THE INFLUENCE OF GASTROINTESTINAL CONDITIONS ON WELLBEING: A PSYCHOSOCIAL ANALYSIS

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Abbreviations

GI: Gastrointestinal

IBS: Irritable bowel syndrome

IBD: Inflammatory bowel disease

CD: Crohn’s disease

UC: Ulcerative colitis

FGID: Functional gastrointestinal disorder

OGID: Organic gastrointestinal disorder

SWB: Subjective wellbeing

QOL: Quality of life

HRQOL: Health-related quality of life

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Declaration

This thesis is my own work and has been submitted for the award of Doctorate of Philosophy in Psychology from the University of Sunderland. This thesis has not been submitted to another institution. Any materials previously published or written by another researcher are referenced in the text. Any publications resultant from this thesis are acknowledged with reference to co-authors on the following page.

Inclusion of Published Work

A version of Chapter 3 of this thesis has been accepted for publication and is currently available for early view:

Dent, E., Davinson, N., & Wilkie, S. (2021). The impact of gastrointestinal conditions on psychosocial factors associated with the biopsychosocial model of health: A scoping review. *Applied Psychology: Health and Well-Being*. https://doi.org/10.1111/aphw.12323

Abstract

Gastrointestinal (GI) conditions such as (irritable bowel syndrome (IBS); inflammatory bowel disease (IBD)) are increasingly prevalent (Molodecky et al., 2012). The global prevalence of IBS ranges between 3 to 22% of the population (Basandra & Bajaj, 2014). The prevalence of IBD exceeds 0.3% globally (Ng et al., 2017). The biomedical model has been the dominant framework to explore health conditions; its suitability for GI conditions is limited because it ignores psychological and social factors within health. Two biopsychosocial models (Engel, 1977; Drossman, 2016) were implemented in this thesis to evaluate the influence of GI conditions on wellbeing. Research questions aimed to address psychosocial aspects of GI conditions, including psychosocial factors and wellbeing outcomes, and how these may vary across active/remission stages.

Three studies comprised the thesis construction, which used mixed methods. Study 1 was a scoping review to understand the breadth of existing literature and knowledge of IBS and IBD on psychosocial factors and wellbeing outcomes. Study 2 was a series of interviews with individuals diagnosed with IBS or IBD; it aimed to understand their lived experiences of these conditions. Study 2 outcomes informed the hypotheses guiding study 3, which required participants to complete published survey measures of SWB, negative emotions, HRQOL, coping and social support to further explore participant’s experiences. Study 3 also explored the emotion recognition ability of those with IBS and IBD and how this may relate to social support.

Findings supported the use of the biopsychosocial model as a theoretical lens for the investigation and explication of IBS and IBD. The unique contribution to the existing

evidence base surrounding knowledge of GI conditions were the focus on presently under-researched areas within the field. These included the remission experiences of those with IBS and IBD, and potential links between social support and relationships on emotion recognition. Recommendations from this research include increased workplace support for individuals with GI conditions, greater focus on psychosocial experiences during remission, and future research is co-produced with those affected by GI conditions. The outcomes of this research will be of potential importance to individuals with IBS and IBD, health researchers and health practitioners in relation to extending knowledge and raising awareness of the study outcomes.

Chapter 1

An introduction to the gastrotinestinal conditions irritable bowel syndrome and inflammatory bowel disease.

1.0 Background

Gastrointestinal (GI) conditions affect the functioning of the GI tract (Stewart & Stewart, 1994). These conditions involve symptoms such as pain, disordered bowel habits, weight loss and discomfort (Lacy et al., 2016; Mekjian et al., 1979; Sayuk & Gyawali, 2015), which can be life-altering and reduce quality of life (Moura & Goulart, 2017). Previously, GI conditions have been classified as either functional or organic. Functional GI conditions (FGIDs) commonly cannot be attributed to anything biochemical or organic within the GI tract (Zeevenhooven et al., 2017). Common FGIDs include functional dyspepsia, gastroesophageal reflux disease, functional dysphagia, and IBS (Mukhtar et al., 2019). IBS is the most common GI seen in primary and secondary care (Thompson et al., 2000; Jones & Lydeard, 1992); it has a global prevalence ranging between 3 to 22% of the population (Basandra & Bajaj, 2014). IBS is classified into two subtypes dependent on symptomology (Drossman, 2016). IBS-C (constipation subtype) is characterised by slow intestinal transit time (Heaton & O’Donell, 1994) and IBS-D (diarrhoea subtype) is characterised by rapid intestinal transit causing loose, watery stools (Degen & Phillips, 1996). It is possible to have a combination of the two subtypes, where individuals alternate between constipation and diarrhoea, this is classified as IBS-M (IBS-mixed) (Lazarki et al., 2014).

Organic GI conditions (OGIDS) are less frequently diagnosed than FGIDs (Drossman, 2016). These result from organic, physical changes, such as sores in the wall of the bowel (Enders, 2017). The most diagnosed OGID is IBD (Enders, 2017), which covers two conditions associated with inflammation of the gut: Ulcerative colitis (UC) and Crohn's disease (CD). Symptoms of UC include abdominal pain, and blood and mucus in stool (Wei et al., 2019). Symptoms of CD are dependent on the location of the disease along the GI tract, but commonly include diarrhoea, cramping and weight loss (Kusalas-Delint et al., 2016). CD has been associated with decreased life expectancy compared to those with UC (Travis, 1997). The burden of IBD is increasing, as the current global prevalence has exceeded 0.3 % (Ng et al., 2017). More recently, Jairath and Feagan (2020) estimated that over 2 million European and 1.5 million North Americans have a diagnosis of IBD, demonstrating its prevalence.

The distinction between FGID/ OGID that once persisted has been challenged, as researchers have noted that bi-directional communication between the gut and brain occurs across these condition classifications (Black et al., 2020). An inclusive diagnosis of gut-brain interaction has instead been proposed as appropriate for both IBS (FGID) and IBD (OGID) (Drossman & Hasler, 2016). The shared symptomology of IBS and IBD supports a collective diagnosis, as pain, bloating and altered bowel function are experienced across both conditions (Drossman & Hasler, 2016; Sayuk & Gyawali, 2015). Further similarities between the conditions are their classification as chronic disorders, and a cyclic disease course marked by periods of remission and activity (Gavrillescu et al., 2015; Evangelista, 2012). Current stage (active or remission) is an important factor to consider when investigating both GI conditions, as remission is viewed as the optimal outcome for both, with the common expectation being that it is a period associated with improved physical and psychosocial outcomes (Qazi, 2020; Sierzantowicz et al., 2020; Stroie et al., 2022). Also, both conditions share an increased prevalence among women (Collen, 2015), and have been found to similarly affect QOL (Knowles et al., 2018; Kopczynska et al., 2018). Health care costs for IBS and IBD are similarly high- a large portion of which is attributed to medications (Canavan et al., 2014; Mehta, 2016). Further costs include hospitalisations, surgeries, nursing care and visits to General Practitioners (Akehurst et al., 2002; Kappelman et al., 2008; Mehta, 2016). Another shared indirect cost associated with IBS and IBD is work absenteeism (Kawalec et al., 2017) which can be costly for both employers and employees. The number of similarities between IBS and IBD supports their consideration together in research and their wide influence indicates these are conditions that warrant further investigation.

1.1 Models of health (and their relation to GI disorders)

A common approach to health condition research has been to adopt the biomedical model of health as the investigative framework (Sheridan & Radmacher, 1992). This model is positioned from a purely biological perspective (Farre & Rapley, 2017; Sheridan & Radmacher, 1992; Patrick et al., 1998) and based on the beliefs of Cartesian dualism, where mind and body are separate and do not interact (Sheridan & Radmacher, 1992). According to Carteisan dualism, disease was an outcome of a biological event or change with treatments designed to address this physical change, for example the use of drugs (Mehta, 2011). This approach has proven effective for the control of infectious diseases, but less so for chronic non-infectious diseases associated with multiple risk factors which are often psychological and social in nature (Havelka et al., 2009). In addition to its limitations in explaining chronic non-infectious disease, other challenges of the biomedical model have been raised. For example, the introduction of psychosomatic medicine which considered how biological, psychological, and social actors interact in health and disease outcomes (Fava & Sonino, 2010; Sheridan & Radhmacher, 1992), suggesting the involvement of factors in addition to the biological aspects. Additional challenges to the biomedical model include the increasing prevalence of IBD (Kaplan & Ng, 2017; Molodecky et al., 2012), and predicted increase in prevalence of IBS (Black & Ford, 2020) which have resulted in a call for a more holistic model, as the biomedical model's narrow biological focus cannot fully explain and account for GI conditions. There has been criticism that considering conditions such as IBS from a biomedical perspective limits their impact to a single part of the body, meaning treatment should only focus on this physical area (Rocca & Anjum, 2020). Finally, the biomedical model is not concerned with an individual's experience with an illness, only its biological process, and which biological treatment is appropriate (Dieppe, 2004). This is not sufficient, as health conditions are more complicated and this model medicalises experiences in life (Anjum et al., 2020). For instance, under the biomedical model experiencing grief would be medicalised as depression (Anjum et al., 2020). It is now more commonly understood and accepted that health, wellbeing and disease are influenced by a range of factors including genetics, psychological functioning, lifestyle and environment, as well as our social status and amount of support we receive from our social network (Zittel, Lawrence & Wodarski, 2002).

The biomedical model addresses health conditions with regards to their biological processes, including cells, organs and tissue (Anjum et al., 2020). This model would view GI conditions such as IBS and IBD as purely the result of biological changes, such as altered gut microbiota or intestinal inflammation, and would focus on how to tackle biological symptoms. This excludes the consideration of any non-biological factors that could contribute to the aetiology or pathology of a condition. Yet, health researchers are starting to acknowledge the benefits of adopting more holistic models to study conditions such as IBS and IBD. One such model is the social model of health, which views health and illness as the result of social factors such as employment and housing (Oliver et al., 2012). With regards to GI conditions, an association between low socioeconomic status and IBS prectivity has been previously reported (Alvand et al., 2020). The social model directly opposes the biomedical model, but other models such as the biopsychosocial model of health (Engel, 1977) aimed to build upon its concepts (Bevan, 2009; Suls & Rothman, 2004). The biopsychosocial model of health has provided a framework for research into how psychological and social factors affect the development and course of somatic diseases (Havelka et al., 2009), as well as being applied in various branches of health sciences such as surgery, intensive care units, physiotherapy, and psychiatry, among others (Havelka et al., 2009). Specific non-communicable health conditions have also been studied using the biopsychosocial model of health, for example, diabetes (Sheridan & Radmacher, 1992) and IBS (Drossman, 2006; 2016). The biopsychosocial model is considered the most appropriate and comprehensive model for the study of GI conditions due to their complexity, with biological symptoms typically accompanied by psychosocial impairment (Pojoga & Stănculete, 2014).

1.2.1 Comparing and contrasting biopsychosocial models applied to GI conditions

Drossman (2016) developed a model to visualise the relationships between psychological, social, and biological factors and how they influence wellbeing outcomes. A very similar model outlining the complex interactions that take place in IBS was developed by Sayuk and Gyawali (2015). Table 1 provides a comparison of the biopsychosocial factors implicated in Drossman (2016) and Sayuk and Gyawali's (2015) models.

Table 1

Factors included in two biopsychosocial models of IBS

	Drossman (2016)	Sayuk and Gyawli (2015)
Biological	Motility	Motility
	Sensation	Sensation
	Inflammation	Inflammation
	Altered microbiota	Intestinal permeability
	Food/diet	Brain response to pain signals
		Altered microbiota
		Bile acid malabsorption
		Pancreatic insufficiency
Psychosocial	Life stress	Life stress
	Personality traits	Abuse history
	Psychologic state	Mood disorders (including depression and anxiety)
	Coping	Somatisation
	Social support	Personality (specifically neuroticism)
		Coping (maladaptive)
		Social support
		Education
Outcomes	Health care use and cost	Symptoms
	Daily function	Behaviour
	Quality of life	Quality of life

Both models outline some of the central biological factors associated with IBS. For example, the presence of altered bacterial flora in IBS and IBD is well-documented (Collen, 2015; Nishida et al., 2018). While the microbiota in our gut is as individual to us as our fingerprint (Collen, 2015, & Enders, 2017), the density and diversity of the gut microbial population is reduced in IBS with decreased levels of gut-friendly bacteria such as Lactobacilli and Bifidobacteria (Distrutti et al., 2016; Liu et al., 2017; Wang et al., 2020). This alteration in gut microbiota (also referred to as dysbiosis) is also present in IBD, most notably with a reduction in the phyla Firmicutes and Bacteroidetes (Frank et al., 2007; Ni et al., 2017; Nishida et al., 2018).

Intestinal inflammation, noted by both models, is another biological factor involved in the pathogenesis of IBS (Ng et al., 2018) and IBD (Bielefeldt et al., 2011). This inflammation is typically the immune system’s response to injury, as it is characterised by symptoms such as swelling (tumour) and pain (Giovanni et al., 2011) - symptoms typical in IBD (Bielefeldt et al., 2011). GI motility is also implicated in the biology of IBS, more specifically enteramine (5-HT) which was first discovered as crucially involved in GI function by Erspamer (1954), more specifically, the receptor 5-HT$_3$ is involved in conditions such as IBS-D characterised by enhanced colonic motility (Camilleri, 2000). A great deal is known about the biology of GI conditions due to the prevalence of the biomedical model, however, biology alone cannot provide the full narrative. Greater consideration of psychological and social aspects associated with IBS and IBD is required to fully understand the experiences of those with these conditions. This understanding can be instrumental in improving the daily lives of those with a GI condition.

Drossman (2016) and Sayuk and Gyawali (2015) consider psychological and social factors together (psychosocial). The following psychosocial factors are involved in IBS according to Drossman (2016): life stress (the experience of stressors in their daily lives), psychological state (an individual's mental state/condition), personality traits, coping (adaptation and strategies employed) and social support (a support network of friends/family). Sayuk and Gyawali (2015) concur that life stress, maladaptive coping and social support are psychosocial factors involved in IBS. However, they proposed the addition of abuse history, and the potential importance of considering whether individuals have experienced abuse in their past. This accords with research that suggests a link between childhood abuse (physical, sexual, and/or psychological) and increased risk of developing IBS as an adult (Grad et al., 2014). Also, childhood abuse has been linked to somatisation and certain personality traits in IBS (Talley, Boyce & Jones, 1998), particularly neuroticism, with scores higher, on average, among those with IBS than healthy individuals (Farnam et al., 2007; Palmer et al., 1974). Sayuk and Gyawali (2015) also considered the role of education, specifically, this refers to whether individuals are well educated on their condition or not. Largely, there is agreement between the models in terms of the factors included. Yet, Drossman's (2016) model is arguably a closer fit for the research in this thesis and its aims, as it provides greater focus on the psychosocial outcomes of IBS compared to Sayuk and Gyawali (2015). Also, Drossman's (2016) model can be better applied to a wider range of individuals, as not everyone with a GI condition will have an abuse history (Fuller-Thompson et al., 2015) and differences in abuse prevalence exist between functional and organic GI conditions, with individuals with IBS more likely to have experienced abuse than those wth IBD (Bradford et al., 2012; Drossman et al., 1990). The inclusion of fewer, more closely related factors in Drossman's (2016) model will also enable a more in-depth and focused investigation as well as the opportunity to build onto this model with additional biopsychosocial factors that contribute to the course of GI conditions.

1.2.2 Model implementation

Drossman (2016) and Sayuk and Gyawali (2015) considered psychological and social factors together, but the research presented in this thesis intends to separate these factors out to more thoroughly investigate their relationship with IBS and IBD. Within this thesis, psychological factors are defined as those related to emotion or cognition. The following psychological aspects from Drossman's (2016) model will be considered: quality of life (QOL)/health-related quality of life (HRQOL), subjective wellbeing (SWB) and coping. Additional to factors in Drossman's (2016) model, the potential influence of remission on psychosocial factors/wellbeing outcomes will be considered, and emotion recognition will also be addressed in this research, in relation to the reported increased prevalence of alexithymia among those with IBS and IBD (Porcelli et al., 1995; Porcelli et al., 2017; Vigano, et al., 2018), and by-way of social relationships. For this thesis, social aspects are related to interactions with others. Social aspects to be addressed are social relationships/ social support and employment. Further exploration as to why these factors are worthy of consideration in relation to GI disorders are discussed in sections 1.3 to 1.8 of this chapter.

1.3 Social Support

A social factor to be considered is social support, which is typically characterised as the network of support an individual has available to them and is inclusive of relationships with friends, intimate partners, neighbours, family and the wider community (Gerson & Gerson, 2012). Social support was highlighted in Drossman's (2016) model as an important part of the biopsychosocial expression of IBS.

Previous research has revealed an association between social support and improved physical health (Crocker et al., 2014; Gerson & Gerson, 2012) and psychological condition, more specifically SWB (Saphire-Bernstein & Taylor, 2015; Umberson & Karas Montez, 2010). Yet, relationship formation can prove challenging for individuals with a GI condition due to concerns around disclosure and potential rejection as a result (Trachter et al., 2002). Once relationships are formed, maintenance can become another concern (Nicholas et al., 2007; Trachter et al., 2002; Bishop, 1994). Romantic relationship maintenance issues may be linked to impaired sexual function, which is often reported among those with IBD (Mantzouranis et al., 2015) and IBS (Luscombe, 2000). The reluctance of those with a GI condition to engage in close, physical relationships (Hakanson, 2014) could be the result of embarrassment over their disorder, as embarrassment felt due to IBD has been reported to increase feelings of loneliness and worry over social relationships (Qualter et al., 2021). Researchers investigating the relationships of individuals with a GI condition have typically focused on social support in general, rather than focusing on romantic relationships (Gerson & Gerson, 2012). This is because a general exploration of social support encompasses a wide range of relationships, including romantic (Gerson & Gerson, 2012), though it is important to note that there are different challenges within romantic relationships such as sexual intimacy and spousal conflict and violence (Becker-Dreps et al., 2010; Talley et al., 1995).

Research has presented evidence of the challenges often associated with social support for those with IBS or IBD, but there has been limited enquiry into the reasons why. One explanation is based on Gerson and Gerson's (2012) finding that conflicts within social relationships can increase IBS symptomology. In this way, relationships may be perceived as a risk to physical health, as potential arguments could cause their symptoms to worsen. As a result, some individuals may wish to avoid relationships. While this explains the relationship behaviours of those diagnosed with a GI disorder, the perceptions and behaviours of those they have relationships with are also worthy of consideration. Gerson and Gerson (2005) suggested that an important part of IBS is the beliefs held by others, such as IBS-related conflict causing tension within a relationship, which can be exacerbated by the loved one becoming frustrated by their partner's symptoms, demonstrating the added strain a GI condition can place on a relationship, for both parties.

1.3.1 The role of emotion recognition in social support

Emotion recognition enables navigation of the social world (Zaja & Rojahn, 2008). This occurs from an early age, as McKown et al. (2013) reported an association between children's socio-emotional understanding and more positive social relationships with peers. The importance of emotion recognition in social relationships is evident in autism spectrum disorder, where, among other impairments, difficulties around the expression and understanding of emotions are associated with impaired social communication and, thus, relationships (Kransy et al., 2003). Research has revealed emotion recognition to be a critical component for effective social communication (Hee Yoo & Noyes, 2015; Paiva-Silva et al., 2016).

Given the association between difficulties with social relationships and emotion recognition, it is then perhaps not unsurprising that individuals with GI conditions often display emotional avoidance (Thakur et al., 2017), have difficulty identifying feelings, and display a negative emotional expressiveness bias (Fournier et al., 2018). This could be a result of difficulties surrounding social relationships, or there could be other factors at work. One such factor is explored in the next section.

1.3.1.1 Emotion recognition and alexithymia

A high prevalence of alexithymia is reported among those with GI conditions (Porcelli et al., 1995; Porcelli et al., 2017; Vigano, et al., 2018). Alexithymia is a trait associated with difficulties recognising emotions (Martinez-Sanchez et al., 2017). There is research to suggest that increased prevalence of alexithymia among those with a GI condition could indicate a reactivity hypothesis, whereby having a GI condition, particularly IBD as it is considered to be more emotionally challenging, may result in impaired emotion recognition (Martino et al., 2020). Typically, individuals with alexithymia have difficulty recognising one’s own emotions (Grynberg et al., 2012). There are researchers who posit that difficulty recognising and describing one’s own emotions should also result in difficulty recognising the emotions of others (Lyvers et al., 2017), though this is largely speculative at present. Overarchingly, the fact that alexithymia is often comorbid with GI conditions might suggest that there is a biological link between the two conditions via the gut-brain axis, however, this explanation might not provide the full picture. As mentioned previously, there is also research to suggest a social explanation for the difficulties recognising emotion that can be present among those with GI disorder, yet we do not know enough to fully support this explanation. Therefore, this research will attempt to better understand if and how emotion recognition is affected in GI disorders, exploring both the prevalence of alexithymia among the sample and whether this relates to their perceived social support.

1.4 Employment

While not included in Drossman's (2016) model, there is research to suggest employment/working life is affected among those with IBS and IBD. A commonly reported work-related issue is reduced productivity due to being unwell, which is referred to as presenteeism (Ballou et al., 2019; Dean et al., 2005; de Boer et al., 2016). Many individuals with IBS or IBD take time off work (sick leave) because of their symptoms (Ballou et al., 2019; Dean et al., 2005; de Boer et al., 2016), which is associated with negative wellbeing outcomes including decreased QOL and increased rates of depression and anxiety (Dean et al., 2005; de Boer et al., 2016). Among a general population, there seems to be a social element to work absenteeism, with low social support at work associated with lower QOL, which is associated with work absenteeism (Unden, 2017). Though Palant and Himmel (2019) reported that, for individuals with IBD, high levels of social support at work can have negative outcomes, including increased work absenteeism, as co-workers are deemed too compassionate, which reinforced the idea that they are not "normal". Work absenteeism and presenteeism are complex challenges that may be faced in the daily life of those with IBS and IBD, but arguably the most severe work-related consequence of these conditions is job loss, as was reported by 35.5% of participants with IBD studied by Ueno et al. (2017). For most of us, work is an important aspect of our lives (Górny, 2018), and since IBS and IBD are associated with negative employment outcomes including work absenteeism and presenteeism, there is a need to further explore this psychosocial factor in more depth.

1.5 Coping

Drossman's (2016) model highlights coping as a psychosocial factor implicated in IBS. Coping is conceptualised as methods by which negative consequences of an illness can be reduced, for example negative emotions (Johnston & Johnston, 1998). Fouche et al. (2006) reported that while females with IBS who perceived themselves as having more available coping resources displayed improved adjustment, the sample overall felt that their coping resource levels were below average. This highlights the importance of coping among those with a GI condition, but also the challenge this presents. Coping is typically considered with regards to strategies used, specifically what behaviours and attitudes might an individual have adopted in response to a situation (Chao et al., 2019). These strategies fall into two broad categories: maladaptive and adaptive (Chao et al., 2019). Maladaptive coping strategies are commonly used among those with a GI condition, and include evasive and fatalistic coping (Torkzadeh et al., 2019), or passive coping strategies including methods to escape or avoid (Jones et al., 2006), substance abuse, self-blame and self-distraction (Chao et al., 2019). Adaptive coping strategies include seeking support from others, positive reframing and acceptance (Roohafza et al., 2016; Chao et al., 2019). The use of maladaptive coping strategies is associated with negative wellbeing outcomes among those with a GI condition (Bandler et al., 2000; Sugawara et al., 2017), and as such reducing reliance on these strategies is critical, meaning more needs to be known about these strategies.

1.6 Subjective wellbeing (SWB)

SWB, most often conceptualised using Diener’s (1984) tripartite model, consists of life satisfaction and judgements of positive and negative affect. Research has revealed a positive association between SWB and social support (Saphire-Bernstein & Taylor, 2015; Umberson & Karas Montez, 2010). In fact, the quality of social support is one of the most consistent predictors of SWB (Diener & Seligman, 2002).

Similarly, Siedlecki et al. (2014) reported that individuals who felt satisfied with their relationships also feel happier more frequently and are more satisfied with their lives (indicators of SWB). There has been limited research conducted into the link between SWB and GI conditions, yet what does exist has suggested a negative relationship between GI conditions and SWB (Emerson et al., 2021; Farhadi et al., 2018). Further justification for the inclusion of SWB in a biopsychosocial exploration of GI conditions comes from the association between SWB and health, as health is one of the most critical influences on SWB (Larson, 1978; Steptoe et al., 2014). SWB is also associated with QOL, as Lex et al. (2019) state that the assessment of quality of life also involves assessing SWB across multiple dimensions. Despite being previously overlooked when exploring GI conditions, an evidence base suggests a link between SWB and GI conditions which could have implications for health and the psychosocial treatment of various conditions. This underpins the importance of including SWB in this research into the experiences of those with IBS and IBD.

1.7 Quality of life/Health-related quality of life

The importance of quality of life (QOL) in health has been acknowledged for decades. For example, the World Health Organisation (WHO, 1948) defines health as a state of complete physical, mental and social wellbeing, not just the absence of disease; this is a definition where life satisfaction and QOL are heavily implicated (Fayers & Machin, 2000). QOL and HRQOL are terms often used interchangeably within health research (Karimi & Brazier, 2016), yet HRQOL is slightly more difficult to define than QOL, and the two differ in what they measure, as HRQOL only considers factors that are involved in a person’s health, with factors included under QOL such as economic status not relevant (Torrance, 1987). Another way to consider HRQOL is that it is only concerned with factors of QOL related to health, such as SWB self-reported associated with the presence of a disorder (Shah, 1995). IBS is consistently ranked as reducing quality of life, even more than for patients receiving kidney dialysis or diabetics who rely in insulin injections (Collen, 2015), supporting its inclusion in Drossman's (2016) model as an outcome of IBS. There is a sizable amount of research that has reported that QOL and/or health-related quality of life (HRQOL) is depleted among those with GI disorders (Cho et al., 2011; Ansari et al., 2008; Gralnek et al., 2000). Therefore, exploration of QOL and/or HRQOL among those with a GI condition could provide further insight into these individual's experiences.

1.8 The role of current stage

Overarchingly, it is important to keep in mind that GI conditions like IBS and IBD are highly cyclic in nature (Gavrilescu et al., 2015; Evangelista, 2012), characterised by periods of symptom remission and activity. Clinical remission is characterised as an absence of symptoms (Teruel et al., 2016), and periods of remission are the most relief these individuals can hope to experience. The same is true for other conditions such as rheumatoid arthritis, with remission being the optimal outcome, yet with rheumatoid arthritis, greater efforts are made to specifically target remission as a priority, due to its positive influence on HRQOL (Scott et al., 2019). As such, remission is a critical time that needs to be better understood. To do this, this research will aim to address the remission and active stages equally. Research into IBS and IBD in remission is limited in comparison to the active stage, yet it reveals that for these conditions, remission is not as straightforward as in other conditions such as rheumatoid arthritis. For example, remission does not always offer the relief hoped for, particularly for those with IBD, with physical symptoms such as pain still often experienced (Sweeney et al., 2018). There is also research to suggest that wellbeing can still be affected during remission, as Iglesias et al. (2010) have reported that HRQOL is often still negatively affected among those with IBD. In fact, those with IBD may not experience a relief from symptoms at all, instead experiencing IBS-like symptoms during remission (Jelsness-Jorgensen et al., 2014; Ozer et al., 2020; Teruel et al., 2016). It is estimated that around one-third of patients with IBD in remission experience IBS-like symptoms (Barbara et al., 2014). Therefore, remission as a stage of IBS and IBD is complex and experiences during this stage are often not aligned with the idea that remission is a symptom-free period (Teruel et al., 2016). There also needs to be greater consideration of psychological and social experiences during remission, as this is currently lacking compared to the active stage of IBS and IBD.

1.9 Patient and public Involvement

There is increasing interest in patient and public involvement (PPI) in health and social care research (Beresford & Russo, 2020). PPI increases the value of research to patients and the public and gives them power and a voice (Wicks et al., 2018). Employing some form of PPI prior to, or alongside, research supports the view that patients have a level of expertise and knowledge that is valuable to researchers (Karazivan et al., 2015). PPI engagement for this research included attendance at meetings of the Crohn’s & Colitis Durham & Wearside branch support groups which provided opportunities to engage with individuals with IBD and discuss what they felt the direction of future research should be. A key outcome of this PPI engagement was that these individuals felt that there was a lack of awareness of GI conditions, but IBD specifically, as many group members revealed that the wider population often weren’t aware of IBD as a condition, instead referring to it as IBS. This finding is reflective of the lack of biopsychosocial model applicable to IBD, which this research sought to develop. To further address this outcome, study 2 aimed to further explore how individuals with a GI condition believe awareness could be increased.

1.10 Thesis overview, aims and research questions

GI conditions such as IBS and IBD have been increasing in prevalence (Molodecky et al., 2012), and have become global health concerns. A great deal of research has explored the biological aspects of these conditions, in accordance with the biomedical model's previous dominance in health research (Anjum et al., 2020). The complexity of conditions such as IBS and IBD means they require exploration using holistic frameworks like Engel's (1977) biopsychosocial model of health (Havelka et al., 2009). The research undertaken within the remit of this PhD aims to investigate the influence of GI conditions (IBS or IBD) on psychosocial wellbeing and health outcomes consistent with the biopsychosocial model of health such as social support, SWB, emotion recognition and coping. To address this aim, the research conducted in this thesis addresses the following research questions:

1. What is the influence of the GI conditions IBS and IBD on psychological and social factors and wellbeing outcomes?
2. What is the influence of GI condition stage on psychological and social factors and wellbeing outcomes?

1.11 Original Contribution

This research aimed to demonstrate the novel application of biopsychosocial models (Drossman, 2016; Engel, 1977) to the study of IBS and IBD by combining existing research frameworks and including additional key factors. Specifically, this research sought to consider the perceived social support of individuals with IBS or

IBD in greater depth than previously done, taking a novel approach to include an exploration of the link between emotion recognition and social support in GI conditions. Typically, difficulties recognising emotions displayed in those with GI disorders are attributed to a comorbid diagnosis of alexithymia, however, this research posits that there might be more to this than just a biological comorbidity, hence why the use of the biopsychosocial model is critical. The integration of the biopsychosocial models with additional factors (subjective wellbeing, health-related quality of life, employment, and emotion recognition) was a contribution designed to better understand the complexities of IBS and IBD.

Drossman (2016) had devised a model to explain the biopsychosocial expression of IBS, and while this model outlined factors similar to those demonstrated as being involved in IBD, such as social support and coping, this model had not been applied to the exploration of IBD. This was an original contribution of this research. While it has been proposed that there is little benefit in exploring IBS and IBD separately as they can both be classified as disorders of gut brain function (Drossman & Hasler, 2016), there is a need to further investigate whether the same psychosocial factors and wellbeing outcomes are involved in the pathogenesis of both conditions before a model can be deemed applicable to both IBS and IBD.

This research aimed to gain more in-depth information into the remission stages of IBS and IBD, since, compared to the active stages, remission has been under-researched. This research aimed to provide opportunities to contrast results/outcomes between individuals in the active and remission stages of IBS or IBD. Since IBS and IBD are chronic conditions, remaining in remission is currently the optimal outcome and should be maintained (Gavrillescu et al., 2015), but despite this, research focus has typically been on the active stage. An aim was to highlight the experiences of remission for those with these conditions and encourage further exploration.

1.12 Thesis Outline

A discussion of the conceptual and methodological underpinnings of this research is included in Chapter 2. Chapter 3 presents the first study, a scoping review which both clarified what is already known regarding the influence of gastrointestinal conditions on wellbeing outcomes associated with the biopsychosocial model of healthand also highlighted gaps in the literature to guide the later studies in this thesis. Chapter 4 presents the second study; a qualitative exploration of the lived experiences of individuals with IBS or IBD. The third study (Chapter 5) built on the findings of the first two studies and was aquantitative exploration of the psychosocial aspects of IBS and IBD. Study three also investigated the potential role of emotion recognition in these conditions. Chapter 6 provides a general discussion of the thesis project, with proposals for future research in the area.

