performance accomplishment through stoma self-care. Following the program, Kim et al. found the self-efficacy promoting program to improve the degree of self-efficacy, psychosocial adaptation, and self-care.

In summary, self-efficacy - through self-management, empowerment, self-care, and copin - plays an important role in reducing psychological distress, improving treatment compliance, and QoL in chronic illness cohorts.

1.8.2 Self-efficacy and IBD.

Few studies have focussed directly on the role of self-efficacy in IBD (e.g., Cooper et al., 2010; Fishman, Barendse, Hait, Burdick, & Arnold, 2010; Friedman et al., 2014;

Izaguirre & Keefer, 2014; Taft, Keefer, Artz, Bratten, & Jones, 2011). One particular study sought to develop a self-efficacy scale for disease specific gastrointestinal complaints (Keefer, Kiebles, & Taft, 2011). Of the few studies that have been conducted, however, two main areas appear to have been explored in relaton to self-efficacy in IBD: (1) adherence to medical care (Friedman et al., 2014), and (2) the transition from paediatric care to symptom self-management in adolescents (Fishman et al., 2010; Goodhand, Hedin, Croft, & Lindsay, 2011; Zijlstra, Heise, Nosek, Heinemann, & Heckermann, 2013; van Staa, van der Stege, Jedeloo & Moll, 2011; Whitfield, Fredericks, Eder, Shpeen, & Adler, 2015).

It has been well established that IBD has an adverse impact upon the development and QoL of children and adolescents (Goodhand et al., 2011; Hait, Arnold, Sands, & Fishman, 2009; McCartney, 2011). Once an adolescent reaches adulthood, transition into adult-orientated health care needs to be carefully considered, uninterrupted, and matched to the individual's abilities (Hait et al., 2009). For a successful transition to occur, barriers arising from the differences between paediatric and adult care need to be identified and addressed to ensure transfer readiness (Goodhand et al., 2011). Zijlstra et al. (2013) suggest that self-efficacy is important for transfer readiness. In order to assess an IBD sufferer's self-efficacy, the authors sought to develop an IBD-specific questionnaire (the "IBD-yourself") to test their readiness whilst adolescents were visiting a transition clinic. Fifty IBD patients aged 14-18 years old, and 40 parents of adolescent IBD patients, completed the questionnaire in order to evaluate the reliability of the measure and to describe the self-efficacy of the adolescent patients and their parents perceived. Results indicated that median self-efficacy scores varied from 70-100%, with parents perceiving their children to be more efficacious in their knowledge about IBD, diagnostic testing, medication use, self-management, and transfer readiness. Although the study compared the different perceptions of self-efficacy between adolescents and parents, it nonetheless highlights its importance in determining transfer readiness.

Adherence to treatment is a challenge across multiple medical disciplines (DiMatteo, 2004; Sabaté, 2003). The risk of non-adherence to treatment in IBD can have serious consequences, including increased risk of colon cancer (Friedman et al., 2014). In order to assess the probability of adherence to surveillance colonoscopies, Friedman and colleagues (2014) recruited 378 patients with a minimum seven-year history of CD and UC and assessed their individual self-efficacy. Utilising their own 20-item self-efficacy scale (Friedman et al., 2014) and eight items assessing scheduling, preparation, and post procedure recovery to create an additional two short self-efficacy scales, Friedman and colleagues (2014) found that high self-efficacy can predict an IBD individual's adherence to surveillance colonoscopy. Self-efficacy was also found to predict adherence with 70% certainty, highlighting that certain patient groups may require further interventions for adherence.

The importance of self-efficacy has been under-studied within the IBD literature despite initial studies highlighting the relevance of its influence on reducing psychological distress, QoL, and the transitional process of going from child/adolescent care to adult care. Not only do these studies highlight the paucity of knowledge in this area, but the limited studies that do exist in this area are themselves limited by small sample sizes.

In summary, research suggests that self-efficacy is an important factor in influencing empowerment, self-management, psychological wellbeing, and QoL in chronic illness and IBD, despite there being inconsistencies involving poor uniformity across studies. This lack of uniformity makes it difficult to assess the efficacy or reproducibility of their findings. In recent times, and with the influence of modern-day mindfulness mediation practice and its influence on psychological wellbeing and health, it is worthwhile to explore this construct within the realm of chronic illness; especially IBD, due to its significant negative impact of QoL and psychological distress.

1.9 Mindfulness

Mindfulness has been subject to research studies aimed at helping individuals cope with stress (Astin, 1997; Grossman, Niemann, Schmidt, & Walach, 2004; Weinstein, Brown, & Ryan, 2009) and its influence of wellbeing (Brown & Ryan, 2003; Shapiro, Oman, Thoresen, Plante, & Flinders, 2008). The origin of mindfulness dates back to Buddhist and other spiritual traditions. The integration of Eastern mindfulness into Western psychology, however, began with the growth of Zen Buddhism in the U.S in the 1950s and 1960s (Keng, Smoski, & Robins, 2011). While the initial focus of mindfulness research involved exploring changes in brain wave patterns and its effect on the body (Anand, Chhina, & Singh, 1961; Bagchi & Wenger, 1957; Benson, Marzetta, Rosner, & Klemchuk, 1974; Kasamatsu & Hirai, 1966; Wallace, 1970; Wallace, Benson, & Wilson, 1971), its influence as an intervention to enhance psychological wellbeing did not begin until the 1970s (Keng et al., 2011). Mindfulness has since been recognised as an important practice for psychological wellbeing, physical health, relationships, and work and sports performance (Brown & Ryan, 2003). Although mindfulness appears to be a simple concept, it has been difficult to define and characterise accurately, with Chalmers (1995) defining it as largely uncharted and mysterious territory.

For example, Martin (1997) defines mindfulness as “a state of psychological freedom that occurs when attention remains quiet and limber, without attachment to any particular point of view” (p.291), and essentially involving a nonbiased and explorative view on meaning, thought, behaviour, and emotion. Bishop et al. (2004), on the other hand, propose a two-component model of mindfulness, incorporating both attention and awareness, and acceptance. Awareness refers to the subjective experience of internal and external phenomena that encompass our given moment in reality, whereas attention refers to a focusing of awareness to outline selected aspects of that reality. During states where one is awake, the two are intertwined.

Researchers have distinguished attention and awareness from other primary mental processing modalities like cognition, motives, and emotions (Averill, 1992; Mayer, Chabot, & Carlsmith, 1997). Westen (1999) highlights that consciousness serves at least two key functions, the first being to monitor experiences and events as they unfold in real-time, and the second being to control and direct the contents of consciousness. However, according to Brown and Ryan (2004), mindfulness cannot be confined to labelling it as a metacognitive skill, due to the contribution of thought, emotion, and other contents of consciousness. Brown and Ryan summarise this well with the example: “if mindfulness involves observing thought, including thoughts about thoughts, it cannot be a thought” (p. 243). This uncertainty again highlights the challenge of what mindfulness actually is. The problem that arises from the attention-awareness proposal of Bishop et al. (2004) is the question of how can a person be solely focusing their attention on a specific event or experience, yet at the same time, be curious about where the mind wanders. Brown and Ryan (2004) highlight that Bishop et al. do not clarify how these two forms of mindfulness are related or contradictory. They instead believe the contradiction can be resolved by understanding the different aspects of meditation practice and how they each play a role in how mindfulness is realised. This clarity, however, is beyond the scope of the present study and can be further explored by reading Brown and Ryan.

Kabat-Zinn’s (1994) definition of mindfulness has been commonly referred to in the literature; that is, “paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally” (p. 4). This definition is the basis of mindfulness-based stress reduction (MBSR) programs (Kabat-Zinn, 1982, 1990). Mindfulness-oriented therapies, including MBSR programs (Kabat-Zinn, 1982, 1990), have been used extensively in the treatment of psychological distress (e.g., Astin, 1997; Bränström, Kvillemo, Brandberg, & Moskowitz, 2010; Oman, Shapiro, Thoresen, Plante, & Flinders, 2008; Shapiro, Astin, Bishop, & Cordova, 2005; Speca, Carlson, Goodey, & Angen, 2000; Williams, Teasdale, Segal, & Soulsby, 2000). Numerous studies provide evidence for the efficacy of MBSR and related programs in the treatment of: depression (Anderson, Lau, Segal, & Bishop, 2007; Grossman et al., 2010; Koszycki, Benger, Shlik, & Bradwejn, 2007; Sephton et al., 2007); anxiety (N. D. Anderson et al., 2007; Shapiro, Schwartz, & Bonner, 1998), rumination (N. D. Anderson et al., 2007; Jain et al., 2007); body image dissatisfaction (Dekeyser, Raes, Leijssen, Leysen, & Dewulf, 2008; Dijkstra & Barelds, 2011); post traumatic avoidance symptoms (Bränsträm, Kvillemo, Brandberg, & Moskowitz, 2010); and improving QoL (Grossman et al., 2010; Koszycki et al., 2007; Shapiro et al., 2005). MBSR programs have also been found to enhance psychological wellbeing in non-clinical populations (Brown & Ryan, 2003; Hodgins & Adair, 2010; Keng et al., 2011; Moore & Malinowski, 2009). For instance, MBSR programs in non-clinical populations focus upon enhancing a sense of forgiveness (Oman et al., 2008), mindfulness (Anderson et al., 2007; Shapiro et al., 1998), self-compassion (Shapiro et al., 1998), empathy (Shapiro et al., 1998), and a sense of spirituality (Astin, 1997; Shapiro et al., 1998).

1.9.1 Mindfulness based interventions and chronic illness.

A number of studies have supported the positive effects of mindfulness practice on reducing physical pain, psychological distress, and improving the QoL associated with chronic illness (Brown, Ryan, & Creswell, 2007; Grossman et al., 2004; Hodgins & Adair, 2010; Moore & Malinowski, 2009).

Chronic pain is known to have a negative impact on QoL (Gold, Mahrer, Yee, & Palermo, 2009; Gormsen, Winter, Kapp, & Hass, 2010). The first MBSR study originated from work with chronic pain patients (Kabat-Zinn, 1982). Kabat-Zinn (1982) studied 51 chronic pain outpatients utilising his 10-week stress reduction program in Massachesetts. A number of chronic pain categories were included in the study including neck, shoulder and back pain, gastrointestinal pain, facial pain, and non-cardiac chest pain. Following the 10-week program, Kabat-Zinn found that 50% of participants reported a ≥ 50 % reduction in the total pain rating index, and 65% of patients reported a ≥ 33 % reduction in the total pain rating index. According to Kabat-Zinn, the majority of patients in the study experienced considerable improvement with the reduction of pain with carry-over effects. The MBSR program for chronic pain has since been validated (Kaplan, Goldenberg, & Galvin-Nadeau, 1993; Rosenzweig et al., 2010; Wong et al., 2011) and reviewed (Chiesa & Serretti, 2011; Cramer, Haller, Lauche, & Dobos, 2012; Reiner, Tibi & Lipsitz, 2013) several times with similar outcomes.

However, Garmon et al. (2014) have questioned these findings; in a recent review, they highlighted possible methodological flaws in the MBSR and chronic pain studies. Their systematic review included 23 clinical studies, which comprised of 13 randomised controlled trials, six case series, and four cohort studies, which explored mindfulness-based stress reduction for chronic pain. The number of participants in these 23 studies ranged from 22 to 225, with a mean of 97 participants. Garmon et al. (2014) found the available literature did not establish whether MSBR does or does not reduce pain severity. In fact, in their conclusion, the authors highlighted that the possible link between MBSR and the benefits of reducing pain severity (or making it more manageable) may be attributed to Type 1 and Type 2 errors. Chiesa and Serretti (2011) also conducted a systematic review of 10 studies (*N* = 951 participants) exploring mindfulness-based interventions for chronic pain. These authors also could not determine the magnitude of effects due to methodological limitations of the studies they reviewed, including lack of randomisation, small sample sizes, and differences among the interventions tested.

Despite possible shortcomings in the research methodology, including small sample sizes and lack of randomisation, MBSR programs have been studied across a variety of chronic illness domains, including: cancer (e.g., Abdollahi & Khan, 2015; Bränsträm et al., 2010; Brown & Ryan (2003); Carlson & Garland, 2005; Carlson, Speca, Faris, & Patel, 2007; Anderson et al., 2007; Saxe et al., 2001; Speca et al., 2000); fibromyalgia (e.g., Sephton et al., 2007; Weissbecker et al., 2002); Type 2 diabetes (e.g., Hartmann et al., 2012, Whitebird, Kreitzer & O'Connor, 2009; Young, Cappola, & Baime, 2009); multiple sclerosis (e.g., Grossman et al., 2004); and rheumatoid arthritis (e.g., Fogarty, Booth, Gamble, Dabeth & Consedine, 2015; Pradhan et al., 2007).

Cancer has been found to significantly contribute to psychological distress and a reducted QoL (Bruce, 2006; Evans et al., 2005; Greimel, Winter, Kapp, & Haas, 2009; Hack et al., 2010; Hong & Tian, 2014; National Breast Cancer Centre, 2003; Neuman, Park, Fuzesi & Temple, 2012). This is especially so for breast cancer patients (Howard-Anderson, Ganz, Bower, & Stanton, 2012; So et al., 2010). The impact of breast cancer, in particular, is not surprising, considering that the World Health Organisation (WHO; Global Health Estimates, WHO, 2013) estimated that 508,000 female deaths in 2011were due to breast cancer.

Adbollahi and Khan (2015) sought to review the research exploring breast cancer and MBSR, finding empirical support for the usefulness of MBSR on improving QoL in these patients. Although the authors found that patients with higher levels of mindfulness following completion of MBSR programs experienced higher levels of QoL and emotional wellbeing, the emotional change mechanisms underlying these benefits is still unknown. These findings were also supported by a recent metaanalysis exploring the benefits of MBSR on breat cancer survivors (Huang, Wang, & Zhou, 2015). Having reviewed nine studies involving 964 participants, Huang et al. found that, compared to control groups, individuals who had undertaken MBSR treatment reported significant improvements in: anxiety (mean difference [MD] = 2.79; confidence interval [CI] = 1.62-3.96; $p < .00001$); depression (MD = 5.09; 95% CI = 3.63-6.55; $p < .00001$); stress (MD = 4.10; 95% CI = 2.46-5.74; $p < .00001$); and QoL (MD = -1.16; 95% CI = -2.21 to -.12; $p = 0.03$).

Similar positive outcomes were also found in RA or Rheumatic Joint Pain (RJP) studies. In order to help manage the negative effects of these diseases, a number of psychological treatments have been employed, including cognitive behavioural therapy (CBT; Knittle, Maes & de Gucht, 2010) and mindfulness-based programs (Zangi et al., 2012). Zangi et al. (2012) utilised a 10-session mindfulness-based program to undertake a randomised control trial of 68 patients with RA/RJP. The program consisted of 10 group sessions (eight-to-12 individuals per group) over a 15-week period. The intervention involved mindfulness-based exercises; for example, encouraging individuals to be more aware of their emotions, thoughts, and bodily experiences; reflecting on these with others; and completing mindfulness exercises by listening to a CD-ROM. Measures used in the study included: the General Health Questionnaire (GHQ-20; Goldberg & Williams, 1988); Arthritis Self-Efficacy Scale (Brekke, Hjortahl, & Kvien, 2001); Emotional Approach Coping Scale (EAC; Stanton, Kirk, Cameron, & Danoff-Burg, 2000); and a numerical rating scale (0 to 10) to measure secondary outcomes including disease activity, pain, and fatigue. Although the authors utilised a relatively small sample size, they reported finding significant treatment effects in psychological distress, self-efficacy, symptoms, fatigue, self-care, emotional processing, and overall wellbeing that was maintained at 12-month follow-up. Zangi et al. however, did not find any significant difference in pain, disease activity or emotional expression.

According to Fogarty, Booth, Gamble, Dalbeth and Consedine, (2015), MBSR programs have also been suggested to reduce disease activity in patients with RA. Using a randomised control trial with 51 individuals diagnosed with RA (MBSR treatment *n* = 26; control *n* = 25), the authors found a positive effect of the treatment on the experience of joint tenderness, pain, and patient global assessment. The authors, however, did not find any reduction in objective disease activity, concluding that the improvements were based on the intervention having changed the patients' experience of the disease. Hartman et al. (2012), however, in their randomised control trial of MBSR with individuals diagnosed with Type 2 diabetes (treatment *n* = 53; control *n* = 57) reported a reduction in disease activity and progression of neuropathy (i.e., albuminuria). The authors also confirmed a prolonged reduction in psychosocial distress (specifically, depression and stress).

Mindfulness based stress reduction programs have not only been utilised for their positive effects on reducing psychological distress, improving QoL, and possible reductions in disease activity, but also on influencing outcomes through treatment compliance and self-care (Rosenzweig at al, 2007). Diabetes is such a condition that requires strict adherence to treatment (Miller & DiMatte, 2013; Schoenthaler, Schwartz, Wood, & Stewart, 2012). In order to reduce psychological distress that contributes to poor glycaemic control, Rosenzweig et al. (2007) utilised a MBSR program in 14 patients diagnosed with Type 2 diabetes. Although only an 8-week pilot study, a small sample size and the absence of a control group, the authors found improved glycaemic control, and a reduction in anxiety and depression following the intervention.

1.9.2 Mindfulness interventions and IBD.

Although extensive research has explored the mindfulness-based practice and psychological and physical distress relationship in chronic illness, little research has explored the relationship between IBD and mindfulness-based interventions. Langhorst et al. (2007) were amongst the first to utilise elements of the MBSR program (e.g., mindfulness meditation, yoga breathing, guided imagerys and body scan) in a study exploring the effects that a lifestyle modification program had on the QoL of patients with UC (Langhorst et al., 2007). The program consisted of a 60-hour training program (e.g., six hours a day for 10 weeks), which included: MBSR techniques; a Mediterranean-type diet (suggested by the German consensus treatment guidelines; Hoffmann et al., 2004); regular exercise; CBT; and psychoeducational approaches. Participants were also informed about other complementary self-care options, including herbal medicine for GI complaints (e.g., probiotics) and hydrotherapy. Three months following the program, the intervention group demonstrated a significantly greater reduction in anxiety and an improvement in some aspects of QoL (e.g., physical function), compared to the control group, who receieved medical care as usual carried out by their gastroenterologist or primary care physician. No effect was found on disease activity nor was any significant effect noted 12 months following the intervention when compared to the usual care group, (Langhorst et al.). Although short-term benefits of the intervention program were reported, it is difficult to ascertain the influence the MBSR elements had on the overall outcome of the intervention. Additional limitations included a small sample size, restricted patient selection (i.e., UC paticipants in remission or low disease activity; individuals likely to have a pre-existing active coping style), and the possibility of Type I error. The study also did not identify whether MBSR or CBT contributed to the benefits.

Jedel et al. (2014) sought to extend the findings of their study exploring dispositional mindfulness in individuals with inactive UC by exploring the effectiveness of MBSR in preventing flare-ups, and improving the QoL of patients. Fifty-five UC individuals were randomised into either the MBSR group (*n* = 27) or the time/attention control group (*n* = 28). Assessments utilised to assess disease status and activity included the Mayo UC-DAI (Schroeder, Tremaine, & Ilstrup, 1987), and assessment of biological markers for inflammation, including faecal calprotectin, cytokines, and C-reactive protein (CRP).

Psychological assessment included the Beck Depression Inventory (BDI; Beck, 1970), Perceived Stress Questionnaire (PSQ; Levenstein et al., 1993), the State-Trait Anxiety Inventory (STAI; Spielberger & Sydeman, 1994), the IBD-Q (Irvine, 1993), the Perceived Health Competance Scale (PHCS; Smith, Wallston, & Smith, 1995), and the MAAS (Brown & Ryan, 2003). Although no significant group differences were found with asbcence of flares, severity of flare and time of flare, over a one-year period, the authors did find that individuals in the MBSR program reported lower stress and prevented a reduction in QoL during flare-up, compared to the control group. The authors also noted the potential benefits of the MBSR program for individuals with high stress reactivity during remission as measured by urinary cortisol levels.

In a more recent study, Neilson et al. (2015) utilised an adapted MBSR program originally developed by Kabit-Zinn (1982) in a randomised control trial of 60 individuals diagnosed with IBD (CD = 44, UC =16; intervention *n* = 33, control *n* = 27). Utilising measures for disease activity (CDAI, Best et al., 1976; UCAI; Martin & Greer 1987), QoL (WHO QoL-BREF; Skevington, Lotfy, & O'Connell, 2004), anxiety and depression (HADS; Zigmond & Snaith, 1983), and mindfulness (Five facet Mindfulness Questionnaire; Baer et al., 2006), Neilson et al. found that the intervention group reported significantly greater improvements to QoL, anxiety, and mindfulness skills, compared to the control group at the time of completion (eight weeks). At the six-month follow up, the authors also found that the intervention group reported an improvement in mindfulness skills and QoL, with a reduction of depressive symptoms compared to the control group.

Although there are a limited number of studies exploing MBSR interventions in the IBD population, the results nonetheless add support to previous chronic illness studies (see Section 1.9.1). Indeed, the findings of MBSR programs with IBD patients appear favourable.

However, further research is required to determine the potential benefit of helping IBD patients develop a mindful disposition as opposed to simply inducing mindful states.

1.9.3 Dispositional mindfulness.

Brown and Ryan (2003) describe mindfulness or ‘dispositional’ mindfulness as the tendency of individuals to be mindful in everyday life. Mace (2008) suggests that the tendency and capacity to be mindful is an inherent part of our daily lives that tends to grow with maturity or is enhanced through practices like mindfulness training. A dispositional mindful state has been considered to imply emotion regulation abilities (Lutz, Slagter, Dunne, & Davidson, 2008), including a better recognition of, and detachment from, current emotional patterns. This is believed to adaptively improve one’s ability to respond to, and regulate, emotional states (Brown & Ryan, 2003). In order to fully understand dispositional mindfulness, it is worthwhile further exploring how this construct is measured.

1.9.4 Measurement of mindfulness.

Brown and Ryan’s (2003) Mindful Attention Awareness Scale (MAAS) measures a particular quality of consciousness that is also related to a variety of wellbeing constructs. It is associated with enhanced self-awareness, which according to the authors, differentiates mindfulness practitioners from others. The MAAS items were designed not only to tap into states of mindfulness (i.e., answering positively), but to also explore being in an automatic, relatively non-conscious state of being (Heppner et al., 2008). The MAAS measures how unaware and inattentive an individual is of their present moment experience; for example, mindfulness would be noted when a person denies items such as “I rush through activities without being really attentive to them”. A higher mindfulness score on the MAAS was found to be associated with higher overall dispositional authenticity (Kernis & Goldman, 2006). Therefore, the MAAS is a good representation of mindfulness, given its well-supported, onedimensional factor structure and good monothetic span (Brown & Ryan, 2003; MacKillop & Anderson, 2007).

Brown and Ryan (2003), and Carlson and Garland (2005), found that higher dispositional mindfulness was associated with positive mood and wellbeing, and lower levels of stress, anxiety and depression. The exact mechanism as to how this occurs is not well understood. Dispositional mindfulness has been suggested to arise from the way being mindful increases the possibility of making behavioural decisions and controlling behaviour, resulting in increased goal attainment and wellbeing (Brown et al., 2007).

Lazarus and Folkman's (1984) stress and coping model suggests that coping responses are initiated by the appraisal of an event that is deemed challenging, threatening or harmful. In order for an appraisal to be made, attention is required. Salmon et al. (2004) suggested that the attentional aspect of mindfulness may be associated with the appraisal of symptoms of stress. Therefore, a lack of attention of these signs of stress would eventually lead to an accumulation of stress with no coping strategies utilised, and resulting in reduced wellbeing and health (Bränström, Duncan, & Moskowitz, 2011). A higher dispositional state of mindfulness would therefore result in increased awareness of symptoms of stress that could positively influence coping, thereby buffering against the negative effects of stress (Brown et al., 2007).

Brown et al. (2007) also suggested that a heightened state of mindfulness "enables increased clarity of awareness and a greater access to one's knowledge and abilities, both intellectual and emotion" (p. 302), resulting in greater access to inner resources that influence stress appraisal in a positive way, thereby facilitating positive coping strategies. In Baer's (2003) review of studies exploring the mechanisms of mindfulness, he concluded that greater ability to react mindfully in day-to-day life experiences might reduce fear of emotion, rumination, and avoidance of emotional stimuli. This reduction in maladaptive behaviour may improve coping ability in the context of the stressful events.

Bränström et al. (2011) explored mindfulness as a human capacity (i.e., disposition) and how it related to different psychological outcomes, both negative (e.g., depression and anxiety) and positive affective states. They used the Five Facet Mindfulness Questionnaire (Baer, Smith, Hopkins, Krietemeyer, & Toney, 2006) to assess the relationship between dispositional mindfulness, and a number of psychological variables, including: the HADS (Zigmond & Snaith, 1983); Positive States of Mind (PSOM) Scale (Adler, Horowitz, Garcia, & Moyer, 1998); Perceived Stress Scale (Cohen et al., 1983); and perceived health degree of satisfaction (using physical health and QoL items from the EORTC-QLQ-C30 questionnaire; Aaronson et al., 1993). In a sample of 382 randomly-assigned participants from a Swedish population, Bränström et al. (2011) found that anxiety, depression, PSOM, and perceived health were strongly related to mindfulness. These findings replicate and support findings from previous dispositional mindfulness studies (e.g., Brown & Ryan, 2003; Carlson & Brown, 2005).

Murphy, Mermelstein, Edwards, and Gidycz (2012) examined the relationship between dispositional mindfulness, physical health, and health behaviour in 441 female college students. Using the MAAS (Brown & Ryan, 2003), they found higher dispositional mindfulness to be associated with healthier eating practices, better physical health, and better quality of sleep even after controlling for traditional health habits. Examining the relationship between dispositional mindfulness, and body comparison and body satisfaction among 1,287 Dutch women, Dijkstra and Barelds (2011) found that body comparison was negatively associated with both dispositional mindfulness and body satisfaction. Dispositional mindfulness was positively related to body satisfaction. Dijkstra and Barelds also found that body comparison partially mediated the relationship between body satisfaction and mindfulness, and mindfulness partially mediated the relationship between body satisfaction and body comparison. This supports Reindl's (2002) suggestion that non-judgement is highly relevant to one's perception of body image by not judging or comparing one's body image against impossible societal standards of attractiveness.

Based on Brown and Ryan's (2003) research, which suggested that mindfulness may be linked to lower levels of ego-involvement, Heppner et al. (2008) conducted two studies to explore the link between lower levels of ego-involvement and lower hostility and aggressive behaviour. In their first study, they found that dispositional mindfulness correlated negatively with self-reported hostile attribution and self-reported aggressiveness. In their second study, they found that less aggressive behaviour from participants became more mindful prior to receiving social rejection feedback compared to rejected participants who did not become more mindful (Heppner et al., 2008).

1.9.5 Dispositional mindfulness and chronic illness.

Few studies have explored dispositional mindfulness and chronic illness (e.g., Brown & Ryan 2003; Salmoirago-Blotcher, Crawford, Carmody, Rosenthal, & Ockene, 2011). Salmoirago-Blotcher et al. (2011) sought to explore the effects that dispositional mindfulness has upon disease severity and psychological co-morbidity in 30 out-patients who were implanted with cardiovascular defibrillators. Using a measure for anxiety and depression (Zigmond & Snaith, 1983), a mindfulness scale (the Five Facets of Mindfulness Questionnaire; Baer et al., 2008), and clinical information regarding the participants' heart disease-related characteristics (e.g., ejection fraction obtained from diagnostic equipment such as an echocardiogram or ventriculogram), Salmoirago-Blotcher et al. observed that patients who were high in dispositional mindfulness reported lower depression scores ($\beta = -7.95$; CI = -14.31 to -1.6) and lower anxiety scores ($\beta = -1.10$, CI = -1.71 to -0.49). However, they found no association between mindfulness and disease severity.

Brown and Ryan (2003) sought to extend the work of Speca et al. (2000), and Carlson, Ursuliak, Goodey, Angen, and Speca (2001), who explored the effect MBSR had upon mood and stress in cancer out-patients. Using a sample of 58 breast and prostate cancer patients, Brown and Ryan sought to investigate the effects the MBSR program had on emotional wellbeing using the MAAS. They found that higher levels of mindfulness (as indicated by a higher score on the MAAS) were related to lower levels of stress and mood disturbance, before and after the clinical intervention study. Their findings support the use of the MAAS in studying wellbeing issues in cancer populations, as well as supporting the suggestions that MBSR interventions enhance dispositional mindfulness (Brown & Ryan, 2003).

1.9.6 Dispositional mindfulness and IBD.

Unfortunately, only one study has explored the relationship of disposotional mindfulness and IBD (Jedel et al., 2013). Jedel et al. (2013) sought to explore the relationship between dispositional mindfulness and perceived stress, psychiatric distress, and QoL in 50 patients diagnosed with inactive UC who had no previous experience with mindfulness practices. Utilsing the MASS (Carlson & Brown, 2005), STAI (Speilberger, 1983), BDI (Beck, 1996), Perceived Stress Scale (Levenstein et al., 1993), IBDQ (Irvine, 1993), and by splitting the participants into a symptomatic and asymptomatic group, Jedel et al. found that the mindfulness scores of the asymptomatic group were significantly, inversely correlated with perceived stress scores, depression, and anxiety, and positively correlated with QoL. In the symptomatic group, however, the mindfulness scores were only significantly, inversely correlated with perceived stress scores and no other psychosocial variables. Jedel et al. suggested that the reason for this may be that QoL in symptomatic UC patients differs in the domain of attention/awareness compared to other medical conditions, although their were not aware of any previous reporting in the literature.

Overall, both dispositional and MBSR studies provide strong evidence that the teaching of mindfulness is efficacious in enhancing and improving psychological wellbeing and QoL in chronic illness and IBD.

1.10 Psychological Distress: Anxiety, Depression and Stress

Psychological distress (e.g., anxiety, depression and stress) is highly comorbid with IBD and negatively influences QoL (Addolorato, Capristo, Stefanini, & Gasbarrini, 1997; Filipović, Filipović, Kerkez, Milinić, & Randelović, 2007; Graff et al., 2009; Helzer, Stillings, Chammas, Norland, & Alpers, 1982; Jones, Wessinger, & Crowell, 2006; Kovács & Kovács, 2007; Lerebours et al., 2007; Magni et al., 1991; Mawdsley & Rampton, 2007). For this section and throughout this thesis, anxiety and depression will be discussed separately, as well as combined as psychological distress, as they are often not easily differentiated and frequently coexist (Clarke & Currie, 2009). A primary outcome measure in this research will be psychological distress. This term will be used to refer to the combination of psychological symptoms associated with anxiety, depression and stress. This definition of psychological distress is consistent with Lovibond and Lovibond's (1995) definition and the scales they developed (DASS-42; DASS-21) to assess psychological distress. Where relevant, specific aspects of anxiety depression and stress will be outlined in review of the literature.

1.10.1 Anxiety.

Although anxiety has a multitude of definitions, Stein and Hollander (2002, p. 72) define it as "a tense emotional state characterized by a variety of sympathetic symptoms, including chest discomfort, palpitations, and shortness of breath; painful uneasiness of mind over an anticipated ill; abnormal apprehension or fear; self-doubt as to the nature of the threat; belief as to the reality of the threat; and lapses of weakness of coping potential". Anxiety primarily involves the psychophysiological response to a threat, that can be either fight, flee, (fight-flight) or freezing. Although this is a typical response to a threat, the anxious person perceives the threat to be real despite the absence of an objectively real threat (Stein & Hollander, 2002).

1.10.2 Depression.

Depression or major depressive disorder can be defined according to the latest criteria of the *DSM-5* (American Psychiatric Association, 2013). A *DSM-5* diagnosis of major depressive disorder requires that at least five of the following symptoms be present for at least two weeks: (1) depressed mood; (2) markedly diminished interest or pleasure; (3) significant weight loss or gain, including decrease or increase in appetite; (4) hypersomnia or insomnia; (5) psychomotor agitation or retardation; (6) loss of energy or fatigue; (7) excessive inappropriate guilt or feelings of worthlessness; (8) impaired concentration, thinking or indecisiveness; and (9) recurrent thoughts of suicide. Additionally, at least (1) depressed mood or (2) markedly diminished interest or pleasure, is required to be present as part of the minimum five symptoms.

Depression is common, representing the third leading cause of disease burden globally, accounting for 4.3% of the total disability (Harada et al., 2012). By 2020, it has been projected that depression will be the second leading cause of disability worldwide (Michaud, Murray, & Bloom, 2001). In Australia, anxiety has been found to have 12-month and lifetime prevalence rates of 11.8% and 20.0%, respectively (McEvoy, Grove, & Slase, 2011), and is considered the sixth leading cause of diability worldwide (Baxter, Vos, Scott, Ferrari, & Whiteford, 2010). Together with anxiety, depression results in a greater deal of functional impairment and disability than the features of disease (Kessler, Ormel, Demler, & Stang, 2003; Sullivan, LaCroix, Baum, Grothaus, & Katon, 1997).

Depression has been found to have a similar disease burden to that of heart disease (Moussavi et al., 2007), and is suggested to be a risk factor for physical illness and premature death (Wulsin, Vaillant, & Wells, 1999). Wilhelm, Mitchell, Slade, Brownhill, and Andrews

(2003) stated that physical illness is one of the strongest risk factors in developing depression. In their study looking at 245,404 participants from 60 countries, Wilhelm et al. found that between 9.3% and 23% of chronic illness participants had comorbid depression. Anxiety and depression are the most common adult psychiatric disorders in the Western world (Airaksinen, 2006). Together, anxiety and depression greatly impact upon a person's QoL (Bodurka-Bevers et al., 2000; Conn, Taylor, & Wiman, 1991; Wilhelm et al., 2003). It is therefore important to explore the complex relationship that physical or chronic illness has with anxiety and depression.

1.10.3 Psychological stress

Psychological stress, according to Lovibond and Lovibond (1995), can be defined by the 5 factors that emerged from the factor analysis whilst creating the DASS-42 scale. These factors include difficulty relaxaing, nervous arousal, easily upset/agitataed, irrtitable/over-reactive, and inpatience. In summary, stress involves "the state of persistent arousal and tension with a low threshold for becoming upset or frustrated (Lovibond & Lovibond, 1995; p. 342). Cohen, Janicki-Deverts and Miller (2007) report that psychological stress occurs following an individuals perception that environmental demands exceed or tax her or his adaptive capacity. Lovibond and Lovibond's analysis confimed that while the depression, anxiety and stress factors can be discriminated from each other, they are still moderately highly correlated with each othe, with stress being more closely related to anxiety than depression.

1.10.4 Psychological distress and chronic illness.

The development of anxiety, depression and stress have been hypothesised to be associated, and co-existing, with patients experiencing chronic medical illness and who are experiencing severe adverse effects (e.g., Aina & Susman, 2006; Delgado, 2007; Felton, Revenson, & Hinrichsen, 1984; Katon & Ciechanowski, 2002; Katon & Sullivan, 1990;

Miller, Cohen, & Riychey, 2002; Patten et al., 2005; Scott et al., 2007). These adverse effects range from: the amplification of functional disability and physical symptoms; poor conformity to treatment self-care regimens; increased automatic nervous system activity resulting in worsening of disease pathophysiology; and modification of immune system activity, to increased mortality (Katon & Ciechanowski, 2002; Katon & Sullivan, 1990; Sullivan, LaCroix, Spertus, & Hecht, 2000; Walker, Gelfand, Gelfand, Creed, & Katon, 1996).

In their review of placebo-controlled, double blind treatment studies, Katon and Sullivan (1990) estimated a 41% increase in the risk of having a psychiatric disorder in patients with one or more chronic medical illnesses. Epidemiological studies revealed that 2-4% of the general population suffer from an affective disorder compared to 15-33% of medical in-patients (Katon & Sullivan, 1990). This association has also been found in chronic illness studies including cancer (Hong & Tian, 2014; Husson et al., 2011; Tel et al., 2011), RA (Matcham et al., 2013; McBain et al., 2013), diabetes (Tovilla-Zarate et al., 2012), and CHD (Pająk & Kozela, 2012).