Chapter 2

Conceptual Frameworks and Methodology

2.0 Existing models of health

In this chapter, commonly applied models of health are discussed in relation to GI conditions. The selection of the biopsychosocial model over other models is justified and considered in relation to its application to qualitative and quantitative research frameworks. The inductive approach undertaken in this thesis is also outlined.

2.0.1 The Biomedical Model

The dominant paradigm used to explore health conditions has previously been the biomedical model (Sheridan & Radmacher, 1992). The biomedical model is influenced by Cartesian dualism, which views the mind and body as separate entities, meaning one can be understood and exist without the other (Burwood et al., 1999). For example, the biomedical model would view emotions as belonging solely to the mind, and so cannot affect the body or physical health (Sheridan & Radmacher, 1992). According to the biomedical model, research into health conditions should be biological in focus, addressing the pathogenesis, aetiology and treatment of disorders (Holtmann et al., 2016; Theede et al., 2013). Application of the biomedical model to GI conditions results in their cause being ascribed to biological changes in the body, such as changes to the gut microbiota, inflammation of the GI tract, or increased gut motility, with no consideration of potential external influences.

While the biomedical model has been hugely influential and useful (Sarafino & Smith, 2014), particularly in the treatment and control of infectious disease (Havelka et al., 2009), it has been less useful when applied to non-infectious conditions (Havelka et al., 2009). For example, over the 20th century, acute problems such as pneumonia and rheumatic diseases which have been successfully studied following the application of the biomedical model (Abelson et al., 2008). However, the application of a singlular cause of illness does not provide sufificent explanation, as factors related to the individual have not been considered (Abelson et al., 2008). This criticism aligns with a social change in health care, which has seen patient rights and autonomy increase in importance (Bolton & Gillet, 2019). Critics of the biomedical model argue strict reliance on biology comes at the detriment of the patient/individual, failing to include them and their attributes in the model (Engel, 1981).These criticisms, in combination with the introduction of psychosomatic medicine, which challenged the biomedical view by suggesting diseases should be considered in relation to the interplay of biological, social and psychological phenomena (Lipowski, 1984), caused health researchers to shift their focus away from the biomedical model and towards more holistic models which better acknowledge the connection that exists between mind and body in health and illness (Fritzche et al., 2020).

2.0.2 Holistic health models- the social model.

Despite criticism, the biopsychosocial model is preferred by health researchers over other models such as the social model of health which emerged from the social model of disability (Oliver, 1990). The social model was developed as a rejection of the biomedical model (Terzi, 2004) and sees disability as the result of factors within the social world including health facilities, employment and housing

(Oliver et al., 2012). According to this model, society is a central cause of illness, as it is societal norms and resources that contribute to illness, rather than the individual (Bolton & Gillett, 2019). For example, the social model has been applied to chronic illnesses such as chronic pain, with focus on how social change could improve such conditions, by increasing inclusion and accessibility and changing attitudes in society (Goering, 2015). This model can be praised for considering an individual's health as a whole, rather than the solely the result of biological processes (Blaxter, 2010); it is consistent with changes to the definition of health, which is no longer just an absence of disease, rather it is an overall positive state (WHO, 1948). However, critics of the social model point out that it fails to account for agency in health since it implicates society as the sole cause for health conditions, ignoring an individual's agency to manage their conditions and cope in society (Oliver et al., 2012; Terzi, 2004). In this way, the social model receives the same criticism as the biomedical model, as its focus is too narrow.

2.0.3 Holistic health models- the biopsychosocial model

A strength of the biopsychosocial moel (Engel, 1977) is that it does not have a narrow focus, which has resulted in this model being preferred in wider health research (Pilgrim, 2015; Wade & Halligan, 2017) and this thesis. Rather than trying to replace the biomedical model, as the social model did, the biopsychosocial model aimed to expand upon it, so as not to waste the vast knowledge the biomedical modlel had accumulated. In this way, the biopsychosocial model can combine biological information with psychosocial information to create a biopsychosocial narrative for each individual (Farre & Rapley, 2017). This has led to it acquiring approval from critical realists and phenomenologists (Pilgrim, 2015). Phenomenologists appreciate the emphasis the biopsychosocial model places on the personal context, such as the experiences and actions of an individual with a condition (Wade & Halligan, 2017), making it well-suited to exploring the lived experiences of a population.

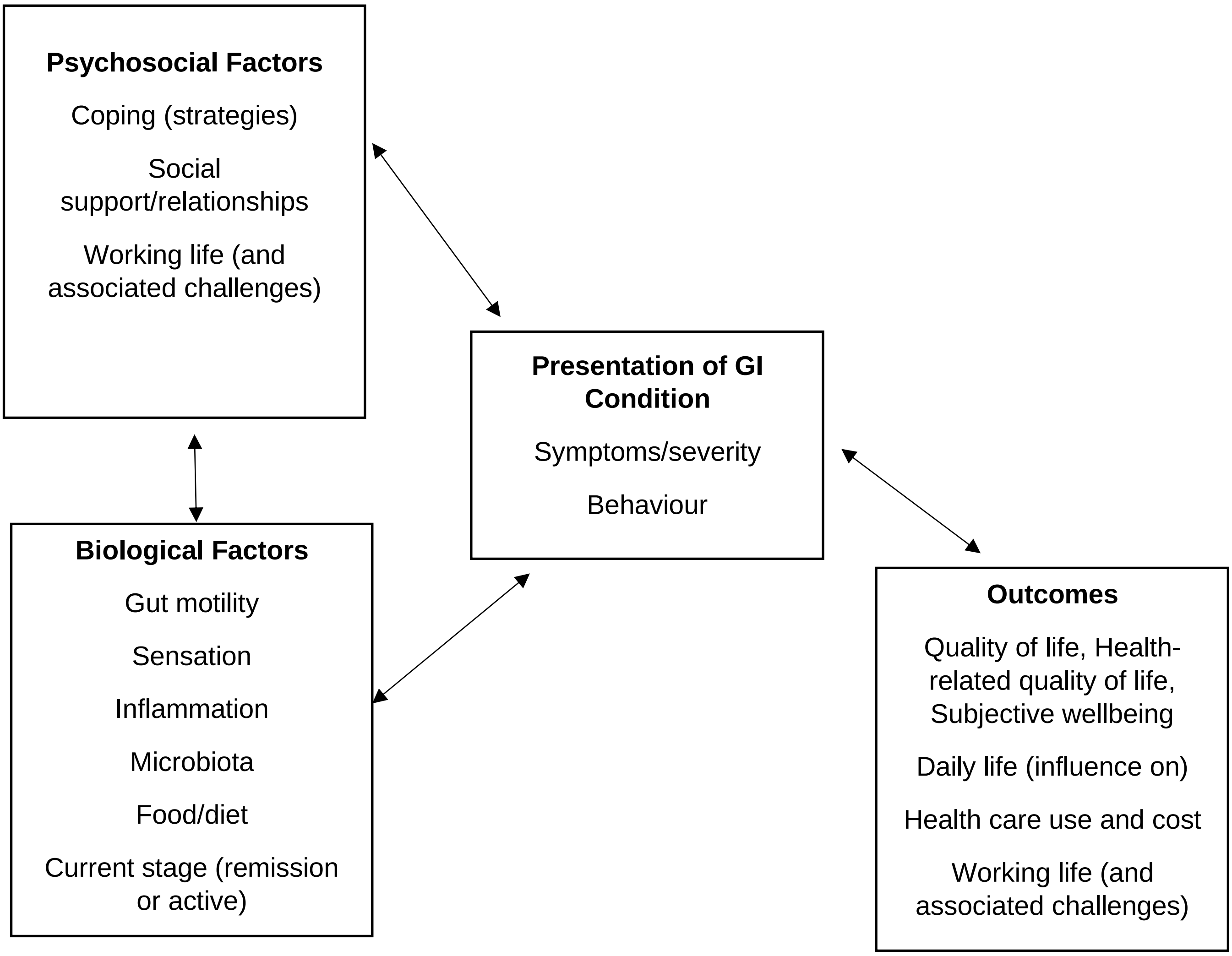
Since Engel's (1977) biopsychosocial model sought to build upon the foundations of the biomedical model, it helped to transform the understanding and definition of health from an absence of disease, as conceptualised by the biomedical model, to one that recognises a wider range of factors involved in health and places the individual at the centre (Farre & Rapley, 2017; Sarafino & Smith, 2014). This definition is also consistent with the World Health Organisation definition that health is more than the absence of disease, it involves biopsychosocial wellbeing (WHO, 1948). The biopsychosocial model highlights the interplay of factors such as genetics, psychological functioning, lifestyle, social status, social support, and environmental influences (Suls & Rothman, 2004; Zittel et al., 2002) in health outcomes. This model has been applied in various branches of health sciences such as surgery, intensive care units, physiotherapy, and psychiatry, among others (Havelka et al., 2009). Specific health conditions have been explored with reference to the biopsychosocial model, including diabetes, (Marks et al., 2020; Sheridan & Radmacher, 1992), asthma (Wright et al., 1999) and IBS (Drossman, 2006; 2016). As such, this model has formed the base for health psychologists, researchers and policy makers, yet it is not without its criticisms, including concerns around its misuse by inappropriately trained healthcare providers (Gatchel & Turk, 2008; Moser & Stagnaro-Green, 2009). Ghaemi (2009) argues that this misuse may be the result of the model being too generic in its extent meaning that health professionals have little direction on its application. There is also argument that the model has not been sufficiently operationalised as the factors within it are only vaguely defined (Ghaemi, 2009)

The biopsychosocial model, which views health as the result an interplay of biological, psychological and social factors, has increased in popularity and application, being progressively applied to health policy (Farre & Rapley, 2017), yet it is argued that healthcare staff, funders and the general public are not as aware of the model as they should be (Lane, 2014; Wade, 2015). Wade and Halligan (2017) argue that highlighting the use and efficacy of the biopsychosocial model will improve healthcare systems. The biopsychosocial model has been applied previously to explore GI conditions. For example, to better understand the factors involved in IBS, Drossman (2016) developed a model to provide a visualisation of the interaction between biological and psychosocial factors specific to IBS. Within Drossman's (2016) model the biological factors of gut motility, sensation, inflammation, altered microflora and food/diet are inter-connected with psychosocial factors such as life stress, personality traits, psychologic state, coping/cognitions and social support. Interaction between these factors determines symptom severity and the display of illness behaviours, with ultimate outcomes related to health care use, daily function, QOL and health care costs, which can also influence symptoms and behaviour (Drossman, 2016). The foundations of this model are factors that occur in early life, such as genetics, culture and environment.

The biopsychosocial model (Engel, 1977) was selected for use as a guiding framework for this thesis as it is well-established and cited as the preferred model for studying IBS (Soares, 2014). There have been multiple conceptualisations of the biopsychosocial model, yet the one most closely linked to the aims of this research was Drossman's (2016) model. This model provides a relatively comprehensive overview of the biopsychosocial expression of IBS and places greater emphasis on the psychosocial outcomes of IBS than other models. However, this research sought to extend the application of this model to the study of IBD, since there is research in support of their shared similarities (Drossman & Hasler, 2016; Rani et al., 2016). Alterations were also made to Drossman's (2016) model, including the substitution of psychologic state and life stress for subjective wellbeing, health-related quality of life, a consideration of emotion recognition and remission as aspects of IBS and IBD experience. The proposed revised model is outlined in Figure 1 and the concepts within this model are further discussed in the following sections.

Figure 1

A biopsychosocial model of factors implicated in the experience of IBS and IBD.



2.1 Theories and models relevant to psychosocial factors to be considered

The biopsychosocial model of health has become a well-established alternative to the biomedical model (Wade & Halligan, 2017), but there does not seem to be consistency and clarity in terms of the factors included within the model and how these are operationally defined. This is evidenced in researcher’s differing definitions of factors included in the biopsychosocial model (Gliedt et al., 2017; Sarafino & Smith, 2014; Taukeni, 2020). In this section, each factor to be considered in line with the biopsychosocial model will be defined, with reference to relevant theories and justification for the selection of those most appropriate to this research.

2.1.1 Subjective wellbeing

Wellbeing as a concept is linked to health and quality of life (Sfeatcu et al., 2014) and can be thought of as existing across a subjective and objective dimension, including life experiences and how these compare with social norms (Sfeatcu et al., 2014). Subjective wellbeing (SWB) is a subset of wellbeing focused solely on the subjective dimension of wellbeing and is which is recognised as belonging to the field of psychology as it involves some evaluation on the part of the individual in terms of the quality of their own life (Adler & Fleurbaey, 2016). SWB demonstrates the importance of an individual’s perceptions (subjectivity) since those with objectively similar circumstances could have opposing perceptions of their life (Adler & Fleurbaey, 2016). SWB is typically defined as having three elements: life satisfaction and experiences of positive affect and experiences of negative affect. SWB is high when life satisfaction and positive affect are both often experienced, along with low levels of reported negative affect (Diener et al., 1997). There is an argument that high SWB indicates that a person is doing well, or thriving (Adler & Fleurbaey, 2016).

Numerous theoretical explanations of SWB exist, including the hedonic treadmill theory of SWB, outlined by Brickman and Campbell (1971), which states that positive and negative life events temporarily affect happiness, but people can quickly adapt and return to neutrality (Diener et al., 2006). According to this theory, everyone has their own set point at which they achieve this hedonic neutrality and this point is dependent on temperament. Support for the hedonic treadmill theory comes from Suh et al. (1996) who reported that life events only influenced judgements of life satisfaction and positive affect if they occurred in the previous three months, suggesting after this neutrality is achieved. Conversely, there is evidence that lasting changes to SWB can occur following life events, which would seem to disagree with the idea that we return to baseline (Luhmann & Intelisano, 2018; Mancini et al., 2011). Ultimately, the hedonic treadmill theory of SWB has mixed support and requires further exploration.

The bottom-up theory of SWB sees wellbeing as the outcome of many small pleasures. When assessing if they are happy, an individual performs a mental calculation to weigh up their positive and negative experiences, perceiving themselves to be subjectively happy if the positives outweigh the negatives in their life. According to the bottom-up theory, SWB could be determined by summing up wellbeing in various domains such as marriage, family life, financial situation and work life (Brenner & Bartell, 1983; Shields & Wooden, 2003; Zyphur et al., 2015).

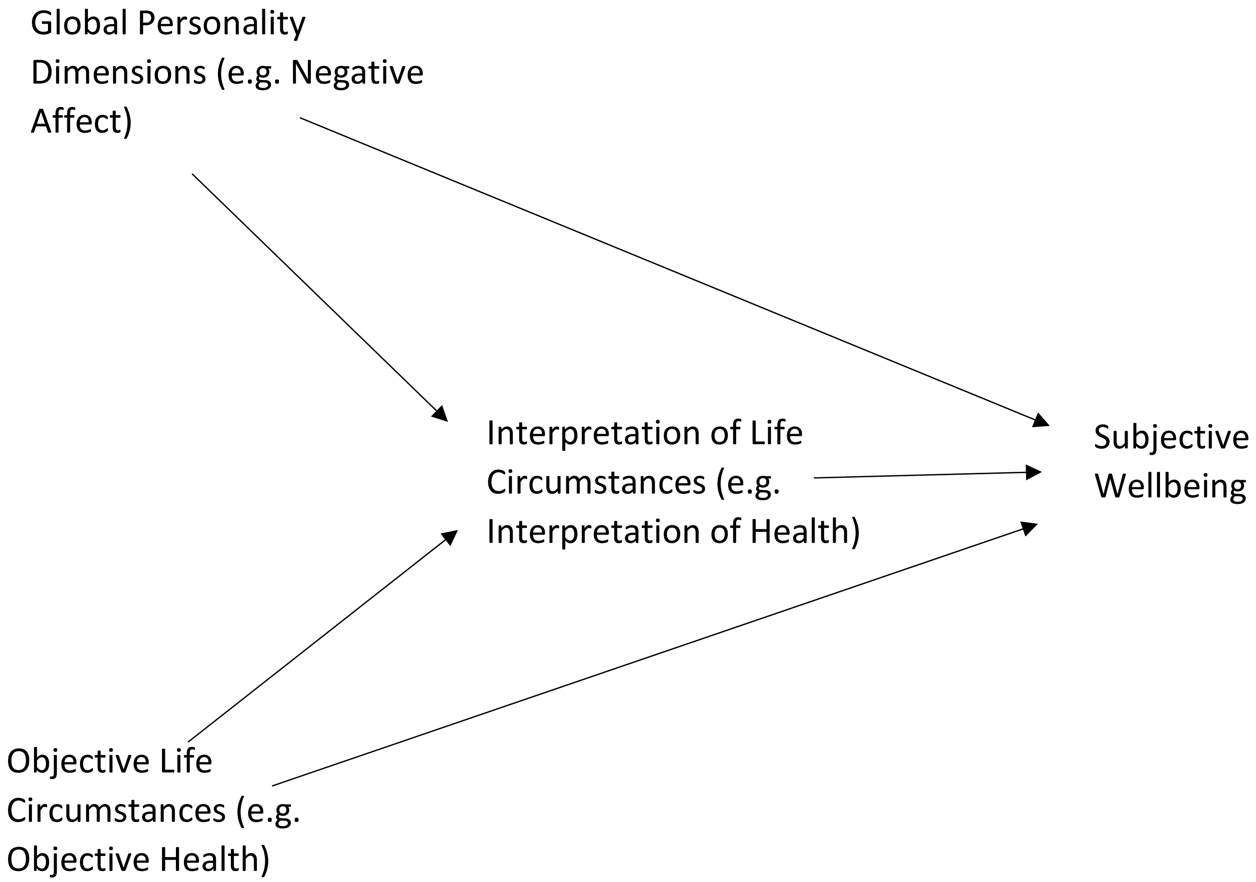
In contrast, the top-down theory of SWB posits we are either inclined to experience things positively or negatively, and this influences the way we interact with the world (Feist et al., 1995). Therefore, an individual experiences pleasure because they are already happy, not vice versa. This theory considers the influence of personality in determining how individuals respond to experiences (Brief et al., 1993), and its association with SWB, with traits such as extraversion repeatedly linked to positive experiences (Steel et al., 2008; DeNeve & Cooper, 1998).

Perhaps a more comprehensive theory of SWB is the bottom-up and top-down theory of SWB, which combines the two opposing theories (Figure 2). This theory states that objective life circumstances (bottom-up) and global personality dimensions (top-down) are both involved in judgements of SWB (Brief et al., 1993). An integrative bottom-up and top-down theory challenges the criticism that theories of SWB have remained separate rather than integrating to form a more holistic construct, with research reporting that both models are equally important, further supporting an integrated theory of SWB (Feist et al., 1995).

The most well-known and applied model when exploring SWB is Diener's (1984) tripartite model, which has been reported as having conceptualised SWB (Metler & Busseri, 2015). This model views SWB as consisting of three factors: life satisfaction, high positive affect and low negative affect (Busseri, 2015). Research has demonstrated links between the tripartite model of SWB and health outcomes, with life satisfaction, positive affect and limited negative affect predictors of mortality and health (Diener & Chan; Pressman & Cohen, 2005). This model remains the dominant model when referring to SWB (Adler & Fleurbeay, 2016), having been applied to thousands of pieces of research, resulting in a strong evidence base to support the validity of this model (Busseri & Sadava, 2011). Typically, it is the tripartite model applied to assess the SWB of individuals with IBS (Farhadi Et al., 2018). Therefore, when exploring the SWB of individuals with a GI condition this research will refer to Diener’s (1984) tripartite model and the integrated bottom-up and top-down theory as these provide the most comprehensive conceptualisations of SWB and view SWB as a holistic evaluation of wellbeing and quality of life.

Figure 2

An integrated bottom-up and top-down approach to SWB. Redrawn from Brief et al. (1993).



2.1.2 QOL

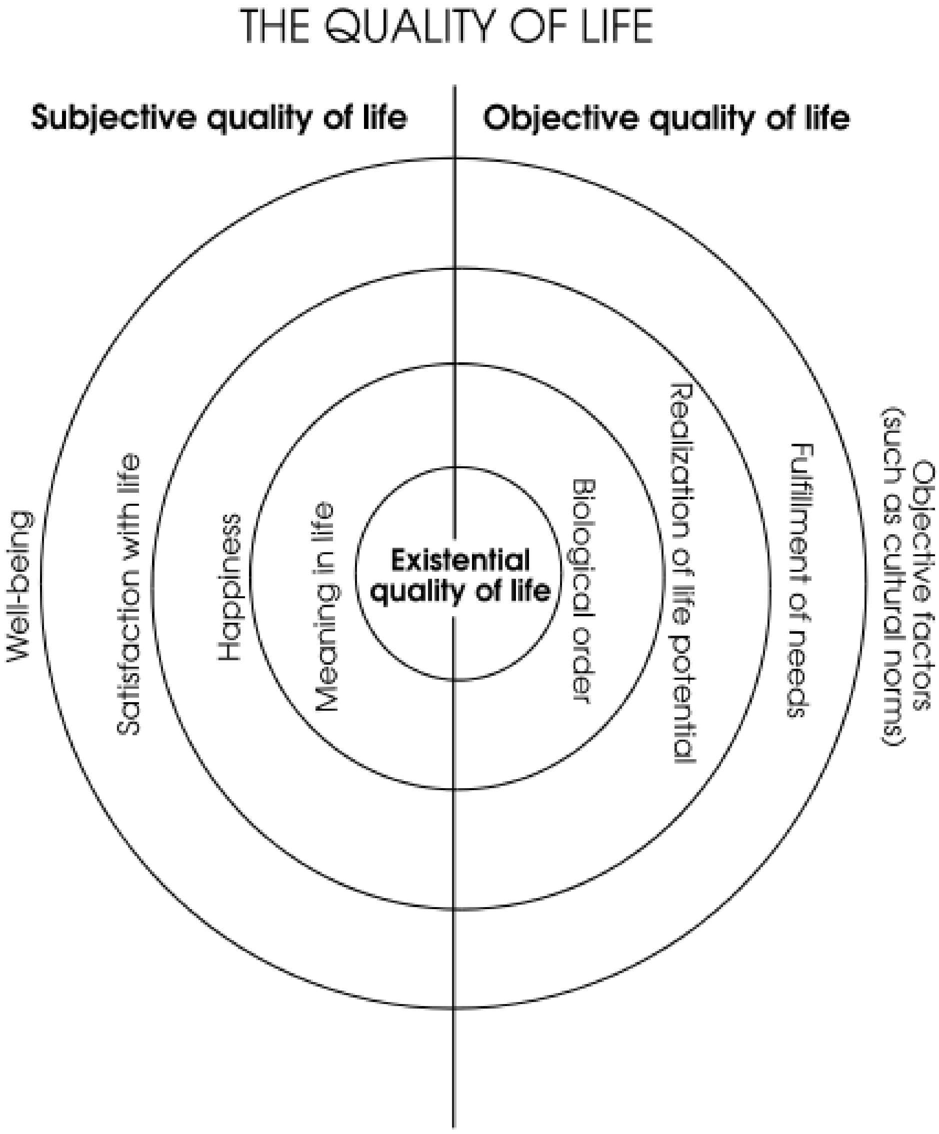
There is a well-established link between QOL and health (WHO, 1948). Across health conditions, QOL is typically impaired (Gralnek et al., 2000; Shofany, 2017), as is the case for IBS and IBD (Irvine, 2007; Kopczynska et al., 2018). Drossman's (2016) model implicates QOL as an outcome of IBS, further supporting that QOL is an important aspect to consider. Numerous theories of QOL exist, with Maslow's (1962) hierarchy of needs one of the most well-known. This theory views QOL as an outcome for those who have their personal needs met and achieve self-actualisation (Marks et al., 2015; Ventegodt et al., 2003). As we advance the hierarchy, we progress from physical concepts such as access to sufficient food, water and shelter, to psychological and social concepts such as love and relationships such as friendship and self-esteem. In essence, this theory sees biological needs as the foundation of QOL, with QOL increasing as psychosocial needs are met.

Maslow's hierarchy of needs has formed the basis of the realising life potential theory, which, as its name suggests, posits that QOL is linked to the realisation of potential (Ventegodt et al., 2003). This theory strongly supports Maslow's concept that life is structured as a hierarchy, and part of this hierarchy is the biological potential of humans. When this biological potential is combined with our tendency to self-organise, it is evident that our biological potential is linked to the realisation of life potential. This is more commonly referred to as the will to live, a will that all living organisms share (Ventegodt et al., 2003). This will to live is evident in our life intentions, the things we aspire to, and would provide us with the feeling our lives are of good quality, for example, a meaningful occupation, a family, supportive friends and so on (Ventegodt et al., 2003).

These ideas are included in the integrative QOL theory (Ventegodt et al., 2003). This theory posits that QOL can be split into three groups: subjective QOL, existential QOL and objective QOL. Subjective QOL is concerned with how we feel about our life, whether we are content with it. It is important to note that, while often used interchangeably, subjective QOL and SWB are conceptually distinct (Skevington & Boehnke, 2018). Subjective QOL is a more broad-ranging concept that accounts for the influence of physical health and social relationships influence an individual's perception of their life (WHO, 1994). Existential QOL takes this concern to a deeper level and is based on the fulfilment of biological needs and living in accordance with religious or spiritual ideals. Objective QOL refers to how others perceive our life, for example symbols such as social status serve to inform others our standing in a particular culture. The integrative QOL theory conceptualises QOL as existing on a spectrum (as evidenced in Figure 3), with subjective and objective QOL at opposite ends united by existential QOL. Within this thesis, QOL will be conceptualised using the integrative QOL theory because it provides a holistic overview of judgements that comprise QOL. This theory also links well with the biopsychosocial model of health (Engel, 1977) as it stresses the importance of psychological aspects such as SWB, life satisfaction, meaning in life, and happiness in QOL, along with social aspects such as marital status and cultural norms, as well as considering biological aspects through the consideration of physical health, fulfilment of needs (Ventegodt et al., 2003). Support for an integrative definition and theory of QOL comes from Costanza et al. (2008) who argue that theories of QOL should combine objective and subjective needs, suggesting that when measuring QOL among those with GI disorders, an integrative approach should be adopted.

Figure 3

The Integrative QOL theory (Ventegodt et al., 2003)



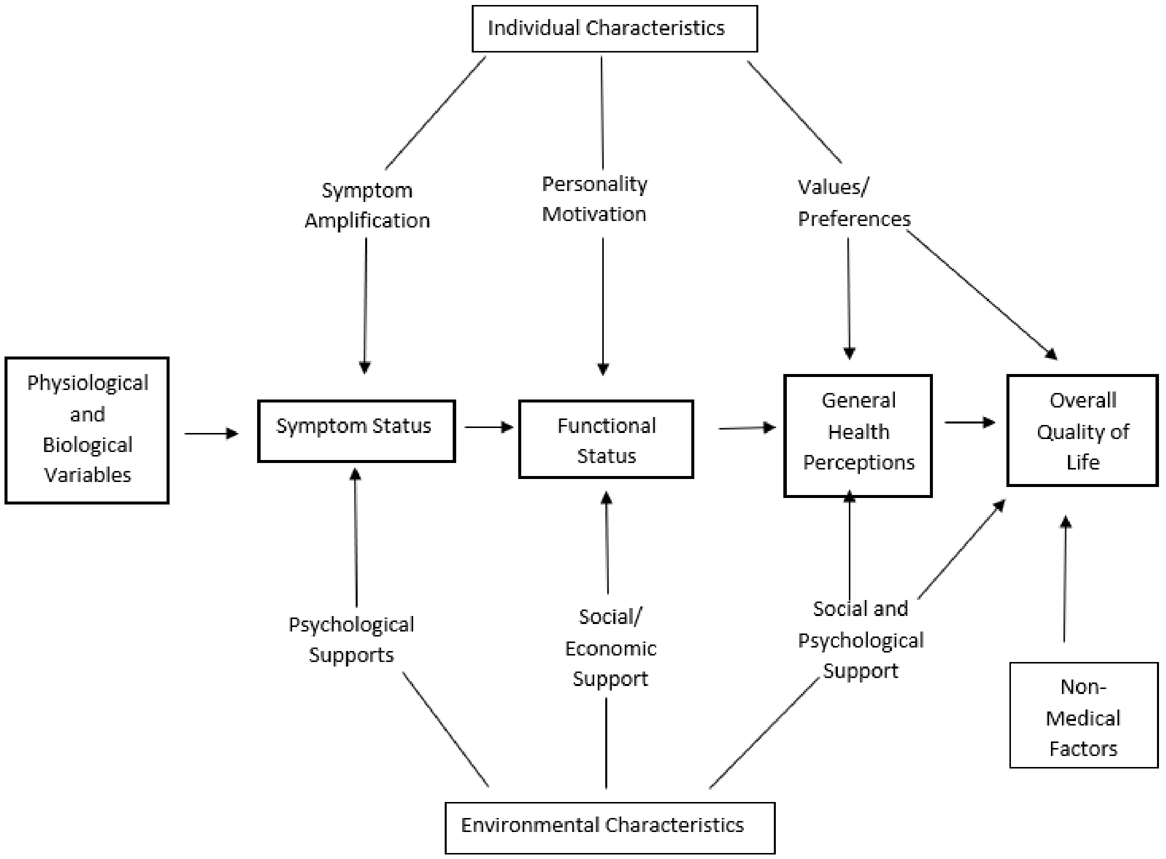
2.1.3 HRQOL

QOL and HRQOL are often used interchangeably as wellbeing terms, but HRQOL has a more specific focus on the relationship between an individual’s health and their QOL (Karimi & Brazier, 2016). It is increasingly important to consider HRQOL in research because of its focus on wellbeing and the acknowledgement that this is affected by health status and social support (Zubritsky et al., 2013). Wilson and

Cleary (1995) proposed a model of HRQOL integrating objective (biological) and subjective (psychological) health constructs (Figure 4). Wilson and Cleary's (1995) model is widely cited and praised for its real-world application since it generates a view of HRQOL that extends beyond only biological factors (Wilson & Clearly, 1995). There are five subsections to this model: biological and physiological factors; symptoms; functioning; general health perceptions; and overall quality of life (Wilson & Cleary, 1995). The relationship between these subsections is linear as they exist on a continuum of increasing biopsychosocial complexity, beginning with biological and physiological variables, such as changes at a cellular or organic level, or a diagnosis (Wilson & Cleary, 1995). Focus then shifts away from the cellular and organic and towards a more holistic consideration of physical symptoms and psychological symptoms related to mental health (Wilson & Cleary, 1995). Symptom status determines functioning which involves physical function, social function, role function and psychological function, concepts all related to whether an individual can function sufficiently in their daily lives. Functioning then leads to general health perceptions, a predictor of health service use (Connelly et al., 1989; Krakau, 1991) which determines overall quality of life, and is thought to be closely related to SWB in that it encompasses judgements of affect and satisfaction (Wilson & Cleary, 1995). Wilson and Cleary's (1995) model provides a holistic consideration of HRQOL which encompasses SWB. As such, this model links effectively to the biopsychosocial model with its focus on physical, social and psychological functioning and how these may contribute to lived experience, meaning this is a highly appropriate model for this research.

Figure 4

Redrawn Wilson and Cleary's (1995) model of HRQOL



2.1.4 Social support

Social support is recognised as important for the maintenance of physical and mental health (Harandi et al., 2017; Uchino, 2006). There are various theoretical perspectives of social support that guide research (Lakey & Cohen, 2000). According to the stress and coping perspective, social support is beneficial to health as it protects from stress and can improve coping (Lakey & Cohen, 2000). In this way, negative life events are perceived as easier to cope with and less stressful due to the moderating effects of social support. The stress and coping perspective is similar to the stress prevention model (Dignam et al., 1986) since both view support as negatively related to stress and distress.

Another theory of social support that is commonly referred to is the theory of perceived social support which views social support as the belief that we are connected to others (Barrera, 1986). Commonly, perceived social support incorporates judgements of support availability and adequacy, and considers whether individuals feel confident that they can receive social support. This theory is related to the stress and coping perspective, as perceived social support increases an individual's resilience to stress (Ozbay et al., 2007) and provides them with resources to better cope (Chi et al., 2011). These theories, which are closely linked, will be referred to when conceptualising and investigating social support within this research.

2.1.5 Coping (strategies)

Research into coping is rooted in psychology and psychoanalysis but is becoming increasingly inter-disciplinary (Duhachek & Oakley, 2007). There are various theories and approaches used to explain coping, with some more accepted than others. For example, the psychoanalytical approach viewed coping in terms of defence and ego functioning (Mitrousi et al., 2013). According to this approach coping is hierarchical in nature, with variation in how healthy defences are (Menninger et al., 1963). The principal belief behind the psychoanalytic approach was that different mental disorders were associated with different defences (Mitrousi et al., 2013), but it has been acknowledged that this belief is too simplistic to explain the complexities of coping (Lazarus, 1993).

Drawing on the psychoanalytic approach, the trait approach positions personality traits as influential in coping (Mitrousi et al., 2013), highlighting the relationship between personality traits and bodily reactions (both physiological and psychological) to stress. There has been debate as to whether personality traits are strong predictors of coping strategies, with argument that personality and coping are psychological constructs with little compatibility (Parker & Wood, 2008). Since personality traits are thought of as stable, yet coping is not, rather it is situationally dependent (Mitrousi et al., 2013), the apparent disconnect between the two constructs is a criticism of the trait approach, as it seemingly neglects any adaptability in strategies used (Mitrousi et al., 2013).

Directly opposing these ideas, Lazarus and Folkman (1984) view coping as a process rather than a set of stable behaviours (Lazarus, 1993; Mitrousi et al., 2013). Lazarus and Folkman’s transactional model (1984) suggests interaction occurs between the individual and the stressful experience and the individual must go through two processes. In the first process, a cognitive assessment of the extent of the situation and how it relates to them is constructed (Mitrousi et al., 2013). The second process relates to how an individual will then go on to deal with the stressful problem (Mitrousi et al., 2013). These stages are not linear. The view that coping is a process has largely replaced approaches which saw coping as a trait dependent on personality, which have been criticised for being one dimensional (Mitrousi et al., 2013). Instead, the transactional model sees coping as flexible, altered by time and situation (Lazarus, 1993). The transactional model also acknowledges the interplay that occurs between social support and coping, particularly evident among those with health conditions (Graham, 2015; Sanaeinasab et al., 2017). As the transacrional model acknowledges advances in how coping is conceptualised, and the link between social support and coping, this research will consider coping with reference to this model.

2.1.6 Emotion recognition

Charles Darwin proposed there is a universality to emotions, which extends across cultures to aid communication (Ekman, 2003). This universality of emotion as displayed via facial expression is corroborated by Ekman's renowned research in the 1960's, which revealed there are six basic emotions; happiness (sometimes referred to as joy), sadness, surprise, disgust, fear, and anger, which have been cross-culturally validated (Paiva-Silva et al., 2016).

A topic for debate among research into emotion recognition has been whether emotions are reflexive to events such as a physiological stimulus, as stated by the James-Lange theory (James, 1884)- a theory that has been criticised for lacking in evidence to support (Thanapattheerakul et al., 2018), or are the result of our interpretation of an event (Barrett, 2011). The Cannon-Bard theory was developed as a theory in response to criticism of the James-Lange theory, with the idea that physiological responses and the emotional experience occur in unison (Cannon, 1927). The two-factor theory proposed by Schachter and Singer (1962) combines both the James-Lange and Cannon-Bard theories by proposing that the first step to emotion is physiological and the second step is understanding this response in relation to the circumstances. This debate has made way for the psychological research into emotion conducted today. Constructionist theories such as the Conceptual Act Model (Barrett, 2011) of emotion view emotion as the outcome of an interaction between core affect (positive or negative and level of arousal) and past experiences. This experience of emotion (which is largely attributed to culture and socialisation) is key, as without it the sensory input (affect) would have no meaning (Barrett, 2018). This explains how individuals' experiences of emotion can be so varied.

This research will consider the potential role of emotion recognition in IBS and IBD via alexithymia- a trait associated with difficulty recognising emotion (Martinez-Sanchez et al., 2017). Higher rates of alexithymia have been observed among those with IBD (Porcelli et al., 1995) and IBS (Poreceli et al., 2017; Porcelli et al., 1999) compared to control groups of those without GI conditions. This suggests these individuals have greater difficulty recognising emotion than the general population. An additional consideration is the link between emotion recognition and social support, since effective recognition of emotions is an integral part of social interaction (Mumenthaler et al., 2020). Social support and relationships may be challenging for individuals with IBS or IBD due to difficulties recognising emotions. Consideration of this argument could have important implications for improving the social support of this population, which would improve SWB (Diener & Oishi, 2005).

2.2 Ontological and epistemological underpinning of the studies.

Central to this research was an inductive process, which leant itself to a mixed methods approach where the outcomes of each study informed the focus of the next. Creswell (2015) states that researchers should provide justification for their use of mixed methods. Increasingly, it is acknowledged that qualitative and quantitative research methods can be used in harmony rather than being methodologically and philosophically at odds (Memon et al., 2017; Wright & Losekoot, 2012). Mixed methods are often used when it is believed that the use of quantitative or qualitative methods alone will not provide sufficient insight or knowledge of a topic (Creswell, 2015). Schoonenboom & Burke Johnson (2017) further this argument, stating that the goal when employing a mixed methods approach is to increase the strength of a researcher’s conclusion. In this way, the suite of studies conducted in support of this thesis were designed to have an inductive, feed-forward approach, with outcomes of one study, or studies, informing the focus and design of the next. This was to ensure focus remained relevant and served to strengthen conclusions. As such, a mixed methods approach uses both a positivist and interpretivist perspective to better understand a phenomena/experience (Burke Johnson & Onwuegbuzie, 2004). Often, a pragmatic philosophical approach is implemented to gain the benefits of both qualitative and quantitative methods and minimising their negatives (Burke Johnson & Onwuegbuzie, 2004).

Used as a research paradigm, pragmatism views there is an objective reality, but this is linked to the environment and can only be accessed through human experience (Kaushik & Walsh, 2019). Reality and knowledge are socially constructed (Kaushik & Walsh, 2019). Pragmatists believe that there is no answer to philosophical argument over which approaches are best, rejecting the competing beliefs of objectivism and subjectivism (Kaushik & Walsh, 2019), therefore bridging the gap between the ideals of positivism and interpretive phenomenology (Creswell, 2015). With pragmatism, researchers can move between the deductive reasoning of a quantitative approach and the inductive reasoning of a qualitative approach, applying abductive reasoning, with the idea that reality does exist (positivism), but individuals have differing interpretations of this reality (Morgan, 2007). Abductive reasoning has been applied in this research, as an inductive qualitative study has been conducted prior to a deductive quantitative study to ensure that topics and measures are appropriate in fit to those involved (Creswell, 2015; Morgan, 2007).

In the context of the topic of this thesis, this pragmatic approach was the most appropriate position and was implemented in the following ways. The first step in this process was to understand the breadth of existing literature in the area, which was achieved through a scoping review. This identified where gaps in knowledge existed and areas that required further investigation. Following this, an exploratory sequential design was employed with qualitative data collection to explore the lived experiences of individuals with IBS or IBD. The interview schedule was developed with reference to study one’s outcomes and the biopsychosocial model. The emergent themes from this study were further tested and explored using a quantitative methodology.

2.3 Implementation of an inductive approach

The use of mixed methods and an inductive, feedforward research process (outlined in figure 5) within the suite of three studies was adopted to better explore the personal experiences of those with IBS and IBD. Initially, this involves a scoping review to demonstrate the breadth and focus of existing literature, while also highlighting gaps in this literature that required addressing. Outcomes of this review determine the selection and focus of subsequent semi-structured interviews with individuals diagnosed with either IBS or IBD. Following analysis, emergent themes from these interviews guide the factors to be further addressed using a quantitative survey method.

Figure 5

The inductive, feedforward research process

2.4 Conclusion

In this chapter, justisifcation for the selection of the most appropriate model of health is provided. The conceptual frameworks employed to operationalise the concepts in the biopsychosocial model and the selection of additional psychosocial factors and wellbeing outcomes expected to be involved in the pathogenesis of IBS and IBD have been outlined in this chapter. Ontological and epitstomological stances are addressed and there is an overview of the pragmatic and inductive approach to be used in this thesis.

Chapter 3

The Influence of Gastrointestinal Conditions on Psychosocial Factors Associated with the Biopsychosocial Model of Health: A Scoping Review.

3.0 Introduction

It is becoming ever more necessary to understand GI conditions such as IBS and IBD, as they continue to increase in prevalence (Moldecky et al., 2015) and are associated with negative biopsychosocial outcomes including life altering symptoms (Sayuk & Gyawali, 2015), high health-care use and associated costs (Akehurst et al., 2002; Canavan et al., 2014; Kappelman et al., 2008; Mehta, 2016). Previously, the trend has been to address GI conditions such as IBS and IBD in relation to their biological causes, course and how they relate to wider aspects of life (Holtmann et al., 2016; Theede et al., 2013). This includes literature reviews, which have been guided by the biomedical model, with commonly addressed areas including the biological causes and symptoms of, and treatments for, GI conditions, with particular focus on the outcomes of clinical trials and medications (Carvahlo et al., 2020; Khurram et al., 2011). Reviews that have addressed the potential influence of psychosocial factors on GI condition have considered these as secondary outcomes (Enck et al., 2018; Hoyeda et al., 2009). There exists a biology first hypothesis, with Enck et al. (2018) proposing that the appearance of bio first within the term biopsychosocial is evidence of its priority ahead of psychosocial factors. As a result, it is anticipated that social and psychological aspects of IBS and IBD will have been under-researched compared to biological, with a lack of reviews that consider psychosocial factors as equally important as biological factors in relation to IBS and IBD.

To address this gap, this review adopted the biopsychosocial model (Engel, 1977) and Drossman's (2016) model as frameworks to examine the breadth of existing literature on IBS and IBD. In response to the previous dominance of the biomedical model, this review primarily focused on psychosocial factors and outcomes, though biological factors were also considered. According to Drossman's (2016) model, the psychosocial factors of life stress, psychologic state, personality traits, coping and social support are just as important as the physiological factors of motility, sensation, inflammation, food/diet and altered bacterial flora in determining the symptoms and behaviour of individuals with a GI condition, leading to negative outcomes related to health care use and cost, daily function, and QOL.

A scoping review was selected over other similar review methods to address these questions. A scoping method was a pragmatic approach in this case as it is concerned with breadth as opposed to depth of knowledge (Moher et al., 2015), and is inclusive of qualitative, quantitative and mixed methods research. (Peterson et al., 2016), whereas systematic reviews and meta-analysis favour quantitative research, presenting quantitative outcomes such as effect size, which would be more appropriate for research aligned with the biomedical model (Shim, 2017). Scoping reviews are also more appropriate for studying the breadth of a research area (Arksey & O'Malley, 2005), in line with the aim of this review, whereas systematic reviews are primarily concerned with the depth of knowledge on a specific area (Moher et al. 2015).

3.0.1 Aims and Research Questions

The aim of this scoping review was to explore the breadth of existing research into the influence of IBS and IBD on psychosocial factors and wellbeing outcomes consistent with the biopsychosocial model, thus addressing research question 1 that guided the overall thesis. The following research questions were specific to this study:

1. Which wellbeing outcomes are most frequently addressed in the literature and how are they being assessed?

2. Which psychosocial factors are most frequently addressed in the literature and how are they being assessed?

3. Do wellbeing outcomes and psychosocial factors vary by GI condition?

4. To what extent does the evidence base investigate the lived experiences of individuals with a GI condition?

3.1 Methods

The methodology adopted for this scoping review was based on Arksey & O'Malley's (2005) guidelines, which specify five stages to the review process. Stage 1 involved the identification of the research question(s) to determine what the review was concerned with. Relevant studies were identified at stage 2 based on their title. These studies were further considered at stage 3 (study selection). At stage 4 data was charted to ensure key study characteristics and outcomes were recorded. Results were collated, summarised and reported at stage 5.

The literature search was conducted using the following databases: Web of Science, PsyArticles, PubMed and Cochrane Library. Initial literature searches began with Web of Science in July 2019 and an updated database search was conducted in June 2021. The search included completed English-language studies, and was inclusive of qualitative, quantitative, mixed-methodology research and case studies. Research published prior to 2000 was not included in the search due to psychosocial factors associated with GI conditions being an emerging area of research (Bernstein, 2015). Studies were excluded if they did not address at least one of the biopsychosocial factor search terms. Table 2 provides an overview of the inclusion and exclusion criteria applied to this review.

Table 2

Inclusion and Exclusion Criteria Applied to Scoping Review

Inclusion criteria	Exclusion criteria
At least one wellbeing outcome consistent with the biopsychosocial model of health	No wellbeing outcomes consistent with the biopsychosocial model of health
Focus on GI conditions including IBD, IBD, CD and UC	Animal/lab studies
Quantitative, qualitative, mixed methods and case-studies	No relevance to GI conditions (e.g. concerned with other health issues)
Completed studies or in development	
Published after 2000	

A full list of indicative search terms is provided in Table 3. Most of the search terms were chosen with reference to Drossman's (2016) model, though selected additional terms were included due to their relevance to IBS and/or IBD. Table 3 provides information on the source of the biopsychosocial factor search terms. Search terms were combined using a pre-determined search strategy that saw each GI health term combined with each biopsychosocial factor. For example, irritable bowel syndrome AND subjective wellbeing, or inflammatory bowel disease AND social support. Studies were excluded for lack of focus on GI health/GI conditions or if they failed to discuss at least one of the biopsychosocial factors. A more in-depth description of the search process and search strategy is included in Appendix M.

Table 3

Indicative Search Terms

Gastrointestinal health	Biopsychosocial factors	Source
Irritable bowel syndrome	Subjective wellbeing/life satisfaction/positive affect/negative affect	Farhadi et al. (2018)
Inflammatory bowel disease/Crohn's'/Ulcerative colitis	Social support/relationships/support network/isolation/loneliness	Drossman (2016)
Gut microbiota	Wellbeing	WHO (2013)
Gut flora	Coping	Drossman (2016)
Gastrointestinal condition	Quality of life/health-related quality of life	Drossman (2016)
Healthy gut	Work absence	Cosnes et al. (2011)/Kawalec et al. (2017)
	Daily function	Drossman (2016)
	Medical visits/health service use/medications	Adapted from Drossman (2016) terms health care use and health care costs

Note: The gastrointestinal health search terms gut microbiota, gut flora and healthy gut were included to provide a wider overview of gut health in the context of the GI conditions IBS and IBD. The only GI conditions explored in this review were IBS and IBD as per the inclusion/ exclusion criteria.

This search strategy returned 462 potential studies. Literature searching was conducted independently, but to ensure decisions were consistent and adhered to a standard method of practice, an independent reviewer (another PhD student) conducted quality control measures. Ten studies were randomly selected for the researcher and independent reviewer to examine using the exclusion/inclusion criteria. There was an agreement rate of 100%, meaning both the researcher and reviewer had agreed on decisions to include or exclude the studies. This 100% agreement suggested consistency and a standard method of practice, meaning all abstracts could be independently assessed by the researcher from this point. After reading abstracts, 253 studies were retained and 185 excluded.

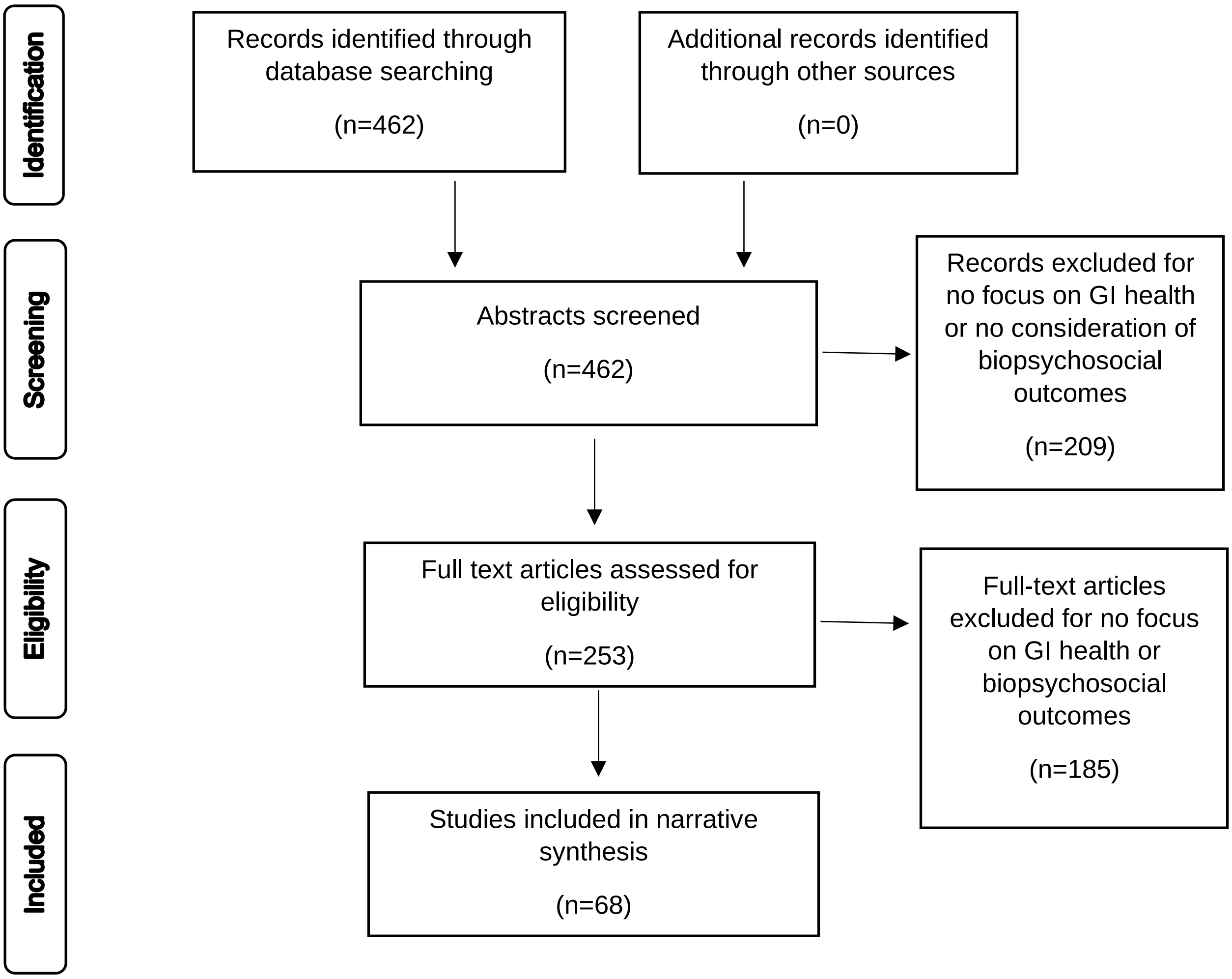
Data for full-text studies were charted using Microsoft Excel. The following variables were charted: full article reference, study location, study population, study aims, study type (e.g., intervention, randomised control trial), sample size, methods, materials, gastrointestinal health term(s), biopsychosocial outcome(s), conclusions (the study's outcome/main findings).

3.2 Results:

Of the 253 studies retained following abstract review, a further 185 were excluded according to the exclusion criteria. Subsequently, 68 full-text studies were included in the final analysis. The scoping review search process is illustrated in Figure 6.

Figure 6

Flowchart of included/ excluded studies



3.2.1 Characteristics of Included Studies

Of the included studies, *n*=25 (37%) were conducted in Europe (Akehurst et al., 2002; Amouretti et al., 2006; Andrzejewsja et al., 2009; Bengtsson et al., 2013; Bernklev et al., 2000; Bernklev et al., 2005; Christiansen et al., 2019; Coffin et al., 2004; Crane & Martin, 2004; Faresjo et al., 2019; Garcia-Sanjuan et al., 2019; Hoivik et al., 2012; Huppertz-Hauss et al., 2015; Huppertz-Hauss et al., 2016; Iglesias et al., 2010; Joc et al., 2015; Kopczynska et al., 2018; Larsson et al., 2016; La Berre, 2019; Nurmi et al., 2013; Ozer et al., 2020; Palant & Himmel, 2019; Ung et al., 2013; Vigano et al., 2016; Yildiz et al.,2020). A total of *n*=14 (21%) of the studies were conducted in Asia (Cho et al., 2019; Dai et al., 2021; Farbod et al., 2015; Ho et al., 2019; Hosli et al., 2020; Kim et al., 2017; Liu et al., 2008; Luo et al., 2018; Park et al., 2009; Si et al., 2004; Sugawara et al., 2017; Ueno et al., 2017; Wang et al., 2012; Yamabe et al., 2019). A further *n*=20 (29%) were conducted in the Americas (Ballou et al., 2019; Buono et al. 2017; Chao et al., 2019; Edman et al., 2017; Frank et al., 2002., Fuller-Thomson et al., 2006; Gralnek et al., 2000; Jones et al., 2006; Lackner et al., 2010; Lackner et al., 2013; Li et al., 2003; Motzer et al., 2003; Nguyen et al., 2018; Oliveira et al., 2007; Pare et al., 2006; Parekh et al., 2015; Parra et al., 2019; Purc-Stephenson & Bowlby, 2015; Singh et al. ,2015; Velonias et al., 2017). There was *n*=1 (1%) study conducted in New Zealand (McCombie et al., 2015) and *n*=1 (1%) in South Africa (Fouche et al., 2006). There were *n*=2 (3%) studies that recruited participants internationally, from countries in Europe, Asia and the Americas (Gerson et al., 2006; Silk, 2001), and *n*=5 (9%) studies recruited participants online, meaning limited data on location was available (Canon et al., 2017; Coulson et al., 2005; Farhadi et al., 2018; Knowles et al., 2017; Lonnfors et al., 2014).

A total of *n*=32 studies included in the final analysis concerned IBS (47%), compared to *n*=30 concerned with IBD (44%), and *n*=6 (9%) considered both conditions together (see Table 4 for an outline of which studies considered which conditions). The data suggested that more females experience IBS than males, yet more males were observed to have IBD than females, a trend supported by Crane and Martin (2004) who reported a significantly greater proportion of men in their IBD sample than in the IBS sample. Similarly, Bengtsson et al. (2013) reported there were more women with IBS (70 women to 11 men) than IBD (34 women to 40 men).

Most studies (*n*=59) included in the final analysis adopted quantitative methods to study IBS and IBD (85%), of which surveys (either conducted in person, online, via mail, or over the telephone) were commonly used (Akehurst et al., 2002; Andrzejewska et al., 2009; Ballou et al., 2019; Bengtsson et al., 2013; Bernklev et al., 2000; Buono et al., 2017; Canon et al., 2017; Chao et al., 2019; Cho et al., 2011; Christiansen et al., 2019; Coffin et al., 2004; Crane & Martin, 2004; Dai et al., 2017; Edman et al., 2017; Farbod et al., 2015; Faresjo et al., 2019; Farhadi et al., 2018; Fouche et al., 2006; Frank et al., 2002; Fuller-Thomson & Sulman, 2006; Gerson et al., 2006; Gralnek et al., 2000; Ho et al., 2019; Hoivik et al., 2012; Hosli et al., 2020; Huppertz-Hauss et al., 2015; Huppertz-Hauss et al., 2016; Iglesias et al., 2010; Joc et al., 2015; Jones et al., 2006; Kim et al., 2017; Knowles et al., 2017; Kopczynska et al., 2018; Lackner et al., 2010; Lackner et al., 2013; La Berre et al., 2019; Li et al., 2003; Liu et al., 2003; Lonnfors et al., 2014; Luo et al., 2018; McCombie et al., 2015; Motzer et al., 2003; Nurmi et al., 2013; Oliveira et al., 2007; Ozer et al., 2020; Pare et al., 2006; Parekh et al., 2015; Park et al., 2009; Parra et al., 2019; Si et al., 2002., Silk, 2001; Singh et al., 2015; Sugawara et al., 2015; Ueno et al., 2017; Velonias et al., 2017; Vigano et al., 2016; Wang et al., 2012; Yamabe et al., 2019; Yildiz et al., 2020). Only *n*=7 (12%) of studies employed qualitative methods (largely interviews) (Coulson et al., 2005; Garcia-Sanjuan et al. ,2018; Larsson et al., 2017; Nguyen et al., 2018; Palant & Himmel, 2019; Purc-Stephenson et al., 2015; Ung et al.,2013), and only *n*=2 (3%) employed a mixed methods design (Amouretti et al., 2006; Bernklev et al., 2006).

Narrative findings are presented in line with the research questions.

3.2.2 Which wellbeing outcomes are most frequently addressed in the literature and how are they being assessed?

Health-related quality of life (HRQOL) was the most frequently addressed wellbeing outcome, included in 40% (*n*=27) of studies included in the final analysis (see Table 4 for a full list of these studies). These studies commonly reported that HRQOL was impaired among those with IBS or IBD (Amouretti et al., 2006; Bernklev et al., 2006; Buono et al., 2017; Canon et al., 2017; Coffin et al., 2004; Frank et al., 2002; Gralnek et al., 2000; Ho et al., 2019; Iglesias et al., 2010; Li et al., 2003; McCombie et al., 2015; Pare et al., 2006; Park et al., 2009; Yamabe et al., 2019). Yet, the passage of time since diagnosis may reduce HRQOL impairment among those with IBD, as Huppertz-Hauss et al. (2015) reported no difference in HRQOL between a sample of IBD and control participants 10 years after diagnosis. A similar result was observed 20 years post diagnosis (Huppertz-Hauss et al., 2016).

QOL was the second most addressed wellbeing outcome, included in 28% (*n*=19) of the studies in the final analysis (Table 4 provides a full overview of these studies). As with HRQOL, these studies reported impaired QOL among those with IBS or IBD compared to control individuals with no GI condition (Bernklev et al., 2000; Knowles et al., 2017; Velonias et al., 2016; Wang et al. 2012). Both QOL and HRQOL were assessed using similar methods, primarily survey measures including the Short-Form 36 Health Survey (SF-36; Ware et al., 1980); the Inflammatory Bowel Disease Questionnaire (IBDQ; Irvine et al., 1994) and the Irritable Bowel Syndrome-Quality of Life (IBS-QOL; Patrick et al., 1998). The use of the same measures to investigate QOL and HRQOL is reflective of how interchangeable these terms are in the literature (Karimi & Brazier, 2016).

Wellbeing outcomes less commonly addressed included subjective wellbeing (SWB), which was included in only two studies. Farhadi et al. (2018) reported it to be negatively associated with IBS, according to scores on a self-created measure, and Lackner et al. (2010) found the SWB of those with IBS to be impaired by stress, as determined by scores on the IBS-QOL (Patrick et al., 1998). Though not included as a search term, two studies addressed psychological wellbeing (PWB) which reported that PWB was decreased among those with IBS (Gralnek et al., 2000; Knowles et al., 2017). Other types of wellbeing addressed in the literature included emotional wellbeing (Gralnek et al., 2000), and physical wellbeing (Li et al., 2003). Ung et al. (2013) did not operationalise a specific type of wellbeing, simply stating that those with IBS fluctuated between periods of wellbeing and illness, suggesting they may have been considering physical wellbeing. The various types of wellbeing considered in the literature could be suggestive of a wider terminology issue, with researchers differing in how they conceptualise and research wellbeing. This would explain the comparative lack of research into the SWB of those with IBS and IBD, since neither of the studies had considered SWB and IBD.

3.2.3 Which psychosocial factors are most frequently addressed in the literature and how are they being assessed?

Social support (inclusive of the search terms relationships, support network, isolation and loneliness) was addressed in 32% (*n*=22) of the studies. Research was largely concerned with whether social support results in positive or negative wellbeing outcomes among those with IBS or IBD, but findings were not conclusive. Purc-Stephenson et al. (2015) reported that positive relationship experiences are common. Positive outcomes included the use of social support as a positive coping strategy (Fouche et al., 2006; Garcia-Sanjuan et al., 2018), improved QOL (Nguyen et al., 2018; Oliveira et al., 2006), and that social support may help to combat depression among those with IBD (Fuller-Thompson and Sulman, 2006). Positive outcomes were not limited to face-to-face interactions, as social support received online from support groups provides members with hope, validation and encouragement (Coulson et al., 2005). Table 4 lists these studies and provides a summary of the direction of study outcomes (positive or negative).

Palant and Himmel (2019) proposed that social support outcomes are dependent on the perceived quality of the support received. For example, support that is perceived as inadequate can result in social isolation and further impaired deteriorated physical health (Palant & Himmel, 2019). Further evidence of negative physical health outcomes is provided by Lackner et al. (2013) and Gerson et al. (2006) who similarly reported that when relationships were described as high in conflict, demands and/or criticism, IBS symptoms were rated as more severe. The link between support quality and symptomology may be bi-directional. Support quality could affect symptomology, OR symptomology could increase sensitivity to conflict and affect perceived support quality. In this way, the decreased symptomology typical of the remission stage (Kim et al., 2017) would be associated with an increased ability to recognise and appreciate social support, comparative to the active stage of IBS and IBD. Future research could apply the biopsychosocial model as a framework to explore the mechanisms by which physical symptoms and social support and related.