Compared to rates reported in the general population, epidemiological studies have reported higher rates of depression in people with diabetes (Ali, Stone, Peters, Davies, & Khunti, 2006; Barnard, Skinner, & Peveler, 2006), heart disease (Agency for Health Care Policy and Research, 1995; Bush et al., 2005; Frasure-Smith & Lespérance, 2006; Katon, Lin, & Kroenke, 2007;, Friis-Hasché, Haghfelt, & Bech, 2005), RA (Alpay & Cassem, 1999; Dickens, McGowan, Clark-Carter, & Creed, 2002), cancer (Bruce, 2006; Evans et al., 2005; National Breast Cancer Centre, 2003), and osteoarthritis (McLennan, 1997).

Hong and Tian (2014) explored levels of anxiety and depression among 1,217 cancer patients in China. Using measures including: the HADS (Zigmond & Snaith, 1983); the Eastern Cooperative Oncology group scale (Wang, Wang, & Ma, 1999); a pain intensity scale, numerically rated from 0-10 (where 0 indicates no pain at all and 10 indiciates extreme pain); and a social support scale developed by the authors, Hong and Tian reported anxiety and depression prevalence rates at 6.49% and 66.72%, respectively. Risk factors for depression included: pain ($p = 0.0003$); performance status ($p < 0 .0001$); education levels ($p < 0.0001$); and age ($p < 0.0001$). Factors influencing anxiety included: gender ($p < 0.0001$); age ($p = 0.0001$); and performance status ($p = 0.0007$), In conclusion, Hong and Tian found that depression was the most important psychological problem when compared with anxiety, pain, old age, poor performance status, and low education as predictive factors.

Anxiety and depression are reported to be highly prevalent in individuals with Type 2 diabetes (Tovilla-Zarate et al., 2012). In their study of 704 Mexican patients diagnosed with Type 2 diabetes, and using measures including the Hamilton Depression rating scale (Hamilton, 1959) and the Hamilton Anxiety rating scale (Hamilton, 1959), Tovilla-Zarate et al. (2012) found rates for anxiety to be 55.10% (95% CI = 51.44–58.93). Rates for depression were 48.27% (95% CI = 44.48–52.06). Factors associated with anxiety included occupation and complications with diabetes, while factors associated with depression included glucose levels and complications resulting from diabetes. Of these factors, Tovilla-Zarate and colleagues found complications to be the most common factor contributing to anxiety and depression ($p = 0.0001$; OR = 1.79, 95% CI = 1.29–2.4).

1.10.5 Psychological distress and IBD.

Psychological distress has also been suggested to be asscociated and coexisting with patients experiencing IBD (Guthrie et al., 2002; Levenstein et al., 1993; Sajadinejad, Asgari, Molavi, Kalantari & Adibi, 2012; Triantafillidis, Merikas & Gikas, 2013). Psychological distress is more prevalent in patients with IBD than in healthy control participants or patients with other diseases (Addolorato et al., 1997; Filipović et al., 2007; Graff et al., 2009;; Helzer et al., 1982; Jones et al., 2006; Kovács & Kovács, 2007; Lerebours et al., 2007;; Magni et al.,

1991) and has been estimated to be as high as 60% for depression and 80% for anxiety during relapse/active disease (Addolorato et al., 1997), and 29-35% during remission (Andrews, Barczak, & Allan, 1987; Mittermaier et al., 2004).

For many years, psychiatric disorders such as anxiety and depression were thought to be pathophysiological causality mechanisms in IBD (Mikocka-Walus et al., 2008; Triantafillidis, Merikas & Gikas, 2013), and that IBD may be partly psychosomatic (Lieberz, 1990; Moser, 1997; Ramchandani, Schindler, & Katz, 1994; Scheib & Wirsching, 1991; Sheffield & Carney, 1976; Smith, Van der Meer, Ursing, Prytz, & Benoni, 1995; Tocchi et al., 1997). In the 1990s, following reviews of IBD, it was found that there was little evidence to support the past belief that IBD was a psychosomatic illness, or that psychological factors played a part in the development of IBD (Fullwood & Drossman, 1995; Maunder, 1998; North & Alpers, 1994; North, Clouse, Spitznagel, & Alpers, 1990). This may have been influenced by the lack of prospective studies, due in part to low IBD occurrence rate that would make the studies costly and impractical (Graff et al., 2009). The three limited studies (Kovács & Kovács, 2007; Tarter, Switala, Carra, & Edwards, 1987; Walker et al., 2008) that have explored anxiety and depression as contributing to onset of IBD found a higher lifetime prevalence of anxiety and depression in IBD patients compared to controls.

Epidemiological data (Kessler, 2007) suggests that anxiety and depression may contribute to an early age of onset of IBD, however, Graff et al. (2009) argued that these studies may be limited due to information gathered from historical chronology and retrospective recall. Kurina, Goldacre, Yeates, and Gill (2001) explored the relationship without potential recall bias, and they did not find higher rates of anxiety and depression prior to the diagnosis of CD. However, they did find two-to-three times higher rates of anxiety and depression prior to the diagnosis of UC.

Although there is very little evidence to suggest anxiety and depression result in the onset of IBD, it may well be that anxiety and depression reflect early signs of IBD (Graff et al., 2009), which may initiate a mood disorder (Rosenkranz, 2007). Following these findings, emphasis has shifted to exploring the influences of psychiatric disorders in patients with IBD in terms of their ongoing adaptation to IBD (Walker et al., 1996).

Comparative cross-sectional and prospective studies have been used to explore the course of IBD and the relationship between psychiatric disorders. These studies have reported higher levels of anxiety and depression in patients with IBD during the active phase of their disease or when symptoms are evident, compared to patients in remission or normal control groups (Calvet et al., 2006; Levenstein et al., 1994; Maunder et al., 2006; Maunder & Levenstein, 2008; Simrén et al., 2002). A number of studies have explored this relationship prospectively (e.g., Angelopoulos, Mantas, Dalekos, Vasalos, & Tsianos, 1996; Mardini et al., 2004; Maunder & Levenstein, 2008; Mikocka-Walus et al., 2008; Mittermaier et al., 2004; Persoons et al., 2005). Using a small sample of 26 UC patients, Angelopoulos et al. (1996) found higher levels of anxiety and depression in patients during the active stage of the disease, and lower levels during remission. Porcell, Leoci, and Guerra (1996) also found support for this relationship using a sample of 104 CD and UC patients, where worsening disease was accompanied by increased anxiety and depression. By contrast, Vidal and colleagues (2008), amongst other researchers (e.g., Helzer, Chammas, Norland, Stillings, & Alpers, 1984; Mikocka-Walus et al., 2008; Robertson, Ray, Diamond, & Edwards, 1989) found contradictory results, with depression and anxiety being similar regardless of disease status. This may been due to low anxiety and depression scores reported in their sample, making it difficult to distinguish between "high" versus "low" anxiety and depression.

Tanaka and Kazuma (2005) and Simrén and colleagues (2002) also argued that IBD patients are equally vulnerable to anxiety and depression during remission and relapse. In fact, no significant difference in psychological wellbeing was found in 43 UC patients and 40 CD patients in remission compared to normal Swedish controls (Simrén et al., 2002). Mikocka-Walus et al. (2008) argued that where studies have found support for anxiety and depression as fluctuating with disease course, the studies have methodological problems.

Although depression and anxiety have largely been dispelled as causative factors in IBD, there is considerable research suggesting depression and chronic psychological distress moderately influences the course of the disease, and represent risk factors for relapse (Caprilli et al., 2006; Mardini et al., 2004; Mawdsley & Rampton, 2005; Mittermaier et al., 2004). It has been suggested that depression (Mardini et al., 2004; Mittermaier et al., 2004; Persoons et al., 2005), psychological stress (Bernstein, Singh, et al., 2010; Bitton et al., 2008; Levenstein et al., 2000), and adverse life events can trigger relapse (Bitton et al., 2003; Duffy et al., 1991). Using a biopsychosocial model of CD, Bitton et al. (2008) found that patients with CD in remission were least likely to relapse under conditions of low stress and least involvement in avoidance coping strategies (i.e., social distraction or diversion). Bitton et al. (2003) also found more recent stressful events were associated with earlier time to relapse in patients with inactive UC. Impaired QoL and depressed mood associated with anxiety was also found to have a negative influence of the course of CD (Mittermaier et al., 2004).

Mikocka-Walus et al. (2008), however, found no relationship between psychological status and QoL at baseline and relapse at 12 months. They did however find a lower risk of relapse after 12 months for patients with inactive disease at baseline. Mikocka-Walus et al. found no relationship between psychological problems; for example, anxiety/depression and total number of relapses. They did, however, find that patients with active disease at baseline had more relapses, and patients with CD were at lower risk of relapse at 12 months compared to UC participants.

Numerous researchers (e.g., Mardini et al., 2004; Mittermaier et al., 2004; Persoons et al., 2005) report that psychological distress and depression are not only common in IBD, but they can also cause the condition to worsen. Goodhand and colleagues (2012) suggest disease course may in fact be influenced by learning to identify the factors associated with the development of the psychological distress and depression, and not only for improving mood or QoL. Filipović et al. (2007), on the other hand, argue that it almost impossible to determine whether psychiatric challenges influence gastrointestinal symptoms or vice versa. They explain that, based on symptoms alone, confusion can result between a condition being IBD or functional, like irritable bowel syndrome.

Several earlier studies supported interactions between psychological factors and IBD activity (Andrews et al., 1987; Duffy et al., 1991; Fullwood & Drossman, 1995; Greene, Blanchard, & Wan, 1994; Mawdsley & Rampton, 2005; McKegney, Gordon, & Levine, 1970; Porcell et al., 1996). These findings, however, have been met with methodological challenges and contradictions (Boye et al., 2011; Levenstein et al., 1994; Goodhand & Rampton, 2009; Riley, Mani, Goodman, & Lucas, 1990). Goodhand and Rampton (2009) highlighted the methodological difficulties in asserting that stress/distress influences disease activity. These challenges included a long study period in order to test the correlation between diarised relapses/gastrointestinal symptoms, and life events. Additional challenges arise with patients' changes in medications over periods of time that would influence disease activity. Goodhand and Rampton also noted challenges regarding how to define stressful life events or even relapse. Although there have been recent studies in the area of psychoneuroimmunology, and the effects stress has on the interaction between hypothalamus-pituitary-adrenal gland and the enteric nervous system (brain-gut axis; Caso, Leza, & Menchen, 2008; Mawdsley & Rampton, 2005; Santos et al., 2008) and mucosal function of the digestive system, the findings are still inconclusive (Goodhand & Rampton, 2009).

Limitations within the stress-disease activity studies also involve the lack of randomised controlled trials aimed at reducing psychological distress, as they can be difficult to blind (Rampton, 2009). Additional challenges include how to assess disease activity that is not reliant upon self-report measures that record the interpretation of symptoms. Although Rampton (2009) concluded that there is little doubt that psychological distress can exacerbate disease activity, and highlighted the need for more rigorous controlled clinical control trials, a more recent by Boye et al. (2011) may shed some light into future findings. Boye et al. (2011) conducted a randomised controlled trial of 114 IBD patients (58 with CD; 56 with UC) who had experienced continuous disease activity over a period of 18 months. The control group involved treatment as usual, while the treatment group involved treatment as usual with the inclusion of stress management psychotherapy. The psychotherapy program involved three group sessions involving relaxation, psychoeducation and psychotherapy, and six-to-nine individual CBT sessions. This was then followed by one-to-three booster sessions at the six- and 12-month intervals. Disease activity was assessed by gastroenterologists who were blinded to the groups at three-, six-, 12-, and 18-month intervals. According to the authors, no disease activity improvements were observed nor any reduction in relapse prevention. Boye et al., however, did note UC patients experienced an improvement in QoL. Although no causal relationship between stress and disease activity can be made at this time, we can simply conclude that this is an area of contention and is difficult to study.

According to Drossman, Patrick, Mitchell, Zagami, and Appelbaum (1989), IBD negatively impairs all aspects of QoL including the patient’s emotional behaviour, including anxiety and depression during and after the active phase of the disease. Helzer et al. (1984) found no evidence of an interaction between psychiatric disorder and CD; however, when compared to controls, they found a significant number of CD participants had depression and met the criteria for a psychiatric disorder at some time in their lives. In fact, Meyer and Mark (1995) state that patients with IBD report serious psychological and emotional morbidities.

There are a number of studies supporting an association between disease activity and mood (Goodhand et al., 2012; Larsson et al., 2008; Porcell et al., 1996). Helzer et al. (1984), with a clinical sample of 50 patients with CD, found that a significant number of patients had a diagnosis of depression; however, an interaction between psychiatric disorder and CD was not found. Despite being in clinical remission, patients with CD were still found to present with anxiety and depression, supporting the need for ongoing psychological support during medical treatment (Iglesias et al., 2009).

Filipović et al. (2007) reported that, compared to IBD patients newly-diagnosed with cancer, newly-diagnosed IBD patients reported higher levels of depression, including: symptoms of transitory insomnia; poor focus; anxiousness and agitation; and somatic symptoms. IBD patients also reported higher levels of anxiety, including: more pronounced neurotic components; gesticulation; vivid facial mimics; belching and gulping during conversation; and musculature of the extremities and intermittent jerk of facial muscles, whilst occasionally staring at the examiner. The results suggested that the pathogenesis of IBD is influenced by psychological conditions. Robertson et al. (1989) on the other hand found depression to only be common in patients with active disease.

Helzer et al. (1982) did not find any significant association of UC patients with increased frequency of diagnosable psychiatric disorder, nor was there significant evidence to suggest that UC patients with psychiatric illness have more serious gastrointestinal involvement. They also did not detect an increase in serious psychiatric disorder in patients with increased severity in UC. Walker et al. (1996) found the presence of a current psychiatric disorder (i.e., anxiety and/or depression), appears to alter the perception of disease severity in patients with CD and UC, which is also associated with increased functional disability.

Goodhand et al. (2012) found possible explanations for the differences in mood states among patients with CD and UC. They found anxiety in UC was associated with being newly-diagnosed with IBD and perceived psychological distress, while anxiety in CD was associated with abdominal pain, perceived stress, and lower socio-economic status. Depression in UC was associated with endoscopically active disease, perceived stress, and hospital admittance. Depression in CD, on the other hand, was associated with increasing age, perceived stress, significantly reduced HADS scores, and colonic disease, with no ileal involvement. Various researchers (e.g., Helzer et al., 1984; Tarter et al., 1987) reported that patients with CD demonstrated higher rates of anxiety and depression. However, according to Andrews et al. (1987) and Drossman, Leserman, Madeline Mitchell, et al. (1991), this higher rate in CD is explained by greater disease severity.

North et al. (1990), however, reported finding no indication of higher rates of psychiatric disorder in UC. Häuser, Janke, Klump, and Hinz (2011) also noted no significant difference of anxiety and depression levels between CD and UC patients, with Graff and colleagues (2006) finding that disease type did not contribute to psychological functioning. In the most recent and comprehensive systamtic review of the comorbidities and controversies surrounding anxiety and depression in IBD, Mikocka-Walus, Knowles, Keefer, and Graff (2016) found higher rates of depression and anxiety in IBD individuals compared to healthy controls, and higher rates in active disease compared to the inactive disease phase. The authors also reported finding mean levels and overall depression and anxiety levels were significantly (but only modestly) higher in CD individuals compared to individuals diagnosed with UC. According to the review, Mikocka-Walus et al. also found that rates of depression and anxiety were lower compared to other health conditions (within 95% CI), most being gastrointestinal illnesses with varying severity. Mikocka-Walus and colleague's review was, however, unable to identify whether anxiety and depression preceeded IBD or developed after the disease onset, due to the majority of included studies being cross-sectional.

In their most recent study, Mikocka-Walus, Pittet, Rossel, von Känel, and the Swiss IBD cohort study group (2016) explored the relationship between anxiety and depression and the clinical recurrence of IBD. This study included a large clinical sample of 2,007 IBD patients (56% CD, 48% male) sourced from the Swiss IBD cohort study group between the years 2006 through to 2015. Measures used in this study were clinically-validated measures for psychologicals distress (HADS; Zigmond & Snaith, 1983); disease activity (CDAI; Best, Becktel, Singleton, & Kern, 1976); and the Modifeied Truelove and Witts Severity Index (Truelove & Witts, 1954; 1955). The authors found a significant association between depression and clinical recuurence over time (for CD, p =.0007; for UC, p =.005; overall IBD patients, p =.000001). Mikocka-Walus, Pittet et al. also found a significant relationship between clinical recurrence over time and anxiety in all IBD subjects (p =.0014) and CD subjects (p =.031), however, not in UC (p =.066).

In summary, despite some inconsistencies in the literature, IBD shares a strong relationship with anxiety and depression. This relationship has been shown to vary: from anxiety and depression having possible causative mechanisms; from reflecting early signs of disease onset; to contributing to onset; and even to the worsening of the disease. Anxiety and depression have also been suggested to influence disease course by contributing to poorer disease outcomes, and even contributing to relapse of the disease. Although the recent study by Mikocka-Walus and colleagues (2016) provides the strongest evidence to date that psychological distress is associated with clinical reoccurrence, explanations for the influence anxiety and depression have upon disease activity may be explained by potential mediators or the non-adherence to medical interventions aimed at controlling their disease. Nonetheless, a considerable amount of research has supported that IBD contributed to a reduction in QoL, highlighting the benefits of psychological evaluation and treatment. Review of psychological interventions however is beyond the scope of this thesis

1.11 Quality of Life (QoL)

QoL is widely utilised as an outcome measure to assess the impact a situation or disease is impacting on an individual's life (Vilhena et al., 2014). The WHO defines QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" (QOL Group, 1995, p. 1,405). QoL places emphasis on the individual's self-perception of their current state, and it is viewed as a multidimensional and subjective state, making it difficult for researchers to reach a consensus regarding what to include within measures of QoL (Bonomi, Patrick, Bushnell, & Martin, 2000). The definition has been used to incorporate *non* health-related QoL, including domains like personal-internal (beliefs and values that influence wellbeing), personal-social (functioning within social networks), and external-natural environment (impact of the geographical and natural environment in which an individual works and resides; Spilker & Revicki, 1996). However, defining QoL can also be focused specifically on health-related QoL (HRQoL; Eisen & Locke, 1999). HRQoL reflects the impact of health on overall wellbeing (Vilhena et al., 2014).

1.11.1 QoL and chronic illness.

Chronic illness has a negative impact on QoL in persons; for example, for individuals with diabetes (e.g., Norris et al., 2011; Sikdar, Wang, MacDonald, & Gadag, 2010; Singh & Bradley, 2006); multiple sclerosis (Devy, Lehert, Varlan, Genty, & Edan, 2014); congenital heart disease (e.g., Fteropoulli, Stygall, Cullen, Deanfield, & Newman, 2013); cancer (e.g., Faller et al., 2013; Howard-Anderson, Ganz, Bower, & Stanton, 2012; Husson, Mols, & van de Poll-Franse, 2011); chronic pain (e.g., Smith & Torrance, 2012); bronchiectasis (e.g., Olveira et al., 2013); asthma (e.g., Wilson et al., 2012); cystic fibrosis (e.g., Bradley, Blume, Balp, Honeybourne, & Elborn, 2013); fibromyalgia (e.g., Kim et al., 2013); stroke (e.g., Mierlo et al., 2014); and RA (e.g., Ambriz Murillo, Menor Almagro, Campos-González, & Cardiel, 2015; Matcham et al., 2014). HRQoL is therefore an important measure of the impact of chronic illness (Patrick & Erickson, 1993) and is taken to encompass the areas of impact on psychological state, physical function, somatic sensations, and social interactions (Kirshner & Guyatt, 1985). It reflects a patient's perception of disease and their functional capacity, as well as their sense of wellbeing (Eisen & Locke, 1999). This information is necessary in assisting clinicians and other health care professionals to decide on the treatment to be implemented for sufferers, and also is necessary when measuring outcomes in intervention trials (Bernklev et al., 2004).

1.11.2 QoL and IBD.

Assessment of QoL is particularly pertinent for individuals with IBD due to its chronic, relapsing nature (Sainsbury & Heatley, 2005; Fedorak, 1992; Farmer, Whelan, & Fazio, 1985). To fully understand the impact IBD has on a sufferer's QoL, it is important to explore the construct of QoL in greater detail.

QoL in IBD, as with other chronic illnesses, can be measured using either generic instruments or disease-specific HRQoL measures. In their study aimed at comparing the discriminating power of a generic (SF-36) and a condition-specific QoL measure (the Inflammatory Bowel Disease Questionnaire; IBDQ, Guyatt et.al., 1989), McColl, Han, Barton, and Welfare (2004) found disease activity was generally more highly correlated with IBDQ scores than with SF-36 scores. However, the only significant differences between correlations were in the SF-36 energy/vitality and the social function domains with respect to disease activity. Patrick and Deyo (1989) suggested that, although generic measures are more cost-effective to develop and can be compared across different populations and interventions, disease-specific measures assess special states and concerns of diagnostic groups, and are more sensitive for the detection and quantification of small changes in the disease that are most important to patients and clinicians. Additional studies supporting a disease-specific measure of QoL have also found that they may be better able to discriminate between sub-groups of QoL related to disease, classified by condition-specific variables; especially disease activity defined in terms of symptom severity (Bombardier et al., 1995; Velanovich, 1998). An additional benefit of using a disease-specific QoL measure is that it can also be considered uni-dimensional, in that it implies that one meaningful sum can be obtained from answers, with the benefit of satisfactory stability over time of the complete QoL structure (De Boer, Spruijt, Sprangers, & De Haes, 1998).

Although there is more than one disease-specific QoL questionnaire (Farmer, Easley, & Farmer, 1991; Guyatt et al., 1989; Irvine, 1993), one of the most commonly used for IBD is the Inflammatory Bowel Disease Questionnaire (IBDQ), as was discussed above (Guyatt et al., 1989). The IBDQ is divided into four subscales assessing: (1) bowel symptoms (abdominal pain, loose stools); (2) systemic symptoms (problems with sleep, fatigue) (3) emotional functioning (anger, depression, irritability); and (4) social functioning (decline in social activity, work and school attendance). This gives the clinician or researcher the ability to assess IBD symptoms within each subgroup or used as a uni-dimensional construct to provide one meaningful sum (Guyatt et al., 1989). The IBDQ was also found to be a valid and reliable assessment tool, and has been translated into different language versions, with research supporting its reliability and validity for different linguistic and cultural milieus (Cheung et al., 2000; Ciccocioppo et al., 2011; de Boer, Wijker, Bartelsman, & de Haes, 1995; Han, McColl, Steen, Barton, & Welfare, 1998; Kim et al., 1999; Leong, Lee, Ching, & Sung, 2003; López-Vivancos, Casellas, Badia, Vilaseca, & Malagelada, 1999; Pallis, Vlachonikolis, & Mouzas, 2001; Russel et al., 1997). Using this measure in patients with active IBD, all dimensions of QoL were significantly lower compared to individuals with non-active IBD (Casellas, Lopez-Vivancos, Casado, & Malagelada, 2002). Multiple studies have found disease activity to be negatively related to HRQoL (de Boer et al., 1995; Drossman, Leserman, Li, et al., 1991; Drossman et al., 1989; Engelmann et al., 2014; Faust, Halpern, Danoff-Burg, & Cross, 2012; Gray, Denson, Baldassano, & Hommel, 2011; Hjortswang et al., 1998; Iglesias-Rey et al., 2014; Irvine et al., 1994; Kunz, Hommel, & Greenley, 2010; López-Vivancos et al., 1999; Russel et al., 1997; Van der Have et al., 2013).

The scale has been validated for both major subtypes of IBD, CD and UC. Irvine and colleague's (1994) multi-centre trial study found the IBDQ to be highly correlated with disease activity as measured by the Crohn's Disease Activity Index (CDAI). Zahn Hinz, Karnerm Ehehalt and Stremmel (2006) also found significant correlations between the CDAI, the Endoscopic activity index (EAI) and the four dimensions of the IBDQ in UC patients, suggesting its utility for measuring QoL in IBD. In his review, Cohen (2002) found HRQoL to be directly correlated with CD activity, and to be worse in patients with active disease compared with patients with CD in remission. Using a Spanish version of the IBDQ, Casellas et al. (2005) also found HRQoL to worsen in parallel to worsening disease activity. This was demonstrated across patients with CD and UC. Casellas et al. also reported significantly lower scores in patients with active disease compared to patients in remission, with relapse in disease resulting in higher scores among the digestive symptoms subscale. Using the SF-36, Lichtenstein, Yan, Bala, and Hanauer (2004) found that HRQoL was better in healthy controls and in patients with UC (except pre-colectomy) when compared with patients with CD. CDAI-assessed remission was found to be associated with reduced surgeries and hospitalisations, increased employment, and normalised QoL (Lichtenstein et al., 2004).

Clearfield (2008) suggests that IBD is among the least "socially acceptable" of the chronic medical disorders, with sufferers finding casual discussion concerning their condition difficult and shameful due to the often embarrassing symptoms of cramp, pain, bowel activity, and rectal bleeding. In fact, the unpredictability of IBD symptoms, such as experiencing a bowel accident in public, can result in anxiety and social avoidance; especially when access to a bathroom facility is unknown or limited. Complications arising from the chronic and relapsing/remitting nature of IBD, including hospitalisations, frequent physician visits, and side effects of pharmacological and surgical treatments, can lead to considerable impairments in HRQoL (Drossman et al., 1989; Guyatt et al., 1989; Mitchell et al., 1988). Despite its negative impact on the sufferer, social impairment was the least affected dimension of the IBDQ in active UC and CD, compared with digestive and systemic symptoms (Casellas, López-Vivancos, Casado, & Malagelada, 2002).

Health-related QoL is affected both by disease activity and psychological symptoms related to IBD. For example, using stepwise multiple regression analyses, Guthrie et al. (2002) found both psychological symptoms and disease severity or activity contributed independently to impaired HRQoL. After severity was taken into account, no significant differences between UC and CD in depression scores and HRQoL. Individuals with psychological disorders alongside IBD had poorer HRQoL, regardless of disease severity or activity (Graff et al.. 2006; Guthrie et al. 2002). Guthrie et al. (2002) further suggest that detecting and treating psychological disorders in IBD carries the potential to improve QoL for sufferers. Hjortswang et al. (2003) found that UC negatively influences HRQoL, primarily in the psychological and social settings. The physical categories were also negatively affected, albeit to a lesser degree, which supports the findings of earlier studies (e.g., Drossman, Leserman, Li et al., 1991; Drossman et al., 1989; Hjortswang et al., 1998).

While HRQoL have been studied in combined samples of IBD, differences between groups have been reported. Nordin, Påhlman, Larsson, Sundberg-Hjelm, and Lööf (2002) found participants with UC to have superior health-related and disease-specific QoL compared to CD. Having ileo–anal anastosmosis was also suggested to affect QoL, whereas having an ileostomy did not. Individuals with CD were also found to exhibit more anxiety and depressive symptoms compared to UC, which may be attributed to more severe symptoms of the disease. Patients with CD were also found to have reported a greater number of hospitalisations than did UC patients.

Although the type of disease or geographical area of residence has not been found to influence the IBDQ results, gender has been found significantly associated with a decline in reported HRQoL (Casellas et al., 2005). Hjortswang et al. (2003) also found gender influenced HRQoL scores. They found that women consistently scored lower on QoL measures. There have been multiple studies supporting this finding (e.g., Bernklev et al., 2004; Blondel-Kucharski et al., 2001; Casellas et al., 2002; Hjortswang et al., 2003; Irvine, 1995; Jeppesen, Langholz, & Mortensen, 1999; Rubin, Hungin, Chinn, & Dwarakanath, 2004). However, some studies have not found women reporting poorer QoL in relation to IBD (e.g., Drossman et al., 1989; Guassora, Kruuse, Thomsen, & Binder, 2000; Kim et al., 1999; Kiran et al., 2003). In their review, Sainsbury and Heatley (2005) suggested a number of possible explanations for the gender diffrences. For instance, in females, psychological factors play a greater role in reducing their QoL (Blondel-Kucharski et al., 2001; Drossman et al., 1989); females worry about being treated differently or being a burden (Moser et al., 1995); females have greater disease-related concerns (Blondel-Kucharski et al., 2001; Kiran et al., 2003; Moser et al., 1995); and females rate their symptoms as being more severe than do males (De Rooy et al., 2001; Moser et al., 1995).

Zimmerman, Gavish, and Rachmilewitz (1985) also suggested that extensive disease may be more common in females compared to males. This discrepancy in ratings may also be found in the general population, where self-rated QoL scores were lower in females compared to males (Dimenäs, Carlsson, Glise, Israelsson, & Wiklund, 1996). Using the SF-

36 with an English, working IBD population, Jenkinson, Coulter, and Wright (1993) found that women reported poorer health for all dimensions compared to men, except for in the general health dimension.

It is important to consider age when assessing QoL in IBD patients. Early disease onset, at a time when adolescents are developing their personal identities and establishing relationships, interferes with and disrupts normal development and can result in psychological morbidity (Sainsbury & Heatley, 2005). On the other hand, elderly IBD patients are more likely to struggle with adjusting to symptoms of increased bowel motion frequency and urgency, and may even lack supportive social networks (Sainsbury & Heatley, 2005). De Rooy et al. (2001) also suggested that increasing age may be associated with greater worries about the stigma of the disease. Hjortswang et al. (1998) and Pallis, Vlachonikolis, and Mouzas (2002) noted that reduced QoL in older populations of IBD patients may in fact be the result of greater concerns relating to social interaction and recreational difficulties. Pallis et al. (2002) argued that this finding may, however, reflect the health and community problems in general, despite an age-matched comparison having being made in their study.

Socioeconomic status (Rubin et al., 2004); ethnicity and culture (Levenstein et al., 2000); knowledge and education (Casellas et al., 2002); personality traits (Weinryb, Gustavsson, & Barber, 2003); self-image and sexuality (Irvine, 1995; Moody & Mayberry, 1993); and smoking (Blondel-Kucharski et al., 2001; Russel, Nieman, Bergers, & Stockbrügger, 1996) have all been demonstrated to affect QoL in IBD sufferers. However, in-depth discussion of these factors are beyond the scope of the present study.

Patients with IBD have a reduced QoL influenced by both symptoms and treatment non-adherence (Larsson et al., 2008; Vidal et al., 2008). In fact, non-adherence to medical treatments is an important reason for relapse of disease in IBD (Kane, Cohen, Aikens, &

Hanauer, 2001). Patient empowerment may play a role in adherence to medical treatment and therefore improve QoL. In their study investigating shared decision-making in the treatment of IBD, Baars, Markus, Kuipers, and Van Der Woude (2010) found that 81% of patients felt it was "very important" to be involved in the decision-making process, while 17% deemed it "quite important". As patient empowerment is suggested to be important in managing chronic diseases (Meyer et al., 2008), including with respect to treatment compliance in IBD, patients may express changes in life priorities and values by developing a greater sense of self-efficacy regarding their treatment and disease-related behaviour (Baars et al., 2010).

In summary, the vast majority of studies support that fact that having IBD contributes to a reduction in a person's QoL. This reduction both contributes to, and influenced by, the sufferer's illness perceptions, coping styles, and other psychological factors, including perceived self-efficacy. These psychological factors in turn also contribute to psychological distress, which also contributes to reduced QoL. In order to gain insight and a clearer understanding into how all these factors contribute to, and influence, an individual's psychological distress to IBD and their QoL, a detailed exploration of a model that incorporates these factors is necessary. One such model is the CSM (Leventhal et al., 1980).

1.12 Common-Sense Model (CSM).

The CSM of self-regulation was developed to provide a framework for understanding the role of cognitive and perpetual factors in response to, management of, chronic illness and threats to health (Leventhal et al., 1980). It is described as an extension of the parallel processing model (Cameron & Leventhal, 2003; Leventhal, 1970), designed to account for the findings of studies focusing on fear-arousing communications and their influence on health behaviours.

According to the CSM, two sets of representatives are generated when threats to health are encountered (see Figure 1.6). These representations include a cognitive representation or interpretation of the nature of threats, and emotional representations such as fear; each generating its own behavioural representation. The first behavioural representation is to the threat itself (danger control) and the second representation is of the emotions engendered by it (fear control). Both fear control and danger control, through parallel actions, are appraised for their efficacy aimed at reducing the negative emotions resulting from potential health threats; and through danger control, reduce the threats themselves (Lazarus & Launier, 1978). The CSM is considered a dynamic model based on the two representations being appraised on an ongoing basis. The CSM can therefore be classified as a parallel-processing model; the CSM both recognises the influence of emotions while simultaneously specifying a role for behavioural attempts to regulate those emotions (Leventhal et al., 1980).

Llewellyn, McGurk, and Weinman (2007) explain the CSM as an underlying control system that can be divided into three broad processes. The first involves the cognitive and emotional representations of the health threat. These representations are sourced from internal cues and/or external cues. Cognitive and emotional representations, or beliefs, are sourced from three sources of information. Leventhal and colleagues (Leventhal et al., 1980; Leventhal et al., 1984) describe the first source of information as that which results from the general pool of “lay” information assimilated by the individual over time. The second source of information is derived from family, friends, and authoritative resources, and the third source of information is derived from the current experience of the illness, including symptoms and somatic experiences. The second process in the model involves an action plan; this is when a coping strategy is utilised, as deemed appropriate by the individual to cope with or respond to a specific belief. The third and final stage is the coping appraisal process, which involves evaluating the effectiveness of the coping strategy on the outcome or goal (Leventhal, Meyer, & Nerenz, 1980; Llewellyn et al., 2007).

According to Horne and Weinman (2002), an extended version of the CSM exists where patients not only “just have their own ideas about the illness, but also of the treatment being offered” (p. 19). This additional information (i.e., beliefs about the treatment) is useful when considering adherence to medication, and the perceptions of outcomes like QoL. Health psychologists have been attracted to the model because it implies that patients with acute and chronic illness can be helped to achieve better outcomes as a result of having a more adaptive understanding of their condition, and its treatment, and evaluating the effects of acting on that understanding (Hagger & Orbell, 2003).

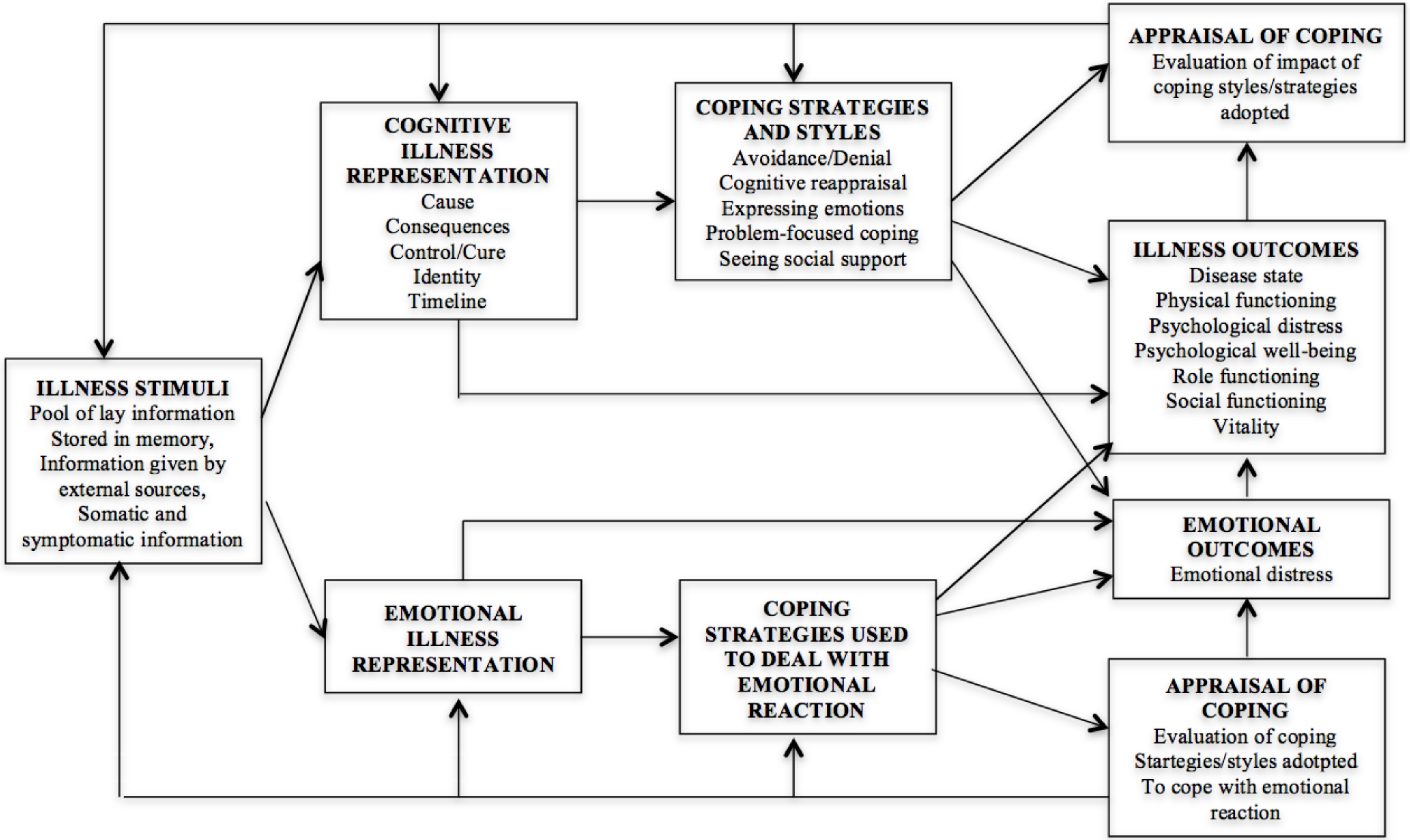


Figure. 1.6. The Common Sense Model (Leventhal, Meyer, & Nerenz, 1980).