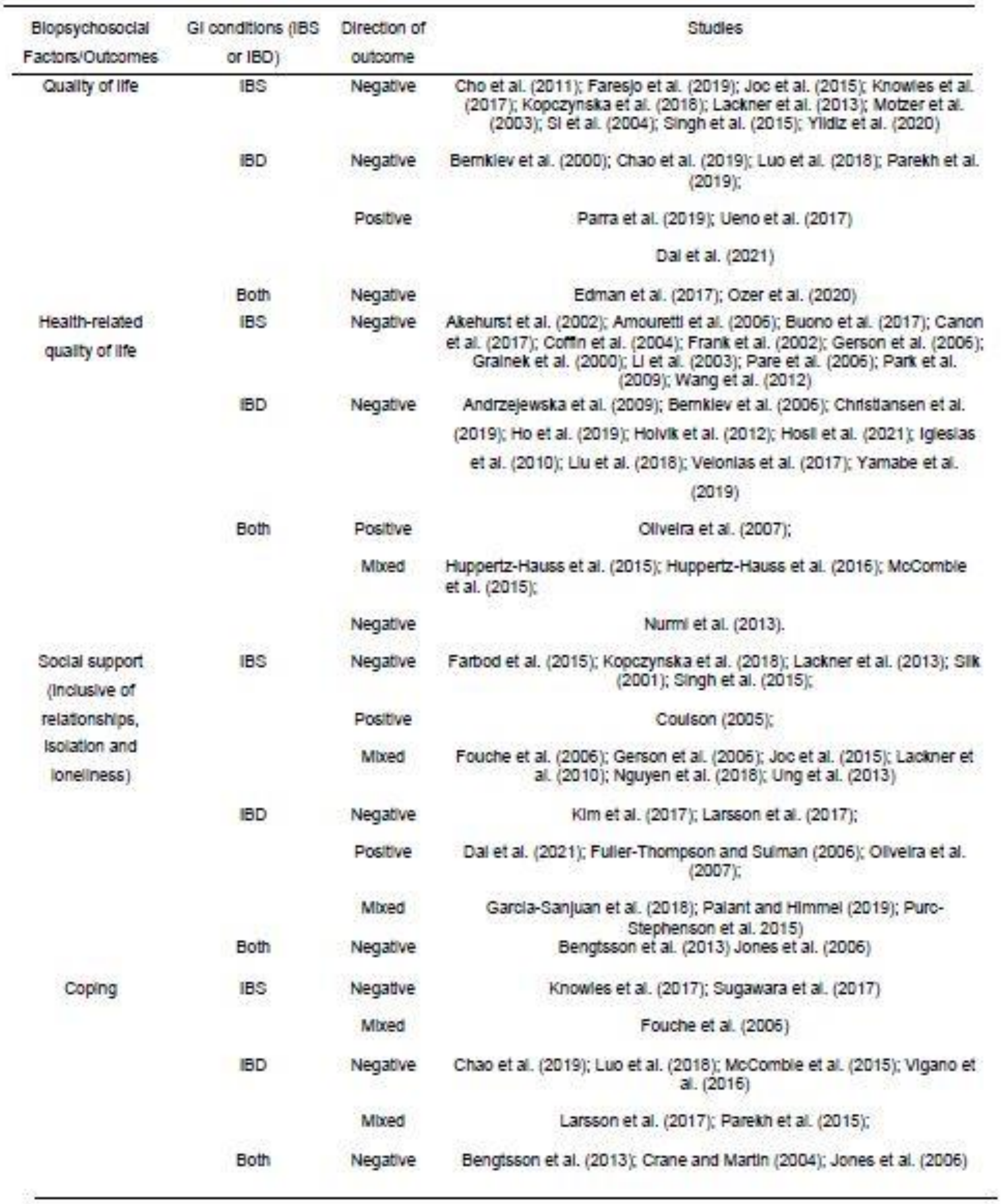
It is noteworthy that six out of the seven studies included in the final analysis that adopted a qualitative methodology assessed social support and relationships (Garcia-Sanjuan et al., 2018; Larsson, Loof & Nordin, 2017; Nguyen et al., 2018; Palant & Himmel, 2019; Purc-Stephenson et al., 2015; Ung et al., 2013). The personal nature of relationships may mean individuals feel more comforted by the increased rapport and trust qualitative methods provide (Jacob & Ferguson, 2012). As relationships can be concerning and embarrassing for individuals with a GI condition (Silk, 2001), qualitative methods such as interviews may be preferable over surveys.

Seeking social support from others was the only adaptive coping strategy adopted by those with a GI condition observed in this review (Fouche et al., 2006; Garcia-Sanjuan et al., 2018). Coping strategies were addressed in 18% (*n*=12) of the studies included in the final analysis (listed in Table 4), generally revealing the use of maladaptive strategies (Bengtsson et al., 2013; Crane & Martin, 2004; Fouche et al., 2006; Knowles et al., 2017; Luo et al., 2018; McCombie et al., 2015; Sugawara et al., 2017; Vigano et al., 2016). For example, emotional passive coping, inclusive of behaviours such as inactivity, immobility and decreased responsiveness (Bandler et al., 2000), was associated with an increased risk of developing anxiety and/or depression. Similarly, Sugawara et al. (2017) reported that IBS patients who adopt avoidance and suppression coping strategies to escape or suppress negative thoughts often experience depressive thoughts and struggle to adjust to their condition. Further information on the outcomes of studies that addressed coping is provided in Table 4.

Coping had been assessed using a variety of methods, the most common being quantitative surveys (used in seven of the eleven studies), with a variety of measures used. For example, the Brief COPE (Carver, 1997) was used by three studies (McCombie et al., 2015; Sugawara et al., 2017; Vigano et al., 2016). Luo et al. (2018) adopted the Medical Coping Modes questionnaire (Feifel et al., 1987), and Bengtsson et al. (2015) explored coping using the Sense of Coherence questionnaire (Antonovsky, 1987). Only one study utilised a qualitative methodology to study coping (Garcia-Sanjuan et al., 2018), suggesting that a quantitative approach has typically been preferred.

Table 4

Summary of most frequently addressed psychosocial factors and wellbeing outcomes in included studies



Biopsychosocial Factors/Outcomes	GI conditions (IBS or IBD)	Direction of outcome	Studies
Quality of life	IBS	Negative	Cho et al. (2011); Faresjo et al. (2019); Joc et al. (2015); Knowles et al. (2017); Kopczynska et al. (2018); Lackner et al. (2013); Motzer et al. (2003); Si et al. (2004); Singh et al. (2015); Yildiz et al. (2020)
	IBD	Negative	Bernklev et al. (2000); Chao et al. (2019); Luo et al. (2018); Parekh et al. (2019);
		Positive	Parra et al. (2019); Ueno et al. (2017)
			Dai et al. (2021)
	Both	Negative	Edman et al. (2017); Ozer et al. (2020)
Health-related quality of life	IBS	Negative	Akehurst et al. (2002); Amouretti et al. (2006); Buono et al. (2017); Canon et al. (2017); Coffin et al. (2004); Frank et al. (2002); Gerson et al. (2006); Gralnek et al. (2000); Li et al. (2003); Pare et al. (2006); Park et al. (2009); Wang et al. (2012)
	IBD	Negative	Andrzejewska et al. (2009); Bernklev et al. (2006); Christiansen et al. (2019); Ho et al. (2019); Holvik et al. (2012); Hosli et al. (2021); Iglesias et al. (2010); Liu et al. (2018); Velonias et al. (2017); Yamabe et al. (2019)
	Both	Positive	Oliveira et al. (2007);
		Mixed	Huppertz-Hauss et al. (2015); Huppertz-Hauss et al. (2016); McCombie et al. (2015);
		Negative	Nurmi et al. (2013).
Social support (inclusive of relationships, isolation and loneliness)	IBS	Negative	Farbod et al. (2015); Kopczynska et al. (2018); Lackner et al. (2013); Silk (2001); Singh et al. (2015);
		Positive	Coulson (2005);
		Mixed	Fouche et al. (2006); Gerson et al. (2006); Joc et al. (2015); Lackner et al. (2010); Nguyen et al. (2018); Ung et al. (2013)
	IBD	Negative	Kim et al. (2017); Larsson et al. (2017);
		Positive	Dai et al. (2021); Fuller-Thompson and Sulman (2006); Oliveira et al. (2007);
		Mixed	Garcia-Sanjuan et al. (2018); Palant and Himmel (2019); Purc-Stephenson et al. 2015)
	Both	Negative	Bengtsson et al. (2013) Jones et al. (2006)
Coping	IBS	Negative	Knowles et al. (2017); Sugawara et al. (2017)
		Mixed	Fouche et al. (2006)
	IBD	Negative	Chao et al. (2019); Luo et al. (2018); McCombie et al. (2015); Vigano et al. (2016)
		Mixed	Larsson et al. (2017); Parekh et al. (2015);
	Both	Negative	Bengtsson et al. (2013); Crane and Martin (2004); Jones et al. (2006)

3.2.4 Do wellbeing outcomes and psychosocial factors vary by GI condition?

The same psychosocial factors and wellbeing outcomes were addressed across IBS and IBD, including social support, coping strategies and QOL (Edman et al., 2017; Jones et al., 2006). While the same psychosocial factors have been addressed across both conditions, there were instances where different conclusions were drawn. For example, Bengtsson et al. (2013) addressed social support and relationships across both IBS and IBD, finding that those with IBD reportedly experienced greater anxiety in relationships than those with IBS. An outcome of research by Crane and Martin (2004) was that individuals with IBD were reportedly more likely to alter or abandon social activities. There were also differences in coping, as individuals with IBS have greater flexibility in terms of strategies they feel able to adopt (Crane & Martin, 2004). These outcomes have been attributed to the physical differences in the two conditions (Crane & Martin, 2004), which contradicts the argument that IBS and IBD should no longer be considered as distinct conditions (Drossman & Hasler, 2016; Rani et al., 2016).

3.2.5 To what extent does the evidence base investigate the lived experiences of individuals with a GI condition?

Only four studies employed a qualitative, phenomenological approach to investigate the lived experiences of individuals with IBS and IBD (Garcia-Sanjuan et al., 2018; Nguyen et al., 2018; Purc-Stephenson et al., 2015; Ung et al., 2013). Garcia-Sanjuan et al. (2018) conducted interviews to explore the lived experiences of individuals with Crohn’s disease in Spain and reported five main themes: protecting oneself against the unknown cause; self-training; learning to live with Crohn’s disease; perceived losses due to Crohn’s disease; and relationships with others.

Here, coping and social support emerged as themes important to participant's lived experiences. Purc-Stephenson et al. (2015) reported that social support was embedded in positive and negative aspects of their IBD. A positive outcome of IBD was that it had improved and strengthened the relationships of some of the participants, but equally, their IBD could result in feelings of social isolation as loved ones struggled to understand their condition accompanied by a lack of desire to engage in social activities (Purc-Stephenson et al., 2015). Social support was also highlighted as a directly relevant aspect of lived experience with IBD by Ung et al. (2013), who reported that while IBS symptoms can prove a barrier to socialising, social support from loved ones facilitated comfort and a chance to discuss their condition with others. A more direct investigation into the relationship experiences of women with IBS revealed that distress caused by their IBS could affect mood and lead to conflict in intimate relationships, and if partners were perceived as lacking in understanding, this could prove a barrier to communication, resulting in feelings of isolation and ultimately relationship breakdown (Nguyen et al. 2018).

The research included in this scoping review goes some way to illustrating the lived experiences of those with a GI condition, with social support/relationships a commonly occurring theme, indicating it is something those with a GI condition hold as important and are keen to discuss. Learning to cope with their condition also appears to be a key component of the lived experience of those with a GI condition. It was somewhat surprising that there were not more studies that employed a qualitative, phenomenological approach to investigate lived experiences as this methodological approach would provide an insight and understanding into which aspects are most relevant to these individuals, who have first-hand knowledge. A recommendation for future research is therefore to explore the lived experiences of individuals with IBS and IBD, particularly using a phenomenological approach.

3.2.6 Additional themes or findings

The search term daily function (listed in Table 3) returned one study (Ballou et al., 2019) which reported that IBS had a negative effect on daily function. Daily life, which shares the same focus on day-to-day functioning, was referenced in 9% (n=6) of the studies included in the final analysis. Buono et al. (2017); Faresjo et al. (2019); Garcia-Sanjuan et al. (2018); Kim, et al. (2017); Singh et al. (2015); Ung et al. (2013) all reported that daily life was impaired for individuals with IBS or IBD, covering aspects such as their work and social life; in line with the themes uncovered in this scoping review. This finding suggests that the term daily life is preferred to daily function when the ability to engage in day-to-day activities.

One aspect of daily life found to be affected by IBS and IBD was work/employment. Of the included studies, 25% (*n*=17) reported that individuals with GI conditions often experience disruptions and difficulties in their working life. For example, work absence (Bernklev et al., 2006; Pare et al., 2006). Silk (2001) reported that 47% of those with IBS they sampled had taken time off work due to their condition. In efforts to combat work absence, individuals may decide to work from home or reduce their hours and work part time, as was observed for 32% of IBD patients studied by Ueno et al. (2017). Work-presenteeism (reduced productivity due to being unwell at work) was another issue highlighted (Buono et al., 2017; Faresjo et al., 2019; Yamabe et al., 2019). Work-related difficulties can limit employment opportunities for those with IBS or IBD, and can limit career plans (La Berre et al., 2019). Unfortunately, these difficulties could result in job loss, as was the case for 35.5% of those with IBD studies by Ueno et al. (2017). The extent of work-related difficulties faced by those with a GI condition was highlighted in this scoping review and it is suggested that there needs to be a better understanding of what needs to be done to improve the working situation of those with GI conditions, to allow them to feel supported at work.

Remission was not included as a search term but was addressed in 12% (*n*=8) of the studies included in the final analysis (Christiansen et al., 2019; Coffin et al., 2004; Hoivik et al., 2012; Iglesias et al., 2010; Kim et al., 2017; Lonnfors et al., 2014; Ozer et al., 2020; Vigano et al., 2016). All eight studies acknowledged remission as an important stage in IBS and IBD. Yet, the literature presented varied outcomes as to whether physical symptoms were experienced during remission or not. Kim et al. (2017) reported a decrease in physical symptoms such as fatigue and weakness during remission, but Lonnfors et al. (2014) reported that most of their IBD sample still experienced physical symptoms during remission. Alongside the potential presence of physical symptoms, there was research to suggest that negative psychological outcomes occur during remission, for example, Iglesias et al. (2010) reported that HRQOL was still affected for individuals with CD in remission. During remission, individuals with CD may also risk developing a depressive-anxious comorbidity (Vigano et al., 2016). An interpretation of these findings is that remission (for both IBS and IBD) is not as well-understood as the active stage and requires further exploration so that, ultimately, experiences during this stage can be improved.

3.3 Discussion

This scoping review aimed to examine the breadth of existing research into the influence of GI conditions on psychosocial factors and wellbeing outcomes associated with a biopsychosocial model of health and provide a narrative summary of findings. It was anticipated that, due to the prior dominance of the biomedical model in health research, psychosocial factors and wellbeing outcomes may have been comparatively neglected in the literature (Cao & Ding, 2019). Yet, there was evidence that the psychosocial factors social support and coping strategies and the wellbeing outcomes QOL and HRQOL had been commonly addressed.

HRQOL followed closely by QOL were found to be the most frequently addressed wellbeing outcomes and were primarily assessed using quantitative methods such as surveys. It was reported that QOL/HRQOL is similarly negatively affected across IBS and IBD (for example, Akehurst et al., 2002; Bernklev et al., 2006; Buono et al., 2017; Canon et al., 2017; Edman et al., 2017; Frank, et al., 2002; Ho et al., 2019; Hoivik et al., 2012; Singh et al., 2015; Yamabe et al., 2019). In this way, GI conditions do not appear to differ from other chronic conditions such as stroke and diabetes which similarly lower QOL/HRQOL (Shofany, 2017). Gralnek et al. (2000) go further, reporting that the HRQOL of those with IBS is more negatively impaired than those with other chronic conditions such as diabetes mellitus.

Improvements in the HRQOL of those with IBD seemed to occur over time, as Huppertz-Hauss et al. (2015) reported no difference in HRQOL between IBD patients and a control sample 10 years post diagnosis. Similar results were also observed 20 years after diagnosis (Huppertz-Hauss et al. 2016). These results were supported by findings from McCombie et al. (2015), who observed that the HRQOL of IBD patients improved over the six months following their diagnosis. Improved HRQOL post diagnosis could be in response to a need to adapt to, and cope with, their condition.

To further improve the HRQOL/QOL of those with IBS and IBD, knowledge gained from the study of chronic conditions can be applied to these conditions. For example, the literature suggests that one way to improve the QOL/HRQOL of those with a chronic disease is to ensure they receive support from family, friends, or the wider community (Megari, 2013; Minnock et al., 2003). This highlights the role of social support in wellbeing, which was similarly evidenced in this review.

It was evident that the quality of social support received determines whether social support outcomes are positive, such as improved coping and decreased depression (Fuller-Thompson & Sulman, 2006; Garcia-Sanjuan et al., 2018; Oliveira et al., 2016) or negative, with worries about intimacy (Silk, 2001) increased symptom severity (Gerson et al., 2006; Lackner et al., 2013) and feelings of social isolation (Puc-Stephenson et al., 2015). Similar outcomes are observed in other chronic conditions explored using the biopsychosocial model (Gatchel et al., 2017; Turk & Adams, 2016). A bi-directional relationship can explain the link between physical symptoms and perceptions of support quality. Physical symptoms may alter an individual's perceptions of social support quality, increasing their sensitivity to conflict (Gerson et al., 2006). This could suggest that perceptions of relationships can differ throughout the course of GI conditions, with social support perceived as of greater quality during periods of remission (due to decreased symptomology) compared to the active stage. This line of argument has not received much research focus but could be worthy of further investigation.

Coping strategies used by those with IBS and IBD were often maladaptive, including passive coping strategies such as avoidance and suppression behaviours, in attempts to escape negative and undesirable thoughts, which can negatively influence adjustment to GI conditions and depressive and/or anxious symptoms

(Knowles et al., 2017; McCombie et al., 2015; Sugawara et al., 2017; Vigano et al., 2016). The use of maladaptive coping strategies among IBS and IBD is consistent with other chronic conditions, as Gatchel et al. (2007) observed that those with chronic pain often adapt a catastrophising coping strategy. Evidently coping strategies determine how individuals manage with their GI condition, which can have implications for wellbeing.

Regardless of classification (organic or functional), the same psychosocial factors and wellbeing outcomes were addressed for IBS and IBD. The only variation that was observed was that those with IBD occasionally report that social support and relationships can be more challenging, causing increased anxiety (Bengtsson et al., 2013), and are more likely to change or cancel social plans (Crane & Martin, 2004). Those with IBD also often report that they have fewer coping strategies to hand compared to those with IBS (Crane & Martin, 2004). These differences have been attributed to the biological differences between IBS and IBD (Crane & Martin, 2004). These findings could be interpreted as evidence of the biological distinction of the conditions resulting in differences in psychosocial functioning, which would suggest, from a biopsychosocial perspective, that individuals with IBD may require more holistic support. Another interpretation could be that these outcomes do not sufficiently support the need to continue distinguishing between IBS and IBD, FGID and OGID, as only limited differences were observed.

Additionally, it was observed that remission has been addressed in previous literature but is not as well understood as the active stage of GI conditions. Research revealed that physical symptoms can still occur during remission (Lonnfors et al.,2014) and psychologically, HRQOL is still negatively affected (Iglesias et al., 2010), and maladaptive coping strategies can still be developed and in use (Vigano et al., 2016). Seemingly, remission can be a negative experience, contradictory to the idea that it is a period of relief from symptoms, suggesting it needs to be better understood in relation to IBS and IBD to improve sufferer's overall experiences.

Another observation was negative working life outcomes often associated with GI conditions. For example, work absenteeism was reported as a problem, with individuals with a GI condition feeling the need to take time off work due to their symptoms (Bernklev et al., 2006; Pare et al., 2006; Silk, 2001). Work-presenteeism was also addressed in the literature (Buono et al., 2017; Faresjo et al., 2019; Yamabe et al., 2019). Individuals with IBS studied by Pare et al. (2006) reported 31.4% work presenteeism and 34.6% overall productivity loss, which equated to 13.8 hours out of a 40-hour working week lost due to their GI condition. The consequences of these work-related challenges can be extreme, with career plans affected (La Berre et al., 2019) and terminated employment, with Ueno et al. (2017) reporting this was the case for 35.5% of a sample of individuals with IBD.

Work-related difficulties seem to be attributed to physical symptoms, yet in line with the biopsychosocial model, psychosocial factors should also be considered. For example, Price and Hoojiberg (1992) reported that workers with reduced wellbeing are less likely to be productive and more likely to be absent from work. It is therefore surprising that La Berre et al. (2019) reported that work satisfaction was still high among the sample of individuals with IBD they studied. It could be the case that some individuals with GI conditions find their work enjoyable because it provides a focus other than their condition, or perhaps it is linked to opportunities for social support (Huppert & Whittington, 2003; Stansfeld et al., 2013). A direction for future research could therefore be to explore reasons why employment may be fulfilling and enjoyable for those with IBS or IBD.

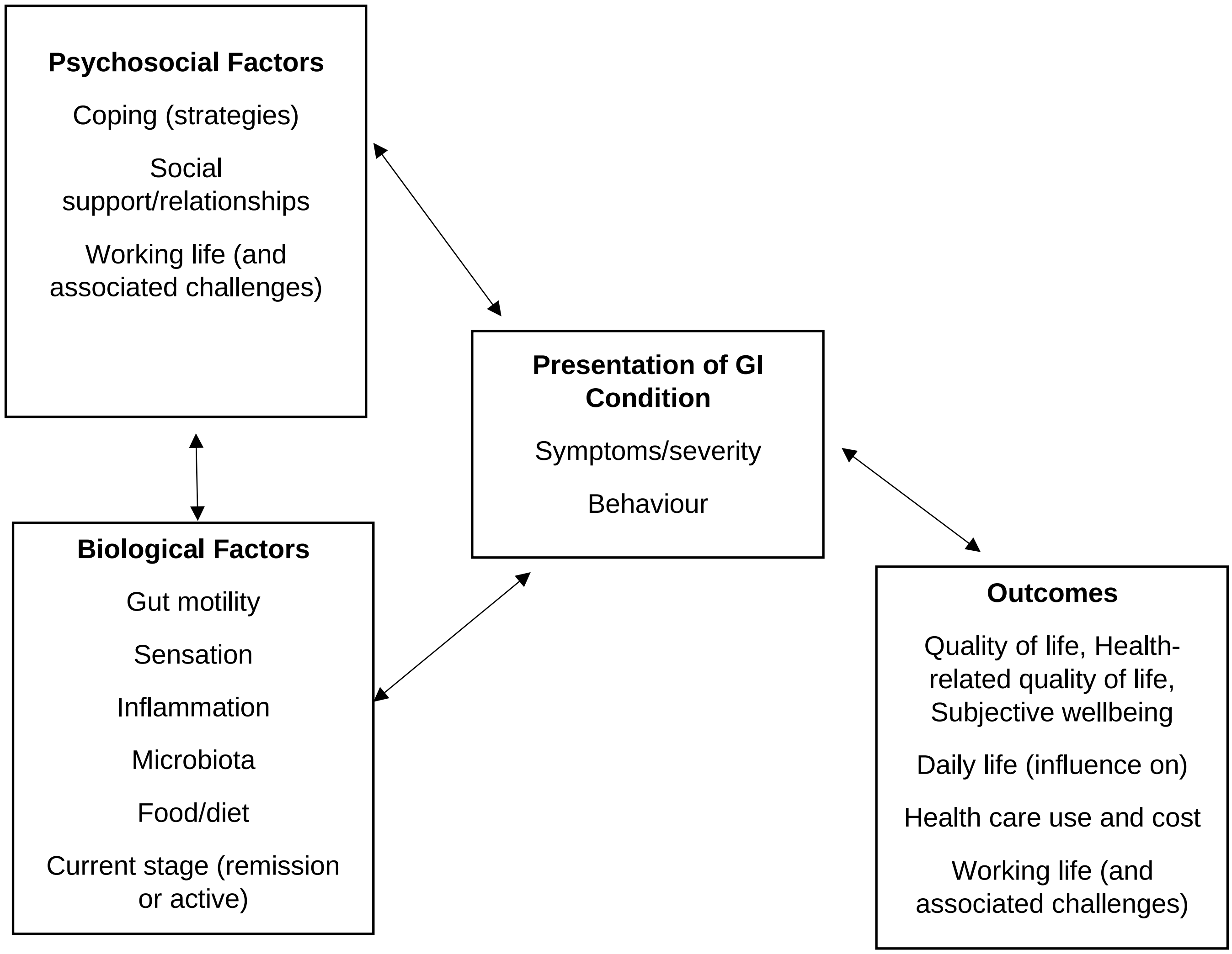
This scoping review highlighted the interconnected nature of factors implicated in GI conditions, in line with Engel's (1977) biopsychosocial model of health. For example, social support and coping are inter-connected (Fouche et al., 2006) and can influence wellbeing outcomes (Oliveria et al., 2006). The stage of an individual's GI condition is also involved in the biopsychosocial expression of IBS and IBD and influences psychosocial factors and wellbeing outcomes (Gerson et al., 2006; Iglesias et al., 2010; Vigano et al., 2016). Another factor that requires further exploration is working life or work-related challenges, which fall under daily function. Typically, research has considered the influence of GI conditions on working life, rather than the influence of working life on the GI condition. However, we know that sick leave as a result of IBS places an economic burden on employers (Cash et al., 2005), and this could lead to concerns around job security, leading to stress, exacerbating symptoms, resulting in more time off work and so on. A direction for future research could therefore be to explore the lived experiences of working life (and sick leave) among those who have a GI condition.

A limited number of studies directly investigated the lived experiences of those with a GI condition. The increased application of the biopsychosocial model to research into IBS and IBD may increase the focus on individual's experiences as the model is appropriate for exploring lived experiences due to its consideration of an individuals' differences and experiences (Wade & Halligan, 2017). This would ensure an individual's experiences can be individually, and holistically, investigated as this would ensure research is focused on the wellbeing factors/outcomes perceived as relevant and critical to their experience. Further use of the biopsychosocial model of health in research into GI conditions could result in changes to research, practice and policy. For example, the biopsychosocial model could help reduce the reliance on medications, instead assisting with the development and application of psychosocial treatments for IBS and IBD (Brown, Bonello & Pollard, 2005). A biopsychosocial model appropriate for IBS and IBD is proposed in Figure 1 in support of the scoping review's findings.

Another unexpected insight was that, within the studies, there was a much stronger evidence base for GI conditions and the wellbeing outcomes QOL and HRQOL, but other types of wellbeing were comparatively under-represented in the literature. For example, only two studies included in the final analysis addressed SWB (Farhadi et al., 2018); Lackner er al., 2010), which was lower than anticipated given the relevance of SWB in IBS (Farhadi et al., 2018). PWB was similarly only addressed in two studies (Knowles et al., 2017; Li et al., 2003). It could be that SWB and PWB are not yet well-established concepts of wellbeing as QOL and HRQOL are, and this would explain why only two studies in the final analysis addressed SWB despite its relevance to GI conditions.

Figure 1

A biopsychosocial model of factors implicated in the experience of IBS and IBD.



3.4. Study Strengths and Limitations

A key strength of this scoping review was that it moved away from the previously used biomedical model, instead attempting to holistically explore GI conditions using the biopsychosocial model of health. This enabled further consideration of how biological, psychological and social factors might interact together in the overall experience of IBS or IBD. An unexpected insight provided by this review was that the remission stage of IBS and IBD does not seem to provide either physical or psychological relief as might be expected, and as such further investigation is warranted. This scoping review was also inclusive, considering research conducted globally, accounting for a wide range of experiences, rather than only those from a Western culture. Therefore, the findings have a greater generalisability. However, this scoping review is not without limitations. Firstly, to ensure this review would be feasible to conduct (in terms of workload and time scale), no research published before 2000 was included for consideration, limiting the scope. The 11 studies included in the final review published between the years of 2000 and 2005, could indicate a considerable amount of literature prior to 2000 was excluded.

3.5 Conclusion

The use of the biopsychosocial model of health when investigating GI conditions results in a more complete overview of their influence on those with such conditions. This review revealed that QOL and /or HRQOL, social support and coping strategies have been the most addressed psychosocial factors/wellbeing outcomes. Quantitative methods were most used, typically survey measures, yet it was observed that a qualitative approach was preferred to explore social support. Outcomes that require further exploration are remission and work-challenges. Further research into GI condition should consider the lived experiences of those most affected and apply the biopsychosocial model (Engel, 1977), as it will provide key insight into the psychological and social experiences of these individuals, which could inform changes in research, practice and policy.

3.6 Direction

This study provided an overview of existing literature on the psychosocial influence of IBS and IBD on those with these conditions. There has been exploration of psychosocial factors/wellbeing outcomes such as social support, coping, QOL and HRQOL in relation to IBS and IBD, with largely negative outcomes reported. As such, research question 1 of the thesis was addressed, as the considered the influence of GI conditions on psychosocial factors and wellbeing outcomes. While study 1 sought to only address research question 1, research question 2 of the thesis (concerned with the influence of condition stage on psychosocial functioning) was also unexpectedly, though to a lesser extent, addressed. Recommendations that determined the focus and design of study 2 include further exploration of remission among those with IBS and IBD and the use of a qualitative approach to explore the lived experiences of this population.

Chapter 4

Exploring the Lived Experiences of Individuals Diagnosed with a Gastrointestinal Condition- A Qualitative Study.

4.0 Introduction

This study progresses from the scoping review (Ch.3), which suggested that the experiences of individuals with IBS or IBD are largely negative. In that study, a need for future research to explore GI conditions through the use of qualitative methods was suggested, particularly to provide an increased understanding of the lived experiences of this population. Reid et al. (2005) postulate that the qualitative exploration of experiences allows for the capture of rich and in-depth data directly from those who have the best understanding of a topic. Adopting this participant led approach could have beneficial outcomes for those with a GI condition, as they continue to increase in prevalence (Molodecky et al., 2012) and are emerging as a serious health concern. Those most affected are arguably best placed to guide the focus of research. This study addresses the need for qualitative exploration of lived experiences through a series of interviews with individuals with either IBS or IBD designed to understand how their conditions influence their biopsychosocial functioning.

Only four of the sixty-eight studies included in the final narrative of the scoping review had employed qualitative methods to gain a phenomenological understanding of the lived experiences of those with IBS or IBD (Garcia-Sanjuan et al., 2018; Nguyen et al., 2018; Purc-Stephenson et al., 2015; Ung et al.,2013). This limited literature identified in the scoping review suggested negative outcomes related to the daily lives of those with a GI condition, with particular focus on work, leisure and academia (Garcia-Sanjuan et al., 2018). Daily life could be improved through social support, as it improves the ability to cope and complete everyday tasks, yet a reliance on social support was found to leave some individuals feeling like a burden (Garcia-Sanjuan et al., 2018). The complex nature of social support as an experience for individuals with IBD was further revealed by interviews conducted by Purc-Stephenson et al. (2015) as participants described feeling isolated because of decreased participation in social activities, but some participants perceived their relationships were strengthened due to their condition. Similar findings were reported by Ung et al (2013) following interviews with individuals diagnosed with IBS, as participants perceived symptoms as a barrier to socialising, but social support from family and loved ones provided comfort. Nguyen et al. (2018) interviewed women with IBS, with a specific focus on their relationship experiences, and it was made apparent that feeling that a partner did not understand their condition was associated with negative outcomes such as feeling isolated and ultimately relationship breakdown. These findings suggest social support and relationships are integral to the lived experiences of individuals with IBS and IBD; but their complexity requires further exploration to enhance our understanding.

Outside the parameters of the scoping review narrative, research into the lived experiences of those with a GI has revealed similar themes. For example, following interviews with individuals with UC, Sammut et al. (2015) observed three overarching themes: living with physical discomfort (the experience and consequences of symptoms), emotional turmoil in living the experience (QOL and emotions associated with the condition such as fear) and social interactions. Commonly, participants felt their social and work lives had suffered due to their condition, with social isolation and work absence reported (Sammut et al., 2015). Dietary changes are a commonly employed coping strategy, as diet is an area within control (Kennedy et al., 2003). Interviews with those with IBS have revealed additional coping strategies, including planning the day around the condition and ensuring toilets are always accessible, yet maladaptive coping strategies such as avoiding new social situations or experiences are also common (Ballou et al., 2019; Campbell, 2015; Farndale & Roberts, 2011). As with IBD, interviews have revealed that social concerns are common among those with IBS, as relationships can be challenging, potentially leading to feelings of isolation (Campbell, 2015).

Previously, there has been limited consideration of remission as part of the lived experience of those with IBS or IBD. Garcia-Sanjuan et al. (2018) reported that remission was a time to compensate for feeling like a burden to loved ones during the active stage by being more independent and aiding others. In response to a lack of qualitative focus on remission among GI conditions, Kitchen et al. (2020) explored lived experiences of remission and how individuals with CD understand and define this stage, reporting that not all participants were familiar with the term remission and that definitions were varied, with one participant believing they had not experienced remission. There needs to be improved understanding of remission as part of the lived experiences of those with a GI condition, since an aim of treatment is to extend periods of remission (Gavrillescu et al., 2015).

4.0.1 Aims and research questions

This study sought to draw upon previous qualitative research findings and the outcomes of the scoping review to further understand the lived experiences of those with IBS and IBD, with greater focus on experiences across these conditions (remission) as a unique contribution to existing literature. The importance and relevance of lived experience research when exploring health conditions is increasingly recognised, and has been found to assist recovery, particularly from mental health challenges (Beames et al., 2021; Honey et al., 2020). There is also a paradigm shift allowing more focus and control to be afforded to participants, enabling the lived experiences of those with specific health conditions to be acknowledged by health care professionals and policy makers (Douglas et al., 2020). As such, the use of qualitative interviews to explore the lived experiences of individuals with IBS or IBD were appropriate over quantitative methods as they provide a depth of first-hand knowledge which can guide and direct the focus of future research (Reid et al., 2005), ensuring that research will be participant-led. As observed in the scoping review, limited variation in wellbeing outcomes has been reported in the literature between those with IBS and IBD. In response, both conditions were again considered within the same study. This was to highlight differences and similarities in experiences. This study aimed to explore the influence of IBS and IBD on psychosocial factors and wellbeing outcomes (Thesis question 1) and consider experiences during remission (thesis question 2). The study-specific research questions addressed are:

1) What is the influence of GI condition on participant’s daily lives, including psychosocial factors such as social support and coping?
2) What are participant’s lived experiences of remission?

3) How do participants feel others could be better educated/informed about their GI condition?

4.1 Methods

To address thesis research questions 1 and 2, the second study builds upon the outcomes of study 1 using a qualitative approach (semi-structured interviews) to explore the lived experiences of those with IBS or IBD. A phenomenological perspective was employed for this study. Phenomenology is a well-known and used qualitative approach (Alase, 2017) which has formed the foundation of much of the qualitative research conducted by social scientists and researchers (Jackson & Drummond, 2007). The aim of phenomenology is to understand phenomena/behaviour from the outlook of those being studied, adopting an emic perspective where the researcher acknowledges the first-hand experiences of the participants to guide their focus (Sharan & Tisdell, 2015). Phenomenology is often used interchangeably with hermeneutics, which is a method of analysis used to interpret the words of others to uncover their meaning (Byrne, 1998). The interchangeable use of the two terms is due to them being closely linked and often used in conjunction within qualitative research (Byrne, 1998). As the data gained from qualitative research methods is textual rather than numerical, a method of data analysis is required, which is often hermeneutics (Smith, 2007). Hermeneutics differs from other types of qualitative research such as grounded theory methods or participant observation which aim to eliminate or reduce researcher bias (subjectivity), rather hermeneutics acknowledges this as part of the research process, with the researcher’s views important in helping to understand the experiences of the participant (Muganga, 2015).

A benefit of employing qualitative methods, particularly interviews, which are the most commonly used qualitative research method (Jamshed, 2014; King, Horrocks & Brooks, 2019), prior to conducting a quantitative study, is that this can help to direct and refine focus on key areas of relevance to the experience of those involved (Saks & Allsop, 2019). This study employed a semi-structured interview format. Semi-structured interviews are increasingly utilised within health research (Jamshed, 2014). Questions asked during semi-structured interviews are open-ended to allow for elaboration, limiting the restrictions placed on participant's responses. The open-ended nature of questions supports the validity of findings as participants can communicate their experience more freely than if they were restricted by pre-set categories. This is important when employing phenomenology and methods like Interpretative phenomenological analysis (IPA) which try to understand an individual's experience.

An interview schedule was created with reference to factors included in Drossman's (2016) model, Engel's (1977) biopsychosocial model and the outcomes of Study 1's scoping review. The interview schedule (included in Appendix E) was used to provide an overarching structure to the interviews, outlining the core concepts and questions to be explored (Jamshed, 2014). Participants could discuss any topic they perceived as relevant to their experience with IBS or IBD, regardless of whether it appeared on the interview schedule. This was critical in ensuring the participant's experiences were captured. All interviews began with questions designed to better understand the biological nature of participant's GI condition experiences. This included asking participants about the duration and severity of their condition. Following these questions, the interviews focused on the psychosocial influence of GI conditions, for example, how daily life may be affected (which encompassed any coping strategies and psychological and social symptoms), experiences of social support and positives and negatives of their experience. In line with thesis research question 2, participants were also asked about their experiences of remission. To gain a better understanding of the current lack of awareness and knowledge of GI conditions, participants were asked to reflect on what they would like others to know about their condition, and whether there are any misconceptions that require address. Answers to this question could help shape the direction of future research and initiatives.

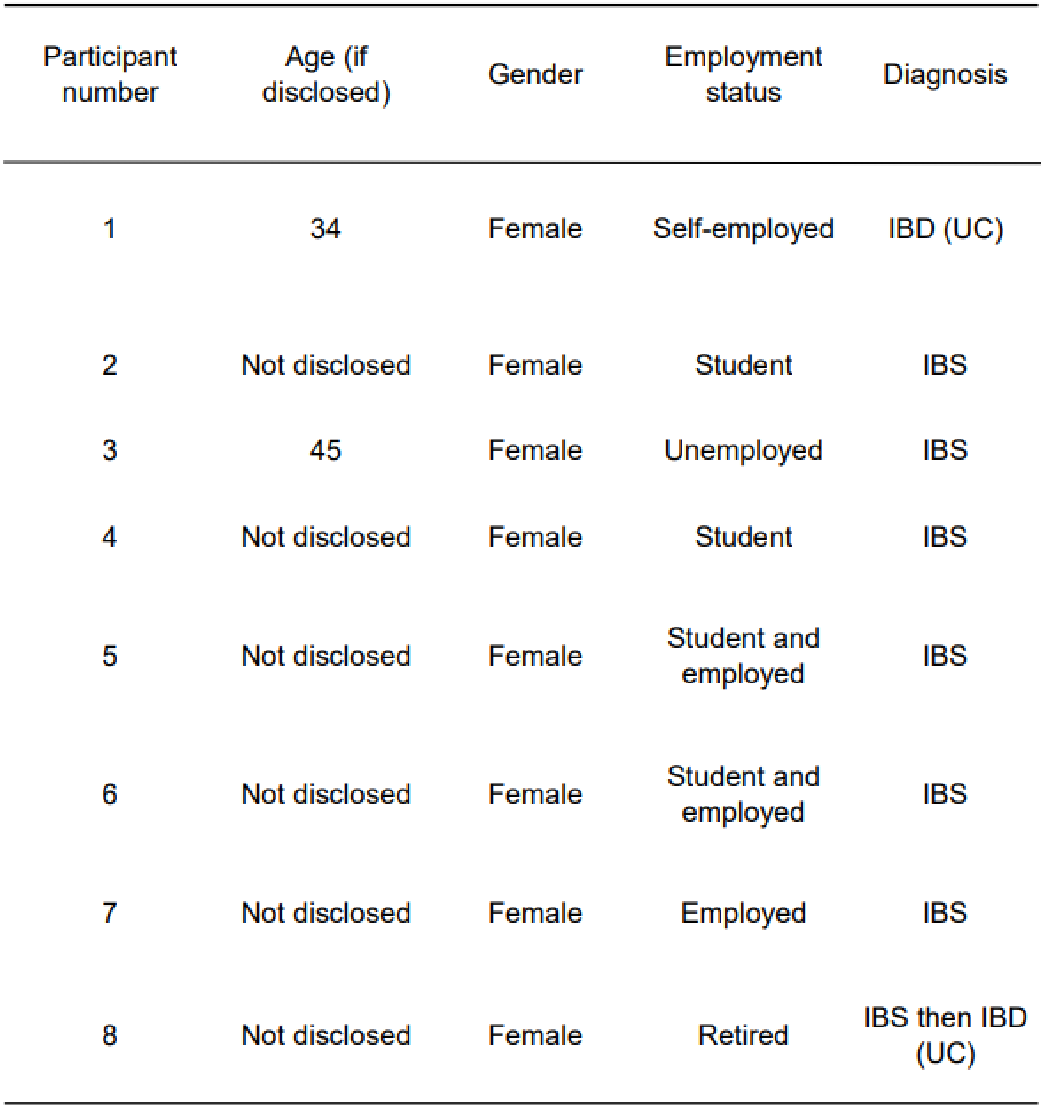
Interpretative phenomenological analysis (IPA) was employed to analyse the data. A common process is followed when analysing data using IPA. First, each transcript was read thoroughly. This allows the researcher to become fully immersed in the experience of the participant (Smith, Flowers & Larkin, 2009). Following this, notes and observations were made in the margins at points in the text thought to be of interest or relevant (Sharan & Tisdell, 2015). From these notes, themes were identified and then clustered to form superordinate themes. There was consideration of whether these themes spanned across cases (Smith, Flowers & Larkin, 2009). Illustrative quotes were used to support each theme. It was noted that the creation of these themes could have been influenced by the researcher’s personal interest in GI conditions, and throughout the analysis these biases were considered (Sharan & Tisdell, 2015). This is a result of the double hermeneutic employed in IPA, as the researcher reflects on the experiences of the participants (Smith & Osborn, 2008). While hermeneutics is concerned with understanding a phenomenon (Vieira & de Queiroz, 2017). In this case, this would be how the participants understand their lived experiences. The double hermeneutic typical of IPA involves an exploration of the meaning participants ascribe to their experiences, with an additional layer regarding how the researcher then interprets this understanding (Smith et al., 2009). This is not considered a methodological issue within qualitative research, rather they are recognised and monitored in terms of how the researcher’s interests may influence the research process (Sharan & Tisdell, 2015). Potential researcher biases can also be overcome by asking open-ended questions, to ensure the interviewee is not restricted in their response (King, Horrocks & Brooks, 2019). For transparency, these practices were employed for this study.

4.1.1 Participants

IPA typically involves small sample sizes (Smith et al., 2009), to ensure each participant’s views and experiences are fully attended to (Pietkiewicz & Smith, 2014). Participants were recruited up to the point of saturation where little or no new information was presented (Boddy, 2016; Mason, 2010), but an upper limit of 10 participants was set with reference to Creswell & Poth (2018) and Morse (2000) who recommend a maximum of 10 participants for phenomenological research. In total 8 participants were recruited using an advert posted on social media support groups related to IBS and IBD as well as the researcher’s own social media page. All participants were female, which was not unexpected, as GI conditions are more prevalent among women than men (Collen, 2015). Participation was open to all genders, and there were males who indicated an interest in taking part, but, despite reminder emails, they did not complete and return the required consent form. This means that this study did not capture male experiences, and as such the study was not as comprehensive as hoped. As a result, it is recommended that future research captures the lived experiences of both males and females with IBS or IBD. Participants all self-reported a clinical diagnosis of IBS or IBD. The following table provides key demographic information.

Table 5

Demographic Information



Participant number	Age (if disclosed)	Gender	Employment status	Diagnosis
1	34	Female	Self-employed	IBD (UC)
2	Not disclosed	Female	Student	IBS
3	45	Female	Unemployed	IBS
4	Not disclosed	Female	Student	IBS
5	Not disclosed	Female	Student and employed	IBS
6	Not disclosed	Female	Student and employed	IBS
7	Not disclosed	Female	Employed	IBS
8	Not disclosed	Female	Retired	IBS then IBD (UC)

To ensure confidentiality, participants were given pseudonyms when transcribing the audio recordings verbatim. Participants were then assigned a number to further protect their identity. Any other names participants mentioned were also changed. Raw data (audio recordings of interviews and transcriptions) were stored separately to information sheets and consent forms.

4.1.2 Procedure

This study was approved by the University of Sunderland Ethics Committee. Documents related to ethics approval (letter of confirmation, information sheet and consent form are included in Appendix A-D). All participants provided informed consent prior to the interview, which were conducted online via Microsoft Teams and audio recorded using a Sony IC. Interviews lasted approximately one hour, and the interview schedule acted as a guide for conversation. In accordance with IPA, questions were concerned with exploring participant's lived experiences, yet were largely open ended to ensure participants were not restricted in their responses (King et al., 2019) and could raise spontaneous points which they felt were relevant.

Interviews were transcribed verbatim and analysed using an interpretative phenomenological approach. Data were managed using NVivo. Each transcript was read thoroughly, with notes and observations made in the margins at points in the text thought to be of interest or relevant (Sharan & Tisdell, 2015). From these notes, themes were identified and then clustered to form superordinate themes. Illustrative quotes were used to support each theme.

Yardley's (2000) four characteristics were followed to ensure this qualitative research was of good quality. Meyrick (2006) note that different research disciplines refer to different characteristics/criteria of research quality, with characteristics by Yardley (2000) and Sherrard (1997) noted as commonly used approaches within psychology/health psychology. A more in-depth discussion of both approaches is provided in Chapter 3. For this study, Yardley's (2000) characteristics were judged to be more well-rounded and were selected over those of Sherrard (1997). The first of

Yardley's (2000) four characteristic is sensitivity to context, which was addressed as participant's experiences were explored and presented through extracts from the verbatim transcription to support arguments. Commitment, rigour, transparency and coherence are all related to the expectation that data collection, analysis and reporting will be thorough, and was addressed by ensuring each step in the research process was outlined in detail with explanations provided for decisions made. As part of this, the researcher was also reflexive throughout the research process, noting any biases which could influence the interpretation of data. The final characteristic, impact and importance, was addressed by outlining the common difficulties faced by those with a GI disorder, as well as highlighting areas where further work or research from policy makers, health workers and the wider community would be beneficial. Thus, this qualitative research is believed to be of good quality.

Reflexivity statement

It is important that researchers are reflexive and acknowledge how they might influence the way data is collected and interpreted, with prior experiences and interests potential factors of influence (Birks et al., 2014; Galdas, 2017). To improve transparency during the research process, these biases were acknowledged prior to the study and considered throughout the analysis (Smith & Noble, 2014). An identified personal interest was that the researcher's husband had been diagnosed with IBS, meaning personal experiences extended beyond an academic interest in GI conditions. It is widely accepted that the researcher's play an important role in qualitative research and it is not possible to remove their personal opinions completely from the research process, and neither is this warranted (Galdas, 2017), yet to limit potential researcher bias, in this study the researcher sought to ensure their role was secondary to that of the participant (Birks et al., 2014). For example, since the interviews were conducted online, the participants had the opportunity choose the location in which they were interviewed, removing researcher control (Birks et al., 2014). Also, while participants accounts were fully attended to on an individual level, data analysis also involved the identification of commonalities (themes) that emerged from their experiences (Birks et al., 2014).

4.2 Results

A total of five superordinate themes were identified following interviews: coping, negative emotional experiences, addressing a lack of awareness, the influence on relationships and daily functioning, and the experiences of remission. These themes are outlined in Table 6.

Table 6

Superordinate and subordinate themes identified following interviews

1. Coping
    - 1.1 Adapting to life with their condition
    - 1.2 Coping strategies employed
    - 1.3 Showing strength
2. Negative emotional experiences
    - 2.1 Embarrassment
    - 2.2 Negative affect
    - 2.3 Stress (as a trigger)
    - 2.4 Gut-brain interaction
3. Addressing a lack of awareness
    - 3.1 These are hidden illnesses
    - 3.2 A need to increase awareness
4. The influence on relationships and daily functioning
    - 4.1 Receiving social support
    - 4.2 Relationships with others
    - 4.3 Academic and work life
    - 4.4 Toilet access and availability
5. Experiences of remission
    - 5.1 Physical experiences
    - 5.2 Psychological experiences (relief)

1. Coping

The theme of coping referred to the methods by which participants’ come to terms with their condition, specifically the ability to accept and adapt accordingly.

This was identified as a necessary part of the coping process. Within coping, the various strategies participants employed were addressed, to explore whether there were any similarities across and within conditions.

1.1 Adapting to life with their condition. The need to adapt to, or come to terms with, their GI condition was discussed by multiple participants, such as Participant 2 who highlighted this succinctly. “I think I’ve just come to terms with it, it is what it is”. The consensus seemed to be that GI conditions can be life-changing, and so it is necessary to adapt to a new way of living. As the participants noted, accepting that life is altered due to the condition is the first step and then methods to adapt can be learned. These are coping strategies for daily life and there are many available, both adaptive and maladaptive. Participant 6 highlighted that it is important to understand your own body’s physical needs in order to adapt “You get to know your own body a bit better so you just your learn your own things and just adapt.” This suggested an awareness of how individual the process of adapting to life with a GI condition is, as well as the importance of working with your body rather than against it. Ultimately, what seemed important was the need to adapt to, rather than deny, the condition.

1.2 Coping strategies employed. The participants spoke a great deal about the coping strategies they employ, with some overlap. A wide variety of coping strategies were discussed, including the use of a hot water bottle, indulging in self-care, using humour to deflect from the situation, altering routines, sleeping and picking up hobbies. Participant 5 spoke at length about how she used humour as a coping strategy and tried to maintain a positive mindset.

> It’s sort of joking about it with people and people just like make a joke about it I’ll laugh it off and I can joke about it as well cause it’s kind of a coping thing, like being able to laugh, not always seeing the bad side of it.

It was refreshing to witness Participant 5 discuss her IBS in this way, maintaining focus on the positive aspects of her IBS rather than the negative. There was evidence that Participant 5’s coping strategies and mindset have altered in the time following her diagnosis, as she was initially reluctant to engage with others and felt more comfortable on her own, perhaps in attempt to deny her IBS.

> In the beginning, I would just shut myself off from everyone… I would make myself a hot water bottle and then I’d just go and shut myself in my room, I wouldn’t speak to anyone about it and then um, compared to now whereas I’ll openly speak to people about it… So, I think my coping mechanisms have really changed from what they were.

During her interview, Participant 5 was open and honest about the difficult situation she had been in, as her diagnosis of IBS was accompanied by an eating disorder. Understandably, simultaneously experiencing both conditions was challenging, but through her perseverance, she developed more positive and adaptive coping strategies for her IBS, speaking to others about her experiences and embracing humour and a positive mindset. Humour was also used as a coping strategy by Participant 3. “But sometimes I think you use humour to kind of get around a really awkward situation.” It was interesting that there was some overlap in the coping strategies used by those with IBS, most clearly evidenced in Participant 5 and Participant 3’s interviews. It seemed that humour was used not only for the benefit of the individual with IBS, but also to help alleviate any worry or embarrassment felt by those around them. Using humour when speaking to others about having a GI condition seemed to demonstrate that it is a topic you feel comfortable discussing and so others should also feel comfortable. This could be particularly useful for alleviating any worries about how others will react and potentially limit negative interactions.

Self-care was also mentioned as a coping strategy among some of the participants, with Participant 4 describing how the self-care she engages in was important in helping her feel better as well as serving a practical purpose.

> It’s more like self-care for me, like it’s more like my eyelashes, my eyebrows, my face masks, my hair, um, my nails, do you know what I mean? Stuff that you know, I’m feeling quite, you know bad, but I know that if I had to get up out of bed I would look presentable.

For Participant 4, self-care in the form of beauty treatments improves her wellbeing, but was also practical, improving her daily routine by reducing the time it takes to get ready. Having these beauty treatments meant Participant 4 could get up and ready for the day with minimal effort.

1.3 Showing strength. This subtheme refers largely to Participant 1 as she particularly demonstrated a great deal of physical and mental strength which were important in her coping with her condition. The physical nature of her job helps her feel strong and in control.

> I think it’s the whole um physical side of my job as well, you know, I’m quite strong, quite athletic, um and I really enjoy feeling that way, um and I think that really helps me if, you know, I’m starting to feel that downside and if I’m having a bad day with it I’ll just think okay well (laughs) let’s do something

> good with my body instead, like let’s feel strong, let’s go ahead and do some training or, you know, and that really makes me feel good.

It is evident here that participant 1 equates the feeling of being physically strong and capable with feeling mentally strong and capable. She even goes so far as to say that her job saved her, enabling her to have the mental strength to live with her ulcerative colitis. Participant one’s mental strength translates into a positive mindset, where positives are maximised, and negatives minimised, which presented as a coping strategy.

> So, you know, if I’m having a bit of a bad day with it, I’ll um, I might (laughs) I might have a quick cry of something, but then it’s out and um I can kind of start fresh and think right I’ve dealt with that, I’ve felt sorry for myself for like five minutes and um yeah kind of focusing on um, what, what makes me feel good and um as well what my body can do as opposed to what it can’t do, or what my challenges are with the body that I have.

It was interesting that participant 1 described negative thinking as a self-fulfilling prophecy leading you to feel worse. She seems to see negative thinking about her condition as a trap she tries not to fall into by focusing on what she is capable of rather than what she is not. Participant 1 further demonstrated her mental strength when discussing how she deals with challenges or barriers. “I think that it’s definitely made me stronger in character, um and that determinedness I was talking about.” This level of determination was inspiring and highlighted her physical and mental strength. Participant 1 seemed to find strength from her diagnosis, which she does not see as something to hold her back, rather she is almost proud to continue living and working with her UC as it shows she is able to overcome challenges thrown her way. Evidently, participant 1's physical and mental strength are used as coping strategies to keep her motivated.

2. Negative emotional experiences

The theme of negative emotional experiences was concerned with the various negative emotions experienced by the participants, which included feelings of embarrassment and negative affect (including experiences of depressive thoughts).

2.1 Embarrassment. Multiple participants disclosed feeling embarrassed about their condition. There were different reasons for this embarrassment, such as disclosing the condition to others and toilet use and habits. Participant 5 spoke about the embarrassment that can surround disclosing your condition to others or discussing it with them.

> I would say it' more like embarrassment really. I don't know if that counts as a psychological thing but it's just embarrassment of telling people like why, why, if someone points out that I look bloated or something and I just, I don't tell them why, which I don't think I should do anyway.
>
> Like if I'm going to Uni and all that I'm completely fine cause I'm with people who know about it, but like whereas in work I feel a little bit sort of, little bit embarrassed telling them.

Disclosing a GI condition seems to be an embarrassing experience, as was further supported by participant 2's experiences. "I think it's because I didn't want to talk about it." Participant 2 described further embarrassment she felt at university, which seemed to be one of the few social situations she engaged in, since her IBS limited her social life. The embarrassment she described centred around people looking at her and making negative judgements.

> It does it affects you because you go right okay it’s Wednesday I’ve got three lectures back-to-back, I cannot go to the toilet because it looks rude, if I stand up everybody’s gonna look at me…oh my God everyone’s gonna sit and watch me, I bet you someone times me as to how long I’ve been out the room, I bet you someone talks to me.

The embarrassment participant 2 described was potential rather than experienced, related to scenarios which could be theoretically embarrassing. She was concerned that someone will time how long she has been out of the room while at the toilet, which seems unlikely but a concern for her, nonetheless. Thinking about potentially embarrassing social scenarios were strongly linked to feelings of anxiety, which could further limit social interaction.

The act of using the toilet was a further source of embarrassment for individuals with a GI condition. Particularly, the smells associated, as described by Participant 8.

> The smells when you went to the toilet, my handbag always full of perfumes, sprays, you know, give a good spray in the toilet before I came out, but then you get people well you know, oh the drains in here want sorting out, or oh what dirty bugger’s come here and done that.

These instances reveal the embarrassment Participant 8 has felt when having to use public toilets, particularly around the smell that could accompany a bowel movement. As well as the smell, sounds accompanying a bowel movement can also be embarrassing, as Participant 7 mentioned.

> The embarrassment factor of the fact that having to go you don't want people to hear (laughs) the process and in the stalls, like in women's toilets, there's like gaps isn't there, at the top and bottom, you can't privately do that.

Simply talking about their GI condition could also be embarrassing, as Participant 7 and Participant 5 revealed. "Like not being able to go to the toilet is something that not a lot of people will talk about." (Participant 5)

> There's other things that I live with that I can talk about, like I'm an asthmatic and I can talk about my asthma, I can talk about not being able to breathe and the times of having to carry my medication with me all the time, having to take medication every day, but it's a completely different thing to talk about problems with your bowels. (Participant 7)

Participant 5 and Participant 7's cases differ as Participant 5 is concerned with issues related to constipation, whereas Participant 7 experiences diarrhoea, yet despite these differences, both experience embarrassment when discussing their conditions. There was a consensus that toilet use, and bowel movements are a taboo subject. Participant 7 described that she finds talking about her IBS more difficult and embarrassing than her asthma which she is happy to discuss openly. This is likely due to the taboo nature of topics related to toilet use and bowel movements, which makes GI conditions a more embarrassing subject than other health conditions. The participants seemed to suggest a stigma exists around IBS and IBD, with these being conditions individuals should be embarrassed about and should not discuss.

2.2 Negative affect/ depression. Many of the participants experienced negative affect and depression as a result of their GI condition. There were numerous instances where participant 2 revealed she had been suffering with negative affect. “I think since being diagnosed with IBS I have become depressed a lot more and a bit more suicidal about it because it does totally just ruin your social life.” It was evident that participant 2’s IBS has been accompanied by mental health difficulties, particularly depression. Potential treatments were discussed, as her mental health was concerning. It was particularly worrying since Participant 2 had mentioned feeling suicidal previously as a result of her condition and how it limits her in her daily life. This demonstrates that IBS can be associated with negative psychological as well as physical health outcomes. While not to the same extent, Participant 4 also discussed negative affect/depression associated with her IBS. “I would say psychologically it exacerbates my anxiety and my depression, because there’s nothing I can do about it.” It was unfortunate to hear that many of the participants experienced negative affect and a diagnosis of depression alongside their GI condition. Many disclosed being prescribed anti-depressants. Participant 2’s case was quite severe and so opportunities for help were discussed with her. These interviews highlighted that GI conditions do not only affect the physical health of those diagnosed, but psychological health can also suffer too, revealing the need for more holistic support for those with GI conditions.

2.3 Stress (particularly as a trigger). Related to negative affect, participants reported experiencing high levels of stress as a result of their GI condition. Participant 2 spoke of the stress she experiences due to her IBS. “You can never just sit back and relax.” Stress was discussed as a trigger to a GI condition flare up. This was true for many of the participants, for example Participant 3 said “If I’m stressed about something then it’s worse.” Participant 5 echoed this; “if I know something stressful is coming up that’s when I start to get bad stomach cramps and start to get bloated.”

These interviews revealed the link bi-directional link between stress and GI conditions, as the condition can cause stress, but stress can also exacerbate symptoms, triggering a shift from remission to the active stage (a flare up). Participant 2 spoke about how thinking about her IBS can cause her to have anxiety. Due to the bi-directional relationship, it is likely that this anxiety will then exacerbate symptoms which can lead to further anxiety, creating a vicious cycle individuals may feel locked into. From these interviews, stress seemed to play a large role in GI conditions, particularly IBS, suggesting that an improved understanding of how to combat stress would benefit those with a GI condition.

2.4. Gut-brain interaction. Some of the participants were aware of the link between their gut and brain, specifically the link between stress and their GI condition. For example, Participant 4 discussed the interaction between gut and brain.

> I think they all sort of interlock with each other, like the physical symptoms obviously go hand in hand with the mental symptoms if I’m not feeling good physically, I’m not gonna be feeling good mentally, if I’m not feeling good mentally then I’m not feeling good physically.

Participant 7 similarly described this interaction, she even disclosed that her GP had determined this to be the cause of her IBS. “They said that what they felt was that, you know there’s the nerve between my brain and my stomach is just hypersensitive.”

> They think as I’ve said I’ve had mental health problems, you know, just about my whole life and they were saying there’s, you know, you get those sorted and then you might find your stomach problems and everything will settle down.

Participant 7 did create some interesting imagery when describing how she felt her IBS was caused by her anxiety. Almost as if she is consuming the stress, as she would food and drink, which is being processed by her gut (the churning she refers to), causing her physical discomfort. “It’s like internalising something and that’s how we cope with it and your stomach is just churning away and eventually that kind of has an impact so.” It was interesting that some participants had made the connection between physical and psychological health, with Participant 7’s GP even suggesting that improving her mental health may be instrumental in improving her IBS. It is evident that the gut-brain axis is increasingly well-known, suggesting that more holistic treatment plans could be in place for individuals with GI conditions. Perhaps even from the point of diagnosis, individuals should be better informed of how to deal with stress and negative emotions, which could help to reduce physical symptomology.

3. Addressing a lack of awareness.

This theme referred to the shared belief that there is a lack of awareness around GI conditions which needs to be addressed. This lack of awareness seems to be driven by the hidden nature of GI conditions, as often there are limited, or no, outward physical signals that a person is unwell.

3.1 GI conditions are hidden illnesses. Participants highlighted the hidden nature of GI conditions, since there are often no outward, visible signs of symptoms of the condition. Participant 8 pointed out a discrepancy in how those with a GI condition are treated compared to those with a more visually obvious condition such as a broken bone. “If you had a broken arm or a broken leg, people would feel sorry for you, but when you’ve got IBS, IBD, oh there’s nothing wrong with her, she’s just lazy.” Interestingly, Participant 4 made a similar comparison. “I started to say right well people wouldn’t be like this is I had a broken leg, they would offer help, do you know what I mean?” This is evidence of a shared experience. There seems to be a disconnect between their condition and the reactions of others, since there are limited physical manifestations to be seen with GI conditions, certainly in comparison to a broken bone. Participant 8 and Participant 4 both disclosed feeling that because of the hidden nature of their conditions, people do not take them seriously and do not always respect their need for help. Both Participant 8 and Participant 4 also similarly mentioned that they think other people will jump to the conclusion that they are making excuses because they are lazy rather than living with a condition. This perception could be linked to previously received comments, but it is effective in demonstrating the struggle and stigma associated with living with a hidden illness. Participant 2 summed this is up. “They think that just because I look normal and I don’t have a wheelchair or you know a support carer walking round with me 24/7, that I don’t have a disability.” The idea of appearing physically “normal” was central to the hidden nature of IBS and IBD. Often there is a lack of outward cues to signal to others that a person with a GI condition is unwell, which can lead to negative judgements, with others choosing not to believe what they cannot see. It was evident that this is distressing for the participants, and there needs to be better understanding that some conditions appear invisible, but this does not decrease their importance.

3.2 A need to increase awareness. One way to address the concerns around IBS and IBD being hidden illnesses would be to increase the amount of public awareness of these conditions. Participants were asked how we could address misconceptions or better inform others about GI conditions, and all suggested that awareness should be increased. The first step in increasing awareness would be improving understanding of what these conditions are and their holistic influence on health, which participant 2 mentioned.

> I think I'd change the sort of overall perception of it that it's IBS, it's not what you eat that kind of affects you, it's all the different factors that can also sort of pose an influence on it, you know, like your mental health, your physical health, your emotional.

Participant 1 suggested that awareness of IBD may be particularly lacking, as it is often confused with IBS, as it is more well-known. "A lot of people when you say oh, I've got IBD, I've got colitis, oh is that IBS? No, it's not IBS (laughs)." Based on participant 1's experience, it seems that IBS is used as a term to cover all GI conditions, and so a good step in increasing awareness of IBD could be to better illustrate how it differs to IBS in terms of course and experiences. Participants did consider methods by which understanding and awareness could be raised. Participant 3 and Participant 4 pointed to a lack of visual representation in common areas such as GP's surgeries.

> I think again it's one of those things that you don't see, you know when you're sitting in a GP waiting area and you see things about meningitis which of course if very important, or um, measles and things like that, it's one of those thing IBS that you don't sort of sit there and see a lot of um media about it, you know like leaflets or on the TV screen in the doctors. (Participant 3).

> Posters in GPs or like you know what they do with the bowel screenings for bowel cancer? Um, it could go alongside that. Um, you know, just general like health advice, like general leaflets in GP surgeries, in hospital waiting rooms,

> you know, websites, social media, you know, anything to raise awareness about it. (Participant 4)

The participants hoped that by increasing the visibility of IBS and IBD, for example via media campaigns, awareness will be increased, and with it the understanding of others. It is anticipated that this improved education will help to combat the stigma and judgement those with these conditions feel.

4. The influence on relationships and daily functioning

This theme was concerned with how the relationships and daily lives of participants are influenced. Experiences of social support are discussed, for example receiving social support from others and the forms which this can take, and how a GI condition can influence relationships with others. The everyday influence is explored through academic and work life and concerns around toilet access and availability.

4.1 Receiving social support. As the prior scoping review revealed social support to be a commonly addressed psychosocial factor involved in IBS and IBD, a question focused on social support was included in the interview schedule to gain further understanding. Generally, participants described receiving good quality social support from loved ones. For example, Participant 6 described having a strong network of support she can rely on.