The above model proposes that an individual generates both a cognitive and emotional representation in response to the perceived threat; in this case, the “threat” being IBD. The individual is then motivated to manage these representations simultaneously by deriving an action plan to cope with the perceived threat. Finally, the individual appraises the action plan by determining its success. These regulating details are critically important for understanding behaviour, including the efforts of human beings to protect, maintain health, and avoid and control illness (Leventhal et al., 1980). On their own, fear messages (whether high or low) or action plans on their own, are unable to elicit sustainable change.

The CSM has mostly been utilised in the literature to examine cognitive illness representations, and how these perceptions influence coping strategies and illness outcomes, such as psychological wellbeing and QoL (Haggar & Orbell, 2002). When exploring the CSM in the literature, the term “self-regulation model” will be used interchangeably with the CSM as some studies choose to define the CSM as a self-regulation model (Arran et al. 2014; Bucks et al., 2009; Leventhal & Diefenbach, 1991). Outlining the complete scope of the CSM construct is beyond the aim of the current study. For more research pertaining to the CSM construct, refer to Leventhal et al. (2003) and Haggar and Orbell (2002).

1.12.1 CSM and chronic illness.

The CSM proposes that somatic information or stimuli about potential health threats are processed as (a) perceived representations of danger and (b) emotional experience. Action plans then act to reduce fear and danger, and actively appraise the efficacy of these plans whilst incorporating this information into the perceived representations (Lazarus & Launier, 1978).

Lazarus and Launier (1978) proposed that the cognitive representation of the stimuli or health threat is a necessary condition of danger control; its specific procedures; criteria; strategies for control; and ongoing perceptions of response efficacy. This, however, does not establish whether these processes are essential for generating motivation to action. Leventhal et al. (2003) suggested that the critical source for the motivational effects of illness representations, and fear itself, was the person's concrete and perceptual experience and how the experience was interpreted (for more information to the types of research refer to pages 46-47 of Leventhal, Brissette, & Leventhal, 2003).

The CSM of self-regulation has widely been used in the field of chronic illness in order to understand how illness perceptions and coping strategies influence the individual's emotional and behavioural reaction to illness. There have been multiple studies exploring this relationship, including in diseases such as: cancer (e.g., Rozema, Vollink, & Lechner, 2009); COPD (e.g., Kaptein et al., 2008; Zoeckler, Kenn, Kuehl, Stenzel, & Rief, 2014); psoriasis (e.g., Wahl et al., 2014); Huntington's disease (e.g., Arran, Craufurd, & Simpson, 2014); heart failure (e.g., Broadbent et al., 2009; MacInnes, 2014); hypertension (e.g., Figueiras et al., 2010; Hekler et al., 2008); cystic fibrosis (e.g., Bucks et al., 2009); chronic kidney disease (CKD; Knowles, Swan, Salzberg, Castles, & Langham, 2014); and in individuals with a stoma (e.g., Knowles et al., 2014). Of these, diabetes has been one of the most extensively studied chronic illnesses (e.g., Harvey & Lawson, 2009; Hudson, Bundy, Coventry, & Dickens, 2014; Rassart et al., 2014; Watkins et al., 2000). This may be due to the high prevalence of depression and anxiety found in individuals who have diabetes (Anderson, Freedland, Clouse, & Lustman, 2001; Grigsby, Anderson, Freedland, Clouse, & Lustman, 2002) and its associated lower self-care (Anderson et al., 2002; De Groot, Anderson, Freedland, Clouse, & Lustman, 2001; Lustman et al., 2000).

Rassart et al. (2014) utilised the CSM to explore illness perceptions and coping as mediators in the relationship between personality traits and illness adaptation in 368 individuals diagnosed with Type 1 diabetes. Utilising measures including the Quick Big Five personality measure (Vermulst & Gerris, 2005), the revised Diabetes Coping Measure (Keers et al., 2006), the IPQ-R (Moss-Morris et al., 2002), and an illness adaptation scale (Problem Areas in Diabetes Scale; Polonsky et al., 1995), the authors found coping to be an important mediator between personality and illness adaptation. The authors also found that perceived personal control and perceived consequences partially mediated the relationship between personality and coping. Rassart et al. also found that illness perceptions not only influenced the individuals' coping, but also influenced the individuals, illness adaptation directly. These findings are in line with those found by Hagger and Orbell (2003), highlighting the importance of an indviduals' illness perception for both objective and subjective indicators of illness adaptations. Although Rassart et al's study utilised a coping scale, it did not indicate whether the individuals utilised adaptive or maladaptive coping.

Rozema et al. (2009) utilised the CSM to examine the relationships between cognitive and emotional representations of illness in 199 women who had been diagnosed with breast cancer within the two years prior to participating in the study. Using questionnaires measuring illness representations, the IPQ-R (Moss-Morris et al., 2002), coping strategies (Utrecht Coping Questionnaire; Schreurs & Van de, 1988), and perceived mental and physical health (RAND-36; van der Zee & Sanderman, 1993), Rozema and colleagues found that breast cancer patients who viewed their illness as chronic, uncontrollable, and with serious symptoms and consequences, reported poorer mental and physical health compared to patients who believed the opposite. According to the authors, however, only partial support for the CSM of illness cognition was found. Cognitive illness representations of identity and consequences explained 57% of variance in physical health, whereas, 47% of the variance in mental health was explained by emotional illness representations and treatment control. According to Rozema et al. the most significant finding in their study was that illness representations showed stronger and more consistent relationships with health compared with coping strategies. Furthermore, it was the cognitive representations, consequences, and identity - not the coping strategies - that fulfilled a key role in explaining physical health. In regards to explaining mental health, however, cognitive representations together with the emotional representations were the most important explaining variables. An explanation for having only found partial support of the model may have been, in part, due to the patients having received treatment, placing them in the coping or appraisal stage of the model, rather than at the stage of illness representations (Rozema et al., 2009).

Arran et al. (2014) also found that illness perception and coping played a significant role in psychological distress in individuals suffering Huntington's disease (*N* = 87). Arran et al. applied the self-regulation model of Leventhal et al. (1980), and used the following measures: the IPQ-R (Moss-Morris et al., 2002); the Brief Cope (Carver, 1997); the medical Outcome Survey Short Form-36 (MOS-SF; Ware & Sherbourne, 1992); and the HADS (Zigmond & Snaith, 1983). Through hierarchical regression, Arran et al. found that the illness perceptions of identity, and causation related to chance, were predictors of depression. Illness perceptions (treatment control, identity, and timeline cyclical) were found to be strong predictors of anxiety. The coping strategy of seeking instrumental support was found to contribute to the depression score. However, this study did not elaborate extensively on the relationship between illness perception and coping strategies. With the exception of seeking instrumental support, the study also did not explore the relationship of these coping styles with outcome.

Knowles, Swan et al. (2014) explored the relationship between disease, illness perception, and coping on psychological adustment in their study of 80 individuals diagnosed with CKD. Utilising the CSM, together with the Health Percepions Questionnaire (Wares, 1976), the BIPQ (Broadbent et al., 2006), Brief COPE (Carver 1989), and the HADS (Zigmond & Snaith, 1983), the authors found that disease activity directly influenced illness perception, which then directly influenced anxiety and depression. These findings were consistent with expectations and in line with the CSM. According to the authors, poorer illness perceptions related to an increase in maldaptive coping, which was found to increase anxiety and depression. These findings add support to previous studies by Broadbent et al. (2006), Knowles et al. (2011), Petrie et al. (1997), and Schiaffino, Shawaryn, and Blum (1989). Knowles, Swan et al. also found that maladaptive and adaptive coping were found to mediate the relationship between illness perceptions and depression and anxiety.

The CSM has also been utilised in studies involving treatment compliance and therapeutic outcomes. As a way of exploring patients' beliefs about heart failure and the treatment involved in their care, MacInnes (2014) applied the CSM in order to identify the beliefs that contribute to limited self-care and non-adherence to medication. Using a qualitative research design with twelve patients with chronic heart failure, MacInnes found that heart failure patients lacked a clear illness identity in terms of label or diagnosis and the identification of symptoms. MacInnes also found heart failure patients were unable to distinguish between symptoms of heart failure, emotional responses to the condition and effects of medication. Illness was also found to be attributed to stressful life events and other external factors; patients were concerned about side effects and drug interactions; and that they held beliefs that their heart failure and its symptoms could be controlled by medication.

The benefits of considering the CSM when developing an intervention for myocardial infarction (MI) patients was explored by Broadbent et al. (2009). Broadbent et al. conducted a randomised controlled trial of 103 patients admitted with acute MI, in which one group received standard care and the other group received standard care plus an illness intervention. Measures included the Brief IPQ, and a health behaviours scale assessing demographics, exercise, smoking and diet. The treatment group involved four, individual half-hour in-hospital sessions with a health psychologist. The purpose of the treatment was to assess the patient's perceptions of their illness across the five factors of illness perception (discussed above), and then to change their perceptions through education and debunking myths. The study also included patients' spouses within the treatment model. According to the findings, the treatment group returned to full-time work within three months of completing the program compared to the control group. Broadbent et al. also found that the treatment group experienced a higher perceived understanding of MI and a change in causal attributions, reduced anxiety, higher attendance to cardiac rehabilitation classes, increase in exercise, and less phone calls to their general practitioners regarding their heart condition.

A summary of the literature surrounding the CSM of illness presentations can be found in Hagger and Orbell's (2002) meta-analitical review. In their review of 45 studies, the authors found that strong illness perception and illness identity was positively and significantly related to utilising avoidance and emotional expression coping strategies. The illness perception of controllability was significantly associated with expressing emotions, cognitive reappraisal and problem-focused coping strategies. Hagger and Orbell also reported that highly symptomatic illness perceptions, serious consequences, and having a chronic timeline was significantly correlated with expressing emotions and avoidance coping strategies. Cure and controllability illness perceptions were positiviley and significantly related to adaptive social functioning and vitality, and psychological wellbeing, and was negatively related to disease state and psychological ditress. Timeline, illness consequences, and identity related to negative and significant relationships to role and social functioning, psychological wellbeing, and vitality (Hagger & Orbell, 2003).

1.12.2 CSM and IBD.

Considering the large number of studies highlighting the negative impact IBD disease activity has on psychological distress and QoL experienced by individuals diagnosed with

IBD (see Sections 1.9.5 and 1.10.2), the CSM may potentially help to explain an individual's adjustment to their illness. This follows a social cognitive model perspective into the influence of cognitive and perpetual factors underlying health-related behaviour (Leventhal et al., 1980).

Dorrian and colleagues (2009) were the first research group to explore IBD within the context of the CSM. Using a sample of eighty adults diagnosed with either CD or UC from an out-patient clinic, and the CSM, Dorrian et al. explored the extent to which adjustment to IBD is influenced by illness perceptions and coping strategies. Using measures including the CDAI (Sandler, Jordan, & Kupper, 1988) and CAI (Lichtiger et al. 1994) for UC disease activity; the IPQ-R (Moss-Morris et al., 2002) for illness perceptions; the COPE (Carver, Scheier, & Weintraub, 1989), HADS (Zigmond & Snaith, 1983), and IBDQ (Guyatt et al., 1989) for adjustment measures; Dorrian et al. found that illness perceptions were the most consistent variables explaining adjustment to IBD according to the results of a hierarchical regression analysis. Despite coping being suggested to mediate the relationship between illness perceptions and psychological adjustment/distress in the CSM in more recent studies (e.g., Knowles et al., 2011; Knowles, Cook et al., 2013; Rochelle & Fidler, 2013), this was not found in Dorrian et al.'s study. Dorrian et al. explained that these unexpected findings may have been due to the COPE measure not being IBD disease-specific. This explanation may, however, be invalid; especially in light of recent findings by Knowles et al. (2011), who found a mediating relationship using the Brief-COPE. Another possible explaination for Dorrian et al.'s unexpected results may have been their choice of statistical analysis. Dorrian and colleague's performed correlational and heirachical regression, whereas Knowles et al. utilised structural equation modelling (SEM) which allows the analysis of multiple variables interacting at once.

Dorrian et al. did, however, find that individuals with a higher illness perception (i.e., believing their disease would result in more serious consequence, is cyclical in nature and is a chronic condition) reported poorer psychological adjustment, functional independence, and therefore poorer QoL. The study also found that poorer adjustment was associated with the tendency of individuals with IBD to attribute a wide range of symptoms to the illness as part of the identity dimension. This aligns with Leventhal and colleague's (1984) and Petrie and Weinman's (2006) suggestions that individuals are driven to find a label for their symptoms, and may therefore misattribute symptoms that are in fact not the result of their condition. This may then contribute to beliefs that their IBD is active, resulting in decreased perceptions of psychological wellbeing, functional independence, and QoL (Dorrian et al., 2009).

Knowles et al. (2011) also explored the CSM in an IBD clincial population of 96 CD patients. Using measures for illness perceptions (BIPQ; Broadbent et al., 2006), disease activity (CDAI; Best, Becktel, Singleton, & Kern, 1976), and psychological distress (HADS; Zigmond & Snaith, 1983), Knowles and colleagues found that disease activity had a direct influence on illness perceptions ($\beta = 0.51$, $p < 0.001$) using SEM. Furthermore, illness perceptions were found to have a direct effect on anxiety ($\beta = 0.40$, $p < 0.001$) and depression ($\beta = 0.41$, $p < 0.001$). These findings were consistent with the author's hypotheses, based upon the CSM, and supported similar findings of Dorrian et al. (2009). Anxiety and depression were also found to be significantly associated with emotion-focused (maladaptive) coping ($p < 0.001$), supporting the findings by Hagger and Orbell (2003).

Knowles et al. (2011) also found several indirect mediating pathways. Illness perception was found to mediate the relationship between disease activity and emotion-focused (maladaptive) and problem-focused coping. These results align with, and confirm, past findings by Leventhal, Meyer, and Nerenz (1980), and Hagger and Orbell (2003). Knowles and colleagues also found emotion-focused (maladaptive) coping mediated the illness perceptions and depression/ anxiety relationship, whereas problem-focused coping only mediated the relationship between illness perceptions and depression, but not anxiety. The authors, however, did not explain the reasons why problem-focused coping did not mediate the relationship with anxiety.

Knowles et al. (2011) found that poorer illness perception was related to increased emotion- and problem -focused coping. Problem-focused coping had a a beneficial relationship with psychological distress, while emotion focused (maladaptive) had an adverse relationship. These findings support past research (Hagger & Orbell, 2003), which suggests that problem-focused (adaptive) coping contributes to reduced psychological distress, whereas emotion-focused (maladaptive) coping is associated with an increase in anxiety and depression. Compared to studies by Dorrian et al. (2009), and van der Have et al. (2013), Knowles et al. did not explore the relationships of disease acitivity, coping or psychological distress with the individual subscales of the illness perception construct. Instead, the authors totalled the illness perception score, where a higher score indicated poorer illness perceptions (i.e., a more threatening view of illness).

van der Have et al. (2013) explored the impact of illness perceptions on QoL according to the CSM (Leventhal et al., 1980), in patients with CD and compared it to patients with RA, head and neck cancer (HNC), and MI. The authors assessed 82 CD patients sourced from a tertiary referral centre between 2004 and 2006. Measures included: the IPQ-R (Moss-Morris et al., 2002); the Dutch Personality Inventory measuring self-perceived health and neuroticism (Luteijn, Starren & van Dijk, 2000); the medical outcomes survey short-form (SF-36; Ware Jr, 2000); Utrecht Coping List (UCL; Schreurs, van de Willige, Brosschot, Tellegen, & Graus, 1993); disease activity (CDAI; Best et al., 1976); CDEIS (Mary & Modigliani, 1989); and the IBDQ-32 (Guyatt et al., 1989). Using correlational and hierarchical multiple regression analyses, van der Have et al. found a strong, inverse association between QoL and neuroticism, perceived consequences of CD (*r* = -.54), self-perceived health (*r* = -.60), and clinical disease activity (*r* = -.79). No inverse relationship was found with the endoscopic disease activity scores (*r* = -.29). A significant inverse relationship was found between QoL and IPQ-R dimensions, consequences, identity, time line, cyclical, and emotional representations. This provides additional support to Dorrian and colleague's (2009) study. Higher QoL was found to be significantly associated with fewer CD symptoms, less strong emotional response, and less strong thoughts about its cyclical nature (van der Have et al., 2013). When compared with RA, HNC and MI, CD patients were also found to have similar strong consequences and thoughts about chronic nature illness perceptions (van der Have et al., 2013). Although passive (maladaptive) coping was associated with lower QoL, and contrary to expectations, van der Have and colleagues did not find coping added any significant additional effect on any of the QoL domains. Van der Have et al. also explained not finding significant meditational effects due to a non-CD specific coping measure being utilised. These results and explainations also support those reported by Dorrian et al. (2009).

Rochelle and Fiddler (2013) also sought to explore IBD, illness perceptions, and QoL within a self-regulation model/CSM. Using the self-regulation model (Leventhal, Diefenbach, & Leventhal, 1992), hierarchical regression analysis and measures including the IPQ-R (Moss-Morris et al., 2002), the UK IBDQ (Cheung, Garratt, Russell, & Williams, 2000), and the HADS (Zigmond & Snaith, 1983) in 102 IBD out-patients, Rochelle and Fidler (2013) found higher anxiety scores were related to reporting serious consequences of IBD. The authors also found depression and an increase in emotional expression to be associated with beliefs that the disease would be long lasting, and the view they had little control over the disease. These findings support Dorrian et al. (2009) and Knowles et al. (2011), who reported poorer illness perceptions to have an adverse negative influence on psychological distress. Beliefs that the disease had serious consequences (i.e., poorer illness perceptions) were related to reduced QoL, whereas beliefs that treatment would help or that the patients had control over the disease, were associated with higher QoL. Rochelle and Fidler (2013) also found that a patient's belief that they had control was associated with better social functioning and general bowel function. These findings support those by van der Have et al. (2013), who also found illness perceptions to influence QoL.

Rochelle and Fiddler (2013) also reported finding that illness perceptions influenced coping strategies. For example, maladaptive coping strategies were utilised when patients perceived their illness to result in serious consequences, and emotion-focused coping or maladaptive coping were associated with anxiety and depression. Although the study did not report what coping measure was used, it still provides additional support to the findings by Knowles et al. (2011), who reported that poorer illness perceptions influence coping styles.

In order to extend upon limited research in the area of IBD and its impact on the sexual health and relationships in patients with IBD, Knowles, Gass et al. (2013) extended the CSM to explore the relationship between: illness perceptions; sexual problems; body image satisfaction and self-consciousness; marital and family functioning; and anxiety and depression. Their study assessed 74 patients diagnosed with IBD (n = 44 CD, n = 30 UC). A number of scales were used to examine body image and impact on patients with IBD, including: the Sexual Problems Scale (SPS; Stewart, 1992); sexual satisfaction scale (Ritvo, 1997); Body Image and Self-Consciousness During Intimacy Scale (BISC; Wiederman, 2000); Family Functioning Scale (FFS; Stewart, 1992); Marital Functioning Fcale (MFS; Stewart, 1992); and the HADS (Zigmond & Snaith, 1983). Using SEM, the authors found that anxiety and depression were directly influenced by illness perceptions ($\beta = 0.55$ and $\beta = 0.49$, $p < .001$, respectivly), adding support to previous studies (e.g., Knowles et al., 2011; Dorrian, Dempster, & Adair, 2009). Illness perceptions were also found to influence family functioning (β = -.017, *p* < 0.001). Knowles and colleagues also found several mediating pathways involving sexual satisfaction, body image, sexual problems, and self-consciousness during intimacy. Exploring gender differences, females were found to report decreased sexual satisfaction and increased sexual problems.

Coping strategies and illness perceptions within the CSM were explored in a preliminary study of the impact a stoma has on IBD patients (Knowles, Cook, & Tribbick, 2013). The study involved assessing 83 IBD stoma patients with measures including: the CDAI (Best et al., 1976); BIPQ (Broadbent et al., 2006); Brief-COPE (Carver, 1997); HADS; (Zigmond & Snaith, 1983); and the health status subscale of the Health Orientation Scale (Snell Jr, Johnson, Lloyd, & Hoover, 1991). According to Knowles, Cook, and Tribbick, health status were found to have a significant inverse relationship with illness perceptions, and a direct and indirect (via maladaptive coping) influence on anxiety and depression. These findings add additional support to previous studies (e.g., Dorrian, Dempster & Adair, 2009; Hagger & Orbell, 2003; Knowles et al., 2011; Leventhal, Nerenz, & Steele, 1984). Although maladaptive coping was found to be a mediator of anxiety and depression, emotion-focused (problem/adaptive) coping was found not to predict anxiety.

According to Knowles, Cook, and Tribbick (2013), emotion-focused coping was found to have negative correlation with depression, adding support to previous studies (e.g., Dorrian, Dempster, & Adair, 2009; Hagger & Orbell, 2003; Knowles et al., 2011; Leventhal, Nerenz, & Steele, 1984). Pellissier et al., 2010; Thomsen et al., 2002; Voth & Sirois, 2009). Knowles and colleagues also found emotion-focused (problem-focused) coping was associated with the number of months elapsed since the surgery and negatively impacting upon mood, while engagement in maladaptive coping was associated with increases in depression and anxiety. The CSM also demonstrated a direct influence of time on emotion-focused coping, suggesting that maladaptive coping strategies like avoidance or ignoring the problem are more likely to be employed closer to the time of surgery.

1.13 Summary

The benefits of exploring the psychological constructs of individuals with IBD and their influence on psychological distress and QoL have been demonstrated. Higher disease activity has been found to influence psychological distress and QoL, however, studies exploring potential mediating factors has been limited. The CSM aims to explore these relationships. Chronic illness studies have demonstrated how illness perceptions influence coping skills, either adaptive (e.g., problem-focused) or maladaptive (e.g., emotion-focused), that influence outcomes including depression, anxiety, and QoL. Although there have been a limited number of studies utilising the CSM within an IBD population, the studies identified have extended the CSM limitations, such as the lack of evidence of mediation identified by Hagger and Orbell (2003).

The general research consensus suggests that illness perceptions influence or mediate the relationships between disease activity and coping/behavioural factors, and illness perceptions directly with psychological distress and IBD. However, there are mixed findings within these studies regarding the influence of coping as a mediating factor between illness perceptions and psychological distress. Further research is needed to clarify the influence of illness perceptions and coping, as the CSM would predict in an IBD cohort. Further, more research is needed to explore the potential utility of an extended CSM, which includes measures known to influence (or with the potential to influence) illness perceptions, coping, and outcomes (i.e., psychological distress, QoL) such as self-efficacy, and dispositional mindfulness. Finally, to date, research applying the CSM with IBD cohorts has been based upon small sample sizes, and for this type of study, a sample size of at least 200 is recommended (Tabachnick & Fidell, 2001).

2. Chapter 2: Present Study

2.1 Research Limitations

Although a number of studies have explored the relationships between IBD and outcomes such as: QoL (e.g., Engelmann et al., 2014; Faust et al., 2012; Gray et al., 2011; Van der Have et al., 2013); psychological distress (e.g., Goodhand et al., 2012; Larsson et al., 2008; Mikocka-Walus et al., 2008; Porcell et al., 1996); illness perceptions (e.g., Dorrian et al., 2009; Han et al., 2005; Kiebles et al., 2010; Knowles, Cook et al. 2013; Knowles, Gass, et al. 2013; Knowles et al., 2011; Rochelle & Fidler, 2013; Van der Have et al., 2013); and coping (e.g., Dorrian et al., 2009; Knowles, Gass, et al., 2013; Knowles et al., 2011; McCombie et al., 2013; Mussell et al., 2004; Pellissier et al., 2010; Raffle & Bush, 2009; Seres et al., 2008), only a few studies have explored the relationships between disease activity and other psychological factors including self-efficacy (e.g., Cooper et al., 2010; Fishman, Barendse, Hait, Burdick, & Arnold, 2010; Friedman et al., 2014; Izaguirre & Keefer, 2014; Taft, Keefer, Artz, Bratten, & Jones, 2011), and dispositional mindfulness (Jedel et al., 2013). Past research has also largely been limited by not contextualising these factors within a theoretical model such as the CSM (Leventhal et al., 1980) or have utilised relatively small sample sizes (e.g., Dorrian et al., 2009; Knowles, Cook, et al. 2013; Knowles, Gass, et al. 2013; Knowles et al., 2011; McCombie et al., 2013; Van der Have et al., 2013).

2.2 Aims and Hypotheses

The aim of the present study was to examine whether illness perceptions, coping styles, self-efficacy, and dispositional mindfulness would mediate the relationships between IBD disease activity, psychological distress, and QoL as guided by the CSM (Leventhal et al., 1980).

It was hypothesised that:

(1) Greater IBD symptom severity would be associated with (a) poorer illness perceptions, (b) higher psychological distress, and (c) reduced QoL; and

(2) Greater IBD symptom severity would be associated with greater engagement in maladaptive coping and less engagement in adaptive coping.

Based on the CSM, it was hypothesised that:

(3) The effect of disease symptom severity on psychological distress and QoL would be fully mediated by other variables (see hypotheses 4-6)

(4) Illness perceptions would mediate the relationship between disease symptom severity and coping styles (adaptive and maladaptive coping), self-efficacy, and mindfulness;

(5) Coping styles (adaptive and maladaptive coping), self-efficacy, and dispositional mindfulness would mediate the relationships between illness perceptions, psychological distress, and QoL; and

(6) Psychological distress would mediate the relationship between illness perceptions and QoL.

2.3 Methodology

2.3.1 Ethics approval.

Ethics approval was granted from Swinburne University of Technology Human Research Ethics Committee and St. Vincent’s Hospital Ethics Committee to conduct research with participants with IBD. The researcher was granted permission to work collaboratively with St. Vincent’s Hospital and secondly to approach the Crohn’s and Colitis Association to recruit participants online via their membership website. Approval date: 02.10.2007 (Protocol No: HREC-A 101/07; Refer to Appendix A).

2.3.2 Recruitment.

Recruitment occurred over two phases. The initial phase involved collaborating with four of the gastroenterologists and researchers at St. Vincent's Hospital in Melbourne. Patients with IBD were handed a questionnaire pack when they attended their regular consultations at the St. Vincent's Hospital Gastroenterology Clinic. Data were gathered in collaboration with Debra Osborne, a fourth-year psychology student as part of her Honours in Psychology thesis.

2.3.2.1 Phase I: St. Vincent's Hospital sample.

The present study began with the involvement and interest of three gastroenterologists at St. Vincent's Hospital. The gastroenterologists were approached and interest was discussed. During the process of initiating ethics approval, further support was sought from other gastroenterologists within the Gastroenterology Department. This occurred in a meeting with the researchers and gastroenterologists at St. Vincent's Hospital. Their involvement would include informing their IBD patients of the study and handing them the questionnaire packs.

2.3.2.2 Phase II: Crohn's and Colitis Australia online sample.

The Crohn's and Colitis Australia (at the time, known as the Australian Crohn's and Colitis Association) was approached and a meeting with their manager undertaken. The manager was informed of the purpose of the study, and how it sought to further the current knowledge in helping their members.

2.3.3 Questionnaire pack.

The questionnaire pack (Appendix B) comprised of self-report demographic questions (e.g., age gender, etc.) and eight questionnaires measuring coping, illness perception, CD activity index, Lichtiger index, QoL, self-efficacy, multidimensional locus of control, and mindfulness. To be eligible to participate in the study, all participants were required to be aged at least 18 years old.

2.3.3.1 St. Vincent's Hospital (Melbourne).

The questionnaire pack was delivered in A4 pre-addressed and stamped envelopes, which contained all of the questionnaires, an information fact sheet, and a stamped return envelope to return the questionnaires. The information fact sheet (see Appendix C) explained the purpose of the study and the expected time it would take to complete the questionnaires. The fact sheet also informed participants that their participation was confidential and voluntary allowing, the participant to withdraw at any time. As the study did not require identifiable information, confidentiality could be assured. Recruitment began on 02.10.2007 and ended on 28.04.2008. Of the 100 questionnaires handed out, 79 were returned, resulting in a 79% return rate.

2.3.3.2 Crohn's and Colitis Australia.

In contrast to the St. Vincent's Hospital sample, the questionnaires for recruitment from the Crohn's and Colitis Australia (CCA) were uploaded to *Opinio*, a Swinburne University of Technology online survey server, and the link placed on the CCA's website. Their members could click on the hyperlink to complete the questionnaires. The fact sheet and questionnaires were identical to the printed version of the St. Vincent's Hospital questionnaire pack. Recruitment began on 21.01.2008 when the CCA uploaded the online survey onto their website and ended on 28.04.2008.

Measures are discussed according to the order in which they were presented in the questionnaire pack and online hyperlink. Reliable and valid brief measures were used when possible in order to reduce participant fatigue. Two hundred and sixty one individuals completed the questionnaires, while nine individuals left them incomplete.

2.3.4 Disease activity measures.

2.3.4.1 Crohn's Disease Activity Index (CDAI).

Crohn's Disease Activity Index (CDAI; Best et al., 1976). The CDAI was originally developed by the National Cooperative Crohn's Disease Study group wanting to measure the disease activity of their patients with CD using a single index of degree of illness (Best et al., 1976). The CDAI has been found to have good criterion and construct validity (Dhruva Rao, Davies, Price, & Torkington, 2007), strong psychometric properties (Best et al., 1976), and has been considered to be the gold standard for assessing CD activity (Dhruva Rao et al., 2007).

Although the CDAI has been highly regarded by some researchers in measuring CD disease activity (e.g., Dhruva Rao et al., 2007), there has been some debate. According to Sands et al. (2005), there is little guidance on the administration, recording or scoring practicalities when using the scale, resulting in possible random error contributing to negative study results. The authors also note that there is considerable variability in the implementation and administration of the scale among experienced researchers.

Although the original CDAI (Best et al., 1976) was utilised to assess disease activity across all participants, the reliability of the outcome became questionable. A number of problems were found using the original CDAI in both sample groups. For example, item four, which explores complications in CD only allowed for a single response in the online sample, despite the measure intending to include multiple complications. An additional challenge using the CDAI involved participants not scoring item seven (haematocrit levels) as they may not have had that knowledge at hand.

For the above reasons, the Short CDAI (Thia et al., 2011) was instead utilised, as it consists of using three of the original items, including item one, item two, and item three.

Reliabilities between the two scales were explored with the CDAI having a reliability of 0.29 and the Short CDAI 0.21 (Thia et al., 2011).

2.3.4.2 Short Chrohn's Disease Activity Index (SCDAI).

Although the CDAI (Best et al., 1976) is the most widely employed questionnaire for assessing CD activity since its inception in 1975 (Thia et.al., 2011), it was constructed for use as an instrument to measure the efficacy of drug therapy (Best et al., 1976). Although it has continued to be used as a measure of drug therapy efficacy, it has also been considered cumbersome to use, requiring laboratory findings as well as physical examination. Thia et al. (2011) also challenged the benefit of some of the items; for example, item five of the original CDAI requires information pertaining to the need for antidiarrheal medication. According to Thia et al. (2011), this information is not responsive to change and accounts for little variation in the total score. Thia et al. also question the value of other variables, including extraintestinal manifestation and body weight. According to Thia et al. these variables also contribute little in the variation of the CDAI and were retained only on a judgment basis (Best et al., 1976).

For these reasons, Thia et al. (2011) developed a shortened version of the CDAI. Utilising the CDAI and IBDQ, data collected from 458 patients with active disease and 215 patients with inactive disease on two 12-month maintenance of remission trials (Greenberg et al., 1996; Hanauer, Sandborn, Persson, & Persson, 2005; Tremaine et al., 2002), Thia et al. found the Short CDAI to be both a valid and reliable measure of CD activity. A strong correlation was found between the original CDAI at baseline and the SCDAI ($r = 0.96$, $p < 0.001$). Thia at al. also found the SCDAI accounted for 82.4% of the variance in the original CDAI. Due to achieving the highest correlation coefficients against the dependent variable (250 IBDQ scores), of the eight items in the original CDAI, only three items were retained; item one ("the number of liquid or soft stools each day for 7 days"), item two ("the sum of seven daily abdominal pain rating"), and item three (general wellbeing ratings). These three items were incorporated into the SCDAI.

In order to simplify the calculation of the SCDAI, coefficients were standardised and a constant of 44 added to yield a mean value as close to the original CDAI as possible (Thia et al., 2011). This would also help simplify comparisons between both indices ("SCDAI = 44 + [2 X the number of liquid or soft stool each day for 7 days] + [5 X the sum of seven daily abdominal pain ratings (0 = none, 1 = mild, 2 = moderate, 3 = severe)] + [7 x the sum of seven general wellbeing ratings [0 = generally well, 1 = slightly under par, 2 = poor, 3 = very poor, 4 = terrible]"; Thia et al., 2011, p. 108). A higher score on the SCDAI indicates greater CD disease activity. For theoretical ranges for all measures, refer to Table 3.2 (p.117).

2.3.4.3 Ulcerative colitis Lichtiger Index (LTI).

Lichtiger Index (LTI; Lichtiger et al., 1994). The LTI is a disease activity measure specific to UC and is a modified version of the Truelove and Witts Severity Index (TWSI; Truelove & Witts, 1955). The advantage of using the LTI is based on it being a self-report questionnaire that did not require laboratory indices or physicians ratings, and that could be scored immediately (Lichtiger et al., 1994).

The LTI is comprised of eight items with variable scales, where the participants are required to tick the most appropriate box. This can be demonstrated with item one: diarrhoea (number of daily stools), which includes five ranges of 1 to 2; 3 to 4; 5 to 6; 7 to 9; and 10 or more; nocturnal diarrhoea (yes or no); visible blood in stool (% bowel movements, ranging from 0% to 100%); faecal incontinence (yes or no); abdominal pain or cramping (four choices ranging from none to severe); general wellbeing (four choices ranging from perfect to terrible); abdominal tenderness (four choices ranging from none to severe); and need for anti-diarrheal's (yes or no). The scoring ranges from 0 to 21, with higher scores indicating greater disease activity. Although Targan et al. (2005) suggest that remission is defined by a score ≤

3, D'Haens et al. (2007) report that neither the definitions of remission nor the LTI have been validated. Despite these potential limitations, the LTI was still found to be almost equally as effective at evaluating disease activity in UC compared to endoscopic indices (Hirai et al., 2010).