> Yeah, so um, my dad was in the NHS and so anything medical I can kind of talk to my dad about he’s not bothered or phased, um my mum and I have a very, very close relationships… we can discuss it and things like that um and the toilet, with my family they’re not too bothered, um with all being in kind of health care and there’s no kind of taboo subject to talk about. I’m quite lucky with my partner’s family, um his Aunt’s like a pharmacist and they’re very close so she

> has a lot of healthcare understanding and needs of people with IBS and things like that, um and his grandma was a nurse so again they all understand.

Participant 6 describes that a lot of her family and her partner's family have medical knowledge and understanding of GI conditions such as the IBS, which makes it easier for them to understand and appreciate her experiences, which is likely why they can provide excellent support and advice. She went on to discuss the support she receives from her partner.

> He's very supportive so like if I do need to go to the toilet, or I'm feeling quite ill, or if I'm having cramps like he'll bring me a hot water bottle or he'll just be like oh just go to bed and have a nap and do something, like he's very supportive. Um, he has changed his diet so if there's something that is triggering my IBS and in particular, like he loves cheese, but he'd never have a cheese board now really like for dinner or anything like that cause he knows I can't join in on that.

It is evident that Participant 6 receives a great deal of social support from loved ones, bolstered by an understanding of what she is going through. The importance of understanding in social support was also discussed by Participant 4 and Participant 8 (who runs a support group for individuals who have had an ileostomy). Participant 4 described the benefits she gains from being a member of an online support group for those with IBS.

> I've got a couple of groups on Facebook that I'm on, um, and it, it's good because you can sort of, you can talk and you can say oh I'm having a really crap day like, literally, do you know what I mean, and they'll be like oh yeah, yeah, and there's no judgement, nobody thinks you're whingeing, nobody

> thinks you’re putting it on.. and I have found that, you know, talking to people with the same sort of symptoms as me, it doesn’t make me feel like a, for want of a better word, it doesn’t make me feel like a freak.

The shared understanding from the support group enables Participant 4 to feel accepted and the group provides a place where she can discuss her symptoms and how they make her feel without fear of judgement, something which is evidently important to her. Using the Participant 8 understands the benefits of support from those in similar positions, as she has set up her own support group for those with GI conditions.

> What we do there is, if anybody has things that they’re worries about, you know that they want to talk about, you know, there’s people, we’ve all had one thing or the other and we try to help each other, it’s a support group.

All participants received some form of social support, from friends, partners, family and from online groups. The shared experience of online support groups seemed to provide a sense of community and acceptance. It is arguably easier to talk about a topic to an individual who is also knowledgeable, which would also help Participant 6 as she had individuals from a medical background in her support network. Regardless of the form social support takes, feeling understood was important for individuals to feel comfortable and truly supported.

4.1 Relationships with others. Alongside receiving social support, Participant 2 and Participant 7 disclosed that their IBS had been associated with negative outcomes in their romantic relationships. From their descriptions, IBS seemed to be in the way of their love life, as participant 2 explained.

> Um, sex life, that’s gone…I think because my IBS has gotten that much worse during lockdown, I think we went about two, three month without even touching each other cause it, it does it just ruins you because you cannot sort of relax your muscles to enjoy it, and then it sounds gross right but it is what it is, you go to the toilet, you wipe your bum and all that crap, ironically crap.

Participant 2 outlined numerous ways in which her IBS has negatively affected her relationship with her boyfriend, both the physical manifestations and the psychological as she worries about her appearance and how her apathy for sexual intimacy upsets her boyfriend. Participant 7 similarly described IBS as an unwanted part of her relationship with her husband.

> I mean it’s not a romantic thing to have in my marriage (laughs), you know it’s not like, my husband and I discuss my bowel habits, I mean that’s not (laughs), it’s not really, um yeah it’s not like a lovely conversation thing to have.

Both participant 2 and participant 7 agreed that IBS interferes with their relationship, with a sense that their IBS is an unwanted presence in their relationships, almost like a third person present in their relationships. Certainly, with romantic relationships there is a level of intimacy which could be causing additional embarrassment and anxiety, as seemed to be the case with participant 2. The physical symptoms of her IBS influences how she feels about her appearance, leading her to feel unattractive and disinclined to engage in sexual activity with her boyfriend because this would involve her having to take her clothes off. Participant 2’s frustration at this was evident, but she seemed almost resigned to the fact that her relationships and sex life have been affected as a result of her IBS.

4.2 Academic and work life. Four of the participants were currently in education and discussed how they managed their academic life while having a GI condition. The participant's responses were largely negative in outcome, for example, participant 2 discussed that they had experienced difficulties with concentration.

I was alright it just affected my studies a lot more because I couldn't concentrate in class and I still can't so I've now got a disability plan put in place, um so it does take me a lot longer to actually process what's gone in cause it effects my short-term memory.

Participant 2 had spoken to her university and had a support plan put in place to ensure she could have extensions on assignments to address the issues she was experiencing with her IBS. She went on to discuss this further.

> Like right now I've got four assignments due but it takes me that long to understand what's going on, I haven't even started on them because I'm only half way through the reading material, and I do have that um, I don't know what the word is, I do sort of have that access where I'm able to go to module leaders saying look I'm not being funny, it's not as if I've been last, it takes me a lot longer to process and can I have an extension, because since they've got that whole disability they go cool, no bother.

Participant 4 disclosed similar struggles to concentrate on her university work due to her IBS.

> I mean, there's times where you know I've been up in the night with cramps and stuff like that, or you know, my children or what you, um and I'm watching lectures, I'm watching seminars and I'm like okay, right, I'm just winging it here, like this is, this is absolute, you know, this is gonna be a disaster, um

> and I have to read the assignment briefs about four or five times before anything sinks in and then I've literally got to go back, I've got to comb over every single lecture, every single seminar slide just to make sure that I've got everything I need because I don't take it in first time.

It was evident that the symptoms of IBS, both physical and psychological, can have negative outcomes on academic life, reducing the ability to concentrate and seemingly impairing short-term memory. This leads to feelings and worries of falling behind with their work and a need to ask for deadline extensions. Employment difficulties were also discussed in relation to physical symptoms, such as fatigue which was described by Participant 8.

> I was getting really like tired and I couldn't do a whole day of what I did and then come home, so I went to part-time, which cut down my hours and my income, which didn't matter like my husband was working.

Participant 8 is retired now, but she had felt it necessary to reduce her working hours to cope with her condition, and she was not alone in having to alter her work schedule to fit around her GI condition, as Participant 7 discussed similar issues.

> Yeah I certainly don't like anything starting before 10, um and actually I've found that 11 is more comfortable for me, so I am, I did change my office hours this semester, in fact I changed them to the afternoon because I realised that actually (laughs) having anything where I've got to be at my computer and where I might be engaging with people, um means that I'm then at risk of potentially having to stop and go to the bathroom and I don't really want to have to do that cause it could, cause like I said it's not just once, you know, um so I moved um some of my like office hours to the afternoon to

> make it easier for me. Um, I do teaching, like there’s teaching that I do that’s at 10 o’clock um on a Tuesday and that was quite hard cause I don’t have a choice about that, cause it has to fit in with the timetable, so I did find that quite challenging.

Participant 7 was able to reschedule her office hours (hours where she is available for students to drop in with queries) to better suit her needs, but her teaching timetable is beyond her control, which she admitted can be a concern. Participant 3, not currently employed, had also previously experienced employment difficulties, describing a time when she was going through a particularly stressful time. This exacerbated her condition and ultimately, she felt compelled to quit her job at the time.

> Eventually I left that job because I just, the stress of the job wasn’t helping the condition, I think you’ve got to find something that um, particularly for work life, you’ve got to find something that you’re comfortable doing and isn’t too stressful. I’ve always worked in quite stressful jobs.

These interviews highlighted how physical and psychological symptoms can result in employment difficulties. A shared experience was the reduction of working hours, dropping from full-time to part-time employment as a result of a GI condition which can have financial implications. In some circumstances, individuals may not feel able to work, as was the case with Participant 3. Certainly, her situation was extremely challenging, but it was apparent how challenging employment could be with a GI condition and how it might feel impossible to balance health and employment.

4.3 Toilet access and availability. Toilets seemed to be a cause of stress and anxiety for the participants, particularly concerns around access and availability to toilets when out socially. The worry about planning a social event like eating at a restaurant around toilet access/availability was discussed by Participant 6.

> I am one of those people who would rather wait to get home, like rather wait to go to the toilet when I, to get home, than go in say a restaurant or something like that where it is quite a small rest room and the people who might be in the cubicle next to you might be sat at a table just over there and they can see you kind of thing cause like I said I can be quite gassy and things like that, so I can make quite a bit of noise almost when I go to the toilet, um which can be quite embarrassing so I'd rather wait till I got home, um so it can impact socially there but I would still go for the meal.

Participant 6 can still hold a full social life, but concerns over toilets do factor into her plans as she tries to refrain from using the toilet until returning home. Her reasons for not wanting to use a public toilet seemed to be related to embarrassment, and fears that others will overhear her using the toilet and judge her negatively. A dislike of using toilets other than their own was also mentioned by Participant 3.

> But I don't like going to the toilet outside, I don't like going at work, I don't like going in other people's houses, I don't like going if I'm out in a social situation, so I've kind of got to think about that.

Participant 3 mentioned comfort and needing to feel comfortable while at the toilet. Arguably, this comfort is dependent on several factors such as not being overheard, a familiarity with the surroundings, the ability to engage in a particular routine and the knowledge that you are not sharing a bathroom with other people. The worry about public toilets having stalls for more than one person was touched upon again when discussing the use of disabled toilets. The participants seemed to feel guilt when using disabled toilets, which was directly linked to IBS and IBD being a hidden illness and concerns that others would judge them for using a disabled toilet without having a visually evident disability. Participant 7 was particularly worried about this.

> One of the things is when I’m out and about and before all of this COVID stuff happened, one of the things that I felt very conscious about was using um a disabled toilet and the reason for using that was actually because it was usually the disabled ones are separate.

Participant 7 discussed the increased privacy disabled toilets afford and how this can alleviate some of the embarrassment the participants indicated experiencing. Participant 7 disclosed that she worries someone would confront her on why she was using a disabled toilet.

> I’m constantly worried about being challenged about going to that toilet and that’s been at work as well, cause I do very specifically use it um and I’ve often, in my head, had the conversation ready to say not all disabilities are seen, and I’ve sort of wondered about having like, you know, like a card or something that can say I can do it or can use, but that’s just as embarrassing having to get a card out kind of thing.

Participant 4 also mentioned that whether to use a disabled toilet can pose a dilemma.

> I’ve only done it a couple of times and it’s been like with seconds to spare, I would normally if I’ve got cramping I would try and make my way to the toilet,

> like a normal toilet, like this is only when I've literally been like right okay, you either wait in the queue there or you run in there.

When asked why she was reluctant to use a disabled toilet, Participant 4 explained that it is because she does not class her IBS as a physically disability and therefore doesn't feel justified in using disabled toilets regularly.

> Because I'm not physically disabled, and if I can, you know if I can sort of get to a toilet, if I can wait in a queue if it's, if it's not that urgent, then you know, I'm fine to wait in a queue, like it's not, but I mean if it dd come where you know I literally had to go that minute then, you know I would have to, I would have to and I would feel really guilty about it but I would have to. Um, and I do think, you know, I've got more options than a physically disabled person so if I can leave that toilet free then, you know, I will.

This could be attributed to differing ideas of what a disability is, as Participant 7 seemed ready to defend herself as someone with a hidden disability, whereas Participant 4 would not class herself as disabled. Regardless of classification though, both seemed to experience some concern about how others would judge them socially for using a toilet marked for disabled individuals, providing evidence of a social stigma attached to their IBS.

5. Experiences of remission

The theme experiences of remission is related to both physical experiences (whether physical symptoms are still experienced and if so how do they compare to the symptoms experienced during the active stage) and psychological experiences (whether participants still experience the stress and negative emotions previously discussed).

5.1 *Physical experiences*. Most of the participants described feelings of physical relief during periods of remission, but their physical symptoms are still present, as participant 1 described that her symptoms of blood and mucus in her stool still occur during remission.

> That tends to calm down quite a bit when I go into remission. Um, I still, still throughout remission take medication obviously because you've got to keep everything in place, um, and I do still experience tiredness regardless of whether I'm in remission or in a bit of a flare, it never seems to go away.

Participant 1 described some physical symptom relief, but her feelings of fatigue are constant regardless of whether her UC is active or in remission.

> I do sort of feel more perky and definitely more energy when I am in remission but it, it's sort of, it's really hard to explain, like, I do have energy but I feel as if it's layered on top of like this tiredness that is just sort of rumbling along (laughs) um, and following me wherever I go.

While some of participant 1's physical symptoms eased, she continues to feel fatigued. When Participant 7 was asked about her experiences of remission, she described feeling that she had not experienced remission as her physical symptoms do not ease enough to detect a difference.

> I don't, I don't see it as, cause that, to me that's that it goes away to a level that's undetectable, and it's never undetectable, so I don't, I don't see it as being like that um, in, not yeah, cause if I think about my asthma, my asthma goes into periods where it's completely managed so that I don't notice problems with it, whereas with my IBS it's a constant thing because of the fact that I've got to be careful about food so any, any moment when I relax, it's

> back and to its full thing so it's like it's always there and I, it, even when it's managed I'm still having to, you know, having those urges to go to the toilet, it's just not going to be an accident so it, it doesn't, the feelings don't go and so that can be hard to then trust that it's not going to be a problem.

The most physical relief Participant 7 experiences is a feeling that her condition is managed, but she still experiences symptoms such as an increased need to go to the toilet, but she is more confident that she will not have an accident. These managed periods could be equated to periods of remission, but as Participant 7 perceives remission as being a symptom free time, she believes she has not experienced remission.

5.1. *Psychological experiences (relief).* Remission was not described as a wholly positive physical experience, but some of the participants described it as a period of relief, with worries around their GI condition reduced. For example, Participant 4 described feeling as though restrictions on her daily life are lifted. "Mentally as well because I'm sort of, I can go out places and not, you know, not try and plan for the nearest toilet." A long period of remission had recently ended for Participant 3 prior to the interview, and she evidently missed the relief it offered. "When you come back to being in remission it's, it's like a really welcome change initially and then of course you just take it for granted." It was apparent that remission can be a mixed experience, which is highly individualised, varying between individuals. Physical symptoms can still be a problem, and some may not feel they experience remission since physical symptoms remain severe. Psychologically, remission can offer relief, with reduced anxiety around going to the toilet, and feelings that daily life can return to normal, freeing individuals up to engage in activities they may have previously avoided. It can be easy to become complacent when in remission, but the shift from remission to the active stage is jarring. Participant 7 was the only participant who did not believe they had experienced remission, but the other participants seemed to agree that remission is a period of relief, more so in a psychological than physical sense.

4.3 Discussion

This study aimed to explore the lived experiences of those living with a GI condition. Five themes were identified: coping, negative emotional experiences, addressing a lack of awareness, the influence on relationships and daily functioning, and experiences of remission. These five themes demonstrate the negative influence GI conditions can have on psychosocial functioning but indicate that a strong support network and a focus on the positive rather than negative can be beneficial. IBS and IBD are hidden illnesses, with limited visual cues, further supporting the need to increase awareness of these conditions.

4.3.1 Coping

Participants discussed a need to adapt to life with their condition, accept that their daily life may have changed, and employ coping strategies. A wide variety of coping strategies were discussed, some of which have been reported in previous research. For example, altering routines to fit around a GI condition was also reported as a strategy among those with IBS by Campbell (2015) and Farndale and Roberts (2011). Attempting to maintain a positive outlook, maximising focus on positive aspects and minimising focus on the negative were also strategies previously reported as used among those with IBS and IBD (Jones et al., 2006; Roohazfa et al., 2016; Wessinger et al., 2009). These strategies are recognised in measures such as the Brief-COPE questionnaire (Carver, 1997). Several other strategies participants discussed are also included on the Brief-COPE (Carver, 1997), including the use of humour and self-distractions such as sleep and hobbies. Coping strategies were fluid, as participants discussed how the strategies they used changed over time. This outcome is consistent with research by Yasmeen et al. (2015) which indicated that coping strategies used by those with a chronic condition such as IBS or IBD can change over time, often dependent on factors such as age, resources available and personality.

4.3.2 Negative emotional outcomes

The negative emotional outcomes that can occur alongside IBS and IBD were evident. Similarly, Sammut et al. (2015) noted that individuals with ulcerative colitis often experience emotional turmoil. Participants described experiencing embarrassment, as an outcome of their condition, on several levels. One source of embarrassment was having to disclose their condition to others. Ferreira et al. (2011) similarly reported that disclosing a GI condition to a partner or close friend can cause emotional distress and embarrassment. Concern around potential negative judgements is commonly addressed with cognitive behavioural therapy for those with IBS (Hunt, 2019). In fact, Taft et al. (2011) had reported that there is a social stigma around IBS and IBD, which would support participants concerns around judgement. Muse et al. (2021) further explored the stigmatisation of individuals with IBD, and reported that this population experience a disconnect where they wish to have their condition understood, but are fearful of being stigmatised. Bowel movements, particularly the associated smells and sounds, were another source of stigma and embarrassment for participants. Haslam (2012) reported that this anxiety is common, as bowel movements are deemed private, meaning their discussion can result in stigma (Dibley et al., 2018). Targeting stigma and embarrassment around GI conditions could be associated with improvements in individual's experiences.

Participants commonly discussed experiencing negative affect (typically depression and anxiety). Unfortunately, GI conditions are often comorbid with a diagnosis of depression and/or anxiety, and experiencing negative affect is common among those with a GI condition (Cho et al 2011; Graff et al., 2009; Fuller Thompson & Sulman, 2006). This accords with research by (Farhadi et al., 2018) who reported that GI conditions are associated with decreased subjective wellbeing, which is partially determined by experiences of negative affect (Diener 1984; 2000). Stress also appeared to be a concern among the participants, as their condition often left them feeling unable to relax. Participants felt that their GI condition was always in the background and if they were not vigilant, it could flare up and catch them off guard. In this way, stress was regarded as a trigger for, or something that could exacerbate, symptoms, as Jaghult et al. (2013) and Sun et al. (2019) reported was true for IBD and for IBS (Qin et al., 2014).

The link between stress and increased symptomology (a flare up) provides evidence to support the biopsychosocial model (Engel, 1977) and the interaction between the gut and brain. It is well established in the literature that bi-directional communication between the gut and brain occurs in GI conditions (Cryan & O'Mahony, 2011; De Palma et al., 2014; Mayer, 2011). Participants identified this gut-brain interaction, which is implicated in both IBS and IBD (Bonaz et al., 2018). One participant described the relationship between stress and anxiety and their gut, leading to it feeling as though it is churning, which she felt was causing her IBS. This evocative description captured the link between brain and gut and was evidence in support of the biopsychosocial model (Engel, 1977) in lived experiences.

4.3.3 Influence on social life and daily function.

Social support is often highlighted as a method for improving the wellbeing of those with a GI condition (Oliveira et al., 2006). Participants all had sources of social support available to them. This social support was largely provided face-to-face, but online support groups were also mentioned as a source of support. Previous research into online support groups for individuals with IBS conducted by Coulson et al. (2005) revealed that messages exchanged were often hopeful and encouraging, providing emotional support for members. Among those with IBD, accessing online support via social media can provide comfort and connectivity (O'Leary et al., 2020). Online support has many benefits since it is available at any time, with a wide geographical reach (Chan et al., 2016). The shared experiences of members of online support groups provides a safe environment to share concerns, ask questions and connect others with similar experiences, decreasing feelings of being alone (Prescott et al., 2019).

Romantic relationships are an often relied upon source of social support (Don & Hammond, 2017), but participants with IBS described that their conditions affected their romantic relationships. Silk (2001) similarly reported that difficulties within romantic relationships are commonly experienced among those with GI conditions, as 6% of their sample felt that their IBS had affected their partner's feelings for them and 45% believed that their IBS affected their sex life. In this research, IBS was described as an interference to romantic relationships (Silk, 2001). In this study, participants described that GI conditions can further challenge romantic relationships via negative body image. Participants discussed that bloating and discomfort made them feel disinclined to be romantic or intimate with their partners, as they felt unattractive. Body image dissatisfaction has been found to be linked to IBD, particularly among females (Beese et al., 2019). Less is known about body image and IBS, but it is arguable that body image could be similarly affected and so more needs to be known about this. While this sample was all female, experiences of relationships appear similar for males too, as Campbell (2015) reported that males with IBS found relationships challenging.

Among the student participants, academic life was also affected as IBS resulted in difficulties related to memory and concentration, which have similarly been documented in the literature (Kennedy et al., 2014; Tanaka et al., 2011). Some of the participants who were employed described that their working life was also affected, which could result in the decision to work part-time. Working part-time is an often-reported outcome of GI condition symptoms, as Ueno et al. (2017) reported that 32% of those with IBD they studies had to work part-time to avoid taking sick days. Some participants felt unable to maintain employment at all, consistent with research suggesting that job loss as a result of a GI condition is a common experience, with 35.5% of Ueno et al's. (2017) sample believing they had lost a job due to their IBD. A range of difficulties associated with employment or academic career were outlined in these interviews, demonstrating that there needs to be greater focus on ensuring individuals with GI conditions feel able to comfortably work or study despite their diagnosis.

Concern around toilet access and availability when out socially was common. There was a consensus that it is better to wait until returning home to use the toilet, as this is where participants felt most comfortable. Part of the worry about public toilet use was whether it is acceptable to use a disabled toilet when you have a GI condition, with debate as to whether they felt IBS was classed as a physical disability. This concern was strongly linked to issues around IBS and IBD being hidden illnesses, with limited or no visual cues to suggest any suffering and issues of being judged by others. Again, the social stigma that exists around GI conditions (Taft et al., 2011) was evidenced. This is a complicated social issue, as one participant pointed out, since labelling individuals with a GI condition as having a disability could be damaging to their identity. Seemingly, individuals make their own judgements around their disability status.

4.3.4 Lack of awareness.

Participants identified that there is a lack of awareness of IBS and IBD, which was largely attributable to their identity as a “hidden illness”. The lack of outward visual signs of their condition meant that the participants felt they were not taken seriously or have their condition acknowledged. This was a shared experience, with concerns that they would be judged as being lazy or making excuses, again evidence of the social stigma experienced by those with a GI condition (Taft et al., 2011). The participants indicated that a lack of awareness was responsible for misconceptions about their condition. Previous research has evidenced common misconceptions of IBS, which include that it can develop into colorectal cancer or colitis (Halpert et al., 2007; Lacy et al., 2007), yet there is no evidence to support this (Nørgaard et al., 2011). IBD is often misconceived as a self-inflicted condition brought n after laxative abuse (Sammut et al., 2015). Ultimately, participants identified a need to increase awareness, which would address concerns around social stigma, misconceptions and the identity as a hidden illness. This increased awareness would highlight the influence of GI conditions on physical and psychosocial health, in support of holistic health models such as the biopsychosocial model (Engel, 1977). Various suggestions were provided as to how awareness could be increased, including more information available in communal areas such as GP surgeries, hospitals and also in the media. Recent research has considered the best way to increase awareness, suggesting the optimal method would be through anti-stigma campaigns in public places like healthcare settings and the workplace (Shorey et al., 2021).

4.3.5 Remission

Remission was an additional finding from study one’s scoping review, and this study aimed to further explore participants experiences during this stage of their conditions. A question about participant’s experiences of remission was included in the interview schedule. Most described remission as a period of relief, yet physical symptoms were often still present for many. This was not surprising as a systematic review (Van Langenberg & Gibson, 2010) revealed that between 41 and 48% of IBD patients in remission still experienced fatigue. Experiences of remission were largely consistently described as a period of relief, yet one participant described having never experienced remission according to her idea that remission meant symptom free. This accords with the findings of Kitchen et al. (2020) who reported that one participant with CD did not perceive themselves as having experienced remission since they defined remission as an absence of symptoms rather than a reduction in their severity. Psychological experiences during remission of the group were not wholly positive either, but were typically described as offering relief, accompanied by decreased worry. These interviews revealed remission to be a highly individual experience. There seemed to be some disconnect between participant’s ideas of what remission should look and feel like and the actuality of this stage, reinforcing the idea that remission requires further research focus.

4.4 Strengths and limitations

This study had several strengths, including the efforts taken to ensure that the participants felt able to discuss anything they felt was relevant to their experience, with no strict adherence to the interview schedule. Open-ended questions were also asked to allow spontaneous points to be raised. This ensured the participant's lived experiences were explored, with limited interference from the researcher.

To address research questions 1 and 2 of the thesis, this study collected first-hand accounts of the influence of GI conditions on aspects of daily life. This also addressed research question 1 associated with this study. Experiences of remission were also addressed in the study, and largely presented the same narrative (that remission was a period of relief), thus addressing study research question 2. The study's third research question was concerned with methods by which the wider population could be better educated and informed about their condition, and participants all agreed that there needs to be an increased awareness of IBS and IBD among the general public, and methods by which this could be achieved were proposed.

In terms of the sample, the final sample size of 8 was satisfactory, but it was hoped that more individuals with IBD would be interviewed. Despite this, the experiences of the two individuals with IBD interviewed did not present any differences to the experiences of those with IBS; consistent with the argument that the distinction between IBS and IBD is not beneficial (Drossman & Halser, 2016). As all participants were recruited via the researcher's own social media platform, the sample may not be wholly representative of the population living with a GI condition, as there will be individuals without social media who had not been considered. Despite this, the lived experiences of females diagnosed with IBS are arguably well-represented in this study, as there was a good range of ages sampled. Yet, the experiences of males were not captured, for both IBS and IBD. As such, future research should ensure the lived experiences of males with IBS and IBD are explored.

4.5 Implications for future research

Following the outcomes of this study, it is recommended that future research explores the social stigma attached to IBS and IBD (Taft et al., 2011) and methods by which this could be reduced as this is likely to improve the lived experiences of this population. Research into how workplace support can be increased is also recommended, to ensure those with IBS or IBD do not feel compelled to reduce their working hours or terminate their employment as a result of their condition. It is also recommended that future research continue to explore IBS and IBD using a biopsychosocial framework and provide greater consideration to the gut-brain axis.

4.6 Conclusion.

This study explored the lived experiences of those diagnosed with IBS or IBD. Outcomes were that there is a need to adapt to these conditions, with a range of coping strategies developed, which are susceptible to change. The importance of a positive mindset as well as social support were discussed, yet negative aspects of the conditions were also evident, such as how IBS can affect romantic relationships and lead to the experience of negative affect. Stress was discussed as a common trigger and can exacerbate symptoms but was also identified as being part of an interaction between the gut and brain. Participants were keenly aware of the interconnectedness of factors within GI conditions, highlighting how these conditions can have wider psychosocial outcomes, supporting the ideals of models like the biopsychosocial model (Engel, 1977). Stress, concerns about stigma/judgements and the perception that IBS and IBD are hidden illnesses were connected, resulting in worries about using public toilets, particularly those marked as for use by disabled individuals. Remission was also revealed to be a highly individual experience and largely up to the definitions of each participant, with not all participants perceiving themselves as having experienced remission. During remission, physical symptoms were still common, yet psychologically, there was some relief offered. Ultimately, participants felt that increasing the public’s awareness of IBS and IBD was important. This would reduce the social stigma, helping diagnosed individuals feel more comfortable and accepted, improving their lived experiences.

4.7 Direction

This study aimed to address research questions 1 and 2 of the thesis overall, contributing to our understanding of psychosocial factors and wellbeing outcomes associated with GI conditions and how experiences may differ across the active and remission stages of these conditions. While this study successfully addressed both overarching research questions, it did not capture the lived experiences of males with IBS or IBD. As such, the next study will aim to address this and recruit more males. Although the experiences of participants with IBS and IBD were similar, there was an imbalance in the number of those with IBD interviewed. Again, the next study will aim to better understand the experiences of those with IBD. Ultimately, the next study will build upon the themes that emerged from this study using quantitative survey methods to gain a large amount of data on the areas directly relevant to the lived experiences of those interviewed and additional factors, such as emotion recognition, aligned with the biopsychosocial model.

Chapter 5

Exploring Psychosocial Aspects Identified as Central to the Experience of Those with a Gastrointestinal Condition- A Quantitative Study.

5.0 Introduction

The aim of this study was to build upon the outcomes of the qualitative study discussed in the previous chapter, which revealed coping, negative emotional experiences, addressing a lack of awareness, the influence on relationships and daily life and experiences of remission as themes which represented the lived experiences of participants with IBS or IBD. The findings suggested that it was beneficial to further explore these aspects more widely and using a quantitative approach, which would allow for more in-depth exploration of the influence of stage (active or remission) was suited to a quantitative approach. An exploratory sequential design (Creswell, 2015) was specifically implemented to allow for data to be collected on a larger scale. Study 2's themes informed hypothesis development for this study, to ensure that the focus of this research was participant led (Morgan, 2015; Saks & Allsop, 2019). The following sections expand on the lived experience outcomes to be further investigated in this study, with focus on findings from previous quantitative research.

5.0.1 Coping

The first two studies in this thesis indicated coping (and coping strategies) as relevant to the experiences of individuals with IBS and IBD. Further exploration of coping among this population using a quantitative research approach will provide information on strategies used and whether these are adaptive or maladaptive. In this way, this study is consistent with previous research into coping among individuals with IBS or IBD, which has typically employed survey measures. Research has indicated the following adaptive strategies employed by individuals with IBD: acceptance, positively framing scenarios, using humour and planning (Chao et al., 2019), and self-reliance and confrontational styles have been commonly used among those with IBS (Torkzadeh et al., 2019). Commonly used maladaptive strategies include self-distraction, self- blame, substance abuse (Chao et al., 2019) and catastrophising (Surdea-Blaga et al., 2012).

The use of maladaptive coping strategies among those with IBS and IBD may be due to a perceived lack of coping strategies/resources compared to individuals without a GI condition, as was reported by Fouche et al. (2006). Jones et al. (2006) similarly reported that individuals with both IBS and IBD reported using fewer adaptive coping strategies than individuals without a GI condition, alongside reporting less social support. This finding accords with the stress and coping perspective (Lakey & Cohen, 2000) and stress prevention model (Dignam et al. 1986) which argue that social support and coping are inter-linked. The potential link between coping and social support will be explored further in this study. To better understand the most used coping strategies among individuals with IBS and IBD, and whether differences in strategies used exist between those with and without a GI condition, participants were asked to complete the Brief Cope questionnaire (Carver,1997).

5.0.2 Negative emotional experiences

In study two, the theme of negative emotional experiences encapsulated instances of depression, anxiety and stress which were common among participants. Previous research has reported similar outcomes to suggest that individuals with IBS and IBD often have negative emotional experiences. For example, individuals with IBD often report experiencing depression (Abautret-Daly et al., 2017; Wong et al., 2019) much more frequently than the general population (Fuller-Thomson & Sulman, 2006). The prevalence of depression among those with IBS is similarly high (Kopczynska et al., 2018). Another negative emotion commonly experienced by those with a GI condition is anxiety (Fond et al., 2014; Neuendorf et al., 2016). Following a review of studies investigating the link between anxiety and depression with GI conditions, Ancona et al. (2020) estimated the prevalence of anxiety and depression among those with IBS or IBD to be between 60-90%. The explanation most referred to for the comorbidity of anxiety and depression among those with a GI condition is the gut-brain axis (Abautret et al., 2017; Cryan et al., 2019). Health care professionals, researchers and patients are increasingly acknowledging this bi-directional connectivity between gut and brain (Clapp et al., 2017; Liang et al., 2018). Patient awareness was confirmed in study two, as two of the participants discussed the connection between their physical and psychological health. The connection between mental and physical health is evident within GI conditions, with mental health conditions a risk factor for IBS (Nanda & Sungono, 2020) and symptoms of depression and anxiety are known to exacerbate or trigger symptoms among those with IBD (Smolovic et al., 2021). This study will further explore the negative emotional experiences of individuals with a GI condition and how this compares with a control population.

Differences in anxiety and depression have been previously reported across the stages of GI conditions. For example, Larsson et al. (2008) reported that emotional distress (increased anxiety and depression) is increased during the active stage of UC and CD. Barberio et al. (2021) reported a similar outcome, with increased prevalence of anxiety and depression among those with active IBD. There has been less research conducted into differences in anxiety and depression symptoms across the active and remission stage of IBS, and as such, this was identified as an area of exploration for this study.

5.0.3 Social support

The first two studies identified social support to be a psychosocial factor relevant to the experiences of those with IBS and IBD. It has been found to be important in terms of wellbeing and coping (Dai et al., 2021; Fouche et al., 2006; Garcia-Sanjuan et al., 2018); and it has also been proposed as a contributing factor to maintaining remission of those with UC (Maunder et al., 2012). Yet not all individuals with a GI condition experience positive social support which may decrease symptomology (Gerson et al., 2006; Dai et al., 2021; Lackner et al., 2013). Further investigation into the role of relationships and social support experiences for those with IBS and IBD will help improve our understanding of their complex experiences. This study also aims to provide greater focus on the social support individuals with IBS and IBD provide to others, as this is an area that has been under-researched in comparison to support received.

5.0.4 Employment

Both studies 1 and 2 suggested employment can be challenging for individuals with a GI condition. Challenges to employment included a need to take time off work in response to physical symptoms, a reduced number of hours individuals felt they could work per week and, at worst, an inability to work. These findings have been similarly reported in previous research (Hosli et al., 2021; La Berre et al., 2019; Ueno et al., 2017; Yamabe et al., 2019). Research has reported that work absenteeism and presenteeism are reduced when in the remission stage (Kuenzig et al., 2019). However, employment outcomes have not been researched extensively; and the continuation of such challenges suggests that not enough is known about work-related impairment among this population. The current study sought to explore the employment status of individuals with and without a GI condition or no GI condition, how it differed across conditions and the extent to which this was related to time off and productivity. This information could be critical to better support the employment of those with a GI condition.

5.1 Additional biopsychosocial model factors

The current study expanded the investigation of psychosocial factors/outcomes identified in studies 1 and 2; however, there are also several additional factors in line with biopsychosocial models (Drossman, 2016; Engel, 1977) that needed to be addressed to explore their potential role in the expression of IBS and IBD. These factors are discussed in the following sections.

5.1.1 Wellbeing outcomes (Subjective wellbeing and HRQOL)

Study 1 revealed that there has been limited research into the SWB of those with a GI condition. Yet, there are reasons to suggest SWB is worth addressing, since it is closely linked to social support (Saphire-Bernstein & Taylor, 2015; Umberson & Karas Montez, 2010) and QOL (Lex et al., 2019). Previous research has also reported a negative association between IBS and SWB (Farhadi, Banton, & Keefer, 2018). More recently, research has explored SWB among those with IBD, and has reported that low SWB is associated with psychological distress (Emerson et al., 2021). Increasingly, SWB is being acknowledged as an important part of the biopsychosocial expression of GI conditions, and, as such, it requires further exploration.

An outcome of study 1 was to highlight HRQOL as one of the most frequently addressed wellbeing outcomes in the literature. Research has commonly reported that the HRQOL of individuals with IBS and IBD is impaired compared to control individuals without a GI condition (Amouretti et al., 2006; Bernklev et al., 2006; Buono et al., 2017; Gralnek et al., 2000; Ho et al., 2019; Iglesias et al., 2010; Li et al., 2003; McCombie et al., 2015; Park et al., 2009; Yamabe et al., 2019). Alongside differences across conditions, there are reported differences in HRQOL across the active and remission stages of IBD, with improved QOL and HRQOL in the remission stage (Larsson et al., 2008). Yet, conflicting research suggests that the HRQOL of those with IBD in remission is still affected and is not like the HRQOL of a control population (Iglesias et al., 2010). This study will explore the effect of stage on HRQOL across IBS and IBD.

5.1.2 Alexithymia (emotion recognition)

Alexithymia is defined as a trait that impairs the ability to recognise emotion Martinez-Sanchez et al., 2017). Specifically, alexithymia is associated with difficulties identifying and describing emotions (Messina et al., 2014). Typically, the difficulty is recognising one’s own emotions (Grynberg et al., 2012). Research has reported an increased prevalence of alexithymia among those with a GI condition (Fournier et al., 2018; Iglesias-Rey et al., 2012; Vigano et al., 2018), which could explain the difficulties recognising emotion displayed by those with IBS or IBD (Fournier et al., 2018; Thakur et al., 2017). This study used alexithymia as a measure for the ability to recognise one's own emotions to explore whether differences in emotion recognition/ identification exist between those with and without a GI condition and specifically whether individuals with IBS and IBD are better able to identify positive or negative emotions. Research has suggested that there is a negative emotion bias among those with IBS; they experience more negative than positive emotion, making them better able to recognise negative over positive emotions in themselves and others (Fournier et al., 2018). Also, Martino et al. (2020) predicted that, over time, the emotion recognition ability of individuals with IBD may worsen due to the increased emotional challenges they face. It is also important to consider the complex links between emotion recognition and social support/interaction among individuals with IBS or IBD. This link could be bi-directional in that impaired emotion recognition ability could be negatively related to social support, or, limited social support could be associated with impaired emotion recognition ability. Challenges related to social support, alongside the social stigma associated with GI conditions, could result in a negative emotional bias, since this population more regularly experience and recognise negative emotions emanating from others. The current study assessed the prevalence of alexithymia between individuals with a GI condition and those without and explores its link with social support outcomes.

5.2 Aims and Objectives

This study's main aim was to explore psychosocial aspects of the experience of GI conditions. Therefore, the hypotheses were:

Hy$_1$: Irrespective of condition, participants with GI conditions will report worse psychosocial outcomes compared to those without a GI condition.

Specifically:

> Hy$_{1A}$: Subjective wellbeing, health-related quality of life, coping and social support will be lower in those with a GI condition compared to those without a GI condition.
>
> Hy$_{1B}$: Employment activity impairment and self-reported negative emotion will be higher in those with a GI condition, compared with their non-GI counterparts.

H$_{2y}$: The subset of participants with a GI condition will report worse psychosocial outcomes when in the active stage compared to those in the remission stage. Specifically:

> Hy$_{2A}$: Subjective wellbeing, health-related quality of life, coping and social support will be lower in those in the active stage compared to those in remission
>
> Hy$_{2B}$: Employment activity impairment and self-reported negative emotion will be higher in those in the active stage, compared with those in remission

Hy$_3$: Recognition of one’s own emotions will differ between those with a GI condition and those without.

Specifically:

Hy$_{3A}$ Participants with a GI condition will have poorer emotion recognition ability compared to those without a GI condition.

Hy4: Among those with a GI condition, recognition of one's own emotions will differ across stage of GI condition.

Specifically:

Hy$_{4A}$: Participants with a GI condition will have poorer ability to recognise one's own emotions when in the active stage compared to those in the remission stage.

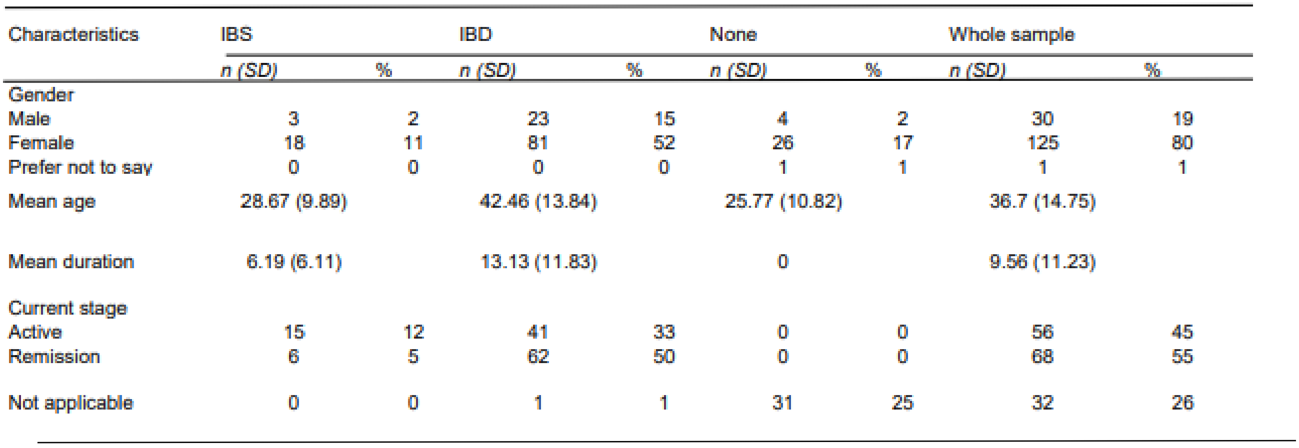
5.3 Methods

5.3.1 Participants

A power calculation determined that 210 participants would be required. A total of 300 individuals began the study; those who did not complete it were removed. The final sample size was 156. Approximately 14% reported a diagnosis of IBS (*n*=21), 67% had IBD (*n*=104), and 20% were control individuals free from any GI conditions (*n*=31). Their mean age was 36.70 (*SD* = 14.75; range 19-77). The mean age by diagnosis is provided in Table 7. This table includes further demographic information such as gender, mean duration (IBS; *M*=6.5; IBD; *M*=13.1) and current stage (the majority were in remission). Comorbid conditions were disclosed by 61.54% of the participants (*n*=96). There were 17 participants with IBS, 46 participants with IBD and 13 participants with no GI condition who disclosed a comorbid diagnosis of depression, anxiety or alexithymia.

Table 7

Participant demographics



Characteristics	IBS		IBD		None		Whole sample	
	n (SD)	%	*n (SD)*	%	*n (SD)*	%	*n (SD)*	%
Gender								
Male	3	2	23	15	4	2	30	19
Female	18	11	81	52	26	17	125	80
Prefer not to say	0	0	0	0	1	1	1	1
Mean age	28.67 (9.89)		42.46 (13.84)		25.77 (10.82)		36.7 (14.75)	
Mean duration	6.19 (6.11)		13.13 (11.83)		0		9.56 (11.23)	
Current stage								
Active	15	12	41	33	0	0	56	45
Remission	6	5	62	50	0	0	68	55
Not applicable	0	0	1	1	31	25	32	26

5.3.2 Design

A between-subjects design was employed. The Independent variables were GI condition (IBS, IBD, or none) and current stage (active or remission); current stage was only applicable to participants who identified as having IBS or IBD. Psychosocial dependent variables derived from the biopsychosocial model included coping, quality of life/health-related quality of life and social support, and additional factors were subjective wellbeing (negative and positive affect and life satisfaction), alexithymia (emotion recognition), employment difficulties and negative emotional experiences (depression, anxiety and stress).

5.3.3 Materials

Study 3 aimed to address research questions 1 and 2 using an online survey comprised of previously published survey measures relevant to the themes of study 2 and the biopsychosocial models applied to this research (Drossman, 2016; Engel, 1977). Online survey measures are increasingly used, but they suffer from response rate issues (Clark-Carter, 2003; Manzo & Burke, 2012). Face-to-face surveys typically yield the highest response rate (Clark-Carter, 2003), yet this was an impractical method due to the restrictions in place following COVID-19.

Efforts were made to select brief survey measures to reduce participant fatigue and improve response rate (Deutskens et al., 2004). The following survey measures were selected: the Brief COPE (Carver, 1997), the Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1995), the 36-item health survey (RAND; Hays et al. ,1993), the Satisfaction with Life Scale (Diener et al., 1985), The Scale of Positive and Negative Experience (Diener et al., 2009), the Work Productivity and Activity Impairment General Health version 2.0 (Reilly et al., 1993), the Social Provisions Scale (Cutrona & Russel, 1987) and the Perth Alexithymia Questionnaire (Preece et al., 2018). Measures were free to use and in the public domain, apart from the Social Provisions Scale (Cutrona & Russel, 1987), but permission for its use was gained.

HRQOL

HRQOL was investigated using the RAND-36 item health survey which was developed as part of the Medical Outcomes Survey (RAND; Hays et al., 1993) and is reported to have high internal consistency and convergent validity (Vander Zee et al., 1996). This measure uses various Likert scales, ranging from three-point scales to six points and also includes items where participants select yes or no. Scores on this measure can be combined to form scores for the physical and mental health summary scales (Hays et al., 1994; Ware et al., 1994) which were used in this study. The physical summary scale included the subscales; physical functioning, pain, role limitations due to physical health, general health and energy/fatigue. The maximum score on this scale is 500 and higher scores indicate improved HRQOL. The mental summary scale included the subscales; emotional wellbeing, role limitations due to emotional problems and social functioning (Hays et al., 1994; Ware et al., 1994). The maximum score on this scale is 300, with higher scores indicative of increased HRQOL. For these scales, Cronbach’s alpha ranged from 0.78 to 0.93. Cronbach’s alpha scores of 0.70 or higher is desirable (Taber, 2018). Higher scores on these summary scales indicate improved HRQOL.

Coping

The Brief Cope (Carver, 1997) is a 28-item measure, where each item is rated using a 4-point Likert scale ranging from 1 (lowest) to 4 (highest). The Brief Cope (Carver, 1997) can produce three summary scales which were used in the analysis of this study: emotion-focused coping (emotional support use, positive reframing, humour, acceptance and religion), problem-focused coping (active coping, instrumental support and planning) and dysfunctional coping (self-distraction, denial, substance use, behavioural disengagement, venting and self-blame) (Sarid et al., 2017). Previous investigation of these three subscales revealed Cronbach’s alpha of 0.72 for emotion-focused coping, 0.85 for problem-focused coping and 0.74 for dysfunctional coping (Sarid et al., 2017). These values are all desirable (Taber, 2018).

SWB

In accordance with Diener’s (1984) tripartite model, SWB is comprised of *satisfaction with life* and judgements of *positive and negative affect*. Satisfaction with life was measured using the Satisfaction with Life Scale (Diener et al., 1985), which is a 5-item measure. Participants answer using a 7-point likert scale which ranges from 1 (strongly disagree) to 7 (strongly agree); higher scores are indicative of higher satisfaction with life and scores range between 5 and 35. The SWLS has good internal reliability and temporal stability (Diener et al., 1985). Abdalla (1998) reported a Crohnbach’s alpha score of 0.79 and Ronsengren et al. (2015) reported a score of 0.90. Positive and negative affect were measured using the SPANE (Diener et al., 2009) which is a 12-item measure, with six items devoted to negative feelings and six items to positive feelings. The SPANE had three subscales: positive, negative and affect balance. This study only explored the affect balance subscale as it provides an overall affect score by subtracting the negative scores from the positive, resulting in scores between -24 and 24. Cronbach’s alpha for the affect balance subscale has been reported as 0.92 (Li et al., 2013), which would suggest it is an excellent measure of SWB.

Negative Emotions

The DASS-21 (Lovinbond & Lovibond, 1995) was used to examine negative emotions (depression, anxiety and stress). This 21-item measure is measured using a Likert scale ranging from 0 (did not apply at all) to 3 (applied very much, or most of the time). The DASS-21 has demonstrated good reliability and validity (Oei et al., 2014). There are seven items related to anxiety, seven related to stress and seven related to depression and a score for each condition can be gained. The depression subscale has a Cronbach's alpha of 0.81, the anxiety subscale is rated at 0.89 and the stress subscale is the lowest at 0.78 (Coker et al., 2018), meaning scores on all subscales are desirable (Taber, 2018). All three of these subscales were included in the analysis.

Social Support

The Social Provisions Scale (SPS; Cutrona & Russel, 1987) was administered as it provides a holistic overview of social support. The SPS has 24 items measures using a 4-point Likert scale where 1 is strongly disagree and 4 is strongly agree. Higher scores indicate higher levels of social support. This measure has been found to have excellent internal consistency and test-retest reliability (Cutrona & Russel, 1987). The SPS investigates six provisions of social support: guidance, reliable alliance, reassurance of worth, attachment, social integration and nurturance. Scores on the SPS can be collated to provide a total score of social support. Previous research has reported that the total score has a Cronbach's alpha value of 0.89, whereas the six subscales range between 0.66 and 0.81 (Chiu et al., 2017). The total score was explored in this research.

Employment

Activity and work impairments were explored using the general health version of the WPAI (version 2.0) (Reilly et al., 1993). The WPAI consists of six items. This study was particularly interested in whether participants were in employment (item 1) and the overall work impairment they experienced due to their health (a summation of items 2, 3 and 4). The WPAI has been successfully applied to the study of various health conditions (Zhang et al., 2010), including Crohn's disease (Reilly et al., 2008).

The internal consistency of the WPAI is good, with Cronbach's alpha of 0.74 (Ciconelli et al., 2006).

Alexithymia

The Perth Alexithymia Questionnaire (PAQ; Preece et al., 2018) is a 24-item measure of alexithymia. A 7-point Likert scale is employed, where 1 means strongly disagree and 7 means strongly agree. Higher scores are indicative of greater alexithymia. The PAQ is comprised of multiple subscales which can highlight differences in the appraisal of positive and negative emotions. These subscales can be collated into the negative difficulty appraising feelings (NDAF) and the positive difficulty appraising feelings (PDAF) which provide an overview of the ability to recognise one's own positive and negative emotions. A total score compiles the scores on all the PAQ's subscales to create an overall score of alexithymia. Scores on the PAQ are interpreted by comparing scores to a normative sample. Scores more than one standard deviation above the mean indicates high levels of alexithymia, scores less than 1 standard deviation from the mean indicate an average level of alexithymia and scores 1 standard deviation or more below the mean indicate low levels of alexithymia (Preece et al., 2018). The PAQ has good internal reliability and discriminant validity (Preece et al., 2018). For this study, alexithymia was primarily investigated using the total score, which has a Cronbach's alpha of 0.96 (Preece et al., 2018).

5.3.4 Procedure

The social media platforms Facebook and Twitter were used to recruit participants. A recruitment advert was posted on the researcher's own Facebook account and Facebook groups for University of Sunderland undergraduate students. Permission was gained to place a participant recruitment advert on online support groups based on Facebook and Twitter. These groups were Crohn's & Colitis UK, Crohn's & Colitis Durham & Wearside and Durham OOOPS.

This study was approved by the University of Sunderland research ethics committee. Participants were required to provide informed consent before they could complete the study. Confirmation of ethical approval, alongside a copy of the participant information sheet, consent form and debrief sheet are included in the Appendices (F-K). The study was completed via Qualtrics and took approximately 30 minutes. To protect the identity of participants and ensure confidentiality, participants were asked to provide a unique six-digit code which would be used as an identifier should they wish to withdraw from the study. No monetary rewards were provided for completing this study. University of Sunderland stage 1 and 2 students who signed up to complete the study via SONA were granted two participation credits. The study was available from May 2021 to September 2021 and was closed for participation when avenues for recruitment had been exhausted and no new responses were collected within a seven-day period. Data was exported to an SPSS dataset for descriptive and statistical analysis in accordance with the study's aims.

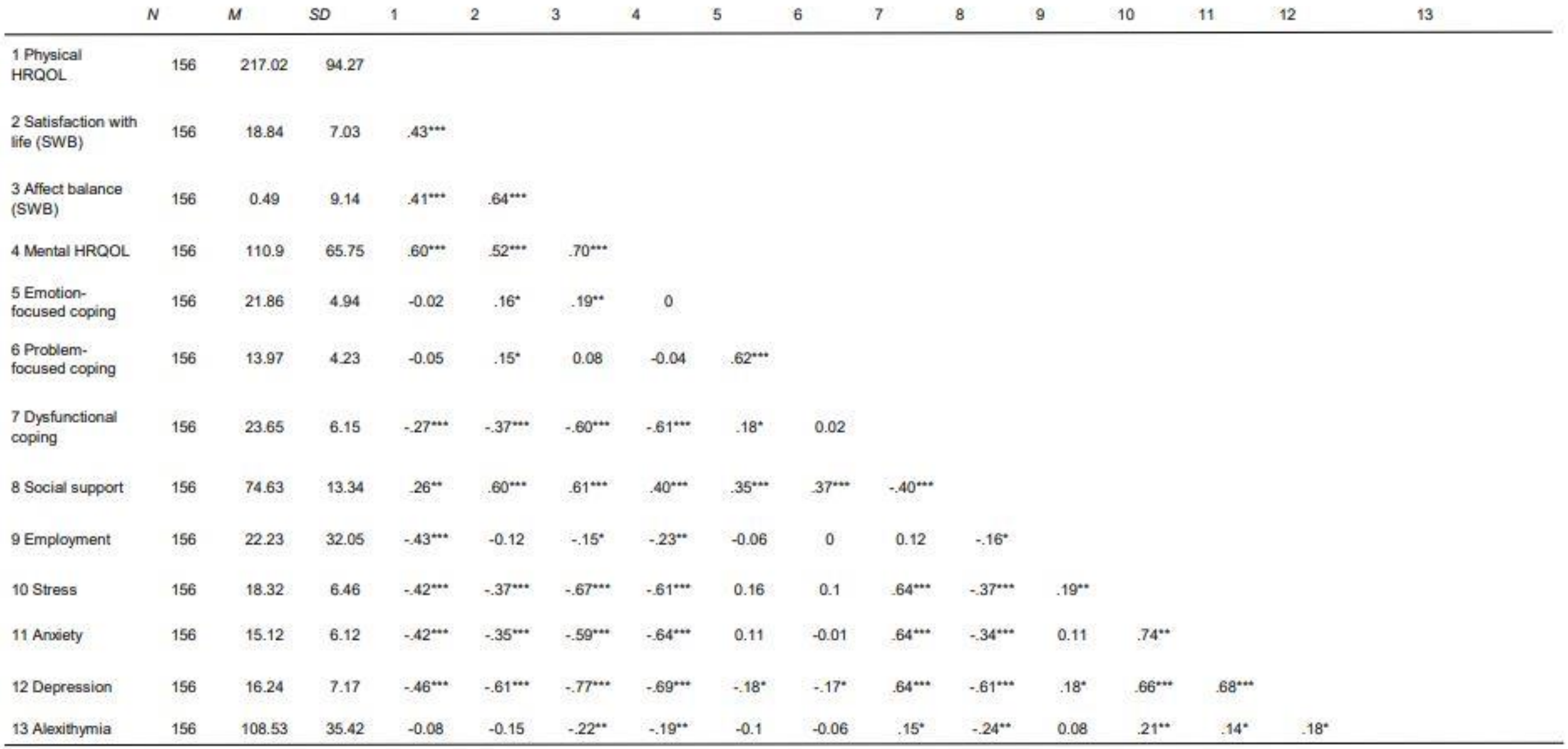
5.4 Results

5.4.1 Main analysis

The aim of this study was to further investigate areas of lived experience found previously to be directly relevant to those with IBS and IBD. There were two independent variables in this study. The first was GI condition (IBS, IBD, or no GI condition). GI condition was used in two ways for analyses. In some analyses, it was used as the 3-level independent variable as stated. GI condition was also used to select the subset of participants with a condition for further analyses, which was operationalised as a 2-level independent variable (IBS, IBD) for analyses amongst only those with a GI condition. This 2-level independent variable was used in conjunction with the second independent variable, current stage (active, remission). The dependent variables were QOL/HRQOL, coping, social support, work difficulties, negative emotions, subjective wellbeing and emotion recognition. Initially, a correlation analysis was conducted to explore whether relationships existed between dependent variables. The following table illustrates the relationship between the dependent variables being considered.

Table 8

Correlations between variables



	N	*M*	*SD*	1	2	3	4	5	6	7	8	9	10	11	12	13
1 Physical HRQOL	156	217.02	94.27													
2 Satisfaction with life (SWB)	156	18.84	7.03	.43***												
3 Affect balance (SWB)	156	0.49	9.14	.41***	.64***											
4 Mental HRQOL	156	110.9	65.75	.60***	.52***	.70***										
5 Emotion-focused coping	156	21.86	4.94	-0.02	.16*	.19**	0									
6 Problem-focused coping	156	13.97	4.23	-0.05	.15*	0.08	-0.04	.62***								
7 Dysfunctional coping	156	23.65	6.15	-.27***	-.37***	-.60***	-.61***	.18*	0.02							
8 Social support	156	74.63	13.34	.26**	.60***	.61***	.40***	.35***	.37***	-.40***						
9 Employment	156	22.23	32.05	-.43***	-0.12	-.15*	-.23**	-0.06	0	0.12	-.16*					
10 Stress	156	18.32	6.46	-.42***	-.37***	-.67***	-.61***	0.16	0.1	.64***	-.37***	.19**				
11 Anxiety	156	15.12	6.12	-.42***	-.35***	-.59***	-.64***	0.11	-0.01	.64***	-.34***	0.11	.74**			
12 Depression	156	16.24	7.17	-.46***	-.61***	-.77***	-.69***	-.18*	-.17*	.64***	-.61***	.18*	.66***	.68***		
13 Alexithymia	156	108.53	35.42	-0.08	-0.15	-.22**	-.19**	-0.1	-0.06	.15*	-.24**	0.08	.21**	.14*	.18*	

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

Analysis Strategy

Correlations between psychosocial dependent variables were appropriate for MANOVA (Tabachnick & Fidell, 2014) A cut-off value of .6 was used to make this judgement. Aspects of SWB (affect and life satisfaction), social support, negative emotion (inclusive of stress, anxiety and depression), dysfunctional coping and the mental health component of HRQOL were intercorrelated in the expected directions outlined in hypothesis 1. Eight of the 13 outcomes were correlated at a level appropriate to the use of MANOVA for testing the main effect of GI condition; the exceptions were emotion & problem-focused coping, physical HRQOL, employment, and emotion recognition. The remaining five outcomes were analyses using separate one-way ANOVA; the type 1 error rate was controlled at .01 for this set of analyses. All post-hoc analyses used Bonferroni correction (Armstrong, 2014). An identical analysis strategy was used to test the main effect of condition status for the sub-set of participants who reported having a GI condition. In the final set of analyses, a one-way ANOVA explored differences in emotion recognition by GI condition and a 2 (condition type) x 2 (condition stage) ANOVA was used to determine the interaction effect.

Descriptive and inferential statistics for these variables are reported in Table 9.

Table 9

Means and Standard deviations of psychosocial outcomes relevant to lived experiences

Psychosocial Outcomes	Overall	GI Condition							Stage				
	X(SD)	X(SD) IBS	X(SD) IBD	X(SD) None	F (df, df)	p	η^2	Post hoc	X(SD) Active	X(SD) Remission	F(df, df)	η^2	p
Satisfaction with Life [a]	18.82(.70)	17.33(7.14)	18.66(7.30)	20.45(5.86)	1.34(2, 153)		0.02		15.52(7.02)	21.04(6.34)	13.58(1, 120)	0.1	***
Affect [b]	-.43(.91)	-3.00(9.65)	1.19(9.51)	.52(6.95)	1.86(2, 153)		0.02		-2.98(9.59)	3.66(8.30)	6.92(1, 120)	0.06	**
Social support [c]	74.98(1.24)	74.14(14.19)	74.13(13.73-)	76.68(11.56)	.45(2, 153)		0.01		71.34(14.22)	76.79(12.66)	3.89(1, 120)	0.05	
Stress [d]	19.49(.63)	22.19(6.30)	17.36(6.33)	18.94(6.13)	5.35(2, 153)	**	0.07	**IBS>IBD=None**	20.59(6.29)	16.13(6.15)	5.88(1,120)	0.05	**
Anxiety [d]	16.51(.59)	18.95(7.07)	13.88(5.50)	16.71(6.18)	7.97(2, 153)	***	0.09	**IBS>IBD=None**	16.75(6.51)	12.99(5.14)	6.89(1,120)	0.05	**
Depression [d]	17.32(.70)	20.43(7.76)	15.44(7.09)	16.10(6.19)	4.42(2, 153)	**	0.06	**IBS>IBD=None**	19.20(7.66)	13.68(6.06)	4.84(1,120)	0.04	
HRQOL physical [e]	217.02(7.55)	175.86(79.58)	207.06(92.93)	278.32(81.41)	10.23(2, 155)	***	0.18	**None>IBD >IBS**	162.34)76.14)	236.26(88.85)	14.68(1, 12)	0.01	***
HRQOL mental [e]	99.56(6.40)	72.44(59.42)	120.08(65.15)	106.16(63.70)	4.93 (2, 153)	**	0.06	**IBD>None >IBS**	84.40(60.91)	136.11(61.60)	6.15(1, 120)	0.05	**
Dysfunctional coping [f]	23.35(.57)	27.62(6.23)	22.03(5.39)	26.39(6.48)	12.73(2, 153)	***	0.14	**IBD<IBS=None**	24.68(6.44)	21.47(5.00)	8.22(1, 12)	0.06	**
Emotional-focused coping [f]	21.86(.40)	21.90(5.75)	21.24(4.92)	23.90(3.91)	3.58(2, 155)		0.05		20.88(2.10)	21.65(4.99)	.01(1, 120)	0	
Problem-focused coping [f]	13.97(.34)	14.67(4.45)	13.65(4.38)	14.55(3.49)	.87(2, 155)		0.01		13.54(4.48)	14.03(4.36)	.38(1, 12)	0	
Work and activity impairment [g]	22.23(2.57)	20.19(33.86)	26.77(33.15)	8.39(22.30)	4.14(2, 155)	**	0.05	**IBD>IBS>None**	31.54(37.36)	19.81(27.61)	.47(1,120)	0	
Alexithymia [h]	108.25(2.78)	107.81(35.09)	107.69(36.66)	110.43(27.74)	.08(2,155)		0		110.04(36.08)	107.70(37.10)	.23(1,120)	0	

*Note: Values in parentheses are standard deviation. p values are for the main effect of ANOVA *p<.05 ** p<.01 ***p<.001. Post hoc values in bold indicate significance*

[a] Within subjective wellbeing, satisfaction with life was measured using the Satisfaction With Life Scale (Diener et al., 1985). Maximum score= 35

[b] Within subjective wellbeing, affect was measured using the affect balance subscale of the Scale of Positive and Negative Experience (Diener et al., 2009). Maximum score=24

[c] Social support was measured using the Social Provisions Scale (Cutrona & Russel, 1987). Maximum score= 96

[d] To measure negative emotions, stress, anxiety and depression were measured using the DASS-21 (Lovibond & Lovibond, 1995). Maximum score for stress =42. Maximum score for anxiety=42. Maximum score for depression=42.

[e] To measure HRQOL (both the mental and physical components) the 36-item Short Form Survey (RAND was used). Maximum score for the physical component=500. Maximum score for the mental component =300.

[f] Coping was measured using the Brief Cope (Carver, 1997) which can be divided into the following subscales during scoring: dysfunctional coping Maximum score=48, emotion-focused coping maximum score=40 and problem-focused coping maximum score=24.

[g] Work impairment was measured using the overall work impairment subscale of the Work Productivity and Activity Impairment questionnaire (General Health version) (Reily et al., 1993). Maximum score=100

[h] Alexithymia was measured using the Perth Alexithymia questionnaire (Preece et al., 2018). Maximum score=168.