2.3.5 Psychological measures.

2.3.5.1 Depression, Anxiety and Stress Scale 21 (DASS-21).

The *Depression, Anxiety and Stress Scale* (DASS-21) is the short-form scale of Lovibond and Lovibond's (1995) 42-item DASS measure. The DASS-21 has been shown to demonstrate good reliability and construct validity in both non-clinical (Henry & Crawford, 2005) and clinical groups (Antony, Bieling, Cox, Enns, & Swinson, 1998). The DASS-21 was chosen over the long-form DASS-42 in order to be suitable for participants with limited concentration without compromising reliability (Henry & Crawford, 2005; McNamara, Durso, & Harris, 2006). The DASS-21 was also shown to have similar psychometric properties when compared to the DASS-42 (Henry & Crawford, 2005). The scale uses seven items to assess depression (e.g. " I couldn't seem to experience any positive feeling at all " and "I was unable to become enthusiastic about anything"); seven items for anxiety (e.g. "excessively rapid breathing, breathlessness in the absence of physical exertion", and "I felt scared without any good reason"); and seven items for stress (e.g. "I tended to over-react to situations" and "I found myself getting agitated"). All items are measured on a 4-point Likert scale (0-3) ranging from *did not apply to me at all* to *applied to me very much or most of the time*. Each subscale is totalled and multiplied by two. The severity is evaluated using table 2.1. The higher the score on the DASS-21, the greater the psychological distress they are experiencing.

Table 2.1

The Depression Anxiety Stress Scale Scoring (Lovibond & Lovibond, 1995)

	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely Severe	28 +	20 +	34+

The DASS-21 has been successfully applied to other chronic illness studies (Almawi et al., 2008; Bucks et al., 2011; Chan et al., 2011), including a recent clinical study involving IBD (Keeton, Mikocka-Walus, & Andrews, 2015).

2.3.5.2 Carver Brief Coping questionnaire (Brief-COPE).

The *Brief-COPE* (Carver, 1997) is a 28-item questionnaire exploring an individual's coping behaviour in response to stressful or challenging life experiences. It consists of 14 subscales, each comprising two items (scored in a 4-point Likert scale; 0 (*I haven't been doing this at all*) to 3 (*I've been doing this a lot*).

The Brief-COPE scale consists of 14 scales including active coping (e.g., "I've been concentrating my efforts on doing something about the situation I'm in"); planning (e.g., "I've been trying to come up with a strategy about what to"); positive reframing (e.g., "I've been trying to see it in a different light, to make it seem more positive"); acceptance (e.g., "I've been accepting the reality of the fact that it has happened"); humour (e.g., "I've been making jokes about it"); religion (e.g., "I've been trying to find comfort in my religion or spiritual beliefs"); using emotional support (e.g., I've been getting emotional support from others"); using instrumental support (e.g., "I've been trying to get advice or help from other people about what to do"); self-distraction (e.g., "I've been turning to work or other activities to take my mind off things"); denial (e.g., "I've been saying to myself, 'this isn't real'"); venting (e.g., "I've been saying things to let my unpleasant feelings escape"); substance use (e.g., "I've been using alcohol or other drugs to make myself feel better"); behavioural disengagement (e.g., "I've been giving up trying to deal with it"); and self-blame (e.g., "I've been criticizing myself"). A higher score on these subscales indicates how strongly the individual is using that particular coping strategy.

The Brief-COPE was included in the study based on its adequate to good internal consistency and acceptable internal reliability (Carver, 1997), and the reduced time it would take participants to complete the questionnaire compared to the time it would take to complete the full, 60-item COPE (Carver et.al., 1989).

According to Carver (1997), the Brief-COPE (as for the full COPE) can be adapted, so that only the scales with the greatest interest to the sample are utilised. Carver, (n.d) advises against the strict collection of subscales, instead recommending an exploratory factor analysis (EFA) be undertaken across different population groups in order to derive subscales specific for that group. For these reasons, an EFA was undertaken within the present study. In general, a higher score on adaptive coping (problem-focused and emotion-focused coping) reflect better outcomes. A higher score on maladaptive coping reflects more ngative outcomes.

2.3.5.3 The Inflammatory Bowel Disease Questionnaire (IBDQ).

The IBDQ is a 32-item, four subscale questionnaire (Guyatt et al., 1989) that measures disease-related dysfunction specific to IBD. These subscales include ten items pertaining to bowel symptoms (e.g., “How frequent have your bowel movements been during the last two weeks?”); five systemic symptoms or symptoms not directly related to bowel disturbance (e.g., “How much energy have you had during the last two weeks?”); 12 emotional functioning items (e.g., “How often during the last two weeks have you felt depressed or discouraged?”); and five social functioning items (e.g., “How often during the last two weeks have you been unable to attend school or do your work because of your bowel problem?”). All items were measured on a 7-point Likert scale ranging from 1 to 7 where originally the higher number represents poorer functioning and QoL, however for the present study, is coded to represent better functioning.

2.3.5.4 The Brief Illness Perception Questionnaire (BIPQ).

The BIPQ (Broadbent, Petrie, Main, & Weinman, 2006) is a nine-item scale designed to rapidly assess the cognitive and emotional representations of illness (Broadbent et al., 2006). It was adapted from the Illness Perceptions Questionnaire Revised (IPQ-R; Moss-Morris et al., 2002) to be more suitable for elderly or ill patients, or for those who are limited in their reading and writing abilities (Broadbent et al., 2006).

The adaptation involved the inclusion of eight new items with the addition of the causal scale used in the IPQ-R. All eight items with the exception of the causal question are rated on a 0-to-10 response scale. For example, 0 = *no effect at all* to 10 = *severely affects my life*. An increase in item score represents a linear increase in negative illness perceptions (Broadbent et al., 2006).

An additional difference to the IPQ-R is that it comprises seven constructs assessing cognitive illness representations (1) consequences (e.g., “How much does your illness affect your life?”); (2) timeline (e.g., “How long do you think your illness will continue?”); (3) personal control (e.g., “How much control do you feel you have over your illness?”); (4) treatment control (e.g., “How much do you think your treatment can help your illness?”); (5)

identity (e.g., “How much do you experience symptoms from your illness?”), (6) emotional representations reflected in two items – one for concern (e.g., “How concerned are you about your illness?”) and one for emotions (e.g., “How much does your illness affect you emotionally? [e.g., does it make you angry, scared, upset or depressed?]”); and (7) illness comprehensibility (e.g., “How well do you feel you understand your illness?”). Causal representations are assessed using an open-ended display adapted from the IPQ-R asking participants to list the three most important factors they believe cause their illness in rank order. The BIPQ demonstrates good concurrent, predictive and discriminant validity, and test-retest reliability in a variety of illness groups. The main advantage of the BIPQ over the IPQ-R is the brevity and speed with which ill and elderly populations can quickly complete it (Broadbent, Petrie, Main, & Weinman, 2006).

2.3.5.5 Mindful Attention Awareness Scale (MAAS).

The MAAS (Brown & Ryan, 2003) is a 15-item scale assessing individual differences in the frequency of mindful states over time. Its focus is on the presence or absence of attention to the present moment, rather than other attributes often attributed to mindfulness such as empathy, gratitude, and trust (Shapiro et al., 1998). Brown and Ryan (2003) highlight the importance of controlling for social desirability in order for participants to answer the questions based on what “really reflects” their experience rather than responding to what they believe they should experience.

Using a 6-point Likert scale from 1 (*almost always*) to 6 (*almost never*), responders indicate how frequently they have the described experiences, with a higher score indicating more mindfulness. All 15 items are distributed across general domains including cognitive (e.g., “I find it difficult to stay focused on what’s happening in the present”), interpersonal emotional (e.g., “I could be experiencing some emotion and not be conscious of it until some time later”), and physical (e.g., “I drive places on “automatic pilot” and then wonder why I went there.”). The MAAS has been described as exhibiting promising psychometric properties as well as theoretical relationships to mindfulness- based intervention outcomes, and to brain activity (Van Dam, Earleywine, & Borders, 2010). It has been demonstrated to be a valid measure of mindfulness (MacKillop & Anderson, 2007) with good internal consistency ($\alpha = 0.87$) in a cancer population (Carlson & Brown, 2005), making it one of the most popular measures of mindfulness (Van Dam et al., 2010).

2.3.5.6 New General Self-Efficacy Scale (NGSE).

The *New General Self-Efficacy Scale* (NGSE; Chen, Gully, & Eden, 2001) was developed to combat the low content and construct validity, and limited multidimensionality found in the original General Self-Efficacy Scale (GSES; Sherer et al., 1982). For more information regarding the development of the NGSE, refer to section 1.6. The NGSE scale consists of eight items (extracted from seven items from Chen and Gully’s [1997] study and seven new additions) to best capture GSE. Using two separate population studies, Chen and colleagues (2001) found the NGSE scale demonstrated unidimensionality, higher construct validity, higher reliability, and higher predicted specific self-efficacy (SSE) compared to the SGSE, despite it containing fewer items.

The measure is assessed on a 5-point Likert type scale, ranging from *strongly disagree* (1) to *strongly agree* (5) (Chen et al., 2001). Example items include “I will be able to achieve most of the goals that I have set for myself” and “I believe I can succeed at most any endeavor to which I set my mind”. The higher the score, the more self-efficacious the individual.

3. Chapter 3: Results

3.1 Data Screening

3.1.1 Participants.

Two-hundred and sixty one participants responded. Participants in the sample had a mean age of 37 years, with a minimum of 18 years old and a maximum of 75 years old. One hundred and ninety six were female, and 61 were males. Four participants did not indicate their gender. One hundred and eighty two participants were recruited via the online platform, while 79 were recruited via the St. Vincent's Hospital IBD outpatient service. The full sample included 261 participants, with the sample size of analyses utilising the standardised disease activity measure consisting of 258 participants (due to three participants not indicating their disease type). Table 3.1 summaries the demographic of the sample.

Table 3.1.

Participant demographics

Demographics	N	%
Gender:		
Male	196	75.1%
Female	61	23.4%
Not reported	4	1.5%
Relationship status:		
Single	89	34.1%
Defacto/married	153	58.6%
Divorced/separated	15	5.7%
Widowed	2	0.8%
Not reported	2	0.8%
Live with:		
Alone	36	13.8%
Partner	156	59.8%
Parents	38	14.6%
Friends	27	10.3%
Other	1	0.4%
Not reported	3	1.1%
Ethnic background:		
Australian/New Zealand	219	83.9%
Europe (excl. UK)	9	3.4%
UK	19	7.3%
Africa	5	1.9%
Other	9	3.4%

Occupational status		
Yes – Full Time	120	46.0%
Yes – Part Time	80	30.7%
Yes – Not Stated	1	0.4%
No	60	23.0%
Occupation		
Professional	120	46.0%
Labourer	57	21.8%
Student	19	7.3%
Homemaker	11	4.2%
Other	18	6.9%
Not Stated	36	13.8%
Disease characteristics:		
Crohn’s disease	169	64.8%
Ulcerative Colitis	89	34.1%
Not Stated	3	1.2%
Disease Status		
Believe disease to *not* be in remission	97	37.2%
Believe disease to be in remission	163	62.5%
Not stated	1	0.4%
Stoma:		
Temporary	5	1.9%
Permanent	4	1.5%
No	250	95.8%
Not stated	2	0.8%
Medications:		
Prednisolon	63	24.1%
Budesonide	9	3.4%
5ASA	120	46.0%
Topical steroids	8	3.1%
Topical 5ASA	7	2.7%
Antibiotics	15	5.7%
Azathioprine	80	30.7%
6MP	15	5.7%
Methotrexate	25	9.6%
Cyclosporine	3	1.1%
Anti-TNFs	27	10.3%
External feeding	4	1.5%
TPN	0	0.0%
Other	53	20.3%

3.1.2 Preliminary data screening.

Data screening and subsequent analyses were performed using SPSS version 23.0. Data were inspected for missing values prior to analysis, where missing values were replaced using the SPSS Expectation Maximisation (EM) algorithm, with values rounded to the nearest valid number. This integrative procedure uses other variables to impute an expected value that then checks whether the imputed value is the most likely fit (maximisation). If the most likely value is not found, the interactive procedure continues to re-impute values until it reaches the most likely value (maximisation). For each of the six measures used in this study, there were less than 5% missing data for all items, except for Item 4 of CDAI ("Do you have any of the following complications"), which had 6.1 % missing. Inspection of data indicated that the online range of the Brief Illness Perceptions Questionnaire (Broadbent et al., 2006) was miscoded (1-10) in comparison to the hardcopy IBQ scale (0-10). To correct for this, the online version of the measure was rescaled using a linear transformation in order to equate the ranges. The following formula was used: $IBQ_{recoded} = ([IBQ_{online} - 1] \times 10/9)$.

3.1.3 Disease activity measures.

The Short CDAI and the LTI scales were used as disease activity measures for analyses separately examining the CD and UC groups. As we wished to examine a model using the largest overall sample, and because there were no hypotheses specifying differences between the two disease groups, for combined group analyses the two disease groups were used together as a Standardised Disease Activity (STDA) measure. To achieve this, Z scores were calculated for each measure within the respective illness group, and then the two scores were combined such that the STDA measure reflects the relative severity of the condition with respect to the mean and deviation of the illness group (i.e., someone with a Z score of 1 would have disease severity of 1 SD above the group mean for their illness group).

3.1.4 Statistical analyses.

Statistical analyses first involved obtaining descriptive statistics including the mean scores of each participant along the different constructs. Subsquently, group comparisons were performed to determine whether there were significant overall mean differences on measures between the following groups: CD versus UC groups, hardcopy versus online groups, and male versus female groups.

Next, in order to: (1) reduce the number of variables; (2) assess the dimensionality of the theoretical constructs; (3) examine the relationship and structure between the variables; and (4) develop a parsimonious analysis for interpretation (Williams, Onsman, & Brown, 2010), EFA was utilised for the coping, illness perceptions, self-efficacy, and mindfulness scales. The DASS-21, and IBDQ scales did not require factor analysis, as their subscales have been extensively validated. Correlational analysis was then utilised to explore the relationships between variables.

Structural equation models (SEM) were constructed to test the hypotheses. Item parcels and/or existing subscales were utilised to assist in creating latent variables that could then be used in the SEM analysis. In order to test for goodness of fit to the data, measurement models for testing mediation[1] effects were examined. Finally, SEM was utilised in order to explore the structural relationships between the latent variables including examination of a number of nested meditational models. Models were examined separately for the two major outcome variables (psychological distress and QoL). A final model was utilised combining both psychological distress and QoL.

3.1.5 Descriptive statistics.

Descriptive statistics for the relevant variables are indicated in Table 3.2. All utilised measures had internal reliability in the acceptable to excellent range, excluding the SCDAI and LTI which could not be determined due to the use of weighting in calculating these variables. Mean depression, anxiety, and stress levels were all in the mild range according to the cut-offs suggested by Lovibond and Lovibond (1995). The mean scores on the SCDAI (M =105.98) are comparable to those of the remitted sample in Thia et al. (2011; M= 107). For

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[1] The term mediation here refers to statistical mediation, not referring causal mediation which is not able to be investigated in cross-sectional study such as the current one.

comparative purposes, descriptive statistics are reported for the previously derived subscales for coping, but note that an EFA was conducted in section 3.3. The subscales of the Brief COPE (Carver, 1997) suggest participants were more likely to participate in emotion-focused coping rather than maladaptive or problem-focused coping. Table 3.2 also suggests that particpants were moderately self-efficacious, mindful, and demonstrated moderate negative illness perceptions. The results also showed that, on average, participants reported moderate levels of QoL.

Table 3.2

Means, Standard Deviations, and Reliabilities (Cronbach's α) of the Variables Prior to Transformations

Variable	***M***	***SD***	**Theoretical Range**	***n***	***α***
SCDAI	105.98	54.91	0-150 = low DA >450 severe DA*	169	N/A
LTI	7.38	4.38	0-21	89	N/A
IPQ	45.92	11.64	0-80	261	.74
PFC	15.06	4.40	6-24	261	.83
EFC	22.52	5.78	10-40	261	.91
MLC	20.70	5.36	12-48	261	.90
SES	29.00	6.96	1-40	261	.94
MFS	3.85	0.90	1-6	261	.91
QoL	146.69	33.99	1-224	261	.94
DEP	11.23	9.92	0-42	261	·92
ANX	9.05	8.28	0-42	261	.82
STR	15.59	10.07	0-42	261	.88
PSYCH	36.18	24.79	0-126	261	.94

Note. DA= Disease activity; SCDAI = Short Crohns Disease Activity Index; LTI = Lichtiger Index; IPQ = Brief Illness Perceptions Questionnaire; PFC = Problem Focused Coping; EFC = Emotion Focused Coping; MLC = Maladaptive Coping; SES = Self-efficacy Scale; MFS = Mindfulness Scale; QoL = IBD Quality of Life; DEP = Depression; ANX = Anxiety; STR = Stress; PSYCH = Psychological Distress Total.

All means are for non-normally adjusted and non-centred variable values.

* Given the nature of the scale, it was deemed more appropriate to examine the clinical range.

3.2 Group comparisons

3.2.1 Disease group differences.

Table 3.3 presents descriptive statistics by group for disease activity, and all independent, mediator, and dependent variables. Also, *t*-tests for differences in group means are indicated, and these are considered significant at $p < .05$ if the 95% confidence interval excludes zero. As noted below, there were remarkably few significant differences in overall variable scores across the groups with the exception that adaptive focused coping (AdFC) was lower in the UC vs CD group, $t(258) = -2.41$, $p < .05$ (see Table 3.3). However, it should be noted that applying family-wise Bonferroni correction due to the number of tests, makes this difference smaller than the corrected critical value of $t(258) = 2.92$, $p = .003$, indicating that the significant difference may be due to a type 1 error.

Table 3.3

Summary and Test Statistics for CD (n = 169) and UC (n = 89) Disease Activity, Predicted Mediated Variables, and Outcome Variables

	CD		**UC**		***t* test**	
Variable	***M***	***SD***	***M***	***SD***	***t^a***	**(95% CI)**
SCDAI	105.98	54.91	-	-	-	-
TLI	-	-	7.38	4.38	-	
IBQF	35.33	10.40	33.95	10.24	-1.02	(-4.04, 1.29)
AdFC	40.83	10.32	37.79	8.19	-2.41*	(-5.53, -0.55)
MIFC	12.15	3.99	11.49	3.59	-1.31	(-1.66, 0.33)
SES	28.81	6.64	29.39	7.53	0.64	(-1.21, 2.38)
MFS	3.84	0.86	3.873	.97	0.28	(-.19, 0.26)
QoLTot	144.46	32.09	150.50	36.71	1.37	(-2.67, 14.74)
QBow	42.51	9.55	42.51	12.41	-0.00	(-2.74, 2.74)
QSys	18.31	6.76	19.79	6.74	1.67	(-.27, 3.22)
QEmo	53.88	12.36	56.73	13.27	1.72	(-.42, 6.12)
QSoc	25.46	7.59	26.64	8.03	1.16	(-.82, 3.17)
DEP	11.99	10.41	10.37	9.31	-1.23	(-4.21, 0.97)
ANX	9.40	8.12	8.41	8.66	-0.91	(-3.13, 1.16)
STR	15.51	9.71	16.02	10.70	0.39	(-2.08, 3.11)
PSYCH	36.90	24.70	34.81	25.05	-0.65	(-8.50, 4.31)

Note. SCDAI = Short Crohns Disease Activity Index; LTI = Lichtiger Index; IBQF = Brief Illness Perceptions Factor analysed; AdFC = Adaptive Focused Coping; MLFC = Maladaptive Focused Coping; SES = Self-efficacy Scale; MFS = Mindfulness Scale; QoL = IBD Quality of Life; QBow = QoL Bowel symptoms; Qsys = QoL Systemic symptoms; QEmo = QoL Emotional symptoms; QSoc = QoL Social symptoms; DEP = Depression; ANX = Anxiety; STRE = Stress; PSYCH = Psychological Distress Total.

The above sample size involved $N = 258$ participants, as three participants within the complete sample did not state which disease they were diagnosed with.

* $p < .05$, ** $p < .01$

3.2.2 Sample differences.

Table 3.4 indicates the overall descriptive statistics for illness activity depending on the sample (hardcopy versus online sample). Table 3.4 shows that overall CD disease activity was slightly higher in the St. Vincent's Hospital sample (hardcopy) compared to the online sample recruited through CCA. UC symptoms were somewhat higher in the online CCA sample compared to the St.Vincent's Hospital sample who completed hardcopy surveys.

However, these differences failed to reach significance. As we are only interested in the relative clinical severity of the two groups, only severity variables were analysed.

Table 3.4

Summary and Test Statistics for CD (n = 169) and UC (n = 89) Across Two Data Collection Sources

	Hardcopy		**Online**		***t* test**	
Variable	***M***	***SD***	***M***	***SD***	t^a	**(95% CI)**
STDA	-0.01	1.11	.00	0.95	0.11	(-0.25, 0.28)
SCDAI	106.53	65.89	104.55	53.71	-0.25	(-17.46, 13.50)
LTI	7.53	4.20	7.80	3.77	0.51	(-0.78, 1.32)

Note. SCDAI = Short Crohn's Disease Activity Index; LTI = Lichtiger Index; STDA = Standardised Disease Activity.

3.2.3. Gender differences.

In addition, variables were examined for differences across gender. As shown below in Table 3.5, males scored higher than females on all variables except for the LTI/UC disease activity, and on measures of coping (adaptive and maladaptive), self-efficacy, and anxiety. However, these differences were not significant except with respect to SES, indicating that gender appears to be a relatively unimportant variable, particularly when considering the large sample size.

Table 3.5

Summary and Test Statistics for Females (n =196) and Males (n = 61) for Disease Activity, Predicted Mediated Variables, and Outcome Variables

	Females		**Males**		***t* test**	
Variable	***M***	***SD***	***M***	***SD***	t^a	**(95% CI)**
SCDAI	103.14	52.28	116.95	64.88	1.30	(-7.25, 34.87)
LTI	7.84	4.73	6.38	3.38	-1.47	(-3.44, 0.51)
STDA	-0.00	0.99	0.00	1.02	.04	(-0.28, 0.30)
IPQFA	34.89	10.09	34.59	11.25	-0.20	(-3.30, 2.69)
AdFC	40.32	9.99	37.93	8.69	-1.68	(-5.19, 0.41)
MlFC	12.04	3.84	11.40	3.83	-1.15	(-1.76, 0.46)
SES	29.55	6.63	27.44	7.66	-2.09*	(-4.10, -0.12)
MFS	3.78	0.89	4.06	0.90	2.08	(.02, 0.53)
QoLTot	145.06	33.80	152.16	33.13	1.44	(-2.61,16.81)
QBow	41.90	10.88	44.71	9.35	1.82	(-0.23, 5.86)
QSys	18.57	6.71	19.72	6.97	1.16	(-0.81, 3.10)
QEmo	54.52	12.68	56.39	12.57	1.01	(-1.78, 5.53)
QSoc	25.74	7.82	26.37	7.58	0.55	(-1.62, 2.87)
DEP	10.87	9.76	13.00	10.77	1.45	(-0.76, 5.02)
ANX	9.06	8.36	8.76	7.91	-0.25	(-2.68,2.08)
STR	15.57	9.99	15.91	10.30	0.23	(-2.57, 3.24)
PSYCH	35.51	24.58	37.68	25.24	0.60	(-4.97, 9.31)

Note. SCDAI = Short Crohns Disease Activity Index; LTI = Lichtiger Index; SDA = Standardised Disease Activity; IPQFA = Brief Illness Perceptions Factor analysed; AdFC = Adaptive Focused Coping; MLFC = Maladaptive Focused Coping; SES = Self-efficacy Scale; MFS = Mindfulness; QoL = IBD Quality of Life; ; QBow = QoL Bowel symptoms; Qsys = QoL Systemic symptoms; QEmo = QoL Emotional symptoms; QSoc = QoL Social symptoms; DEP = Depression; ANX = Anxiety; STRE = Stress; PSYCH = Psychological Distress Total.

3.3 Exploratory Factor Analyses (EFA).

3.3.1. Carver Brief COPE.

Prior to utilising the scales in the analysis, we examined the factor structure of the Brief COPE, as recommended by Carver (1997). An EFA with principal axis factoring extraction was performed. Examination of the Kaiser-Meyer-Olkin (KMO) criteria (.782) suggested the data was suitable for analysis, as per Pett, Lackey, and Sullivan's (2003) recommended minimum .7 KMO value. Consistent with Carver (1997), the derived scales were expected to correlate, an oblique rotation was utilised in the analysis (specifically, direct oblimin).

Prior to performing the analyses, the data was inspected to determine the most appropriate number of factors to extract using the combined criteria of the scree plot, Velicer's minimum average partial (MAP) method and parallel analysis. These three methods were performed using random data. The criteria suggested that two or seven factors (MAP); three factors (parallel analysis); and three factors (scree plot) were appropriate, with the first eight eigenvalues being 6.58, 3.56, 1.93, 1.78, 1.46, 1.26, 1.19, 1.17. Therefore, the factor solutions were examined utilising two, three, four, and seven factors to determine the most parsimonious solution. Examination of factor solutions using these different numbers of extracted scales suggested a two factor solution was most appropriate, with the other solutions either having multiple cross-loading items or scales with only one or two items predominantly loading on them.

The two derived scales (factors) were represented as adaptive (including both problem-focused and emotion-focused coping) and maladaptive coping, with the highest loading items on adaptive coping being: "I've been trying to come up with a strategy about what to do"; "I've been thinking hard about what steps to take"; "I've been getting comfort and understanding from someone"; and "I've been getting help and advice from other people". The highest loading items on the maladaptive scale were: "I've been criticizing myself"; "I've been using alcohol or other drugs to help me get through it"; and "I've been giving up trying to deal with it".

Following determination of the number of scales to extract, the solutions for item loadings were further examnied. Based on examination of the solutions, items 1 ("I've been turning to work or other activities to take my mind off things"), 9 ("I've been saying things to let my unpleasant feeling escape"), and 19 ("I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping") were sequentially removed from the factor solution, as these items either: did not have a high primary loading on a single scale; had cross-loadings at a similar level to the primary loading; and/or had low communalities. Examination of item content was consistent with removal, with the items not clearly representing adaptive or maladaptive item domains. Re-running the analysis following removal of these three items resulted in a clear and interpretable factor solution. These final derived scales were subsequently used within the analyses. In summary, the emergent factors in the sample were (1) adaptive coping (including subsets of both of Carver and colleague's [1997] problem and emotion focused coping) and (2) maladaptive coping (negative emotion focused). See Table 3.6 for the final factor loadings. Descriptive statistics for the derived scales utilising summed scales are indicated in Table 3.7.

Table 3.6

Pattern Matrix for Brief Coping

Item	AdFC	MlFC
14. I've been trying to come up with a strategy about what to do.	.73	
25. I’ve been thinking hard about what steps to take.	.69	
15. I've been getting comfort and understanding from someone.	.69	
10. I’ve been getting help and advice from other people.	.68	
23. I’ve been trying to get advice or help from other people about what to do.	.68	
12. I've been trying to see it in a different light, to make it seem more positive.	.65	
7. I've been taking action to try to make the situation better.	.64	
5. I've been getting emotional support from others.	.62	
2. I've been concentrating my efforts on doing something about the situation I'm in.	.59	
17. I've been looking for something good in what is happening.	.55	
20. I've been accepting the reality of the fact that it has happened.	.52	
27. I’ve been making fun of the situation	.44	
21. I've been expressing my negative feelings.	.44	
24. I've been learning to live with it.	.42	
18. I've been making jokes about it.	.41	
26. I’ve been praying or meditating.	.38	
22. I've been trying to find comfort in my religion or spiritual beliefs.	.35	
13. I’ve been criticizing myself.		.61
11. I've been using alcohol or other drugs to help me get through it.		.59
6. I've been giving up trying to deal with it.		.59
16. I've been giving up the attempt to cope.		.59
28. I’ve been blaming myself for things that happened.		.58
4. I've been using alcohol or other drugs to make myself feel better.		.58
3. I've been saying to myself "this isn't real".		.47
8. I've been refusing to believe that it has happened.		.36

Note. AdFC = Adaptive-focused coping; MlFC = Maladaptive-focused coping. Loadings of .30 and below are not displayed.

Table 3.7

Means, Standard Deviations, and Reliabilities (Cronbach's α) of the Coping Subscales, Post EFA

Variable	*M*	*SD*	*N*	*α*
AdFC	39.78	9.73	258	.89
MlFC	11.92	3.87	258	.78

Note. AdFC = Adaptive-focused coping; MlFC = Maladaptive-focused coping

3.3.2. Brief illness perceptions.

The factor structure of the Brief Illnesses Perception questionnaire was also examined. As above, EFA with principal axis factoring extraction was utilised. TKMO statistic was .77, which suggested that the data were suitable for analysis, although two individual measures of sampling adequacy (MSA) were low (Item 2, "How long do you think your illness will continue?" = .56; Item 7, "How well do you feel you understand your illness?" = .60). The data was again inspected to determine the most appropriate number of factors to extract, again using the scree plot, MAP method and parallel analysis, using random data. All three criteria suggested a single factor, representing illness perceptions.

Once the number of scales were determined, we again examined solutions for the appropriateness of solutions. Following examination of the solutions, Items 2 and 7 were removed from the factor analysis, as these items either did not have a high primary loading and/or had low communalities. This was also consistent with their low values on the individual MSA. The analysis was re-run following the removal of the two items in a clear and interpretable factor solution. Following this, the KMO statistic increased to .78 and individual MSA statistics ranged between .76 and .81. This final derived scale was used within the analysis. See Table 3.8 for their final factor loadings and Table 3.9 for their descriptive statistics.

Table 3.8

Pattern Matrix for the IPQ

Item	**Factor Loading**
1. How much does your illness affect your life?	.81
5. How much do you experience symptoms from your illness?	.73
8. How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)	.67
6. How concerned are you about your illness?	.65
3. How much control do you feel you have over your illness?	.59
4. How much do you think your treatment can help your illness?	.35

Table 3.9

Means, Standard Deviations, and Reliabilities (Cronbach's α) of the Illness Percepions Questionnaire (IPQ,) Post EFA

Variable	***M***	***SD***	***N***	***α***
IPQ	34.85	10.25	258	.79

3.3.3. Mindfulness.

As the Mindfulness Attention Awareness Scale (MASS; Brown & Ryan 2003) has not been extensively explored within an IBD population, it was considered important to examine whether the factor structure holds within the current sample. The factor structure of the MAAS was explored using an EFA with the same extraction method as noted above. The KMO statistic (.92) and individual MSA statistics (range = .81-.95) suggested that the data were suitable for analysis. Extraction criteria suggested a single factor. All items were retained in the final solution. See Table 3.10 for the final factor loadings.

Table 3.10

Pattern Matrix for Mindfulness

Item	**Factor Loading**
14. I find myself doing things without paying attention.	.83
8. I rush through activities without being really attentive to them.	.81
7. It seems I am "running on automatic," without much awareness of what I'm doing.	.81
10. I do jobs or tasks automatically, without being aware of what I'm doing.	.80
9. I get so focused on the goal I want to achieve that I lose touch with what I'm doing right now to get there.	.71
11. I find myself listening to someone with one ear, doing something else at the same time.	.69
12. I drive places on "automatic pilot" and then wonder why I went there.	.67
13. I find myself preoccupied with the future or the past.	.62
3. I find it difficult to stay focused on what's happening in the present.	.62
4. I tend to walk quickly to get where I'm going without paying attention to what I experience along the way.	.61
15. I snack without being aware that I'm eating.	.56
2. I break or spill things because of carelessness, not paying attention, or thinking of something else.	.56
5. I tend not to notice feelings of physical tension or discomfort until they really grab my attention.	.49
1. I could be experiencing some emotion and not be conscious of it until some time later.	.48
6. I forget a person's name almost as soon as I've been told it for the first time.	.35

3.3.4. Self-efficacy

The SES was also examined for its factor structure, using the same procedure as specified above. Examination of the KMO statistics (.93) and the individual MSA statistics (range = .92-.95) suggested the data were suitable for factor analysis. A single factor was the most appropriate to represent the self-efficacy construct. No items were removed. See table 3.11 for factor loadings.

Table 3.11

Pattern Matrix for Self-efficacy

Item	Factor Loading
6. I am confident that I can perform effectively on many different tasks.	.87
5. I will be able to successfully overcome many challenges.	.86
4. I believe I can succeed at most any endeavor to which I set my mind.	.86
3. In general, I think that I can obtain outcomes that are important to me.	.85
2. When facing difficult tasks, I am certain that I will accomplish them.	.81
1. I will be able to achieve most of the goals that I have set for myself.	.77
7. Compared to other people, I can do most tasks very well.	.77
8. Even when things are tough, I can perform quite well.	.71

3.4. Correlational Analyses

For correlation analysis, the DASS-21 (Lovibond & Lovibond, 1995) subscales of depression, anxiety and stress were examined separately. For illustrative purposes, the separate subscales of the IBDQ (Guyatt et al., 1989) (e.g., the bowel symptoms, systemic symptoms, social symptoms, and emotional symptoms subscales) were also shown in addition to the total QoL which was used in the analysis.

As outlined in Table 3.12, and consistent with hypothesis 1 and 2, disease activity was positively related to illness perceptions, maladaptive coping and psychological distress (depression, anxiety, and stress) and negatively related to QoL. This suggests that as disease activity increases, individuals are more likely to have poorer perception of their illness, will be more inclined to utilise maladaptive coping strategies, and experience increased psychological distress and reduced QoL. Disease activity was also inversely related to self-efficacy, and all QoL subscales, with the bowel symptoms subscale demonstrating the highest correlation ($r = -.74$). This indicates that as disease activity increases, the individual is less likely to be self-efficacious and to report high QoL. Illness perceptions were shown to be inversely related to mindfulness and QoL. Adaptive focused coping was found to be positively related to self-efficacy and anxiety. Disease activity was found to have a minimal negative relationship with mindfulness.

Maladaptive coping was found to be inversely related to self-efficacy, mindfulness and QoL, whilst positively related to psychological distress. Self-efficacy was positively related to mindfulness and QoL, and was inversely related to psychological distress. Mindfulness was found to positively correlate with QoL and inversely correlate with psychological distress. The results also indicated that the lower the psychological distress an individual experiences, the more likely they are to experience higher QoL. As expected, depression, anxiety, and stress were all highly positively correlated with each other.

In the correlations between dependent and independent variables examined separately for the CD and UC groups, there were no major differences between the relationships across disease types (see Table 3.13). Examining the pairwise absolute value of the differences between correlations (see Table 3.14) indicated a range of $r = .01$ (Stress-QoL systemic symptoms) to $r = .17$ (STDA-IPQ), with an average difference of $r = .07$. All of these differences are of small magnitude according to Cohen’s conventions, indicating that pairwise relationships are generally comparable for CD and UC groups.

Table 3.12

Correlations in the Full Sample (N =258)

	STDA	**IPQFA**	**AdFC**	**MlFC**	**SES**	**Mfs**	**QoLT**	**QBow**	**QEmo**	**QSys**	**QSoc**	**DEP**	**ANX**	**STR**	**PSYCH**
IPQFA	.53**														
AdFC	.02	.10													
MlFC	.20**	.29**	.08												
SES	-.25**	-.45**	.21**	-.35**											
MFS	-.14*	-.15*	.-10	-.44**	.19**										
QoLT	-.71**	-.71**	.02	-.42**	.42**	.36**									
QBow	-.74**	-.56**	-.02	-.23	.22**	.13**	.87**								
QEmo	-.50**	-.66**	.08	-.56**	.45**	.42**	.88**	.62**							
QSys	-.60**	-.61**	.04	-.36**	.43**	.39**	.86**	.66**	.70**						
QSoc	-.62**	-.62**	-.06	-.26**	.39**	.24**	.84**	.68**	.64**	.69**					
DEP	.29**	.41**	-.05	.58**	-.49**	-.36**	-.58**	-.32**	-.68**	-.56**	-.44**				
ANX	.28**	.40**	.17**	.55**	-.39**	-.45**	-.56**	-.37**	-.61	-.51**	-.45**	.63**			
STRESS	.22**	.35**	.12	.01**	-.28**	-.49**	-.50**	-.31**	.-63	-.44**	-.29**	.62**	.66**		
PSYCH	.31*	.45**	.01	.67**	-.45**	-.52**	-.61**	-.43**	-.70**	-.57**	-.40**	.88**	.87**	.88**	

Note. SCDAI = Short Crohns Disease Activity Index; LTI = Lichtiger Index; IPQFA = Brief Illness Perceptions Factor analysed; AdFC = Adaptive Focused Coping; MlFC = Maladaptive Focused Coping; SES = Self-efficacy Scale; MFS = Mindfulness Scale; QoL = IBD Quality of Life; ; QBow = QoL Bowel symptoms; Qsys = QoL Systemic symptoms; QEmo = QoL Emotional symptoms; QSoc = QoL Social symptoms; DEP = Depression; ANX = Anxiety; PSYCH = Psychological Distress Total.

* $p < .05$, ** $p < .01$

Table 3.13

Correlations Between Dependent and Independent Variables, Split by UC (n=89; above the diagonal) and CD (n=169; below the diagonal) Groups

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**
1. STDA	-	-[a]	1	.60**	-.07	.23*	-.25*	-.23*	-.77**	-.82**	-.65**	-.56**	-.64**	.28**	.27**	.27**	.31**
2.SCDAI	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
3.LTI	-[a]	-	-	.60**	-.07	.23*	-.25*	-.23*	-.77**	-.82**	-.65**	-.56**	-.64**	.28**	.27**	.27**	.31**
4.IPQFA	.43**	.43**	-	-	-.18	.32**	-.43**	-.25*	-.65**	-.55**	-.59**	-.64**	-.46**	.38**	.38**	.42**	.45**
5.AdFC	-.00	.00	-	-.09	-	.00	.16	-.15	.09	-.08	.07	.16	-.03	-.08	.06	.05	.01
6. MlFC	.18**	.18**	-	.28**	.10	-	-.32**	-.52**	-.40**	-.29**	-.35**	-.53**	-.15	.54**	.66**	.55**	.67**
7. SES	-.28**	-.28**	-	-.45**	.24	-.36**	-	.16	.35**	.20	.44**	.36**	.31**	-.46**	-.38**	-.34**	-.45**
8.MFS	-.09	-.09	-	-.09	-.13	-.41**	.20**	-	.40**	.34**	.46**	56**	.25*	-.41**	-.44**	-.49**	-.52**
9. QoLT	-.62**	-.62**	-	-.74**	.00	-.43**	.47**	.28**	-	.90**	.87**	.90**	.82**	-.54**	-.56**	-.49**	-.61**
10. QBow	-.66**	-.66**	-	-.57**	-.07	-.20**	.24**	.11	.86**	-	.69**	.70**	.68**	-.37**	-.43**	-.34**	-.43**
11.QSys	-.52**	-.52**	-	-.62**	.05	-.36**	.43**	.34**	.85**	.66**	-	.76**	.69**	-.52**	-.54**	-.45**	-.57**
12.QEmo	-.42**	-.42**	-	-.67**	.07	-.57**	.51**	.33**	.87**	.58**	.66**	-	.62**	-.61**	-.58**	.63**	.70**
13.QSoc	-.58**	.58**	-	-.70**	-.07	-.30**	.44	.23**	.86**	.70**	.69**	.64**	-	-.38**	-.41**	-.26**	-.40**
14.DEP	.29**	.29**	-	.41**	-.04	.60**	-.52**	-.34**	-.60**	-.30**	-.57**	-.68**	-.47**	-	.68**	.63**	.88**
15.ANX	.28**	.28**	-	.42**	.21**	.61**	-.39**	-.46**	-.56**	-.32**	-.49**	-.61**	-.48**	.60**	-	.62**	.87**
16. STR	.20**	.20**	-	.31**	.16*	.56**	-.24**	-.49**	-.50**	-.29**	-.44**	-.63**	-.31**	.62**	.70**	-	.88**
17. PSYCH	.30**	.30**	-	.44**	.11	.68**	-.44**	-.50**	-.64**	-.36**	-.58**	-.77**	-.48**	.86**	.86**	.89**	-

Note. SCDAI = Short Crohns Disease Activity Index; LTI = Lichtiger Index; IPQFA = Brief Illness Perceptions Factor analysed; AdFC = Adaptive Focused Coping; MlFC = Maladaptive Focused Coping; SES = Self-efficacy Scale; MFS = Mindfulness Scale; QoL = IBD Quality of Life; QBow = QoL Bowel symptoms; Qsys = QoL Systemic symptoms; QEmo = QoL Emotional symptoms; QSoc = QoL Social symptoms; DEP = Depression; ANX = Anxiety; STR = Stress.

* $p < .05$, ** $p < .01$ Values above the diagonal are in the UC group, values below the diagonal are in the CD group.

[a]There is no SCDAI scale in the UC group, and no LI in the CD group.

Table 3.14

Pairwise Absolute Value of the Differences between Correlations in the UC and CD Groups

	STDA	IPQFA	AdFCFA	MlFCFA	SES	MFS	QoL	QBow	QSyst	QEmo	QSoc	Dep	Anx	Stress Tot
STDA														
IPQFA	.17													
AdFCFA	.07	.09												
MlFCFA	.05	.04	.09											
SES Tot	.03	.02	.08	.04										
Mindf	.14	.16	.07	.12	.04									
QoL	.16	.09	.09	.03	.12	.19								
QoL Bow	.16	.02	.14	.09	.05	.23	.04							
QoL Syst	.13	.03	.02	.01	.01	.12	.02	.03						
QoL Emo	.15	.03	.09	.04	.15	.23	.03	.12	.11					
QoL Soc	.06	.24	.04	.16	.13	.02	.04	.02	.01	.03				
Dep	.01	.03	.04	.06	.06	.08	.06	.07	.05	.11	.09			
Anx	.02	.04	.15	.05	.01	.02	.01	.11	.05	.04	.07	.08		
Stress	.07	.10	.12	.01	.10	.01	.01	.05	.00	.01	.05	.00	.07	
Psych Total	.12	.01	.10	.02	.01	.02	.03	.08	.07	.00	.08	.01	.01	.01
	MINIMUM		0.00											
	MAXIMUM		0.24											
	AVERAGE		0.07											

Note. STDA =Standardised Disease Activity; IPQFA = Illness perceptions factor analysed total; AdFCFA = Adaptive focused coping factor analysed total; MLFCFA = Maladaptive coping factor analysed total; SES = Self-efficacy total; Mindf= Mindfulness total; QoL = QoL of life total; QoL Bow = QoL Bowel symptoms total; QoL Syst = QoL systemic symptoms totsl; QoL Emo = QoL Emotional frustration total; QoL Soc = QoL Social symptoms total; Dep = Depression; Anx = Anxiety.

Table 3.15

Correlations Between Latent Variables- Psychological Distress and QoLT Outcome (N = 258)

	IPQFA	AdFC	MlFC	SES	MFS	STDA	QoLT
IPQFA	-						
AdFC	-.10	-					
MlFC	.29**	.09	-				
SES	-.45**	.21**	-.35**	-			
MFS	-.15*	-.10	-.44**	.19**	-		
STDA	.53**	-.02	.20**	-.25**	-.14*	-	
PSYCH	.45**	.08	.68	-.44**	-.51**	.31**	
QoLT	-.71**	.02	-.42**	.42**	.36**	-.71**	-

Note. STDA = Standardised Disease Activity; Brief Illness Perceptions Factor analysed; AdFC = Adaptive Focused Coping; MlFC = Maladaptive Focused Coping; SES = Self-efficacy Scale; MFS = Mindfulness Scale; PSYCH = Psychological distress; QoLT = Quality of life total .

STDA represents an observed variable, all other variables are latent variables based on subscales/item parcels as described in-text.

* $p < .05$, ** $p < .01$

For comparative reasons, table 3.15 indicates correlations between the latent variables in the structural equation models (see later sections 3.5). Illness perceptions (IPQFA) were significantly positively related to disease activity (STDA), maladaptive coping (MlFC), and psychological distress (PSYCH), and negatively related to self-efficacy (SES). A significant negative relationship was found between MlFC and mindfulness (MFS), and SES and mindfulness, and a positive relationship between MlFC and SES. Self-efficacy was also found to have a significant inverse relationship with psychological distress. Results also indicated that the more mindful the individual, the less psychological distress they were likely to report. Disease activity and MIFC were found to have a significant negative relationship with QoL. Self-efficacy and mindfulness were found to relate positively to QoL. Disease activity demonstrated a significant negative correlation with QoL.

3.5. Structural Equation Modelling (SEM)

Analysis was undertaken using AMOS 22.0 (IBM Corp, 2013). Prior to analysis, latent variables were created using item parcels or existing subscales. Model testing was performed using the following order. First, separate CSM models with QoL and psychological distress were estimated using the STDA as the dependent variable. This was tested in the order of: (1) measurement model; (2) structural model with increasing constraints corresponding to the potential mediation models; and (3) separate models in the UC/CD groups to examine whether these patterns “hold” within the groups. Finally, mediation models were tested including both QoL and psychological distress together.

The measurement model was examined in order to ascertain that the latent variables were adequately extracted and represent the parcels or sub-factors. Structural models were defined based on the hypotheses, separately for QoL and for psychological distress. Note that due to the complexity of its derivation, STDA was included as an observed variable rather than a latent variable for all analyses.

In the present study, the following recommended indices were used (see Hu & Bentler, 1999; Quintana & Maxwell, 1999): the standardised root-mean-square residual (SRMR; values of .08 or less are desirable); the root-mean-square error of approximation (RMSEA; values of .06 or less are desirable); the comparative fit index (CFI; values of .95 or greater are desirable); and the chi-square difference test was used to compare nested models (significance indicates poorer fit). As the chi-square difference test is considered to be highly sensitive to sample size, complexity of the model, and normality (and in practice is rarely non-significant), the chi-square ratio divided by its degrees of freedom was utilised (χ^2/df; values of < 3 are desirable).

3.5.1 Item parcelling

Prior to the evaluation of models, a parcelling procedure was undertaken for four of the scales. Parcelling enables the researcher to create several measures (rather than one) for each of the latent variables thereby reducing measurement error (for discussion, see Russell, Kahn, Spoth, & Altmaier, 1998). Parcelling also offers the advantage of more normal distributions and increased reliability (Coffman & MacCallum, 2005; Little, Cunningham, Shahar, & Widaman, 2002). Parcels were created for the illness perceptions, coping, self-efficacy and mindfulness variables. The items were then rank-ordered on the basis of the magnitude of their factor loadings with pairs of the highest and lowest items successfully assigned to each parcel (see Tables 3.16; 3.17; 3.18; 3.19). This aims to equalise the average loadings of each parcel in order for the parcels to reflect the underlying construct to an equal degree.

Parcels were not created for the outcome variables of QoL (IBDQ) and psychological distress (DASS21). Instead the established subscales were used to create the corresponding latent variables. The latent variable of IBDQ was constructed using the four domain-specific variables (i.e., body symptoms, systemic symptoms, emotional symptoms, and social symptoms), previously shown to represent QoL in people with IBD (Guyattt et al., 1989). For the psychological distress measure, the separate depression, anxiety and stress scales were utilised (Lovibond & Lovibond, 1996).

Table 3.16

Parcels for Adaptive Coping (AdFC) and Maladaptive Coping (MlFC)

Parcels	**AdFC Items**
1	Item14. I've been trying to come up with a strategy about what to do. Item 7. I've been taking action to try to make the situation better. Item 12. I've been trying to see it in a different light, to make it seem more positive. Item 24. I've been learning to live with it. Item 27. I’ve been making fun of the situation
2	Item 25. I’ve been thinking hard about what steps to take. Item 23. I’ve been trying to get advice or help from other people about what to do. Item 5. I've been getting emotional support from others. Item 20. I've been accepting the reality of the fact that it has happened. Item 26. I’ve been praying or meditating. Item 22. I've been trying to find comfort in my religion or spiritual beliefs.
3	Item 15. I've been getting comfort and understanding from someone. Item 10. I’ve been getting help and advice from other people. Item 2. I've been concentrating my efforts on doing something about the situation I'm in. Item 17. I've been looking for something good in what is happening. Item 21. I've been expressing my negative feelings. Item 18. I've been making jokes about it.

Table 3.16 continued

	MIFC Items
1	Item 13. I’ve been criticizing myself.
	Item 16. I've been giving up the attempt to cope.
	Item 28. I’ve been blaming myself for things that happened.
	Item 8. I've been refusing to believe that it has happened.
2	Item 11. I've been using alcohol or other drugs to help me get through it.
	Item 6. I've been giving up trying to deal with it.
	Item 4. I've been using alcohol or other drugs to make myself feel better.
	Item 3. I've been saying to myself "this isn't real".

Table 3.17

Parcels for Illness Perceptions Variable (IPQ)

Parcels	**IPQ Items**
1	Item 1. How much does your illness affect your life?
	Item 4. How much do you think your treatment can help your illness?
2	Item 3. How much control do you feel you have over your illness?
	Item 5. How much do you experience symptoms from your illness?
3	Item 6. How concerned are you about your illness?
	Item 8. How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

Table 3.18

Parcels for Mindfulness (MFS)

Parcels	**MFS Items**
1	Item 1. I could be experiencing some emotion and not be conscious of it until some time later. Item 6. I forget a person's name almost as soon as I've been told it for the first time. Item 7. It seems I am "running on automatic," without much awareness of what I'm doing. Item 12. I drive places on "automatic pilot" and then wonder why I went there.
2	Item 2. I break or spill things because of carelessness, not paying attention, or thinking of something else. Item 5. I tend not to notice feelings of physical tension or discomfort until they really grab my attention. Item 8. I rush through activities without being really attentive to them. Item 11. I find myself listening to someone with one ear, doing something else at the same time. Item 14. I find myself doing things without paying attention.
3	Item 3. I find it difficult to stay focused on what's happening in the present. Item 4. I tend to walk quickly to get where I'm going without paying attention to what I experience along the way. Item 9. I get so focused on the goal I want to achieve that I lose touch with what I'm doing right now to get there. Item 10. I do jobs or tasks automatically, without being aware of what I'm doing. Item 15. I snack without being aware that I'm eating.

Table 3.19

Parcels for Self-efficacy (SES)

Parcels	SES Items
1	Item 1. I will be able to achieve most of the goals that I have set for myself. Item 6. I am confident that I can perform effectively on many different tasks. Item 7. Compared to other people, I can do most tasks very well.
2	Item 2. When facing difficult tasks, I am certain that I will accomplish them. Item 5. I will be able to successfully overcome many challenges. Item 8. Even when things are tough, I can perform quite well.
3	Item 3. In general, I think that I can obtain outcomes that are important to me. Item 4. I believe I can succeed at most any endeavor to which I set my mind.

3.5.2 Measurement model for STDA and psychological distress outcome.

The maximum-likelihood method was used to estimate the measurement model. Testing of the measurement model resulted in a good fit to the data, $\chi^2(132, N = 258) = 272.29$ $p < .001$, $\chi^2/\text{df} = 2.06$, CFI = .95, SRMR = .06, and RMSEA = .06, 90%CI (.05, .08). A number of studies have found parameter estimates remain valid in SEM analysis even when data are non-normal (see McDonald & Ho, 2002). Regardless, given that multivariate kurtosis was extreme, log transformations were undertaken on the maladaptive coping parcels, and the psychological distress subscales with Mardia's coefficient still being high but less so (14.897, Z = 4.235). Statistical significance ($p <.001$) was found across all of the loadings of the measured variables on their respective latent variables, suggesting that all of the latent variables appeared to have been measured well by their respective indicators.

3.5.3 Measurement model for STDA for QoL outcome.

The measurement model was estimated for QoL using the maximum-likelihood method. The fit was adequate; $\chi^2(80, N = 258) = 396.99$, $p <.001$, $\chi^2/\text{df} = 2,647$, CFI = .93, SRMR = .07, and RMSEA = .08, 90% CI (.07, .09), although it was not as strong as when psychological distress was an outcome. This is largely due to additional implied relationships between the QoL subscales, particularly the QoL emotion subscales, with the IPQ and maladaptive coping parcels. However, to avoid complicating the model, the fit was deemed adequate enough to proceed with mediational analysis. Statistical significance (p <.001) was found across all of the loadings of the measured variables on the latent variables.

3.5.4 Structural model for STDA and psychological distress.

In order to establish the model that best fits the data, six alternative nested models were tested. The first model (Model 1) was the default model that included all structural pathways. The second, Model 2 (full mediation STDA) constrains only the direct pathway between STDA and psychological distress to 0. The third Model (partial mediation) constrains the direct paths from STDA to the psychological mediators to 0 (i.e., it assumes that all pathways are via the IPQ as mediator). The fourth model (full mediation) combines the constraints of both of these models. The fifth model (indirect mediation) is equivalent to this model but additionally constrains the pathway between illness perceptions and psychological distress to 0 (i.e., assumes all pathways from the IPQ to psychological distress are mediated via the psychological variables). The sixth model (IPQ mediation) is equivalent to Model 2, but alternatively tests that the direct effects from the IPQ to psychological distress are significant (i.e., paths from IPQ to psychological mediators are 0; see Table 3.21). Nested model comparisons suggested that Model 4 (full mediation) was the preferred model (Table 3.20). Overall fit statistics for this model suggested it provided a good fit to the data (Table 3.21).

Table 3.20

Nested Model Comparisons for STDA Psychological Distress (PSYCH) (Assuming Model Unconstrained to be Correct)

Model	**df**	**CMIN**	***p***
Model 2: Full Mediation STDA	1	0.49	.484
Model 3: Partial mediation	4	1.52	.822
Model 4: Full mediation	5	2.06	.838
Model 5: Indirect mediation	6	26.22	.000
Model 6: IPQ Mediation	9	68.08	.000

Table 3.21

Standardised Disease Activity With Psychological Distress (PSYCH) Outputs; Structural Paths, Chi-Squire, and Fit Indices Among Different Models

Path coefficients and fit indices			**Model 1** Default	**Model 2** Full mediation STDA	**Model 3** Partial mediation	**Model 4** Full mediation	**Model 5** Indirect mediation	**Model 6** IPQ mediation
STDA	>>	PSYCH	.04	-[a]	.04	-[a]	-[a]	-[a]
STDA	>>	IPQ	.57***	.57***	.56***	.57***	.56***	.57***
STDA	>>	AdFC	.06	.07	-[a]	-[a]	-[a]	-[a]
STDA	>>	MlFC	.01	.02	-[a]	-[a]	-[a]	-[a]
STDA	>>	SES	.04	.05	-[a]	-[a]	-[a]	-[a]
STDA	>>	MFS	-.07	-.07	-[a]	-[a]	-[a]	-[a]
IPQ	>>	AdFC	-.16	-.16	-.12	-.12	-.11	-[a]
IPQ	>>	MlFC	.28	.28	.29***	.29***	.34***	-[a]
IPQ	>>	SES	-.56***	-.56***	-.53***	-.53***	-.53***	-[a]
IPQ	>>	MFS	-.14	-.14	-.19	-.19	-.19	-[a]
IPQ	>>	PSYCH	.29***	.32***	.28***	.32***	-[a]	.34***
AdFC	>>	PSYCH	.06	.07	.06	.06	.05	.07
MlFC	>>	PSYCH	.47***	.47***	.47***	.47***	.53***	.51***
SES	>>	PSYCH	-.14	-.14	-.15	.14	-.28***	-.18
MFS	>>	PSYCH	-.23***	-.23***	-.23***	.23***	-.24***	-.25***
Df			132	133	136	137	138	141
CFI (baseline comparisons)			.95	.96	.96	.96	.95	.94
CMIN			272.29	272.79	273.82	274.38	298.52	340.38
CMIN/DEF			2.06	2.05	2.01	2.00	2.16	2.41
p			.00	.00	.00	.00	.00	.00
RMSEA			.06	.06	.06	.06	.07	.07
CI for RMSEA			.05, .06	.05, .06	.05, .07	.05, .07	.06, .08	.06, .08
SRMR			.06	.06	.07	.07	.07	.13

Note. $p < .001$ significance levels, RMSEA, SRMR, ΔX^2 (*df*), DF, CFI, CMIN, CMIN/DEF.

[a] Paths constrained to 0 by model design.

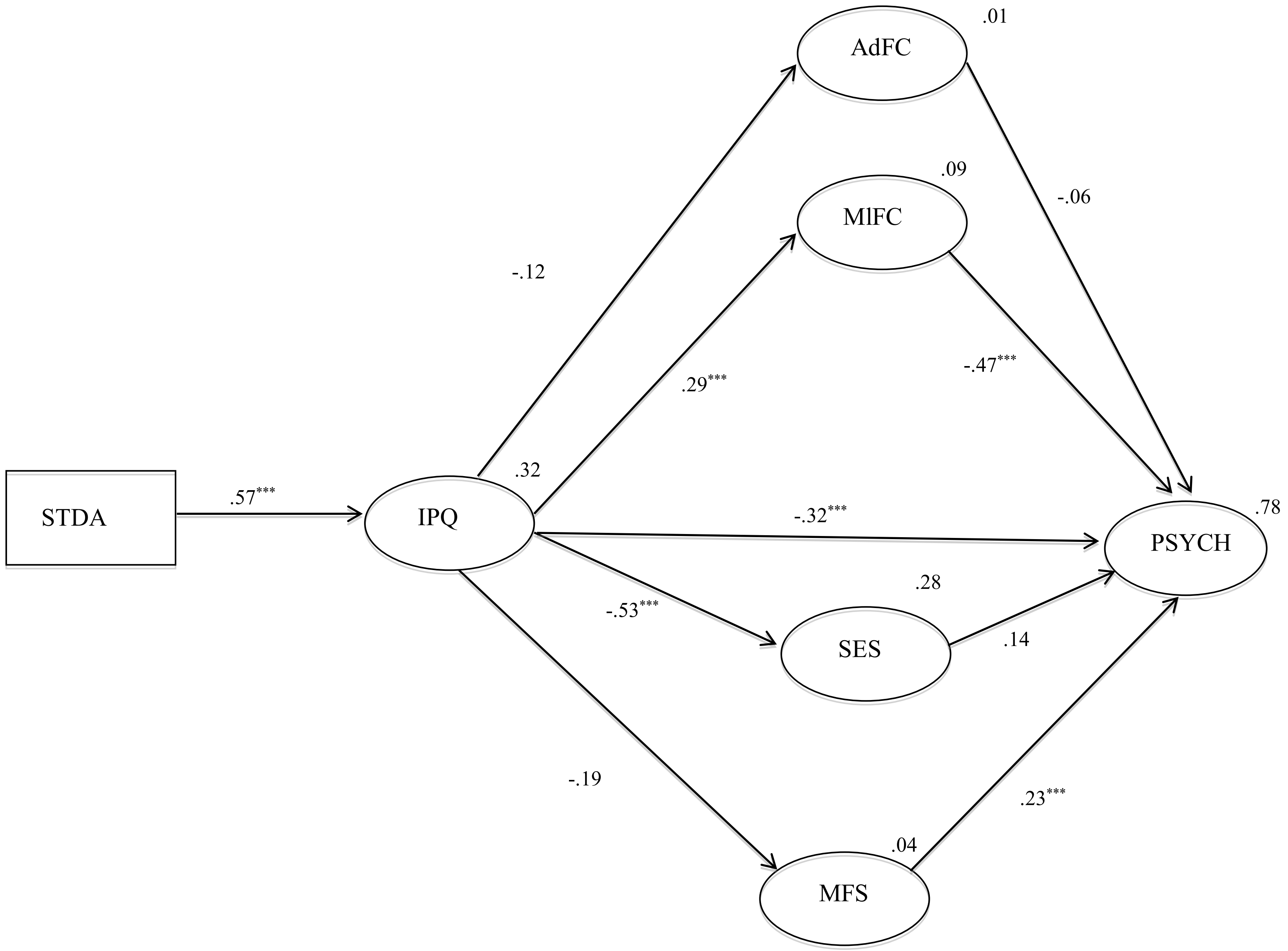

Figure 3.1. The model supported by the data. STDA Psychological output: full mediation model. Note that only latent variables presented with error terms removed from diagram for simplicity. *** $p < .001$

The final model had an excellent fit. In addition, it accounted for 32% of the variability in illness perceptions, 28% for self-efficacy, and 78% for psychological distress; however, it only explained 1% of the variance in adaptive coping, 9% for maladaptive coping, and 4% for mindfulness. Disease activity exerted a statistically significant effect on illness perceptions ($\beta = .57, p < .001$). Illness perceptions exerted a statistically significant effect on psychological distress ($\beta = .32, p < .001$), maladaptive coping ($\beta = .29, p < .001$), and self-efficacy ($\beta = .53, p < .001$). Maladaptive coping ($\beta = .47, p < .001$) and mindfulness exerted significant influences on psychological distress.

In order to explore the significance of the indirect effects amongst latent variables (Efron & Tibshirani, 1993), bootstrap methods were incorporated. This involved a bias-corrected re-sampling method of 5000 bootstrap samples in order to calculate mean indirect effects at 95% confidence intervals for the final model (Figure 3.1). For Model 4, the full mediation model, the mediated effect between STDA and psychological distress had a point estimate of .32 with a 90% CI of .25 to .40, with the path significant at $p <.001$. A point estimate of .25 with a 90% CI of .16 to .34, $p <.001$, was found from IPQ to psychological distress. As such, two mediating pathways were identified: (1) illness perception was found to mediate the relationship between disease activity and psychological distress; and (2) the relationship between illness perception and psychological distress were partially mediated.

3.5.5 Structural model for STDA and QoL.

For the analysis of the QoL structural models, we tested the same six model pathways, with the psychological distress variable as the outcome. The model with the best fit was Model 3, the partial mediation model (see Table 3.22). The model had acceptable fit indices (see Table 3.23).

Table 3.22

Nested Model Comparisons for STDA QoL (Assuming Model Measurement Weights to be Correct)

Model	***df***	**CMIN**	***p***
Model 2: Full Mediation STDA	1	29.71	.00
Model 3: Partial mediation	4	1.66	.80
Model 4: Full mediation	5	37.23	.00
Model 5 Indirect mediation	6	209.27	.00
Model 6 IPQ Mediation	9	100.93	.00

Table 3.23

Standardised Disease Activity with QoL Outputs; Structural Paths, Chi-Squire, and Fit Indices Among Different Models

Path coefficients and fit indices			**Model 1** Default	**Model 2** Full mediation STDA	**Model 3** Partial mediation	**Model 4** Full mediation	**Model 5** Indirect mediation	**Model 6** IPQ mediation
STDA	>>	QoL	-.33***	-^{a}	-.34***	-^{a}	-^{a}	-^{a}
STDA	>>	IPQ	.56***	.68***	.56***	.67***	.57***	.68***
STDA	>>	AdFC	.07	.12	-^{a}	-^{a}	-^{a}	-^{a}
STDA	>>	MlFC	.01	-.07	-^{a}	-^{a}	-^{a}	-^{a}
STDA	>>	SES	.04***	.22	-^{a}	-^{a}	-^{a}	-^{a}
STDA	>>	MFS	-.08	-.06	-^{a}	-^{a}	-^{a}	-^{a}
IPQ	>>	AdFC	-.16	-.22	-.12	-.11	-.12	-^{a}
IPQ	>>	MlFC	.27	.36	.28***	.29***	.31***	-^{a}
IPQ	>>	SES	-.55	-.72***	-.52***	-.52***	-.55***	-^{a}
IPQ	>>	MFS	-.13	-.15	-.18	-.19	-.20	.000
IPQ	>>	QoL	-.59***	-.93***	-.59***	-.88***	-^{a}	-.88***
AdFC	>>	QoL	-.04	-.06	-.04	-.04	-.01	-.04
MlFC	>>	QoL	-.09	-.06	-.09	-.08	-.19	-.12
SES	>>	QoL	.02	-.09	.02	-.03	.39***	.08
MFS	>>	QoL	.18***	.21***	.18***	.19***	.23***	.22***
Df			150	151	154	155	156	159
CFI (baseline comparisons)			.93	.92	.93	.92	.87	.90
CMIN			396.99	426.71	398.66	434.23	606.27	497.93
CMIN/DEF			2.65	2.83	2.59	2.80	3.89	3.13
p			.00	.00	.00	.00	.00	.00
RMSEA			.08	.08	.08	.08	.11	.09
CI for RMSEA			(.07, .09)	(.08, .09)	(.07, .09)	(.07, .09)	(.09, .12)	(.08, .10)
SRMR			.07	.07	.07	.07	.12	.14

Note. $p < .001$ significance levels, RMSEA, SRMR, ΔX^2 (*df*), DF, CFI, CMIN, CMIN/DEF.
[a]Paths constrained to 0 by model design.

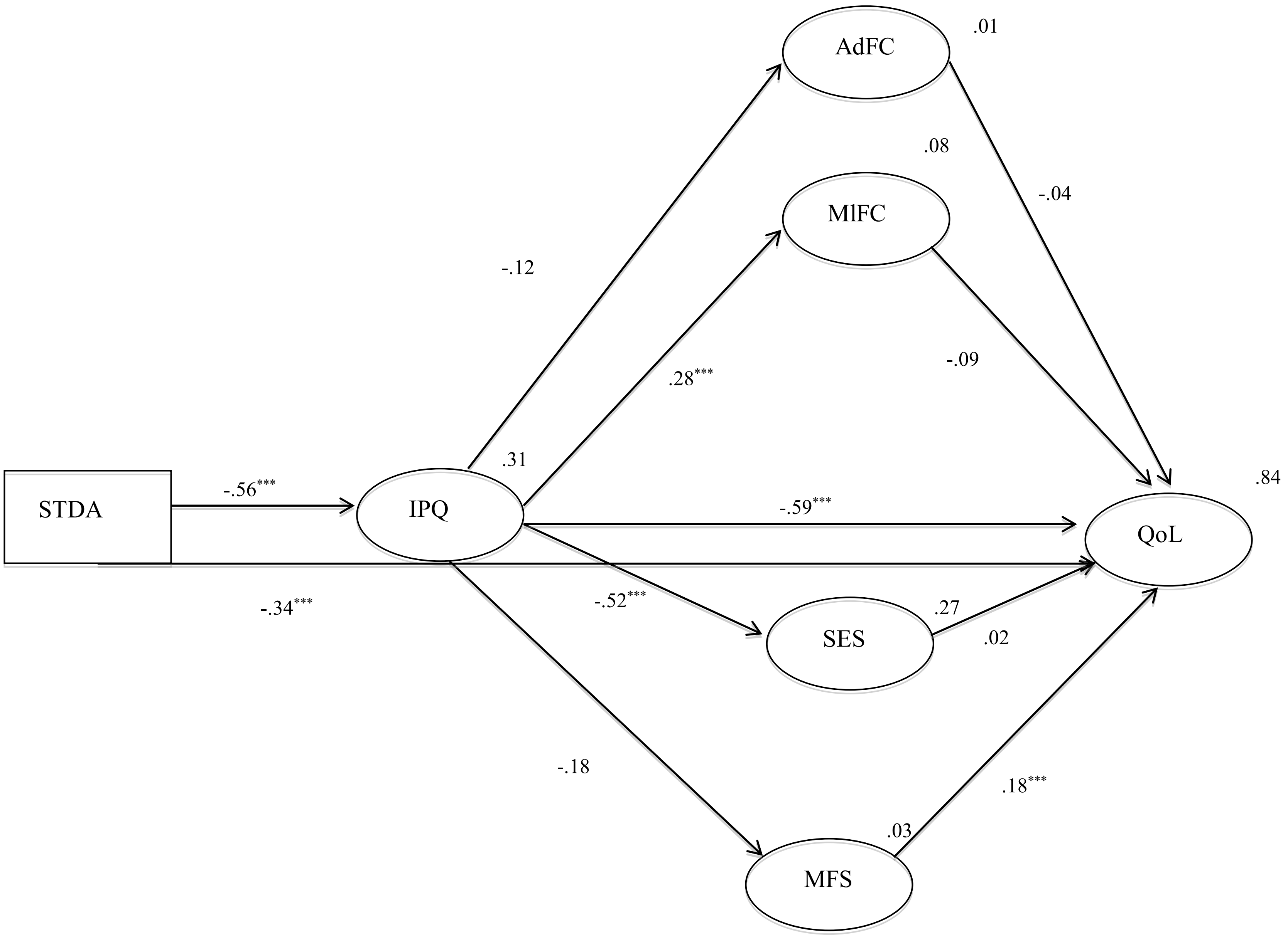

Figure 3.2. The model supported by the data. STDA QoL output: partial mediation model. Note that only latent variables presented with error terms removed. *** *p*< .001

As shown in Figure, 3.2, the partial mediated indirect effect model was preferred. This model accounted for 31% of the variability in illness perception, 84% for QoL, 27% for self-efficacy, 1% for adaptive coping, 8% for maladaptive coping, and 3% for mindfulness. Disease activity exerted a significant effect on illness perceptions ($\beta = .56, p < .001$), Illness perceptions was significantly related to QoL ($\beta = .59, p < .001$), to maladaptive coping ($\beta = .28, p < .001$), and self-efficacy ($\beta = .52, p < .001$). Mindfulness was found to exert a statically significant effect on QoL ($\beta = .18, p < .001$).

The indirect effects amongst latent variables was once again explored using the 5,000 bootstrap resampling method. The point estimate between STDA and QoL was -.37 with a 90% CI of -.45. to -.29, p <.000. There was a point estimate of -.07 at the 90% CI [-.12, -.02] at p =.036 from IPQ to QoL. As a direct pathway from disease activity and QoL ($\beta = .34, p < .001$) was also found, this adds support for a partially mediation model where illness perceptions mediates the relationship between disease activity and QoL. Mindfulness, coping, and self-efficacy were found to mediate the relationship between illness perceptions and QoL.

3.5.6 Replicating the measurement models using CD only

In order to fully explore the CSM models among the different disease activity groups, the measurement model and SEM was replicated utilising the Short CDAI (Thia et al., 2011) among CD participants only, and for UC participants utilising only the Lichtiger scale. Although the participant numbers separated within CD and UC groups may be low for adequate SEM analysis, similar results would nonetheless support findings utilising the STDA using both groups.

3.5.6.1. Measurement model – CD sample.

The measurement model was re-estimated using the CD sample only with PSYCH included. Transformations undertaken in the previous analysis for STDA were utilised on the maladaptive coping parcels and the mood scales. Mardia's coefficient was again high but not extreme (10.368, Z = 2.39). The model fit was adequate; $\chi^2(77, n = 169) = 256.80, p <.001$, $\chi^2/\mathrm{df} = 1.95$, CFI = .94, SRMR = .074, and RMSEA = .08, 90% CI [.06, .09]. Statistical significance ($p < .001$) was found across all of the loadings of the measured variables on the latent variables.

The maximum-likelihood method was used to re-estimate the measurement model within the CD sample, with QoL as the outcome variable. Again, the fit was found to be adequate; $\chi^2(80, n = 169) = 317.74, p <.001$, $\chi^2/\mathrm{df} = 2.12$, CFI = .93, SRMR = .08, and RMSEA = .08, 90% CI (.07, .09). Statistical significance ($p < .001$) was again found across all of the loadings of the measured variables on the latent variables.

Table 3.24

Nested Model Comparisons for SCDAI and PSYCH (Assuming Model Measurement Weights to be Correct)

Model	***df***	**CMIN**	***p***
Model 2: Full Mediation STDA	1	.19	.17
Model 3: Partial mediation	4	1.47	.83
Model 4: Full mediation	5	3.68	.60
Model 5 Indirect mediation	6	23.82	.01
Model 6 IPQ Mediation	9	45.59	.00

3.5.6.2 Structural model for CD sample (psychological distress).

For the analysis of psychological distress structural models for CD only, the same six model pathways as was explored in section 3.5.4.

Table 3.25

Psychological distress (PSYCH) Model for CD only; Structural Paths, Chi-Squire, and Fit Indices Among Different Models

Path coefficients and fit indices			**Model 1** Default	**Model 2** Full Mediation STDA	**Model 3** Partial mediation	**Model 4** Full mediation	**Model 5** Indirect mediation	**Model 6** IPQ Mediation
SCDAI	>>	PSYCH	.09	$-^{a}$	.10	$-^{a}$	$-^{a}$	$-^{a}$
SCDAI	>>	IPQ	$.53^{***}$	$.54^{***}$	$.53^{***}$	$.54^{***}$	$.53^{***}$	$.54^{***}$
SCDAI	>>	AdFC	.11	.11	$-^{a}$	$-^{a}$	$-^{a}$	$-^{a}$
SCDAI	>>	MlFC	.07	.09	$-^{a}$	$-^{a}$	$-^{a}$	$-^{a}$
SCDAI	>>	SES	.03	.04	$-^{a}$	$-^{a}$	$-^{a}$	$-^{a}$
SCDAI	>>	MFS	-.02	-.03	$-^{a}$	$-^{a}$	$-^{a}$	$-^{a}$
IPQ	>>	AdFC	-.17	-.17	-.10	-.10	-.09	$-^{a}$
IPQ	>>	MlFC	.24	.23	.29	.29	$.35^{***}$	$-^{a}$
IPQ	>>	SES	$-.54^{***}$	$-.55^{***}$	$-.53^{***}$	$-.53^{***}$	$-.53^{***}$	$-^{a}$
IPQ	>>	MFS	-.11	-.11	-.12	-.12	.13	$-^{a}$
IPQ	>>	PSYCH	.28	.35	.28	$.35^{***}$	$-^{a}$	.36
AdFC	>>	PSYCH	.07	.08	.07	.07	.07	.08
MlFC	>>	PSYCH	$.49^{***}$	$.49^{***}$	$.48^{***}$	$.48^{***}$	$.56^{***}$	$.52^{***}$
SES	>>	PSYCH	-.09	-.08	-.09	-.08	$-.25^{***}$	-.13
MFS	>>	PSYCH	$-.27^{***}$	$-.26^{***}$	$-.27^{***}$	$-.27^{***}$	-.24	$-.29^{***}$
Df			132	133	136	137	138	141
CFI (baseline comparisons)			.94	.94	.94	.94	.93	.92
CMIN			256.79	258.68	258.27	260.47	280.61	302.38
CMIN/DEF			1.95	1.95	1.89	1.90	2.03	2.15
p			.00	.00	.00	.00	.00	.00
RMSEA			.08	.08	.07	.07	.08	.08
CI for RMSEA			.06, .09	.06, .09	.06, .09	.06, .09	.07, .09	.07, .09
SRMR			.07	.07	.07	.08	.08	.13

Note. $p < .001$ significance levels, RMSEA, SRMR, ΔX^2 (df), DF, CFI, CMIN, CMIN/DEF.

[a]Paths constrained to 0 by model design.

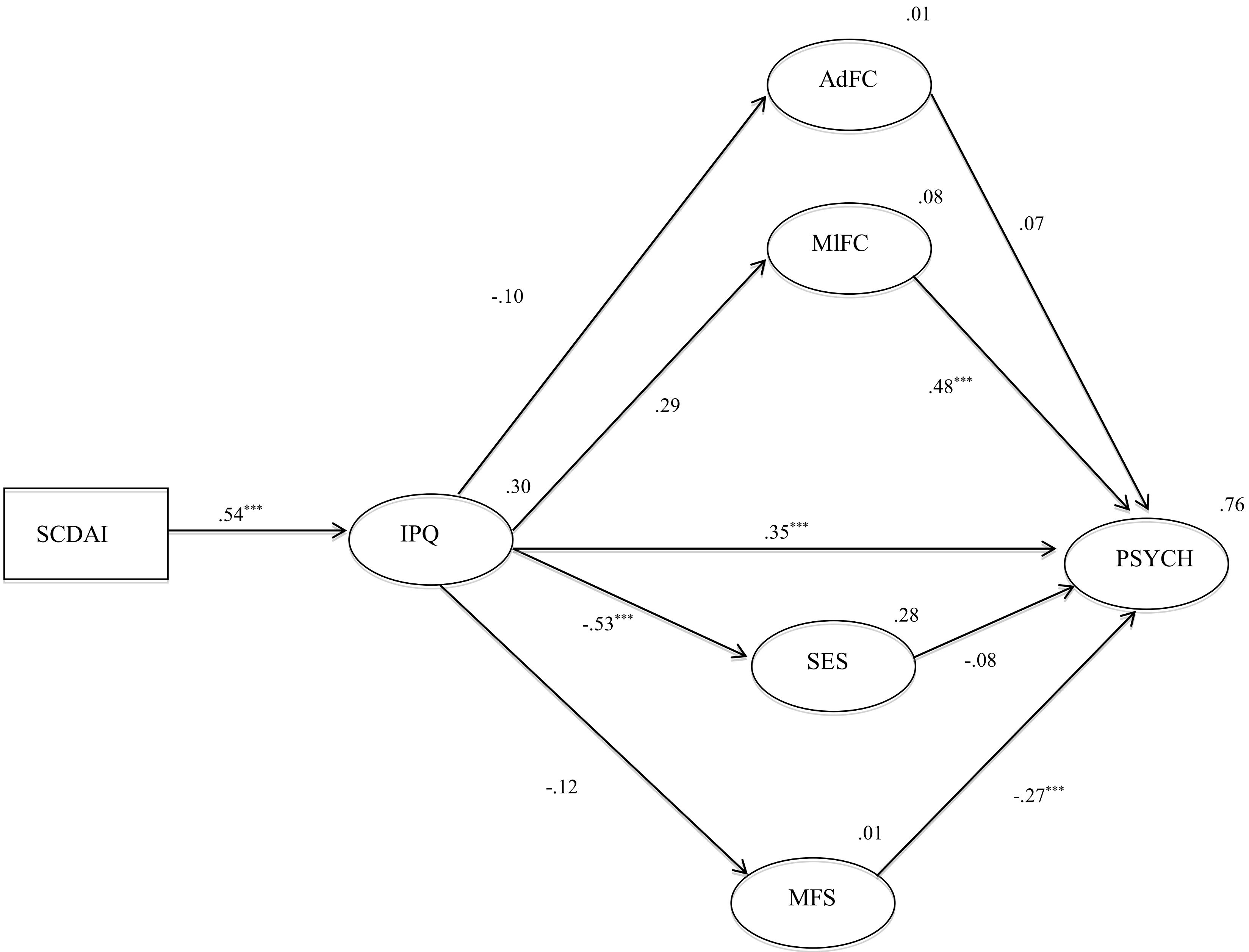

Figure 3.3. The full model supported by the data. Using SCDAI for CD sample. Note that only latent variables presented with error terms removed. *** $p< .001$

As shown in Table 3.24 the full mediated direct effect model was preferred. This accounted for 30% of the variability in illness perception, 76% for psychological distress, 28% for self-efficacy, 1% for adaptive coping, 8% for maladaptive coping, and 1% for mindfulness (Figure 3.3).

As noted in Table 3.25, disease activity exerted a significant effect on illness perceptions ($\beta = .54, p < .001$), Illness perceptions were significantly related to psychological distress ($\beta = .35, p < .001$), maladaptive coping ($\beta = .29, p < .001$), and self-efficacy ($\beta = -.53, p < .001$). Maladaptive coping was significantly related to psychological distress, and mindfulness exerted a statically significant effect on psychological distress ($\beta = -.27, p < .001$).

The indirect effects amongst latent variables were once again explored using the bootstrap resampling method for the model of best fit (Model 4, the full mediation model). There was a point estimated between the SCDAI and psychological distress of -.30, 90% CI [.21, .41], $p = .002$. The point estimate between IPQ and psychological distress was .21, 90% CI [.09, .33], $p = .009$. Generally, the relationships were of similar strength, and the main mediation findings were equivalent to when using the STDA in the full sample.

3.5.6.3 Structural model for CD sample (QoL outcome).

For the analysis of QoL structural models for CD only, we tested the same six model pathways as was explored in section 3.5.5.

Table 3.26

Nested Model Comparisons for SCDAI and QoL (Assuming Model Measurement Weights to be Correct)

Model	***df***	**CMIN**	***p***
Model 2: Full Mediation STDA	1	21.77	.00
Model 3: Partial mediation	4	1.45	.84
Model 4: Full mediation	5	27.21	.00
Model 5 Indirect mediation	6	162.44	.00
Model 6 IPQ Mediation	9	68.87	.00

Table 3.27

QoL Model; Structural Paths, Chi-Square, and Fit Indices Among Different Models - CD Only

Path coefficients and fit indices			**Model 1** Default	**Model 2** Full Mediation STDA	**Model 3** Partial mediation	**Model 4** Full mediation	**Model 5** Indirect mediation	**Model 6** IPQ Mediation
SCDAI	>>	QoL	-.32***	-[a]	-.32***	-[a]	-[a]	-[a]
SCDAI	>>	IPQ	.53***	.67***	.53***	.66***	.53***	.67***
SCDAI	>>	AdFC	.11	.17	-[a]	-[a]	-[a]	-[a]
SCDAI	>>	MlFC	.07	.01	-[a]	-[a]	-[a]	-[a]
SCDAI	>>	SES	.03	.22	-[a]	-[a]	-[a]	-[a]
SCDAI	>>	MFS	-.03	-.01	-[a]	-[a]	-[a]	-[a]
IPQ	>>	AdFC	-.17	-.24	-.10	-.09	-.09	-[a]
IPQ	>>	MlFC	.23	-.28	.28	.29	.31***	-[a]
IPQ	>>	SES	-.54	-.73***	-.53***	-.53***	-.55***	-[a]
IPQ	>>	MFS	-.09	-.11	-.11	-.12	-.13	-[a]
IPQ	>>	QoL	-.66***	-.99***	-.66***	-.93***	.00	-.93***
AdFC	>>	QoL	-.05	-.06	-.04	-.04	-.07	-.05
MlFC	>>	QoL	-.09	-.09	-.09	-.09	-.24	.13
SES	>>	QoL	.04	-.09	.04	-.02	.46***	.11
MFS	>>	QoL	.16	.17	.16	.16	.10	.17
Df			150	151	154	155	156	159
CFI (baseline comparisons)			.93	.92	.93	.92	.86	.90
CMIN			317.74	339.51	319.19	344.96	480.18	386.61
CMIN/DEF			2.12	2.25	2.07	2.23	3.08	2.43
p			.00	.00	.00	.00	.00	.00
RMSEA			.08	.09	.08	.09	.11	.09
CI for RMSEA			.07, .09	.07, .09	.07, .09	.07, .09	.10, .12	.08, .10
SRMR			.08	.08	.08	.08	.13	.14

Note. $p < .001$ significance levels, RMSEA, SRMR, ΔX^2 (*df*), DF, CFI, CMIN, CMIN/DEF.

[a] Paths constrained to 0 by model design.

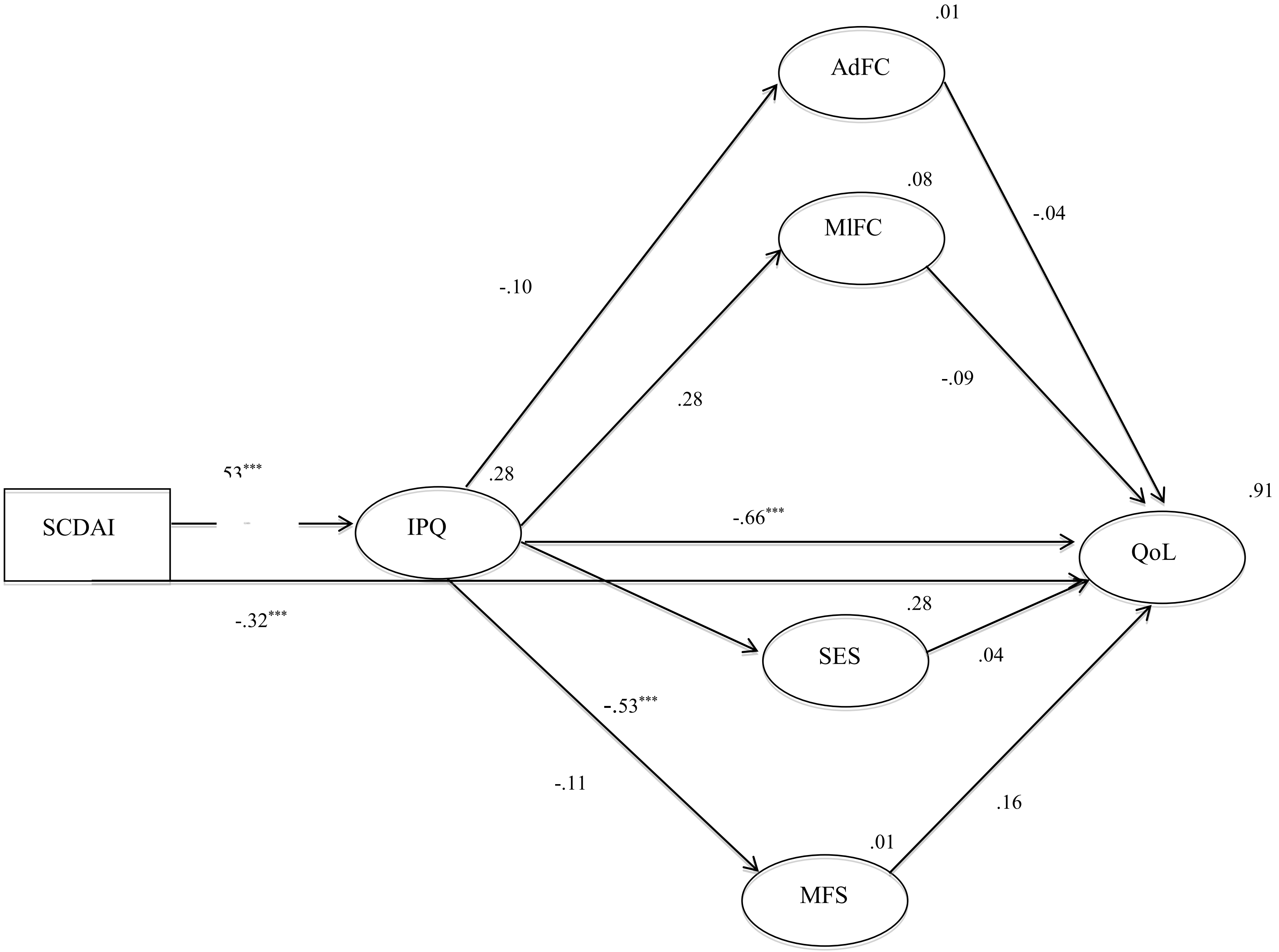

Figure 3.4. The partial mediation model supported by the data for SCDAI using CD sample. Note that only latent variables presented with error terms removed. *** *p*< .001

As shown in Table 3.26 and Table 3.27, the partial mediated indirect effect model was preferred. This model accounted for 28% of the variability in illness perception, 91% for QoL, 28% for self-efficacy, 1% for adaptive coping, 8% for maladaptive coping, and 1% for mindfulness (Figure 3.4). Disease activity exerted a significant effect on illness perceptions ($\beta = .53$, $p < .001$), Illness perceptions was significant related to QoL ($\beta = .66$, $p < .001$), illness perception was related to self-efficacy ($\beta = -.53$, $p < .001$).

The indirect effects amongst latent variables with QoL as output were once again explored using the bootstrap resampling method. For the indirect relationship of the SCDAI and QoL, there was a point estimate of -.38 at 90% CI [-.48, -.2] at p <.002 significance level. There was a point estimate of -.06 at 90% CI [-.13, .00] at p <.120 from IPQ to QoL.

3.5.7 Replicating the measurement models using UC only.

Using the UC sample and the LTI, the measurement model with psychological distress was re-estimated using the maximum-likelihood method. The fit was adequate; $\chi^2(77, n = 89) = 165.72$, $p = .025$, $\chi^2/df = 1.26$, CFI = .97, SRMR = .07, and RMSEA = .05, 90% CI [.02, .08], (see Table 3.29). Statistical significance ($p < .001$) was found across all of the loadings of the measured variables on the latent variables.

The measurement model was re-estimated using the UC sample only with QoL as the outcome. The fit was adequate; $\chi^2(80, n = 89) = 255.57$, $p <. 001$, $\chi^2/df = 1.70$, CFI = .91, SRMR = .08, and RMSEA = .09, 90% CI [.07, .11]. Statistical significance ($p < .001$) was found across all of the loadings of the measured variables.

Table 3.28

Nested Model Comparisons for LTS and PSYCH (Assuming Model Measurement Weights to be Correct)

Model	***df***	**CMIN**	***p***
Model 2: Full Mediation STDA	1	0.16	.00
Model 3: Partial mediation	4	6.95	.14
Model 4: Full mediation	5	7.07	.22
Model 5 Indirect mediation	6	12.52	.05
Model 6 IPQ Mediation	9	30.65	.00

3.5.7.1 Structural model for UC group (psychological distress outcome).

For the analysis of PSYCH structural models for UC only, we tested the same six models as in section 3.5.4.

Table 3.29

Psychological Distress (PSYCH) Model for UC only; Structural Paths, Chi-Squire, and Fit Indices Among Different Models

Path coefficients and fit indices			**Model 1** Default	**Model 2** Full Mediation STDA	**Model 3** Partial mediation	**Model 4** Full mediation	**Model 5** Indirect mediation	**Model 6** IPQ Mediation
LTI	>>	PSYCH	-.02	-[a]	-.01	-[a]	-[a]	-[a]
LTI	>>	IPQ	.72***	.71***	.69***	.69***	.69***	.71***
LTI	>>	AdFC	.16	.16	-[a]	-[a]	-[a]	-[a]
LTI	>>	MlFC	-.08	-.08	-[a]	-[a]	-[a]	-[a]
LTI	>>	SES	.28	.27	-[a]	-[a]	-[a]	-[a]
LTI	>>	MFS	-.08	-.08	-[a]	-[a]	-[a]	-[a]
IPQ	>>	AdFC	-.31	-.31	-.17	-.17	-.17	-[a]
IPQ	>>	MlFC	.35	.35	.27	.27	.32	-[a]
IPQ	>>	SES	-.73***	-.73	-.50***	-.50***	-.51***	-[a]
IPQ	>>	MFS	-.21	-.21	-.28	-.28	-.28	-[a]
IPQ	>>	PSYCH	.29	.27	.27	.27	.00	.28
AdFC	>>	PSYCH	.05	.05	.04	.04	-.00	.04
MlFC	>>	PSYCH	.42	.42	.43	.43	.45	.46
SES	>>	PSYCH	-.20	-.21	-.22	-.22	-.33***	-.26
MFS	>>	PSYCH	-.21	-.21	-.21	-.21	-.26	-.24
Df			132	133	136	137	138	141
CFI (baseline comparisons)			.97	.97	.97	.97	.96	.95
CMIN			165.72	165.73	169.61	169.61	175.22	194.53
CMIN/DEF			1.26	1.25	1.25	1.24	1.27	1.38
p			.03	.03	.03	.03	.02	.00
RMSEA			.05	.05	.05	.05	.06	.07
CI for RMSEA			.02, .08	.02, .08	.02, .08	.02, .08	.03, .08	.04, .09
SRMR			.07	.07	.07	.07	.07	.14

Note. $p < .001$ significance levels, RMSEA, SRMR, ΔX^2 (*df*), DF, CFI, CMIN, CMIN/DEF.

[a] Paths constrained to 0 by model design.

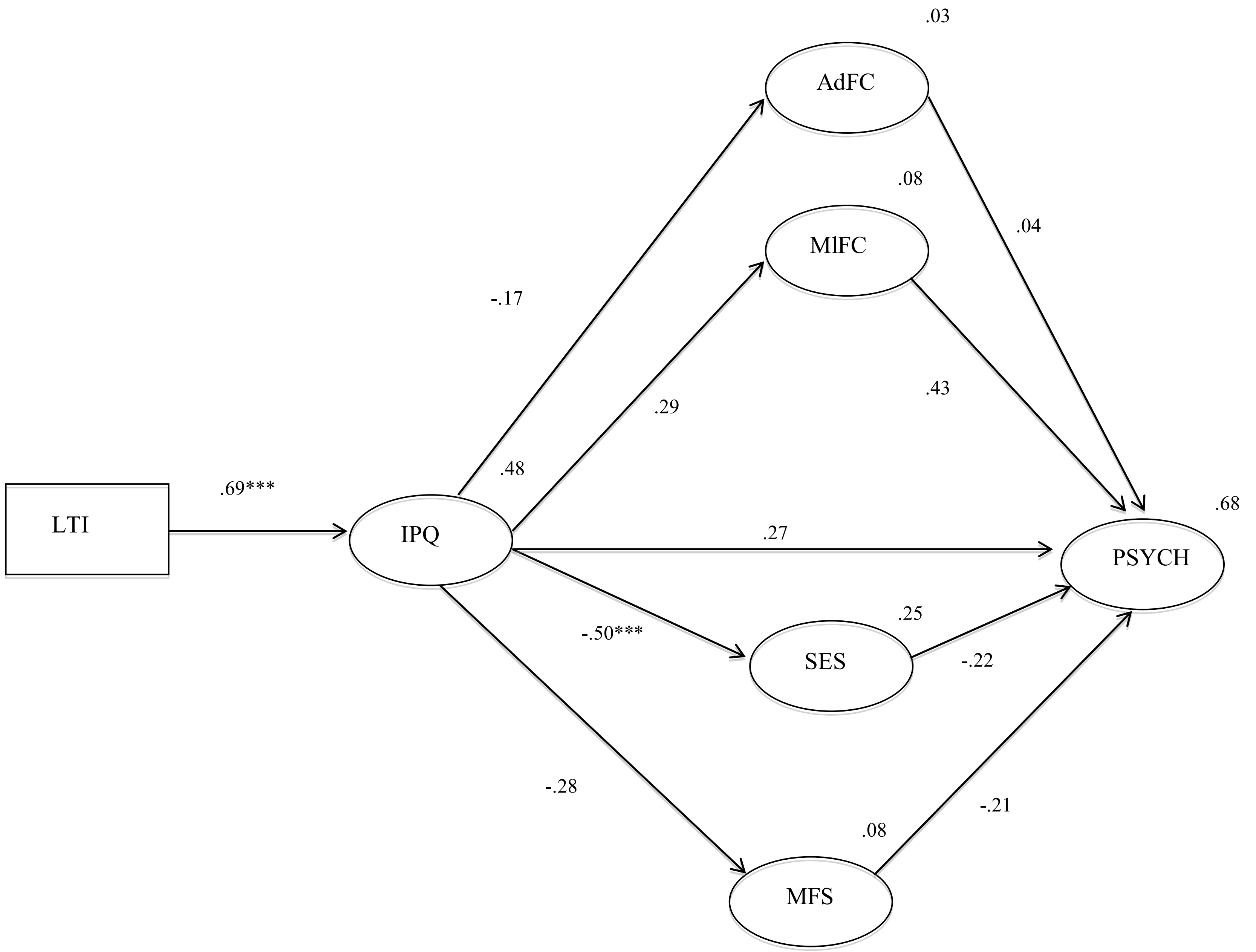

Figure 3.5. The full mediation model supported by the data. Using LTS scale for UC sample. Note that only latent variables presented with error terms removed. *** $p < .001$

Model 5 was the model of best fit (see Table 3.28), however, it just missed significance (*p*=.051). Given the small sample size of the UC cohort, this may be due to low power and randon variation. Therefore for consistency, we have regarded the full mediation model (Model 4) as being the model of best fit.

The full mediation model accounted for 48% of the variability in illness perception, 68% of psychological distress, 25% of self-efficacy and 3% of adaptive coping, 8% of maladaptive coping, and 8% of mindfulness (Figure 3.5). Disease activity exerted a significant effect on illness perceptions (β = .69, *p* < .001; Table 3.29). Illness perceptions were significantly related to psychological distress (β = .27, *p* < .001), and to self-efficacy (β = -.50, *p* < .001).

The indirect effects amongst latent variables with QoL as output were once again explored using the bootstrap resampling method. For the model of best fit - Model 2 the full mediation model - there was a point estimate between the LTI and psychological distress of .38, 90% CI [.25, .51], *p* = .002. There was a point estimate of .28, 90% CI [.13, .45] at *p* < .007 from IPQ to PSYCH.

Table 3.30

Nested Model Comparisons for LTS and QoL (Assuming Model Measurement Weights to be Correct)

Model	***df***	**CMIN**	***p***
Model 2: Full Mediation STDA	1	5.97	.02
Model 3: Partial mediation	4	6.66	.16
Model 4: Full mediation	5	18.80	.00
Model 5 Indirect mediation	6	59.93	.00
Model 6 IPQ Mediation	9	40.07	.00

3.5.7.2 Structural model for UC group (QoL outcome).

For the analysis of QoL structural models for UC only, we tested the same six model pathways as was explored in section 3.5.5.

Table 3.31

QoL Model (UC only); Structural Paths, Chi-Squire and Fit Indices Among Different Models

Path coefficients and fit indices			**Model 1** Default	**Model 2** Full mediation	**Model 3** Partial mediation	**Model 4** Full mediation	**Model 5** Indirect mediation	**Model 6** IPQ mediation
LTI	>>	QoL	-.52***	-[a]	-.54***	-[a]	-[a]	-[a]
LTI	>>	IPQ	.71***	.81***	.69***	.81***	.69***	.84***
LTI	>>	AdFC	.17	.37	-[a]	-[a]	-[a]	-[a]
LTI	>>	MlFC	-.08	-.29	-[a]	-[a]	-[a]	-[a]
LTI	>>	SES	.27	.68***	-[a]	-[a]	-[a]	-[a]
LTI	>>	MFS	-.08	.01	-[a]	-[a]	-[a]	-[a]
IPQ	>>	AdFC	-.32	-.53	-.18	-.16	-.18	-[a]
IPQ	>>	MlFC	.35	.57	.29	.28	.29	-[a]
IPQ	>>	SES	-.73***	-1.14	-.50***	-.46***	-.52***	-[a]
IPQ	>>	MFS	-.21	.31	-.28	-.29	-.29	-[a]
IPQ	>>	QoL	-.27	-.95	-.25	-.81***	-[a]	-.85***
AdFC	>>	QoL	-.02	.13	-.01	-.05	.08	-.02
MlFC	>>	QoL	-.02	.06	-.02	-.01	-.05	-.02
SES	>>	QoL	.08	-.16	.09	-.00	.34	.08
MFS	>>	QoL	.28	.26	.27	.26	.46***	.32***
Df			150	151	154	155	156	159
CFI (baseline comparisons)			.91	.91	.91	.90	.86	.89
CMIN			255.57	265.25	259.42	277.57	328.39	298.66
CMIN/DEF			1.70	1.76	1.67	1.79	2.11	1.88
p			.00	.00	.00	.00	.00	.00
RMSEA			.09	.09	.09	.09	.11	.10
CI for RMSEA			.07, .11	.07, .11	.07, .11	.08, .11	.09, .13	.08, .12
SRMR			.08	.08	.08	.08	.12	.15

Note. $p < .001$ significance levels, RMSEA, SRMR, ΔX^2 (*df*), DF, CFI, CMIN, CMIN/DEF.

[a] Paths constrained to 0 by model design.

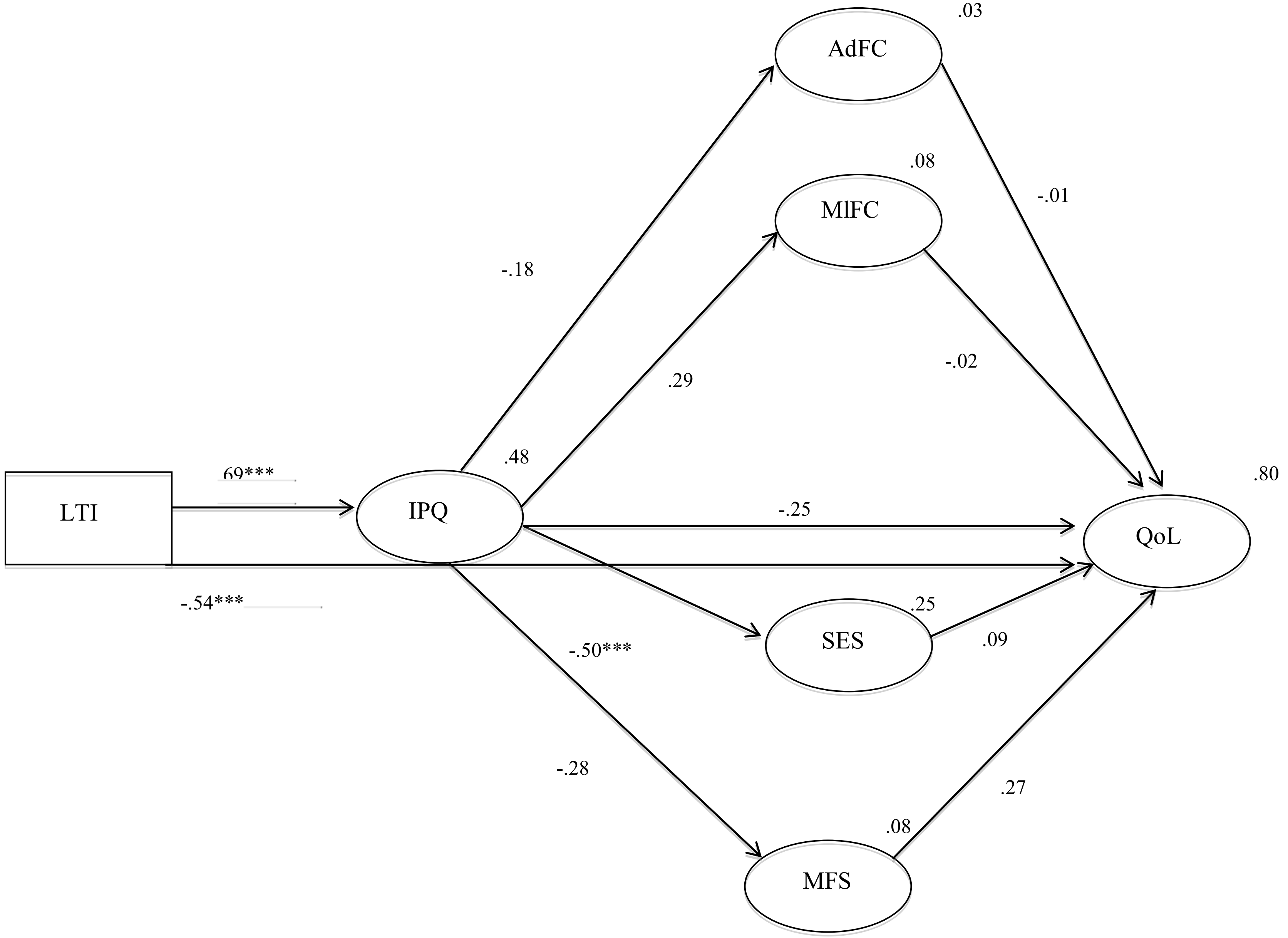

Figure 3.6. The partial mediation model supported by the data. For LTI for UC sample. Note that only latent variables presented with error terms removed. *** $p < .001$

The partial mediated indirect effect model was again preferred with QoL as the outcome (Table 3.30). This model accounted for 48% of the variability in illness perception, 80% of QoL, 25% of self-efficacy and 3% of adaptive coping, 8% of maladaptive coping, and 8% of mindfulness (Figure 3.6). Disease activity exerted a significant effect on QoL (β = .-54, $p < .001$). Illness perceptions were related to self-efficacy (β = -.50, $p < .001$; Table 3.31).

Using the bootstrap resampling method in order to explore the indirect effects of the model, a point estimate between the LTI and QoL was-.26 with a 90% CI [-.46, -.12], p = .008. The point estimate between IPQ and QoL was -.13 with a 90% CI [-.23, -.04], p = .028. In summary, these two outcome models (LTI -> PSYCH; LTI -> QoL) again show very similar findings compared with the full sample using STDA, suggesting that the overall model is valid for the two disease groups.

3.5.8 Models with both psychological distress and QoL.

The measurement model was estimated using the maximum-likelihood method. A good fit was indicated: $\chi^2(203, N = 258) = 570.20, p < .000$, χ^2/df = 2.81, CFI = .91, SRMR = .073, and RMSEA = .08, 90% CI (-25.16, 5.95). Log transformations were undertaken on maladaptive coping parcels and mood scales, given that multivariate kurtosis was high (Mardia's coefficient = 25.12, Z = 5.95). All the loadings were found to have statistical significance ($p < 0.001$), indicating that all the latent variables were measured well by their respective indicators.

Five alternative nested models were tested in order to establish the model that best fit the data in which psychological distress was used as an additional mediator of QoL. The first model (Model 1) was the default model that included all structural pathways. The second model (full mediation) constrains the direct pathway between STDA and psychological distress is 0 and constrains the direct paths from STDA to the psychological mediators to 0 (i.e., it assumes that all pathways are via the IPQ as mediator). This model was selected as it was the resultant model in the psychological distress analyses earlier, and was considered to be the base model to test additional mediation effects from (i.e., Models 3-5 all build on the base model's constraints). The third model (partial mediation) constrains the direct pathway between STDA to psychological distress and STDA to QoL (both pathways constrained to 0; assumes that all pathways are via the IPQ as mediator). The fourth model (indirect mediation) is equivalent to Model 2, with an additional constraint from IPQ to QoL. The fifth model (psychological distress/QoL constrained) is equivalent to Model 2 in previous model comparisons, however, with a constraint from PSYCH to QoL (Refer to Table 3.33). The model of best fit was Model 2, a full mediation model (see Table 3.32).

Table 3.32

Nested Model Comparisons for STDA, Psychological Distress (PSYCH) and QoL (Assuming Model Measurement Weights to be Correct)

Model	***df***	**CMIN**	***p***
Model 2: Full mediation	5	1.54	.91
Model 3: Full mediation to Psych & QoL	6	39.40	.00
Model 4: Indirect mediation	6	51.27	.00
Model 5: PSYCH/QoL Constrained	6	54.51	.00

Table 3.33

Standardised Disease Activity With Psychological distress (PSYCH) and QoL Outputs; Structural Paths, Chi-Squire, and Fit Indices Among Different Models

Path coefficients and fit indices			**Model 1** Default	**Model 2** Full mediation from STDA to Psych	**Model 3** Full mediation to Psych & QoL	**Model 4** Indirect mediation	**Model 5** PSYCH/ QoL Constr
STDA	>>	QoL	-.31	-.31***	-[a]	-.47***	-.29***
STDA	>>	PSYC	.04	-[a]	-[a]	-[a]	-[a]
STDA	>>	IPQ	.56	.57***	.66***	.56***	.57***
STDA	>>	AdFC	.06	-[a]	-[a]	-[a]	-[a]
STDA	>>	MlFC	.03	-[a]	-[a]	-[a]	-[a]
STDA	>>	SES	.03	-[a]	-[a]	-[a]	-[a]
STDA	>>	MFS	-.06	-[a]	-[a]	-[a]	-[a]
IPQ	>>	AdFC	-.16	-.12	-.11	-.12	-.07
IPQ	>>	MlFC	.26	.28***	.28***	.29***	.38***
IPQ	>>	SES	-.53	-.51***	-.49***	-.53***	-.54***
IPQ	>>	MFS	-.16	-.20	-.22	-.19	-.29***
IPQ	>>	PSYC	.30	.33***	.34***	.41***	.43***
IPQ	>>	QoL	-.43	-.43***	-.67***	-[a]	-.74***
AdFC	>>	PSYC	.06	.06	.06	.05	.06
MlFC	>>	PSYC	.46	.46***	.46***	.42***	.44***
SES	>>	PSYC	-.14	-.14	-.13	-.13	-.09
MFS	>>	PSYC	-.24	-.24***	-.23***	-.24	-.19
PSYC	>>	QoL	-.42	-.42***	-.40***	-.62***	-[a]
CMIN			577.27	578.81	616.68	628.54	631.78
CMIN/DEF			2.79	2.73	2.89	2.95	2.97
p			.00	.00	.00	.00	.00
RMSEA			.08	.08	.09	.09	.09
CI for RMSEA			.08, .09	.07, .09	.08, .09	.08, .09	.08, .09
SRMR			.07	.07	.07	.08	.08

Note. p < .001 significance levels, RMSEA, SRMR, ΔX^2 (*df*), DF, CFI, CMIN, CMIN/DEF.

[a] Paths constrained to 0 by model design.

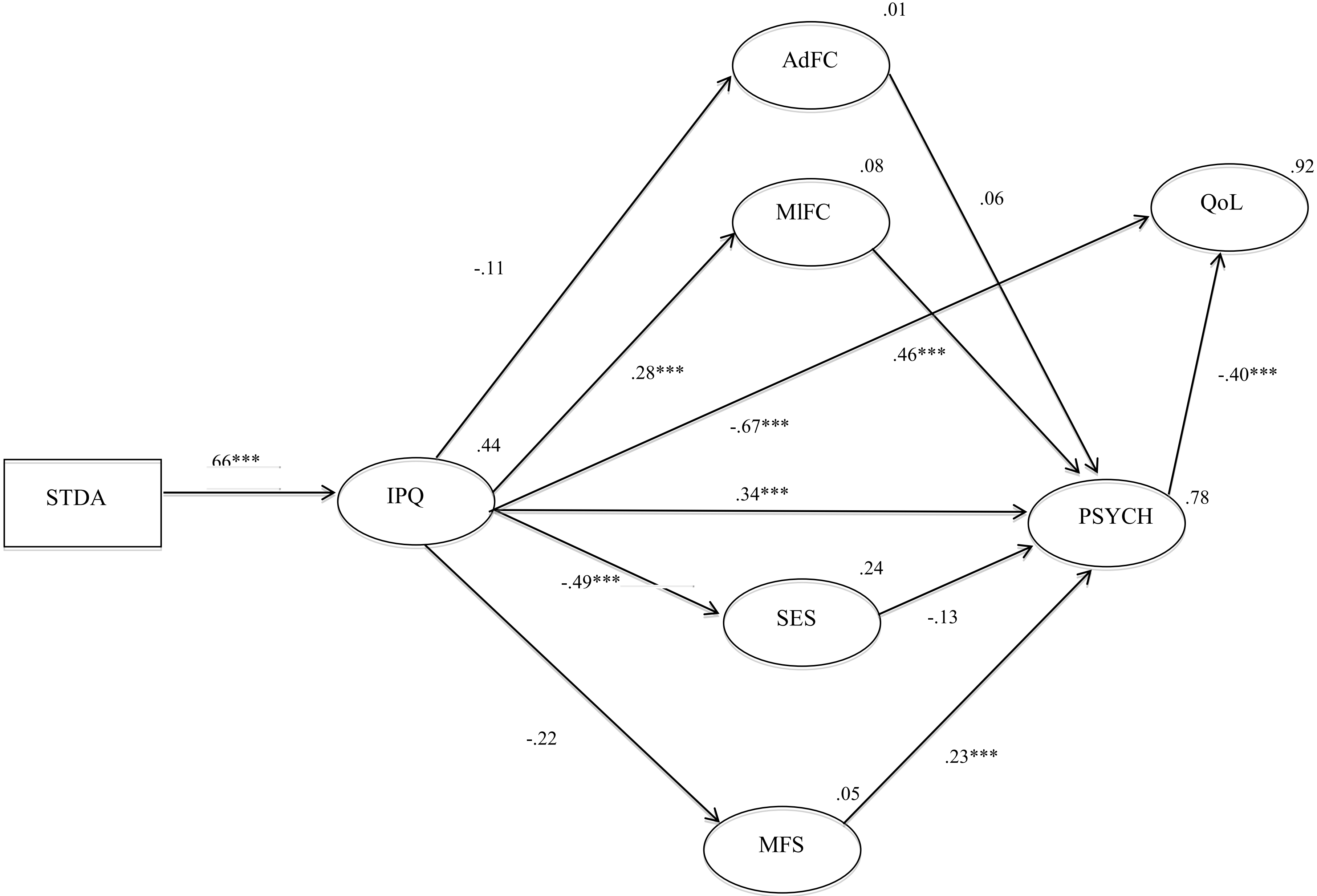

Figure 3.7. The full mediation model supported by the data for STDA activity and psychological distress as mediator to QoL. Note that only latent variables presented with error terms removed. *** *p*< .001

The model of best fit -Model 3, the full mediation model- is shown in Figure 3.7. The model accounted for 44% of the variability of illness perceptions, 78% of psychological distress, 92% of Qol, 24% of self-efficacy, 1% of adaptive coping, 8% of maladaptive coping, and 5% of mindfulness. Disease activity exerted a significant positive effect on illness perceptions ($\beta = .66$, $p < .001$), and illness perceptions has a significant positive effect on psychological distress ($\beta = -.34$, $p < .001$) and Qol ($\beta = -.67$, $p < .001$; see Table 3.33). Illness perceptions were found to exert a significant effect on maladaptive coping ($\beta = .28$, $p < .001$) and self-efficacy ($\beta = -.49$, $p < .001$). Additional significant pathways were found between maladaptive coping and psychological distress ($\beta = .46$, $p < .001$), and mindfulness to psychological distress ($\beta = .56$, $p < .001$). Psychological distress was also found to exert a significant effect on QoL ($\beta = .23$, $p < .001$).

The indirect effects amongst latent variables with QoL as output were once again explored using the bootstrap resampling method. The point estimate for the STDA to psychological distress pathway was .38 with a 90% CI [.29, .46] with a significance of p <.001. The STDA to QoL pathway point estimate was -.59 with a 90% CI [-.69, -.49] at a significance of p <.001. The IPQ to psychological distress point estimate was .24 at 90% CI [.16, .32], and IPQ to QoL, with a point estimate of -.23 at 90 % CI [-.31, -.17], with both pathways at a significance of $p < .001$.

Consistent with the third hypothesis, disease symptom severity did not have a direct influence on psychological distress and QoL, but was mediated by other variables . Illness perceptions was found to mediate the relationship between disease activity and psychological distress, and illness perceptions mediated the relationship between disease activity and QoL.

Consistent with the fourth hypothesis, illness perceptions was found to mediate the relationship between disease symptom severity and coping styles, self-efficacy and mindfulness.

The psychological variables, including coping, self-efficacy, and mindfulness were found to be partial mediating factors in the relationship between illness perceptions and psychological distress and QoL, partially supporting the fifth hypothesis. Inconsistent with expectations psychological distress partially mediated the relationship between illness perceptions and QoL therefore only partially supporting the sixth hypothesis.

4. Chapter 4: Discussion

The aim of the present study was to utilise the framework of the CSM in order to understand the relationships between IBD illness activity, illness perceptions, coping, self-efficacy, and dispositional mindfulness on psychological distress and QoL. To date, there have been very few studies that have explored the efficacy of the CSM within an IBD cohort. Those that have are limited by either methodological flaws or small sample sizes (Dorrian et al., 2009; van der Have 2013; Knowles et al., 2011; Knowles, Cook, & Tribbick, 2013; Knowles, Gass et al., 2013; Rochelle & Fiddler, 2013). Furthermore, no study to date has expanded on the CSM to include other potentially mediating factors, such as self-efficacy or dispositional mindfulness in an IBD cohort. The current research has extended the limited findings by utilising a large sample size and exploring psychological constructs, including self-efficacy, coping and mindfulness within a complete model, and how they influence psychological distress and QoL.

4.1 Review of Hypotheses 1 and 2: Based Upon Correlational Analyses

The following provides a discussion of hypotheses based upon correlational analyses found in Table 3.12 (p.131)

4.1.1 Hypothesis 1: Greater disease activity will be associated with (a) poorer illness perceptions, (b) higher psychological distress, and (c) reduced QoL.

The first hypothesis was supported; results indicated increased disease activity was positively associated with poorer illness perceptions. These relationships were consistent with past research (Dorrian, Dempster, & Adair, 2009; Kiebles, Doerfler, & Keefer, 2010; Knowles, Wilson, Connell & Kamm, 2011; Knowles, Cook, & Tribbick, 2013; Knowles, Gass, & Macrae, 2013; Rochelle & Fidler, 2013; van der Have et al., 2013). These findings suggest that as CD and UC symptom severity increases, so too does the negative perceptions of their illness.

Disease activity was also found to be positively related to psychological distress. These findings add additional support to previous studies (Angelopoulos et al., 1996; Filipovic et.al., 2007; Goodhand et al., 2012; Knowles et al., 2011; Mauder & Levenstein 2008; Mikocka-Walus et al., 2008; Tanaka & Kazuma, 2005). No significant difference was found between the CD and UC groups (see Tables 3.12; 3.13; 3.14) contrary to the findings by Mikocka-Walus et al. (2016) who reported mean anxiety and depression levels to be significantly higher (albeit modestly so) in individuals diagnosed with CD compared to individuals diagnosed with UC.

The relationship between disease activity and psychological distress has demonstrated mixed results in past studies. For example, there have been several studies that have found anxiety and depression to be similar regardless of disease status (Helzer, Chammas, Norland, Stillings, & Alpers, 1984; Robertson, Ray, Diamond, & Edwards, 1989; Vidal et al., 2008). However, according to Mikocka-Walus and colleague's (2016) systematic review, individuals with active disease experience higher levels of anxiety and depression. Additional differences to the present study can be found in early studies by Andrews et al. (1987), Drossman, Leserman, Madeline, Mitchell et al. (1991), and Mikocka-Walus et.al., all of whom reported higher rates of anxiety and depression in CD compared to UC. The differences between the present study's findings and those of previous studies may be due to CD being considered the more severe of the two disease types, with more negative outcomes and multiple complications (Bernstein, Fried et al., 2010; Orchard, Willimas, Tekkis, Goldin, & Goldin, 2011).

The results also identified a significant adverse relationship between disease activity and an individual's QoL, adding additional support to an already thoroughly investigated area (De Boer, Wijker, Bartelsman, & de Haes 1995; Drossman, Lesserman, Zi, Mitchell, Zagmani, & Patrick, 1991; Drossman, Patrick, Mitchell, Zagami, & Appelbaum, 1989;

Engelmann et.al., 2014; Fuast, Halpern, Danoff-Burg, & Cross, 2012; Gray, Denson, Baldassano, & Hommel, 2011; Hjortswang, Strom, & Almer, 1998; Hoivik et al., 2012; Iglesias-Rey et.al., 2014; Irvine et.al 1994; Kunz, Hommel, & Greenley, 2010; Lopez-Vivancos, Casellas, Badia, Vilaseca, & Malagelada, 1999; Nurmi et.al., 2013; Russell et al., 1997; van der Have et.al., 2013). A possible explanation for this strong relationship may be found by examining the QoL construct. Although there are multiple QoL measures used within chronic illness populations (Farmer, Easley, & Farmer, 1991; Guyatt et al., 1989; Irvine, 1993; Patrick & Deyo, 1989), disease specific QoL measures have been found to be the most valid for the IBD population (Guyatt et al., 1989). The IBD QoL measure (IBDQ; Guyatt et al., 1989) has been throughly researched and validated within the IBD population (Cheung et al., 2000; Ciccocioppo et al., 2011; de Boer, Wijker, Bartelsman, & de Haes, 1995; Han, McColl, Steen, Barton, & Welfare, 1998; Kim et al., 1999; Leong, Lee, Ching, & Sung, 2003; López-Vivancos, Casellas, Badia, Vilaseca, & Malagelada, 1999; Pallis, Vlachonikolis, & Mouzas, 2001; Russel et al., 1997). Interestingly the Lichtiger scale (UC) demonstrated a stronger relationship with QoL (-.54) compared to the SCDAI/CD (-.32). This may have been due to the Lichtiger scale containing more items than the short CDAI (three items), which are related and relevant to the items within the IBDQ.

A closer look at the IBDQ reveals a construct that is composed of four subscales; bowel symptoms, systemic symptoms, emotional symptoms and social symptoms. Therefore, both bowel symptoms and disease activity scales are essentially measuring the same factors/symptoms. Even though there are no known studies exploring the LTI and QoL, it is not surprising that it also relates strongly to the IBDQ as it too measures bowel and systemic symptoms, as well as general well-being (i.e., emotional and social influencing factors), such asthe number of daily stools, abdominal pain, and general well being (Lichtiger et al., 1994).

4.1.2 Hypothesis 2: Greater IBD symptom severity will be associated with greater engagement in maladaptive coping and less engagement in adaptive coping.

Consistent with previous research (Hundt et al., 2013; Iglesias-Rey et al., 2013; Van der Zaag-Loonen et al., 2002 & Knowles et al., 2011), support was found for the second hypothesis of this study, where greater disease activity was more strongly associated with individuals utilising maladaptive coping compared to adaptive coping. However, not all past studies have reported finding maladaptive coping strategies as being the most utilised. For example, Lindqvist, Carlsson, and Sjödén (1998), among others (Gurklis & Menke, 1988; Powers, Baldree, & Murphy, 1982), found that patients on haemodialysis were more likely to employ adaptive problem focused coping strategies. This inconsistency in the research may be explained by the disease type and whether the illness is deemed uncontrollable. This supports Lazarus' (1980) suggestion that when an individual perceives their illness to be uncontrollable, their coping resources are limited and are therefore more likely to be maladaptive. Hundt et al. (2013) in their study of COPD patients, suggested that the more severe the disease and the less support one has access to, the more likely the individual will employ maladaptive coping strategies. It is therefore possible that patients receiving dialysis are more likely to receive regular medical support in their treatment, and are therefore less likely to employ maladaptive coping strategies. Other potential explainations for these inconsistencies may include the different coping scales used or the differnces in the items used to represent maladaptive coping.

4.2 Review of Hypotheses 3, 4 and 5: Based Upon SEM

Hypotheses 3, 4 and 5 were assessed based upon a series of SEMs. Prior to the final model being developed (Figure 3.7), a systematic series of statistical tests were undertaken. This included the development of measurement models, individual modelling based upon disease type (i.e., CD, and UC), and primary outcome measure (i.e., psychological distress and QoL). Based on these models, a final model was constructed and evaluated that incorporated both outcome measures with a validated standardised disease activity measure along with illness perceptions, coping styles, self-efficacy, and dispositional mindfulness. The following review of the results (based opon their respectivehypotheses) will be based upon the final model (see Table 3.33, Fig 3.7). However, where relevant, a review of findings from the previous models we used to derive the final model will also be included.

4.2.1 Hypothesis 3: The effect of disease symptom severity on psychological distress and QoL would be fully mediated by other variables (see hypotheses 4-6).

This study found support for the third hypothesis; namely that a direct effect was not found in the relationship between (a) disease activity and psychological distress, and (b) disease activity and QoL (see Figure 3.7). The model that best fit was therefore the full mediation model (see Table 3.33), supporting the findings by Knowles et al. (2011). Full mediation was also reflected in the SEM analysis exploring CD and UC disease activity separately with psychological distress as outcome (see Figures 3.1; 3.3; 3.5). However, when evaluating the SEM analysis where psychological distress and QoL were explored separately, a direct and indirect effect was found in the relationship between disease activity and QoL, suggesting a partial mediated model being the model of best fit (see Figures 3.2; 3.4; 3.6). A possible explanation may be that in order for full mediation to occur, psychological distress as a potential mediator needs to be included.

The final model (Figure 3.7) supports the CSM by Leventhal, Meyer, and Nerenz (1980), which suggests that disease activity or illness stimuli do not have a direct effect on psychological distress or QoL (i.e., illness outcomes; see Figure 1.6, pg.85), but is better explained by mediating factors. Therefore, once an individual is diagnosed with IBD, they are likely to develop illness perceptions relating to their illness and its symptoms, that in turn influence coping strategies that will then determine outcome (Kiebles, Doerfler, & Keefer, 2010; Leventhal, Meyer, & Nerenz, 1980; Llewellyn et al., 2007). Further exploration of the effects illness perceptions have on psychological constructs, coping, self-efficacy, mindfulness, psychological distress, and Qol will be discussed next.

4.2.2 Hypothesis 4: Illness perception mediates the relationship between disease symptom severity and coping, self-efficacy, and mindfulness.

Support was found for the fourth hypothesis that illness perceptions mediate the relationship between disease activity and coping, self-efficacy, and dispositional mindfulness (figure 3.7). This was again supported across all models, whether psychological distress and QoL where assessed separately, or whether CD and UC were tested separately, see Figures 3.3; 3.4; 3.5; 3.6). This mediation adds additional support for the past studies by Knowles et al. (2011) who found that illness perceptions mediated the relationship between disease activity and coping strategies (problem-focused and emotion-focused coping).

A closer exploration of the final SEM model showed that disease activity had a significant direct influence on illness perception ($\beta = .66, p < .001$), adding support to the study by Knowles et al. (2011). Illness perceptions in the current study had a significant direct influence on maladaptive coping ($\beta = .28, p < .001$), again adding support to the study by Knowles et al. who labelled maladaptive coping as emotion-focused coping. Knowles et al. (2013) and Knowles, Tribbick et al. (2014) also found illness perception to strongly influence maladaptive coping ($\beta = .68$ $p < .001$; $\beta = .72$, $p < 0.001$ respectively). A difference was, however, found in the relationship between illness perceptions and adaptive (problem-focused) coping. According to the current study, a negative weak influence on adaptive coping was found ($\beta = -.12, p < 0.001$). However, according to Knowles et al. (2011), a significant positive influence on problem-focused (adaptive) coping was found ($\beta = .36, p <$

.001). A significant positive influence on adaptive coping (i.e., emotion-focused coping) (β =.47, $p < .001$) was also found in the study by Knowles et al. (2014). These contradictions were unexpected, as both studies utilised the same measures, namely, the Brief COPE (Carver, 1997) and the BIPQ (Broadbent, Petrie, Main, & Weinman, 2006). A likely explanation for these inconsistencies may lie in the limited small sample used by the authors (Knowles, Tribbick et al., 2014; Knowles et al., 2013; Knowles et al., 2011). Another possible explanation for the inconsistencies may have been the result of the different factors emerging from the current study's factor analyses (i.e., in that different items comprised the factors in the current study).

Additional support for the present study's findings comes from Folkman and Lazarus (1980), who suggested that an individual is more likely to employ emotion-focused coping (maladaptive) over problem-focused (adaptive) coping strategies when they are confronted with a health problem that is appraised as uncontrollable. This explanation is further supported by Felton and Revenson (1994), who suggested the perception of controllability determines which coping strategy will be utilised to either alleviate the emotional distress or address the problem directly. In the current study, correlational analyses also demonstrated a strong positive relationship between illness perceptions and maladaptive coping, and a weak negative correlation with adaptive coping. Rochelle and Fidler (2013) also found that when individuals with IBD perceive their illness as having serious consequences (i.e., poorer illness perception), they are more likely to utilise maladaptive coping, which in turn contributed to anxiety and depression. These findings add additional support to the present study.

Unfortunately, there are no known studies exploring the relationship or mediating effect of illness perceptions to self-efficacy within the IBD population. Few studies have explored these relationships within the chronic illness literature (e.g., Bean, Cundy & Petrie, 2007; Bonsakaksen, Lerdal, & Fagermoen, 2012; Griva, Myers, & Newman, 2000; Schüz, Wurm, Warner, & Ziegelmann, 2012). For example, Griva, Myers, and Newman (2000) in their study exploring treatment adherence in 64 insulin-dependent adolescents and young adults, found that identity, control, and consequences of illness perceptions were significantly correlated with self-efficacy expectations. The study by Griva and colleagues (2000), however, is limited in its exploration of the mediation role of illness perceptions and self-efficacy within the CSM, therefore making a comparison challenging. No known studies – neither investigating IBD or other chronic illness – have explored the influence illness perceptions have on dispositional mindfulness.

The results of the present study also confirm the importance of illness perceptions reported in previous research (Arran et al., 2014; Borge et al., 2014; Dorrian et al., 2009; Kiebles et al., 2010; Knowles et al., 2011; Knowles, Swan et al., 2014; Knowles, Cook et al., 2013; Knowles, Gass et al., 2013; McCorry et al., 2103; Pachalidis et al., 2004; van der Have et al., 2013). The findings also reinforce the importance of the emotional and behavioural regulators within the CSM, and the influence illness perceptions have on coping styles (Dorrian et al., 2009; Hagger & Obber, 2003; Knowles et al., 2011; Knowles, Gass, et al., 2013; McCorry et al., 2013). In summary, once an individual develops a perception about their illness or symptoms, in line with Leventhal and colleague's (1980) CSM, they will then likely employ coping strategies (adaptive or maladaptive) in order to reduce the threat imposed by their illness perceptions or regulate the emotions surrounding the threat, which can have either a positive or negative outcome.

4.2.3 Hypothesis 5: Coping styles (adaptive and maladaptive coping), self-efficacy, and dispositional mindfulness would mediate the relationships between illness perceptions, psychological adjustment, and QoL.

Partial support was found for the hypotheses that coping styles, self-efficacy, and dispositional mindfulness would mediate the relationship between illness perceptions and (a) psychological distress and (b) QoL. Both a direct and indirect effect was found in the relationship between illness perception, and psychological distress and QoL (see figure 3.7). These results were found across all of the models tested, including when psychological distress or QoL were separately assessed or when exploring CD and UC disease activity, individually (see Figures 3.3; 3.4; 3.5; 3.6). These findings add support to the mediating relationships reported by Knowles et.al. (2011), Knowles, Cook et al. (2013), Knowles, Gass et al. (2014), Knowles, Swan et al. (2014) and Rochelle and Fiddler (2013), who also found that coping strategies mediated the relationships between illness perceptions, psychological distress, and QoL. No mediating relationship, however, was found in the studies by Dorrain et al. (2009) and van der Have et al. (2013). These contrasting findings may have been due to the studies by Dorrian et al. and van der Have et al. utilising hierarchical regression rather than SEM or a using a smaller sample size. Although the authors reported their use of COPE scale (Carver et al., 1989) as being a factor in not finding mediation (see section 1.11.3, p. 92), this is unlikely given the mediating effects found in Knowles and colleague's (2011) study using the Brief COPE.

The direct relationship between illness perceptions and outcome (psychological distress and QoL) has also been validated in several studies, both in IBD (Knowles, Cook, & Tribbick, 2013; Knowles, Gass et al., 2013; Knowles, Swan et al., 2014; Rochelle & Fiddler, 2013; van der Have et.al., 2013) and other chronic illnesses (Arran et al., 2014; Rassart et al., 2014; Rozema et al., 2009). Another possible explanation for the inconsistencies in the research may be that that there is both a direct and indirect relationship between illness perception and outcome. This may be explained by Leventhal and colleague's (1980) CSM (see Figure 1.6, p.85), which illustrates the dual pathways.

Besides the current study, no other known IBD study has explored self-efficacy or dispositional mindfulness as potential mediating factors in the relationships between illness perceptions, psychological distress, and QoL. A study by Phillips and McAuley (2014) did, however, find self-efficacy to mediate the relationship between physical activity and QoL in individuals diagnosed with breast cancer. Although no past studies have tested the mediating effects of self-efficacy within an IBD sample, there are several chronic illness studies exploring self-efficacy and its influence on reducing psychological distress (Benka et al., 2014), increasing treatment compliance and self-management (Curtin et al., 2008; Iannotti et al., 2006), and improved QoL (Andenæs et al., 2014; Kit-Man Wu, Pak-Chun Chau, & Twinn, 2007; Phillips & McAuley, 2014). Of the limited IBD studies, Friedman et al. (2014) found that high self-efficacy predicted adherence to surveillance colonoscopy in participants with IBD, while Zijlstra et al. (2013) explored self-efficacy in regards to transitional care from paediatric care to adolescent symptom self-management (also in IBD patients).

There have been no known studies exploring dispositional mindfulness as a potential mediator in the relationship between illness perceptions and psychological distress or QoL. To the author’s knowledge, no previous study has explored dispositional mindfulness within the CSM in any chronic illness population. There has, however, been one study exploring the relationship of dispositional mindfulness and IBD (Jedel.et.al., 2013). Jedel et al. (2013) explored dispositional mindfulness in both asymptomatic and symptomatic UC. Following a mindfulness-based intervention for IBD, the researchers found that asymptomatic individuals who scored higher on mindfulness reported reduced perceived stress scores, anxiety and depression, and an improvement in QoL. However, in the symptomatic group, the authors found a weaker relationship, where mindfulness scores were only significantly inversely correlated to perceived stress scores. Jedel et al. explained that this difference may be due to differences in the self-report ratings in the domain of attention/awareness among IBD patients compared to patients with other chronic illnesses. Overall, there have been few studies that have explored dispositional mindfulness in other chronic illness conditions (e.g., Brown &

Ryan, 2003; Salmoirago-Blotcher, Crawford, Carmody, Rosenthal, & Ockene, 2011). In these studies, individuals who scored higher score in dispositional mindfulness also reported lower anxiety, depression, and stress scores.

Although not tested in the present study, there have been several studies within the chronic illness literature that report benefits of a mindfulness-based stress reduction program, such as reduced psychological distress and improved QoL (e.g., Brown, Ryan, & Creswell, 2007; Grossman et al., 2004; Hodgins & Adair, 2010; Moore & Malinowski, 2009). Similar benefits of mindfulness-based stress reduction programs have been reported for IBD patients (Jedel et al., 2014; Langhorst et al., 2007; Neilson et al., 2015).

4.2.4 Hypothesis 6: Psychological adjustment would mediate the relationship between illness perceptions and QoL.

Partial support was found for the sixth hypothesis, where psychological distress mediated the relationship between illness perceptions and QoL. The final model (see Figure 3.7) suggested that a direct relationship existed between illness perceptions and QoL, as was found in previous models (see Figures 3.4 & 3.6). These models suggest that once an individual formulates an illness representation or perception about their illness, they will experience a level of psychological distress that will then affect their QoL. Although there has not been any previous known research within the IBD or other chronic illness populations exploring the CSM where psychological distress was considered to be a mediator to QoL, there are a number of studies that support the relationship between psychological distress and QoL in an IBD population (e.g., Blondel-Kucharski et al., 2001; Drossman et al., 1989; Graff et al., 2006; Guthrie et al., 2002; Hjortswang et al., 2003). This strong relationship may also be influenced by the construct of the QoL scale (IBDQ; Guyatt et al., 1989), as it contains an emotional functioning subscale (anger, depression, irritability). The mediating effect of psychological distress implies that in order to improve an individual's QoL, psychological therapies aimed at reducing psychological distress are important for IBD patients.

4.3 Limitations and Future Studies

A number of methodological limitations were present in the following study. Although a sample size of 261 is the largest known sample to date to explore the present models, a larger sample would provide additional statistical power and allow the results to be more generalisable – particularly beyond treatment-seeking populations, as all participants were recruited from a specialist treatment clinic and CCA members group. A larger sample size would also add the benefit of exploring the differences between active and non-active disease states. Another potential limitation in the present study includes challenges faced with the inability to utilise the full CDAI, as specific information regarding haematocrit and previous body weight were not provided. Problems also arose with the online coding of item four of the CDAI that offered the option of multiple complicating factors in CD disease activity. Although these limitations limited the effectiveness in utilising the CDAI, the Short CDAI (Thia et al., 2011) was a statistically suitable and valid replacement in the analysis. An additional limitation involved the revision of several scales based on statistical prudence. This meant that the validity and reliability of these revised scales were relevant only to the current cohort being assessed. Future studies would require to replicate the current research findings.

Limitations also include the use of the MASS, which raises the questions around the measurement of mindfulness, either as a disposition (i.e., trait-like) or a skill (i.e., more state-like) that is malleable to mindfulness-based interventions. To the author's knowledge, there has been only one other study that has explored dispositional mindfulness within an IBD population (Jedel et al., 2013). An additional limitation regarding exploring mindfulness included not asking which individuals were or have been practising mindfulness-based practices (e.g., MBSR) that may have influenced the MAAS score.

As this treatment-seeking sample completed survey questionnaires using different methods (i.e., hardcopy versus online), the homogeneity of the sample is questionable. For example, the regional locations of the participants in Australia is not known. Finally, the present study was limited in using the IPQ-Brief (Broadbent, Petrie, Main & Weinman, 2006) rather that the IPQ-R (Moss-Morris et al., 2002), which would have enabled more in-depth exploration of the effect the five illness perceptions subscales had on each of the mediators and outcomes.

Additional limitations include not testing for pain, psychotropic or IBD treatment medication use, or including biological data; for example, the inclusion of faecal calprotectin and lactoferrin testing would also be a valuable indicator utilised in measuring disease activity (Sipponen et.al., 2008; Van Rheenen, Van de Vijver, & Fidler, 2010). Nor was anxiety, depression, and stress evaluated separately within SEMs. The main reason for this involved the likely complications arising from splitting outcome variables, which require an even larger sample size (e.g., reduced statistical power).

The current study explored the CSM within a cross-sectional approach, which unfortunately is limited due to it only capturing a brief moment in time and not allowing to make causal inferences about the relationships identified in the present study. Therefore true mediation cannot be determined. Future studies would benefit from utilising a longitudinal approach, given that the symptom severity of IBD is prone to fluctuation, and overall, due to the disease complexity. Future studies could also benefit from undertaking and comparing an international sample to test for cultural differences.

Additional extension of the CSM could also incorporate other psychological factors found to be valuable in chronic illness studies; for example, social support Marquez et al., 2016), locus of control (as locus of control relates to self-efficacy; Judge et al., 2002), and other clinical variables like age of IBD onset (as impact is reported as greater at a younger age; Kelsen & Baldassano, 2008). Exploration of personality differences would also add value, as neuroticism in RA has been shown to affect overall psychological adjustment (Suurmeijer et al., 2005).

Future studies could also examine the model using different scales, for example using a more thoroughly published scale for UC like the Simple Ulcerative Colitis Disease Activity Index (Walmsley, Ayres, Pounder & Allan, 1998). The addition of endoscopy disease activity index (Mary & Modigliani, 1989) may also lead to valuable extensions of the models reported in the present study.

Although the COPE and Brief Cope have been utilised within a clinical IBD population (e.g., Iglesias-Rey et al., 2013; Knowles, Cook, et al., 2013), future studies may choose to explore the CSM and coping utilising the more disease specific scales, for example, the recent IBD coping scale developed by McCombie et al. (2016) and the newly developed IBD self-efficacy scale (Keefer, Kiebles, & Taft, 2011).

4.4 Implications for Treatment

Results in the present study highlight the importance of the CSM when considering psychological and behavioural treatments in helping individuals with IBD better understand their condition, cope with the disease, reduce their associated psychological distress, and improve their QoL. The recent study by Mikocka-Walus, Pitett et al. (2016) highlights the importance of reducing psychological distress in IBD, as anxiety and depression were found to increase the likelihood of disease re-occurrence. Therefore, not only is reducing psychological distress important in improving QoL, but also for reducing the likelihood of disease progression and physical complication that can arise in IBD.

The CSM in the present study, and in previous studies (Dorrian et.al., 2009; Hagger and Orbell, 2003; Knowles et al., 2011; Knowles, Cook, & Tribbick, 2013; Knowles, Gass, et al., 2013; Knowles, Swan et al., 2014; Rochelle & Fiddler , 2013; van der Have et al., 2013) highlights the importance of illness perceptions and its implications on outcome (i.e., psychological distress and QOL both directly, and via the mediators of coping, self-efficacy and mindfulness). Of all these findings, illness perceptions have been found to have a significant influence on psychological outcomes. No known treatment study has focused directly on changing illness perceptions within an IBD population. However, other chronic illness studies have explored interventions aimed at changing illness perceptions in order to improve treatment compliance. For example, Broadbent and colleague's (2009) developed a brief in-house illness perception intervention program for individuals with acute myocardial infarction. The four half-hour sessions were aimed at improving education and changing illness perceptions, and it was discovered that this simple intervention resulted in: improved treatment compliance; a quicker return to work; less reporting of angina symptoms; and a more optimistic outlook on the future. A similar program could be developed to help individuals diagnosed with IBD, as treatment compliance has also been found to be challenging (Horne, Parham, Driscoll & Robinson, 2009).

CBT or mindfulness-based therapies (e.g., MBSR) have been found to be useful therapeutic interventions aimed at challenging irrational beliefs, reducing maladaptive-focused coping (avoidance behaviours) and psychological distress, and improving QoL in IBD, and may therefore be considered to be helpful in challenging negative illness perceptions (Mikocka-Walus, Andrews, & Bampton, 2016). The present study also reinforced the importance of considering coping strategies that are utilised by individuals diagnosed with IBD. Maladaptive coping has been shown in the present study to be highly correlated with disease activity, and in other studies, to contribute to psychological distress and reduced

QoL (Allman et al., 2009; Hundt et al., 2013; Iglesias-Rey et al., 2013; Kinash et al., 1993; Knowles, Cook et al., 2013; McCombie, Mulder, & Gearry., 2012; van der Zaag-Loonen et al., 2002). Therefore, psychological treatments such as CBT and MBSR aimed at helping individuals to reduce maladaptive coping strategies (e.g., self-blame, substance use) and to develop more problem-solving and adaptive emotional-coping strategies, may help these individuals to better regulate their emotions and distress.

The findings of the present study also highlight the importance of increasing self-efficacy in order to reduce psychological distress and improve QoL in people with IBD. Self-efficacy is related to locus of control, self-esteem, empowerment, self-management, effort, resilience, and perseverance; all of which characterises an individual's behaviour in adverse situations (Curtin et al., 2008; Judge et al., 2002; Kreitler et al., 2007). However, self-esteem remains a relatively new construct to be studied within an IBD population, even though it has been found to assist in reducing psychological distress and improve health outcomes in other chronic illnesses (Andenæs et al., 2014; Curtin et al., 2008; Benka et al., 2014; Kit-Man Wu et al., 2007; Phillips & McAuley, 2014). Self-efficacy has also been considered to be vital to treatment compliance in patients diagnosed with Type 1 diabetes (Iannotti et al., 2006) and IBD (Friedman et al., 2014), including in the transition from paediatric care to symptom self-management in adolescents diagnosed with IBD (Fishman et al., 2010). It would therefore be expected that improving the self-efficacy of IBD patients would be beneficial. Interventions shown to enhance self-efficacy in other chronic illnesses (Curtin et al., 2008) that may be useful in an IBD population include goal-setting, problem-solving, education, and self-management. One such intervention was carried out by Kim et al. (2007), who reported improved self-efficacy in 21 colostomy bag patients. The intervention involved increasing vicarious experience of the individual through a compact disk program, incorporated verbal persuasion through telephone and education coaching, and through these procedures, enhanced the patients' self-care behaviours and psychosocial adaptation.

The present study also offer support for the potential benefit of mindfulness in reducing psychological distress and improving QoL. Again, there have been studies exploring the positive effects of MBSR on reducing psychological distress and improving QoL in IBD (see Section 1.8.2), however, no study has assessed the influence these interventions have on improving dispositional mindfulness.

In summary, the present study suggests that, for individuals who score high in illness perceptions, maladaptive coping, and psychological distress, they may benefit from interventions aimed at changing illness perceptions, reducing maladaptive coping strategies, improving self-efficacy, and introducing MBSR exercises in order to reduce psychological distress and improve QoL.

4.5 Conclusion

The present study has addressed several limitations within the IBD literature, including small sample sizes, exploring individuals with CD or UC separately, and the limited contextualising of self-efficacy and mindfulness within the CSM. The present study has extended on the research surrounding the CSM and IBD by: (1) utilising the largest known sample size of participants with IBD in this topic of research (*N* = 261), and (2) assessing both CD and UC individuals, separately, in the analyses; and (3) extending the CSM to include self-efficacy, mindfulness, and the relationships between psychological distress and QoL. Disease activity was found to be associated with higher levels of psychological distress and reduced QoL. Poorer illness perceptions were found to be significantly related to maladaptive, but not adaptive, coping styles. Several mediation pathways explaining the relationships between these variables were also found. A full mediation model better explained the relationship between disease activity, and psychological distress and QoL. Illness perceptions were found to be important mediators in the relationship between disease activity, and psychological distress and QoL. Partial mediation was found between illness perceptions and outcomes (i.e., psychological distress and QoL), and psychological distress was found to partially mediate the relationship between illness perceptions and QoL.

In conclusion, the present study highlights the benefits of using a multidimensional model of psychological adjustment in IBD care. Benefits include being able to guide alternative psychological and behavioural treatment options (CBT or MBSR) aimed at changing illness perceptions through education, aiding treatment compliance, transitional care, as well as helping sufferers to reduce their use of maladaptive strategies and instead employ more adaptive coping strategies to reduce psychological distress, and ultimately, improve their QoL. In combination with previous research, the findings of the present study suggest that the CSM may add additional value in helping improve the self-efficacy of IBD patients through programs aimed at: (1) increasing vicarious experience, (2) incorporating verbal persuasion, and (3) build performance accomplishments by incorporating mindfulness practices to reduce psychological distress (as has recently been suggested to negatively influence disease reoccurrence; Mickoka-Walus, Pittet et al., 2016).

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Appendix A

Ethics Approvals

From: RESEARCH Ethics [Research.ETHICS@svhm.org.au]
Sent: Wednesday, 16 January 2008 9:31 AM
To: Kantidakis, Jim
Cc: Simon Knowles
Subject: HREC-A 101/07

Dear Jim,

Thank you for your request to change members of the research team dated 7th January 2008, received in the Research and Grants Unit on 15 January 2008.

Changes have been made to the following study/ies:

PROTOCOL number: ***HREC-A 101/07***

Title: ***'Impact of cognitive appraisal perceived stress and quality of life in those with IBD.'***

The following personnel have been added to the research team: Dr. Steven Brown

This approval also includes:

Participant Information and Consent Form **("Information Sheet")** dated 28/12/07.

Kind Regards,

Ms. Jane Carolan

B.Med.Sci (USyd)

Secretary- HREC A

Research and Grants Unit

SVH (Wed-Fri)

Ph: x3924

Attachments area
Preview attachment noname.eml

From: Keith Wilkins <kwilkins@swin.edu.au>
To: Simon Knowles <sknowles@swin.edu.au>, "daosborne@kpmg.com.au" <daosborne@kpmg.com.au>, "daccord@westnet.com.au" <daccord@westnet.com.au>
Cc:
Date: Tue, 2 Oct 2007 00:17:53 +0000
Subject: SUHREC Project 0708/064 Ethics Clearance
To: Dr Simon Knowles/Ms Debra Osborne/Mr Jim Kantidakis, FLSS

Dear Simon, Debra and Jim

SUHREC Project 0708/064 Impact of cognitive appraisal on perceived stress and quality of life in those with IBD
[Related to St Vincent's Hospital HREC Project HREC-A 101/07]
Dr S Knowles FLSS Ms Debra Osborne Mr Jim Kantidakis et al
Approved Duration: 02/10/2007 To 28/04/2008

I refer to the ethical review of the above project protocols undertaken by Swinburne's Human Research Ethics Committee (SUHREC). Your responses to the review, as emailed on 28 September 2007 with revised consent and survey instruments attached, were put to a delegate of SUHREC for consideration. I also acknowledge receipt of further documentation separately received in my office on 28 September, including updated information submitted to St Vincent's Hospital HREC-A.

Subject to evidence of ethics clearance from St Vincent's Hospital (as applicable), I am pleased to advise that on-going Swinburne ethics clearance has been given for the project to proceed in line with standard conditions here outlined. Evidence of the Swinburne clearance may need to be communicated to St Vincent's Hospital HREC-A.

- All human research activity undertaken under Swinburne auspices must conform to Swinburne and external regulatory standards, including the current National Statement on Ethical Conduct in Research Involving Humans and with respect to secure data use, retention and disposal.

- The named Swinburne Chief Investigator/Supervisor remains responsible for any personnel appointed to or associated with the project being made aware of ethics clearance conditions, including research and consent procedures or instruments approved. Any change in chief investigator/supervisor requires timely notification and SUHREC endorsement.

- The above project has been approved as submitted for ethical review by or on behalf of SUHREC. Amendments to approved procedures or instruments ordinarily require prior ethical appraisal/ clearance. SUHREC must be notified immediately or as soon as possible thereafter of (a) any serious or unexpected adverse effects on participants and any redress measures; (b) proposed changes in protocols; and (c) unforeseen events which might affect continued ethical acceptability of the project.

- At a minimum, an annual report on the progress of the project is required as well as at the conclusion (or abandonment) of the project.

- A duly authorised external or internal audit of the project may be undertaken at any time.

Please contact me if you have any queries about on-going ethics clearance. The SUHREC project number should be quoted in communication.

Best wishes for the project.

Yours sincerely

Keith Wilkins
Secretary, SUHREC
****
Keith Wilkins
Research Ethics Officer
Swinburne Research (H68)
Swinburne University of Technology
P O Box 218
HAWTHORN VIC 3122
Tel: 9214 5218

From: Keith Wilkins <kwilkins@swin.edu.au>
To: Simon Knowles <sknowles@swin.edu.au>, "daosborne@kpmg.com.au" <daosborne@kpmg.com.au>, "daccord@westnet.com.au" <daccord@westnet.com.au>
Cc:
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Yours sincerely

Keith Wilkins
Secretary, SUHREC
****
Keith Wilkins
Research Ethics Officer
Swinburne Research (H68)
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P O Box 218
HAWTHORN VIC 3122
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StV

Research and Grants Unit
Ph: (03) 9288 3930 Fax: (03) 9288 3205

Tuesday, 22 January 2008

Dr S Knowles
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ABN 64 074 683 748
Prague House Limited
ABN 17 066 184 585

Dear Dr Knowles

Protocol No: HREC-A 101/07

'Impact of cognitive appraisal perceived stress and quality of life in those with IBD.'

Dr S Knowles	**Dr W Connell**	**Dr J Wilson**	**Ms D Osborne**
Mr J Kantidakis	**Prof M Kyrios**	**Dr S Brown**	

The Human Research Ethics Committee-A (HREC-A) has granted final approval to the following amendment:

> Letter dated 07/01/08 from Associate Researcher Jim Kantidakis submitting an alteration to the protocol's Questionnaire. Modifications include the addition of the Lichtiger Scale in section 15 and some rephrasing of question 4 in section2.

This approval will be noted by the full Human Research Ethics Committee - A at its next meeting on Wednesday 06 February 2008.

There will be no further correspondence regarding this amendment unless a member of the HREC-A raises a concern at that meeting.

The conditions of approval of this amendment are the same as those governing approval of the original protocol.

Yours sincerely

Jacqui Ryan

Ms Jane Carolan
Secretary, Human Research Ethics Committee-A

Appendix B

Questionnaire Pack

Impact of cognitive appraisal perceived stress and quality of life in those with Inflammatory Bowel Disease (IBD).

Investigators: Dr. Simon Knowles, Dr. William Connell, Dr. Jarrad Wilson, Dr Steven Brown, Prof. Mike Kyrios, Jim Kantidakis, and Debra Osborne.

Each component of the questionnaire is slightly different. You will be asked to either circle or tick the most appropriate answer, or rate answers on a graded scale. Please ensure that you've answered every question

EXAMPLE

This question has a graded response ranging from none of the time to all of the time. After reading the question carefully, **cross out (or tick)** the answer which best describes how you have been feeling over the past two weeks.

How often have you felt unwell as a result of your bowel problem in the past two weeks?

☐ All of the time
☐ Most of the time
☐ A good bit of the time
☒ Some of the time
☐ A little of the time
☐ Hardly any of the time
☐ None of the time

If you are having trouble understanding a question, STOP for a moment and think about what the question means to you. Please note there are no right or wrong answers, and you should simply give the answer that seems most appropriate.

Please return the questionnaires in the stamped, pre-addressed envelope provided.

Thank you in advance.

Please note this questionnaire is printed on both sides.

SECTION 1 Demographic Information

What is the postcode where you live? ☐☐☐☐	**Your age?** (nearest whole year) ☐☐
Gender? ☐ Male ☐ Female **Number of dependents?** ☐	**Marital Status?** ☐ Single ☐ Married ☐ DeFacto ☐ Separated ☐ Divorced ☐ Widowed
Who do you live with? ☐ Alone ☐ Partner ☐ Parents ☐ Friend(s)	
What country are you from? ________________________	
What is your ethnic background? ________________________	
Working?	☐ No ☐ Yes ☐ Full-time ☐ Part-time Occupation: ________________________

SECTION 2 Disease Activity

Please answer all of the following questions.

1. **Number of liquid or very soft stools in the last 24 hours:**
   ____

2. **Abdominal pain in the last 24 hours:**
   None ☐
   Mild ☐
   Moderate ☐
   Severe ☐

3. **General well being in the last 24 hours, compared to a healthy person:**
   Generally well ☐
   Slightly under par ☐
   Poor ☐
   Very poor ☐
   Terrible ☐

4. **Have you taken antidiarrheal medication (e.g., Lomotil or Imodium) in the last 24 hours?**
   Yes ☐
   No ☐

5. **Have you had a fever over the past week?**
   Yes ☐
   No ☐

6. Current Height: _______________

7. Current Weight: _______________

8. Identify what medications and the dosage you are currently taking:

Medications	***Dose***	***Medications***	***Dose***
Prednisolone		6MP	
Budesonide		Methotrexate	
5ASA		Cyclosporine	
Topical steroids		Infliximab	
Topical steroids		Enteral feeding	
Antibiotics		TPN	
Azathioprine		Other	

9. **What year were you first diagnosed with IBD?** ________________________

10. **In what year did your symptoms first appear?** ________________________

11. If you have been symptom free, how long has this been for (in months)?

____

12. What type of IBD have you been diagnosed with?
Crohn’s Disease☐ Ulcerative Colitis ☐

SECTION 3 Illness Beliefs

For the following questions, please tick the number that best corresponds to your views.

	0	1	2	3	4	5	6	7	8	9	10
1. How much does your illness affect your life?	**No affect at all** ☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	**Severely affects my life** ☐
2. How long do you think your illness will continue?	**A very short time** ☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	**Forever** ☐
3. How much control do you feel you have over your illness?	**Absolutely no control** ☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	**Extreme amount of control** ☐
4. How much do you think your treatment can help your illness?	**Not at all** ☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	**Extremely helpful** ☐
5. How much do you experience symptoms from your illness?	**No symptoms at all** ☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	**Many severe Symptoms** ☐
6. How concerned are you about your illness?	**Not at all concerned** ☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	**Extremely concerned** ☐
7. How well do you feel you understand your illness?	**Don't understand at all** ☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	**Understand very clearly** ☐
8. How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)	**Not at all affected emotionally** ☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	**Extremely affected emotionally** ☐

SECTION 4 Self-Efficacy

For the following questions, please tick the box that best corresponds to your views.

	1 Strongly Disagree	**2**	**3**	**4**	**5 Strongly Agree**
1. I will be able to achieve most of the goals that I have set for myself.	☐	☐	☐	☐	☐
2. When facing difficult tasks, I am certain that I will accomplish them.	☐	☐	☐	☐	☐
3. In general, I think that I can obtain outcomes that are important to me.	☐	☐	☐	☐	☐
4. I believe I can succeed at most any endeavor to which I set my mind.	☐	☐	☐	☐	☐
5. I will be able to successfully overcome many challenges.	☐	☐	☐	☐	☐
6. I am confident that I can perform effectively on many different tasks.	☐	☐	☐	☐	☐
7. Compared to other people, I can do most tasks very well.	☐	☐	☐	☐	☐
8. Even when things are tough, I can perform quite well.	☐	☐	☐	☐	☐

SECTION 5 Social Support

For the following questions, please tick the box that best corresponds to your views.

	1 Very strongly Disagree	2	3	4	5	6	7	8	9	10 Very strongly agree
1. My friends, family and spouse give me the emotional support I need.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
2. I share my joys and sorrows with my friends, family and spouse.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
3. I can talk about my personal problems with my friends, family and spouse.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
4. I can talk about my work problems with my friends, family and spouse.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
5. My friends, family and spouse are a real source of comfort to me.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
6. My friends, family and spouse are willing to help me make decisions.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
7. I can count on my friends, family and spouse to help me when things go wrong.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

SECTION 6 Psychological well-being

Please read each of the following statement and indicate how much the statement applied to you **over the past week**.

	Did not apply to me at all	**Applied to me to some degree or some of the time**	**Applied to me a considerable degree or a good part of the time**	**Applied to me very much or most of the time**
1. I found it hard to wind down.	☐	☐	☐	☐
2. I was aware of dryness of my mouth.	☐	☐	☐	☐
3. I couldn't seem to experience any positive feeling at all.	☐	☐	☐	☐
4. I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion).	☐	☐	☐	☐
5. I found it difficult to work up the initiative to do things.	☐	☐	☐	☐
6. I tended to over-react to situations.	☐	☐	☐	☐
7. I experienced trembling (e.g. in the hands).	☐	☐	☐	☐
8. I felt that I was using a lot of nervous energy.	☐	☐	☐	☐
9. I was worried about situations in which I might panic and make a fool of myself.	☐	☐	☐	☐
10. I felt that I had nothing to look forward to.	☐	☐	☐	☐
11. I found myself getting agitated.	☐	☐	☐	☐
12. I found it difficult to relax.	☐	☐	☐	☐
13. I felt down-hearted and blue.	☐	☐	☐	☐
14. I was intolerant of anything that kept me from getting on with what I was doing.	☐	☐	☐	☐
15. I felt I was close to panic.	☐	☐	☐	☐
16. I was unable to become enthusiastic about anything.	☐	☐	☐	☐
17. I felt I wasn't worth much as a person.	☐	☐	☐	☐
18. I felt that I was rather touchy.	☐	☐	☐	☐
19. I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat).	☐	☐	☐	☐
20. I felt scared without any good reason.	☐	☐	☐	☐
21. I felt that life was meaningless.	☐	☐	☐	☐

SECTION 7	**Coping styles**

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. The following scale asks you to indicate **what you generally do and feel when you experience stressful events.** Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress. Please tick the most appropriate response for each statement.

	I haven't been doing this at all	**I've been doing this a little bit**	**I've been doing this a medium amount**	**I've been doing this a lot**
1. I've been turning to work or other activities to take my mind off things.	☐	☐	☐	☐
2. I've been concentrating my efforts on doing something about the situation I'm in.	☐	☐	☐	☐
3. I've been saying to myself "this isn't real".	☐	☐	☐	☐
4. I've been using alcohol or other drugs to make myself feel better.	☐	☐	☐	☐
5. I've been getting emotional support from others.	☐	☐	☐	☐
6. I've been giving up trying to deal with it.	☐	☐	☐	☐
7. I've been taking action to try to make the situation better.	☐	☐	☐	☐
8. I've been refusing to believe that it has happened.	☐	☐	☐	☐
9. I've been saying things to let my unpleasant feelings escape.	☐	☐	☐	☐
10. I’ve been getting help and advice from other people.	☐	☐	☐	☐
11. I've been using alcohol or other drugs to help me get through it.	☐	☐	☐	☐
12. I've been trying to see it in a different light, to make it seem more positive.	☐	☐	☐	☐
13. I’ve been criticizing myself.	☐	☐	☐	☐
14. I've been trying to come up with a strategy about what to do.	☐	☐	☐	☐
15. I've been getting comfort and understanding from someone.	☐	☐	☐	☐
16. I've been giving up the attempt to cope.	☐	☐	☐	☐
17. I've been looking for something good in what is happening.	☐	☐	☐	☐
18. I've been making jokes about it.	☐	☐	☐	☐
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	☐	☐	☐	☐
20. I've been accepting the reality of the fact that it has happened.	☐	☐	☐	☐
21. I've been expressing my negative feelings.	☐	☐	☐	☐
22. I've been trying to find comfort in my religion or spiritual beliefs.	☐	☐	☐	☐
23. I’ve been trying to get advice or help from	☐	☐	☐	☐

	I haven't been doing this at all	**I've been doing this a little bit**	**I've been doing this a medium amount**	**I’ve been doing this a lot**
other people about what to do.				
24. I've been learning to live with it.	☐	☐	☐	☐
25. I’ve been thinking hard about what steps to take.	☐	☐	☐	☐
26. I’ve been praying or meditating.	☐	☐	☐	☐
27. I’ve been making fun of the situation.	☐	☐	☐	☐
28. I’ve been blaming myself for things that happened.	☐	☐	☐	☐

SECTION 8 Depression

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the **past week** by ticking the appropriate boxes.

	Rarely or none of time (less than 1 day)	**Some or a little of the time (1-2 days)**	**Occasionally or a moderate amount of time (3-4 days)**	**Most or all of the time (5-7 days)**
1. I was bothered by things that usually don't bother me.	☐	☐	☐	☐
2. I did not feel like eating; my appetite was poor.	☐	☐	☐	☐
3. I felt that I could not shake off the blues even with help from my family and friends.	☐	☐	☐	☐
4. I felt I was just as good as other people.	☐	☐	☐	☐
5. I had trouble keeping my mind on what I was doing.	☐	☐	☐	☐
6. I felt depressed.	☐	☐	☐	☐
7. I felt that everything I did was an effort.	☐	☐	☐	☐
8. I felt hopeful about the future.	☐	☐	☐	☐
9. I thought my life had been a failure.	☐	☐	☐	☐
10. I felt fearful.	☐	☐	☐	☐
11. My sleep was restless.	☐	☐	☐	☐
12. I was happy.	☐	☐	☐	☐
13. I talked less than usual.	☐	☐	☐	☐
14. I felt lonely.	☐	☐	☐	☐
15. People were unfriendly.	☐	☐	☐	☐
16. I enjoyed life.	☐	☐	☐	☐
17. I had crying spells.	☐	☐	☐	☐
18. I felt sad.	☐	☐	☐	☐
19. I felt that people dislike me.	☐	☐	☐	☐
20. I could not get "going."	☐	☐	☐	☐

SECTION 9 Quality of Life

This scale is designed to find out how you have been feeling during the last week. You will be asked about symptoms you have been having as a result of your inflammatory bowel disease, the way you have been feeling in general, and how your mood has been. Please read each question carefully and tick the answer which best describes how you have been feeling in the past two weeks.

	1	2	3	4	5	6	7
1. How frequent have your bowel movements been during the last two weeks?	**Bowel movement as or more frequent than they have ever been** ☐	**Extremely frequent** ☐	**Very frequent** ☐	**Moderate increase in frequency of bowel movements** ☐	**Some increase in frequency of bowel movements** ☐	**Slight increase in frequency of bowel movements** ☐	**Normal, no increase in frequency of bowel movements** ☐
2. How often has the feeling of fatigue or of being tired and worn out been a problem for you in the last two weeks?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
3. How often during the last two weeks have you felt frustrated, impatient or restless?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
4. How often during the last two weeks have you been unable to attend school or do your work because of your bowel problem?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
5. How much of the time during the last two weeks have your bowel movements been loose?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
6. How much energy have you had during the last two weeks?	**No energy at all** ☐	**Very little energy** ☐	**A little energy** ☐	**Some energy** ☐	**A moderate amount of energy** ☐	**A lot of energy** ☐	**Full of energy** ☐
7. How often during the last two weeks did you feel worried about the possibility of needing surgery because of your bowel problem?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
8. How often during the last two weeks have you had to delay or cancel a social engagement because of your bowel problem?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐

	1	2	3	4	5	6	7
9. How often during the last two weeks have you been troubled by cramps in your abdomen?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
10. How often during the last two weeks have you felt generally unwell?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
11. How often during the last two weeks have you been troubled because of fear of not finding a washroom?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
12. How much difficulty have you had, as a result of your bowel problems, doing leisure or sports activities you would like to have done during the last two weeks?	**A great deal of difficulty; activities made impossible** ☐	**A lot of difficulty** ☐	**A fair bit of difficulty** ☐	**Some difficulty** ☐	**A little difficulty** ☐	**Hardly any difficulty** ☐	**No difficulty; the bowel problems did not limit sports or leisure activities** ☐
13. How often during the last two weeks have you been troubled by pain in the abdomen?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
14. How often during the last two weeks have you had problems getting a good nights sleep or been troubled by waking up during the night?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
15. How often during the last two weeks have you felt depressed or discouraged?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
16. How often during the last two weeks have you had to avoid attending events where there was no washroom close to hand?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
17. Overall, in the last two weeks, how much of a problem have you had with passing large amounts of gas?	**A major problem** ☐	**A big problem** ☐	**A significant problem** ☐	**Some trouble** ☐	**A little trouble** ☐	**Hardly any trouble** ☐	**No trouble** ☐
18. Overall, in the last two weeks, how much of a problem have you had maintaining, or getting to, the weight you would like to be at?	**A major problem** ☐	**A big problem** ☐	**A significant problem** ☐	**Some trouble** ☐	**A little trouble** ☐	**Hardly any trouble** ☐	**No trouble** ☐

	1	**2**	**3**	**4**	**5**	**6**	**7**
19. Many patients with bowel problems often have worries or anxieties related to their illness. These include worries about getting cancer; worries about never feeling any better, and worries about have a relapse. In general, how often during the last two weeks have you felt worried or anxious?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
20. How much of the time during the last two weeks have you been troubled by a feeling of abdominal bloating?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
21. How often during the last two weeks have you felt relaxed and free of tension?	**None of the time** ☐	**Hardly any of the time** ☐	**A little of the time** ☐	**Some of the time** ☐	**A good bit of the time** ☐	**Most of the time** ☐	**All of the time** ☐
22. How much of the time during the last two weeks have you had a problem with rectal bleeding with your bowel movements?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐

	1	2	3	4	5	6	7
23. How much of the time during the last two weeks have you felt embarrassed as a result of your bowel problem?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
24. How much time during the last two weeks have you been troubled by a feeling of having to go to the bathroom even though your bowels were empty?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
25. How much of the time during the last two weeks have you felt tearful or upset?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
26. How much of the time during the last two weeks have you been troubled by accidental soiling of your underpants?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
27. How much of the time during the last two weeks have you felt angry as a result of your bowel problem?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
28. To what extent has your bowel problem limited sexual activity during the last two weeks	**No sex as a result of bowel disease** ☐	**Major limitation as a result of bowel disease** ☐	**Moderate limitation as a result of bowel disease** ☐	**Some limitation as a result of bowel disease** ☐	**A little limitation as a result of bowel disease** ☐	**Hardly any limitation as a result of bowel disease** ☐	**No limitation as a result of bowel disease** ☐
29. How much of the time during the last two weeks have you been troubled by feeling sick to your stomach?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
30. How much of the time during the last two weeks have you felt irritable?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐
31. How often during the last two weeks have you felt a lack of understanding from others?	**All of the time** ☐	**Most of the time** ☐	**A good bit of the time** ☐	**Some of the time** ☐	**A little of the time** ☐	**Hardly any of the time** ☐	**None of the time** ☐

32. How satisfied, happy, or pleased have you been with your personal life during the past two weeks?	**Very dissatisfied, unhappy most of the time** ☐	**Generally dissatisfied, unhappy** ☐	**Somewhat dissatisfied, unhappy** ☐	**Generally satisfied, pleased** ☐	**Satisfied most of the time, happy** ☐	**Very satisfied most of the time, happy** ☐	**Extremely satisfied, could not have been more happy or pleased** ☐

SECTION 10 Locus of Control

The following statements determine the way in which different people view certain important health-related issues. Each item is a belief statement with which you may agree or disagree. Please tick the box that best corresponds to your views.

	Strongly disagree	Moderatel y Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1. If I become sick I have the power to make myself well again.	☐	☐	☐	☐	☐	☐
2. Often I feel that no matter what I do, if I am going to be sick, I will get sick.	☐	☐	☐	☐	☐	☐
3. If I see an excellent doctor regularly, I am less likely to have health problems.	☐	☐	☐	☐	☐	☐
4. It seems to me my health is greatly influenced by accidental happenings.	☐	☐	☐	☐	☐	☐
5. I can only maintain my health by consulting health professionals.	☐	☐	☐	☐	☐	☐
6. I am directly responsible for my health.	☐	☐	☐	☐	☐	☐
7. Other people play a big part in whether I stay healthy or become sick.	☐	☐	☐	☐	☐	☐
8. Whatever goes wrong with my health is my fault.	☐	☐	☐	☐	☐	☐
9. When I am sick, I just have to let nature run its course.	☐	☐	☐	☐	☐	☐
10. Health professionals keep me healthy.	☐	☐	☐	☐	☐	☐
11. When I stay healthy, I’m just plain lucky.	☐	☐	☐	☐	☐	☐
12. My physical well-being depends on how well I take care of myself.	☐	☐	☐	☐	☐	☐
13. When I feel ill, I know it is because I have not been taking care of myself properly.	☐	☐	☐	☐	☐	☐
14. The type of care I receive from other people is responsible for how well I recover from an illness.	☐	☐	☐	☐	☐	☐
15. Even when I take care of myself, it’s easy to get sick.	☐	☐	☐	☐	☐	☐
16. When I become ill, it’s a matter of fate.	☐	☐	☐	☐	☐	☐
17. I can pretty much stay healthy by taking good care of myself.	☐	☐	☐	☐	☐	☐
18. Following doctor’s order to the letter is the best way for me to stay healthy.	☐	☐	☐	☐	☐	☐

SECTION 11 Recovery Locus of Control

These are statements other people have made about their recovery. Please will you indicate the extent to which you agree or disagree. Please tick the box that best corresponds to your views.

	1 Strongly Disagree	2	3	4	5 Strongly Agree
1. How I manage in the future depends on me, not on what other people can do for me.	☐	☐	☐	☐	☐
2. It's often best to just wait and see what happens.	☐	☐	☐	☐	☐
3. It's what I do to help myself that's really going to make all the difference.	☐	☐	☐	☐	☐
4. My own efforts are not very important, my recovery really depends on others.	☐	☐	☐	☐	☐
5. It's up to me to make sure I make the best recovery possibly under the circumstances.	☐	☐	☐	☐	☐
6. My own contribution to my recovery doesn't amount to much.	☐	☐	☐	☐	☐
7. Getting better now is a matter of my own determination rather than anything else	☐	☐	☐	☐	☐
8. I have little or no control over my progress from now on.	☐	☐	☐	☐	☐
9. It doesn't matter how much help you get, in the end it's your own efforts that count.	☐	☐	☐	☐	☐

SECTION 12 Individual attitudes

This part of the questionnaire lists different attitudes or beliefs which people sometimes hold. For each statement please tick the box corresponding with how much you agree or disagree. To decide whether a typical statement is typical of your way of looking at things, simply keep in mind *what you are like most of the time*. Because people are different, there is no right or wrong answer to these statements.

	Totally disagree	**Disagree very much**	**Disagree slightly**	**Neutral (neither disagree or agree)**	**Agree slightly**	**Agree very much**	**Totally agree**
1. It is difficult to be happy unless one is good looking, intelligent, rich, and creative.	☐	☐	☐	☐	☐	☐	☐
2. Happiness is more a matter of my attitude towards myself than the way other people feel about me.	☐	☐	☐	☐	☐	☐	☐
3. People will probably think less of me if I make a mistake.	☐	☐	☐	☐	☐	☐	☐
4. If I do not do well all the time, people will not respect me.	☐	☐	☐	☐	☐	☐	☐
5. Taking even a small risk is foolish because the loss is likely to be a disaster.	☐	☐	☐	☐	☐	☐	☐
6. It is possible to gain another person’s respect without being especially talented at anything.	☐	☐	☐	☐	☐	☐	☐
7. I cannot be happy unless most people I know admire me.	☐	☐	☐	☐	☐	☐	☐
8. If a person asks for help, it is a sign of weakness.	☐	☐	☐	☐	☐	☐	☐
9. If I do not do as well as other people, it means I am a weak person.	☐	☐	☐	☐	☐	☐	☐
10. If I fail at my work, then I am a failure as a person.	☐	☐	☐	☐	☐	☐	☐
11. If you cannot do something well, there is little point in doing it at all.	☐	☐	☐	☐	☐	☐	☐
12. Making mistakes is fine because I can learn from them.	☐	☐	☐	☐	☐	☐	☐
13. If someone disagrees with me, it probably indicates he does not like me.	☐	☐	☐	☐	☐	☐	☐
14. If I fail partly, it is as bad as being a complete failure.	☐	☐	☐	☐	☐	☐	☐
15. If other people know what you are really like, they will think less of you.	☐	☐	☐	☐	☐	☐	☐
16. I am nothing if a person I love doesn’t love me.	☐	☐	☐	☐	☐	☐	☐
17. One can get pleasure from an activity regardless of the end result.	☐	☐	☐	☐	☐	☐	☐
18. People should have a chance to succeed before doing anything.	☐	☐	☐	☐	☐	☐	☐
19. My value as a person depends greatly on what others think of me.	☐	☐	☐	☐	☐	☐	☐

	Totally disagree	**Disagree very much**	**Disagree slightly**	**Neutral (neither disagree or agree)**	**Agree slightly**	**Agree very much**	**Totally agree**
20. If I don’t set the highest standards for myself, I am likely to end up a second-rate person.	☐	☐	☐	☐	☐	☐	☐

SECTION 13 Mindfulness

Below is a collection of statements about your everyday experience. Using the scale below, please indicate how frequently or infrequently you currently have each experience. Please answer according to what reflects your experience rather than what you think your experience should be. Please treat each item separately from every other item.

	Almost always	Very frequently	Somewhat frequently	Somewhat infrequently	Very Infrequently	Almost never
1. I could be experiencing some emotion and not be conscious of it until some time later.	☐	☐	☐	☐	☐	☐
2. I break or spill things because of carelessness, not paying attention, or thinking of something else.	☐	☐	☐	☐	☐	☐
3. I find it difficult to stay focused on what's happening in the present.	☐	☐	☐	☐	☐	☐
4. I tend to walk quickly to get where I'm going without paying attention to what I experience along the way.	☐	☐	☐	☐	☐	☐
5. I tend not to notice feelings of physical tension or discomfort until they really grab my attention.	☐	☐	☐	☐	☐	☐
6. I forget a person's name almost as soon as I've been told it for the first time.	☐	☐	☐	☐	☐	☐
7. It seems I am "running on automatic," without much awareness of what I'm doing.	☐	☐	☐	☐	☐	☐
8. I rush through activities without being really attentive to them.	☐	☐	☐	☐	☐	☐
9. I get so focused on the goal I want to achieve that I lose touch with what I'm doing right now to get there.	☐	☐	☐	☐	☐	☐
10. I do jobs or tasks automatically, without being aware of what I'm doing.	☐	☐	☐	☐	☐	☐
11. I find myself listening to someone with one ear, doing something else at the same time.	☐	☐	☐	☐	☐	☐
12. I drive places on "automatic pilot" and then wonder why I went there.	☐	☐	☐	☐	☐	☐
13. I find myself preoccupied	☐	☐	☐	☐	☐	☐

	Almost always	**Very frequently**	**Somewhat frequently**	**Somewhat infrequently**	**Very Infrequently**	**Almost never**
with the future or the past.						
14. I find myself doing things without paying attention.	☐	☐	☐	☐	☐	☐
15. I snack without being aware that I'm eating.	☐	☐	☐	☐	☐	☐

SECTION 14 Misc.

1. What factors do you believe caused your illness?

____
____
____
____

2. How many times do you see the following in an average year?

- GP ☐ ______________________________
- Gastroenterologist ☐ ______________________________
- Psychologist/Counsellor ☐ ______________________________
- Other ________________ ☐ ______________________________
- Other ________________ ☐ ______________________________
- Other ________________ ☐ ______________________________

3. Are you using alternative therapies to manage your Inflammatory Bowel Disease?

☐ No ☐ Yes **Please List**

____
____
____
____

4. Please list in order, the most effective strategies you use to manage your symptoms

____
____
____
____

5. Are you currently seeing a counsellor/psychologist for help to manage your Inflammatory Bowel Disease?

☐ No ☐ Yes **In what way has this been useful/not useful**

____

____

____

____

SECTION 15 Lichtiger Scale

Please answer all of the following questions by ticking the most appropriate box.

1. Diarrhoea (No of daily stools)

0 to 2 ……………………….. ☐
3 to 4 ……………………….. ☐
5 to 6 ……………………….. ☐
7 to 9 ……………………….. ☐
10 or more ………………….. ☐

2. Nocturnal Diarrhoea

No………………………….... ☐
Yes.................................... ☐

3. Visible Blood in Stool (% Bowel Movements)

0…………………………….. ☐
<50 % ……………………… ☐
50 % or more ……………… ☐
100 % ……………………… ☐

4. Faecal Incontinence

No………………………….. ☐
Yes................................. ☐

5. Abdominal Pain or Cramping

None……………………….. ☐
Mild................................. ☐
Moderate………………….. ☐
Severe…………………….. ☐

6. General Well-Being

Perfect…………………….. ☐
Very good…………………. ☐
Good……………………….. ☐
Average……………………. ☐
Poor……………………….. ☐
Terrible……………………. ☐

7. Abdominal Tenderness

None……………………… ☐
Mild and localized………. ☐
Mild to moderate and diffuse… ☐
Severe………………………… ☐

8. Need for Antidiarrheals

No……………………………… ☐
Yes…………………………… ☐

9. Bowel Symptoms in the Last 3 Months

Nil problems………………….. ☐
Mildly disruptive……………… ☐
Moderately troublesome……. ☐
Severe……………………….... ☐

10. Do You Currently Have a Stoma

Yes (Permanent) ☐
Yes (Temporary) ☐
No ☐

If Yes, how many months have you had a stoma? ___________

11. Do You Have Any of the Following Complications

Arthralgia/arthritis ☐
Iritis/uveitis ☐
Skin or mouth lesion (Erythema nodosum) ☐
Skin or mouth lesion (pyoderma gangrenosum) ☐
Skin or mouth lesions (aphthous stomatitis) ☐
Anal fissure, fistula or abscess ☐
Other fistula ☐
Fever over 37.8 degrees during the past week ☐
Nausea ☐
Reduced appetite ☐

12. Do You Have an Abdominal Mass

None ☐
Questionable ☐
Definite ☐
Definite and tender ☐

13. Do You Suffer From Anemia (i.e., low Iron/ Hematocrit Levels; Males: Hematocrit < 47; Females: Hematocrit < 42)?

Yes ☐
No ☐

If you have answered yes to question 10 (above) please specify the length of time below (in months):
__________ months.

14. Overall, how would you rate the severity of your IBD:

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No affect at all										**Severely affects my life**
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

13. Do You Believe Your IBD is in Remission?

Yes ☐
No ☐

PLEASE CHECK THAT YOU HAVE ANSWERED ALL QUESTIONS ON BOTH SIDES OF EACH PAPER
THANK-YOU FOR YOUR PARTICIPATION

Appendix C
Information Sheet

Impact of cognitive appraisal perceived stress and quality of life in those with Inflammatory Bowel Disease

Investigators: Dr. Simon Knowles, Dr. William Connell, Dr. Jarrad Wilson, Dr. Steven Brown Prof. Mike Kyrios, Jim Kantidakis, and Debra Osborne.

Information Sheet

The following study is an initiative between researchers at St Vincent's Hospital Gastroenterology Department (Dr William Connell, Dr Jarrad Wilson, and Dr Steven Brown) and the Psychology Department (Dr Simon Knowles, Professor Mike Kyrios, Jim Kantidakis, and Debra Osborne) at Swinburne University of Technology. The purpose of this study is to explore the relationship between cognitive processes, perceived stress and its impact on quality of life on those diagnosed with Inflammatory Bowel Disease (IBD). A further purpose of this study is to explore the difference between individuals with active versus non-active IBD symptoms with regard to psychological well-being and quality of life. The findings from this research will also be used by the student investigators (JK and DO) as part of the research component in their coursework degrees.

Should you choose to participate in this study; the attached questionnaire will first request that you provide some general information, such as age, gender, marital status and education, which will enable the full sample to be described. A series of questions about disease activity, psychological well-being, quality of life, disease management are also contained in the questionnaire.

The questionnaire will take approximately 30 minutes to complete. Almost all questions simply ask that you indicate the most appropriate response. Please respond honestly to each question after thinking about it, but you don't need to spend a lot of time on any one question. Your initial response is probably the most accurate. Your responses will be completely anonymous and confidential. Results of this study may be published in a scientific journal, however only group data will be presented and no individual will be identifiable.

Please note that your participation in this study is completely voluntary. Your initial agreement to participate does not stop you from discontinuing participation and you are free to withdraw at any time. **The submission of the questionnaire will be taken as consent for your data to be used in the study.** All responses will be stored in a secured location at Swinburne University of Technology for no less than 7 years post publication of results.

Although unlikely, the questionnaire may raise some concerns for you because of some personal experiences or questions. If you are feeling distressed at any time as a consequence of participating in this study and you wish to talk to a counsellor, please contact Lifeline on 131114 or Dr. Simon Knowles 9214 8206.
If you have any questions about this study, please contact: Simon Knowles on 9214 8206 or sknowles@swin.edu.au

If you have any concerns or complaints about the conduct of this research project, please contact:

Research Ethics Officer
Office of Research and Graduate Studies
Swinburne University of Technology
PO Box 218, Hawthorn, Victoria, 3122
Tel: (03) 9214 5218 or resethics@swin.edu.au

Complaints can also be referred to: Executive Officer, Research & Grants Unit, St.Vincent's Hospital,
Ph: 9288 3930.
Please retain this information for your records. Your participation is very important to this study and is greatly appreciated. Thank your for your time and assistance.