Psychosocial outcomes associated with GI conditions (Hy1)

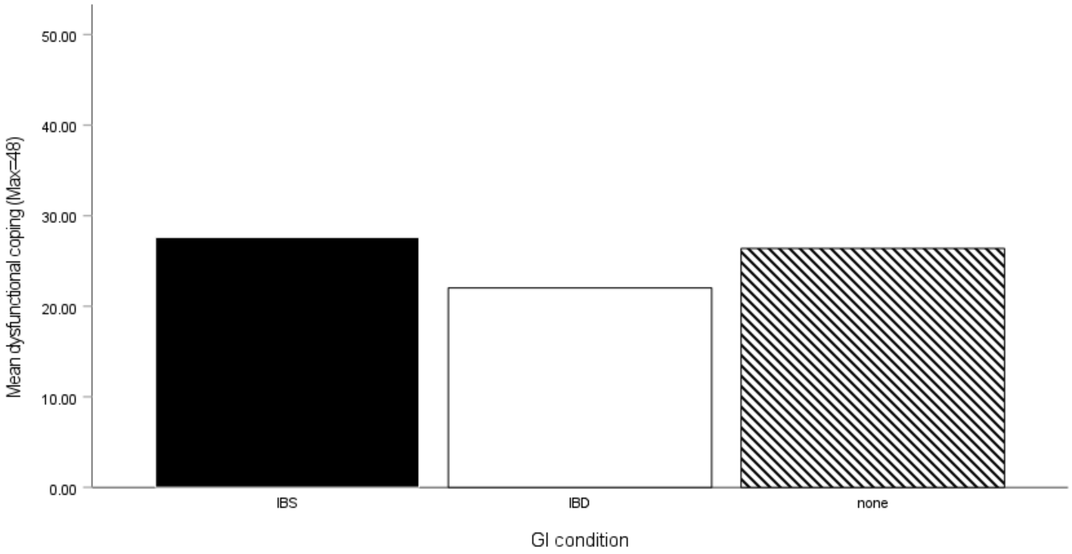
Hypothesis 1 predicted that participants with a GI condition would report worse psychosocial outcomes compared to those without a GI condition. This hypothesis was sub-divided into two more specific hypotheses. Variables that were sufficiently correlated (Tabachnick & Fidell, 2014) were entered into a MANOVA. These variables were SWB (life satisfaction and affect balance), the mental component of HRQOL, dysfunctional coping, negative emotions (depression, stress and anxiety) and social support. There was a significant multivariate main effect of GI condition on these psychosocial dependent variables, $V=.26$, $F(16, 294) = 2.75$, $p<.001$, $\eta^2=.13$.

Hypothesis 1A: Subjective wellbeing, health-related quality of life, coping and social support will be lower in those with a GI condition compared to those without a GI condition.

The MANOVA revealed no main effect of GI condition on measures on satisfaction with life, affect balance, or social support. There was a significant effect of GI condition on dysfunctional coping (Figure 7), which post-hoc analysis revealed to exist between IBS and IBD ($p<.001$) with increased instance of dysfunctional coping among those with IBS ($M=27.62$) compared to those with IBD ($M=22.03$) and also between those with IBD and no GI condition ($p<.001$) with increased instance of dysfunctional coping among those without a GI condition ($M=26.65$) compared to those with IBD ($M=22.03$).

Figure 7

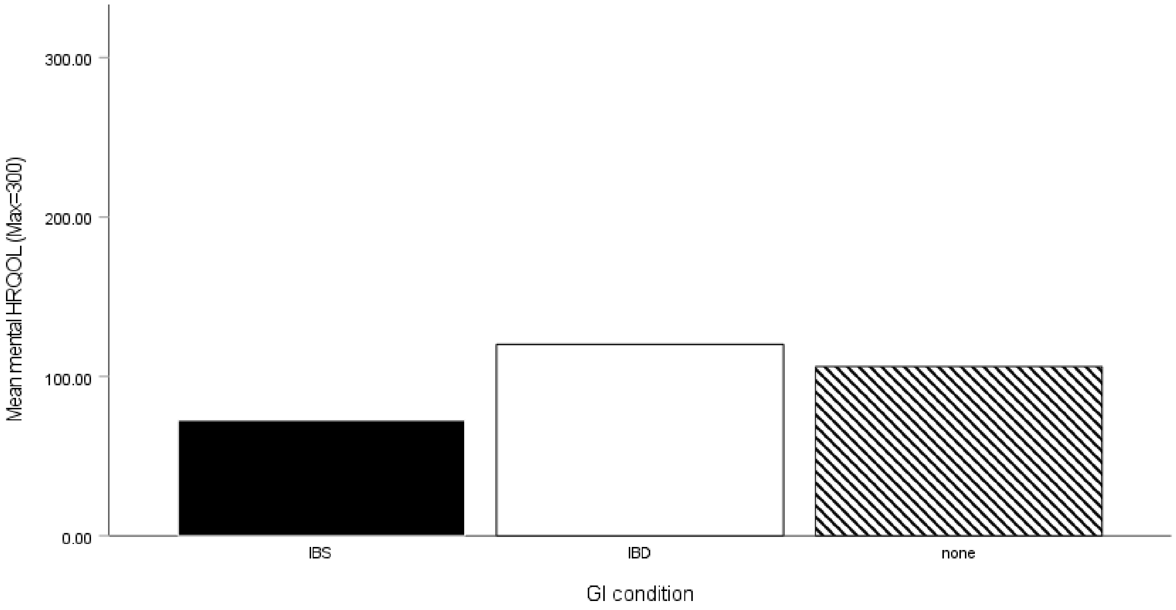
Dysfunctional coping by GI condition



There was a significant effect of GI condition on the mental component of HRQOL (Figure 8). Post-hoc analyses revealed the difference to be between those with IBS and IBD (*p*=.007) with increased HRQOL (mental component) among those with IBD (*M*=120.08) compared to those with IBS (*M*=72.44).

Figure 8

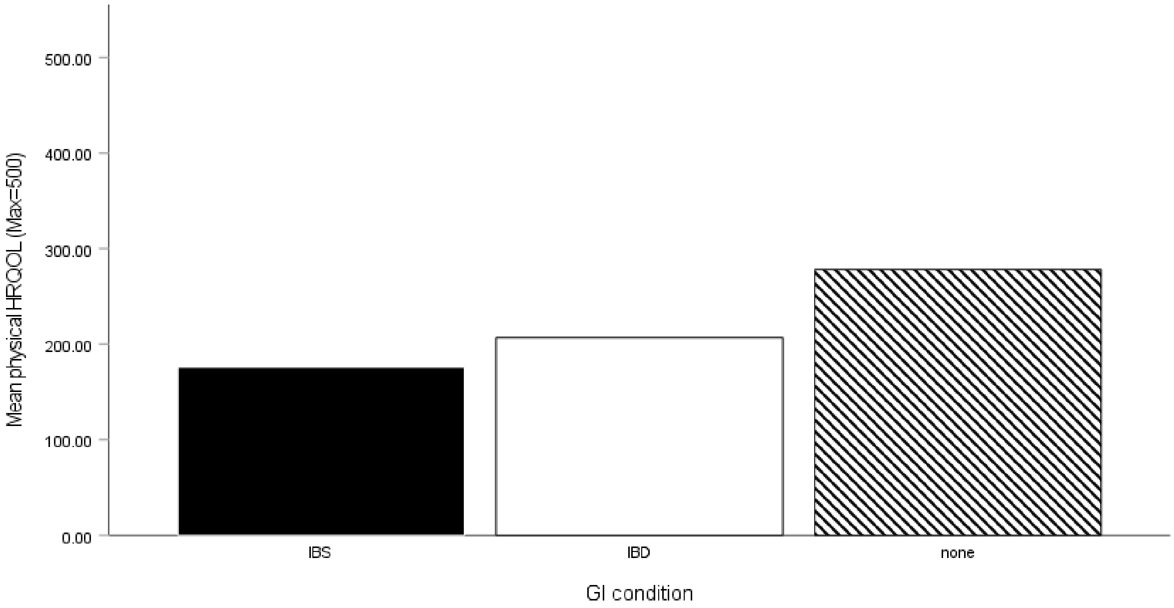
Mental HRQOL by GI condition



To test the remaining variables outlined in hypothesis 1A (emotion-focused coping, problem-focused coping and physical HRQOL), ANOVAS were conducted. There was no significant effect of GI conditions on emotion-focused coping or problem-focused coping. There was a significant effect of GI condition on scores on physical HRQOL (Figure 9). Post-hoc analyses revealed that participants with no GI condition had the highest physical HRQOL (*M*=278.32, *SD*=94.27), followed by those with IBD (*M*=207.06, *SD*=92.93) and those with IBS had the lowest physical HRQOL (*M*=175.86, *SD*=79.58).

Figure 9

Physical HRQOL by GI condition



Hypothesis 1 B: Employment activity impairment and self-reported negative emotion will be higher in those with a GI condition, compared with their non-GI counterparts.

Negative emotions were explored within the MANOVA. This revealed a significant effect of GI condition on stress, anxiety and depression, with increased levels reported among those with IBS as shown in Figure 10-12.

Figure 10

Stress by GI condition

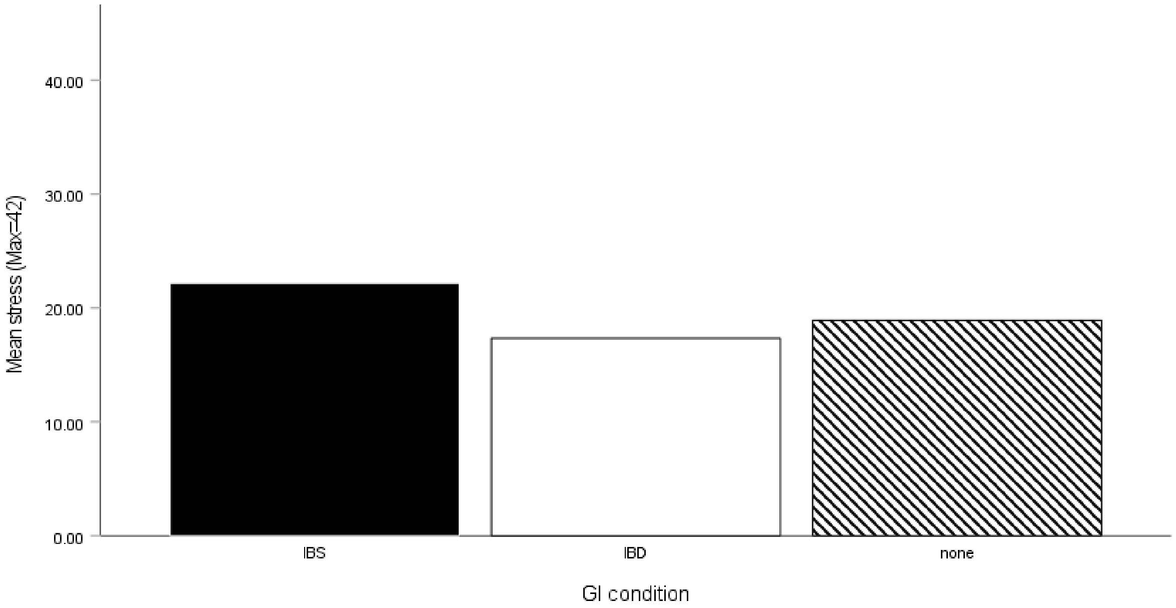


Figure 11

Anxiety by GI condition

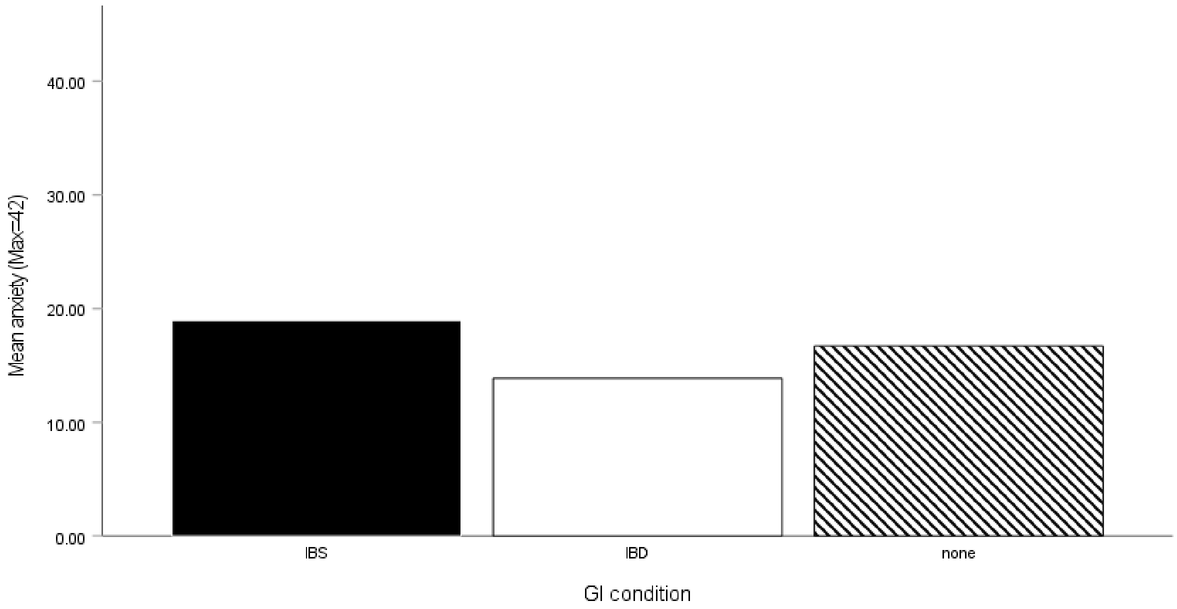
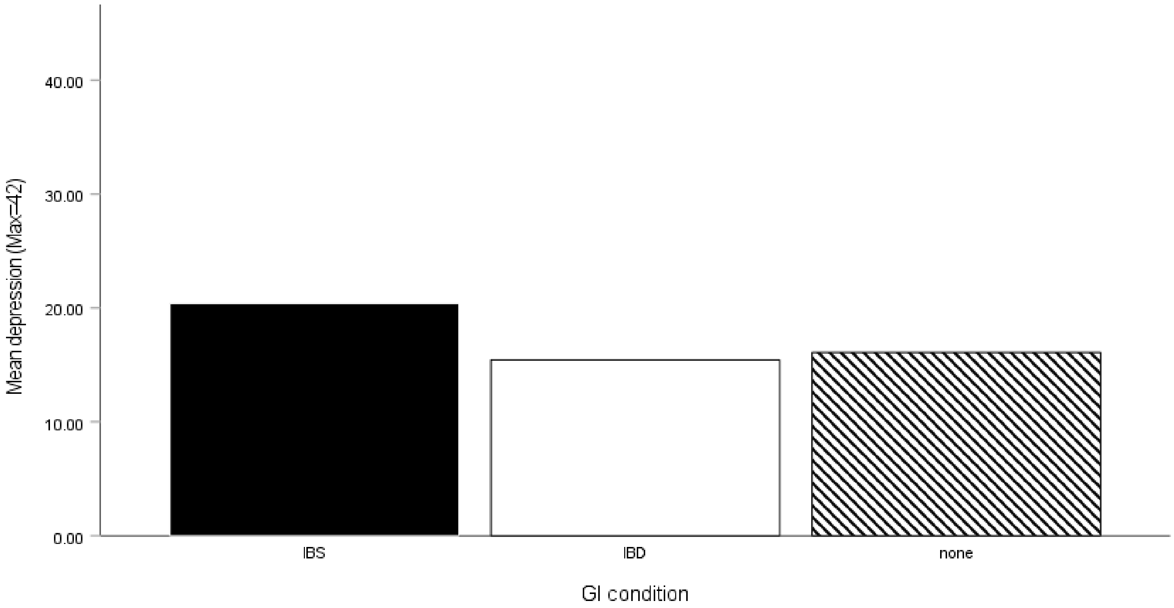


Figure 12

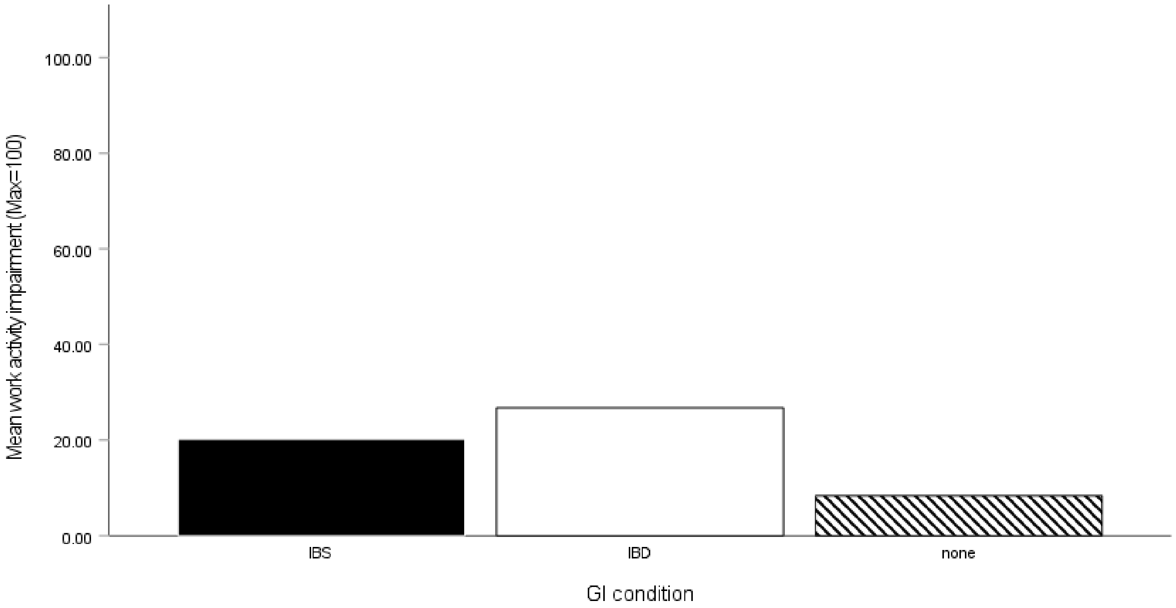
Depression by condition



Hypothesis 1B also predicted increased work activity impairment among those with a GI condition. An ANOVA was conducted to test this, which revealed a significant effect of GI condition on overall work impairment (Figure 13). Participants with IBD reported the most work impairment (*M*=26.77, *SD*=22.15) followed by those with IBS (*M*=20.29, *SD*=33.86) and then those without a GI condition (*M*=8.39, *SD*=22.30).

Figure 13

Work activity by GI condition



To explore whether differences in employment existed between the conditions, a Chi square analysis was conducted. This revealed an association between GI condition and whether participants were in work or not $X^2(2) = 10.34$, $p=.006$. There were more participants with IBD in work than expected, but fewer participants with IBS and no GI condition in work than expected.

Psychosocial outcomes by current condition stage (HY2)

Hypothesis 2 predicted that participants with a GI condition will report worse psychosocial outcomes when in the active stage compared to those in the remission stage. This hypothesis was only applicable to a subset of the sample (those with a

GI condition). At this stage, one participant who did not have a GI condition identified as being in the remission stage, and their data was removed before any analysis on this subset was conducted. This resulted in an analysis *N* of 124.

To address this hypothesis, five analyses were conducted (1 MANOVA and 4 ANOVAS) which resulted in a Bonferroni adjusted alpha level of p=.01. First a 2 X 2 MANOVA was conducted including the intercorrelated variables: SWB (life satisfaction and affect balance), social support, dysfunctional coping, HRQOL (mental component) and negative emotions (depression, stress and anxiety). Following the corrected alpha level, the results did not confirm the significant effect of GI condition V=.144, $F(8, 113)$=2.38, p=.02, η^2=.14, and did not reveal a significant effect of current stage on the psychosocial dependent variables V=.14, $F(8, 113)$=2.34, p=.02, η^2=.14. There was no significant interaction effect of GI condition and current stage V=.112, $F(8, 113)$=1.79, p=.09, η^2=.11. While it is not typical to follow a non-significant MANOVA with exploration of ANOVAS, this was done in this case to explore whether current stage had a significant effect on the variables individually as opposed to as a group (Warne, 2014).

Hypothesis 2A: Subjective wellbeing, health-related quality of life, coping and social support will be lower in those in the active stage compared to those in remission.

According to hypothesis 2A, SWB, HRQOL, coping and social support would be lower in participants in the active stage compared to participants in remission. Current stage had a significant effect on SWB; as satisfaction with life was higher among those in the remission stage across IBS and IBD (Figure 14). There was also a significant effect of current stage on affect balance. Scores on affect balance were lower for both conditions in the active stage as shown in Figure 15.

Figure 14

Life satisfaction by current stage

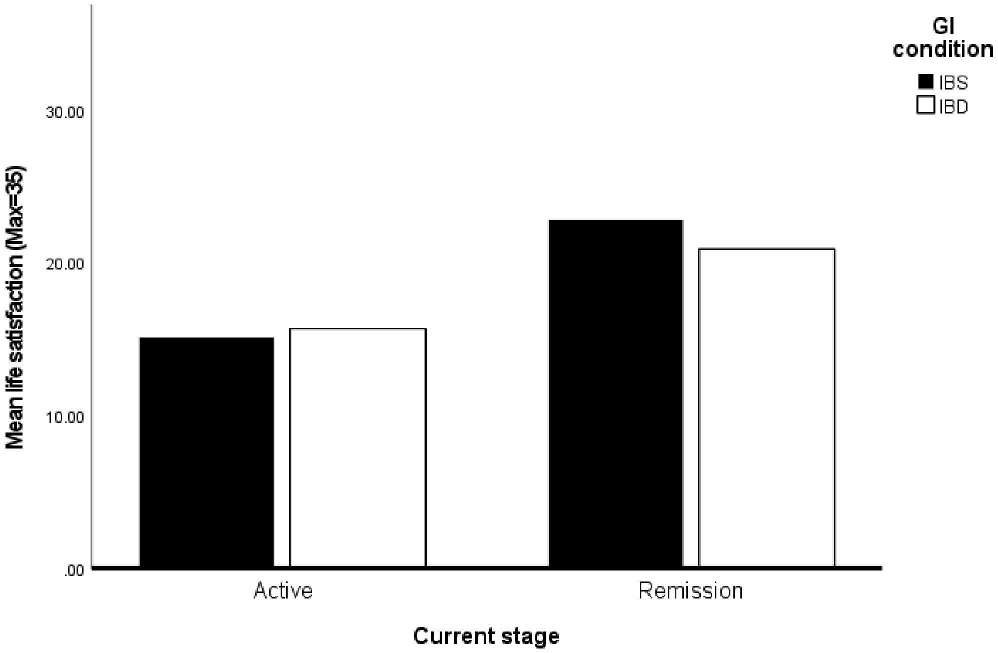
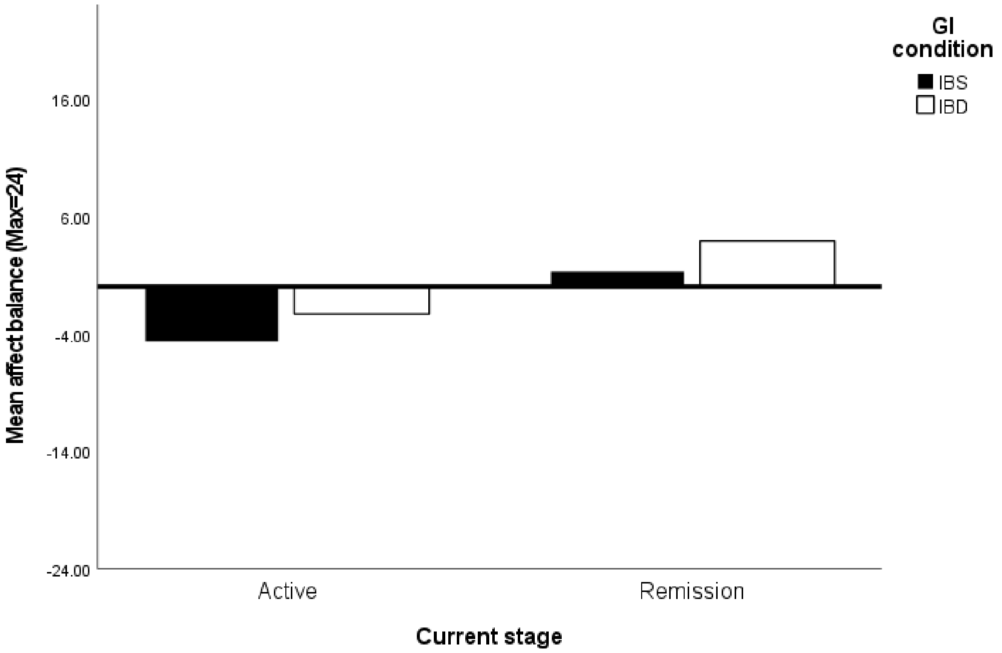


Figure 15

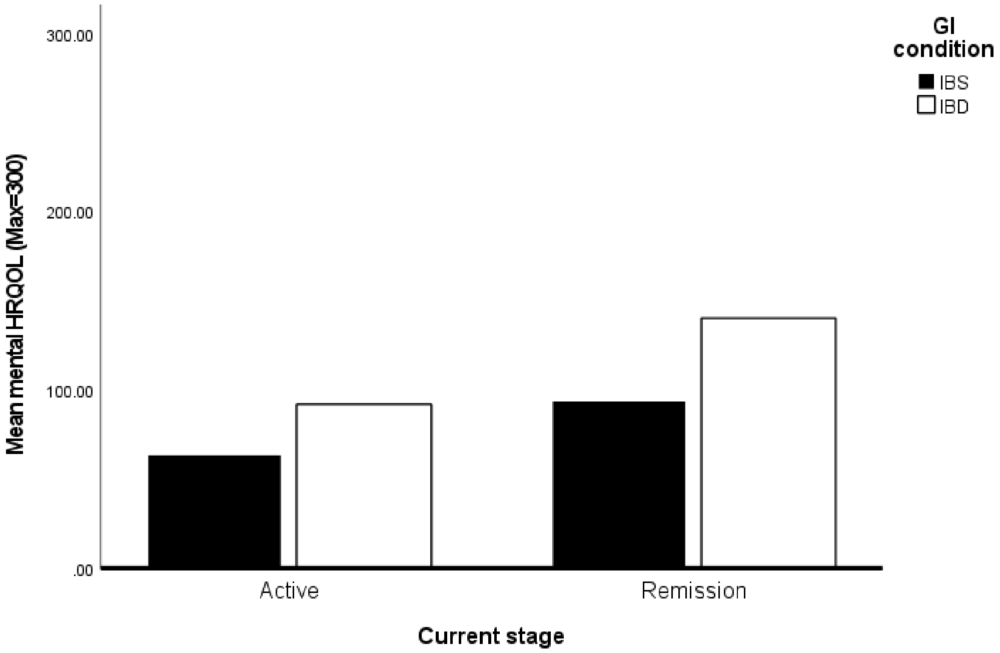
Affect balance by current stage



There was a significant effect of current stage on HRQOL (mental component). As highlighted in Figure 16, participants with IBS and IBD in the remission stage reported their HRQOL (mental) as higher those in the active stage.

Figure 16

Mental HRQOL by current stage

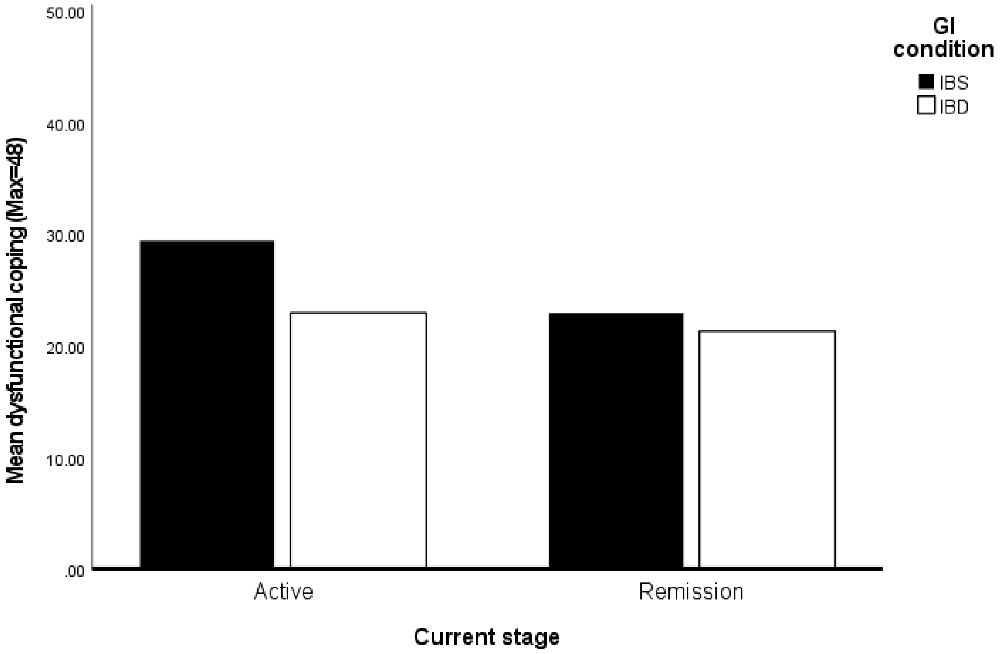


There was no significant effect of current stage on social support.

There was a significant effect of current stage on dysfunctional coping. As Figure 17 shows, participants in the active stage reported an increased use of dysfunctional coping strategies compared to those in the remission stage. There was no significant effect of current stage on problem-focused coping.

Figure 17

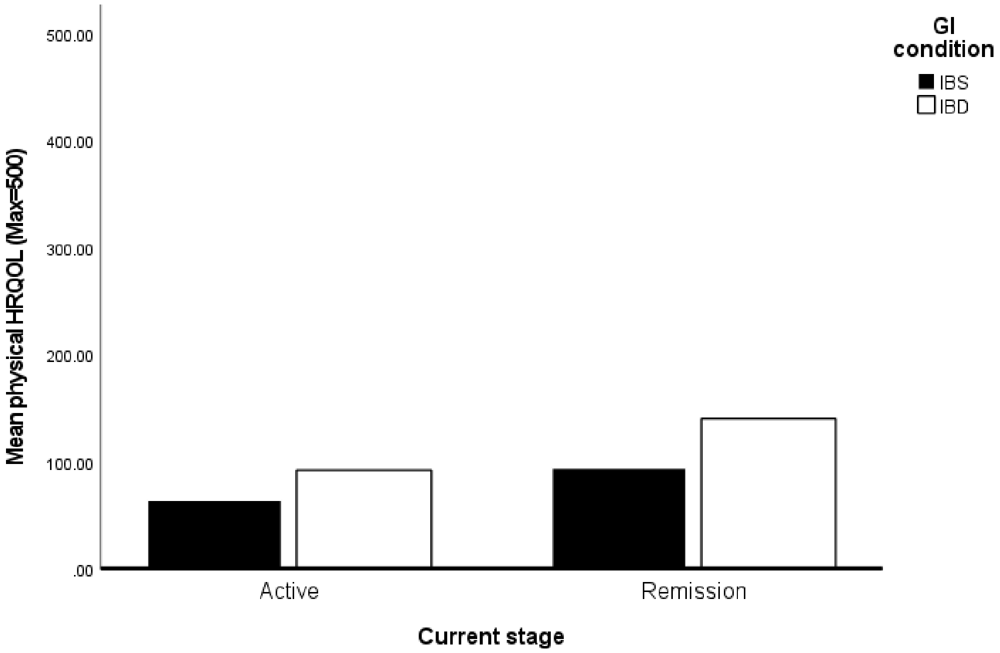
Dysfunctional coping by current stage



The remaining variables included in hypothesis 2A were investigated using ANOVAS as they were not sufficiently correlated to be included in the MANOVA. There was a significant effect of current stage on HRQOL (physical component). Physical HRQOL was rated as higher for participants in the remission stage across both IBS and IBD (Figure 18).

Figure 18

Physical HRQOL by current stage



There was no significant effect of current stage on problem-focused coping or emotion-focused coping.

Hypothesis 2B: Employment activity impairment and self-reported negative emotion will be higher in those in the active stage, compared with those in remission.

Negative emotions were explored via the MANOVA. There was a significant effect of current stage on stress which was rated higher during the active stage (Figure 19). There was a significant effect of current stage on anxiety, which was increased among those in the active stage (Figure 20). There was no significant effect of current stage on depression.

Figure 19

Stress by current stage

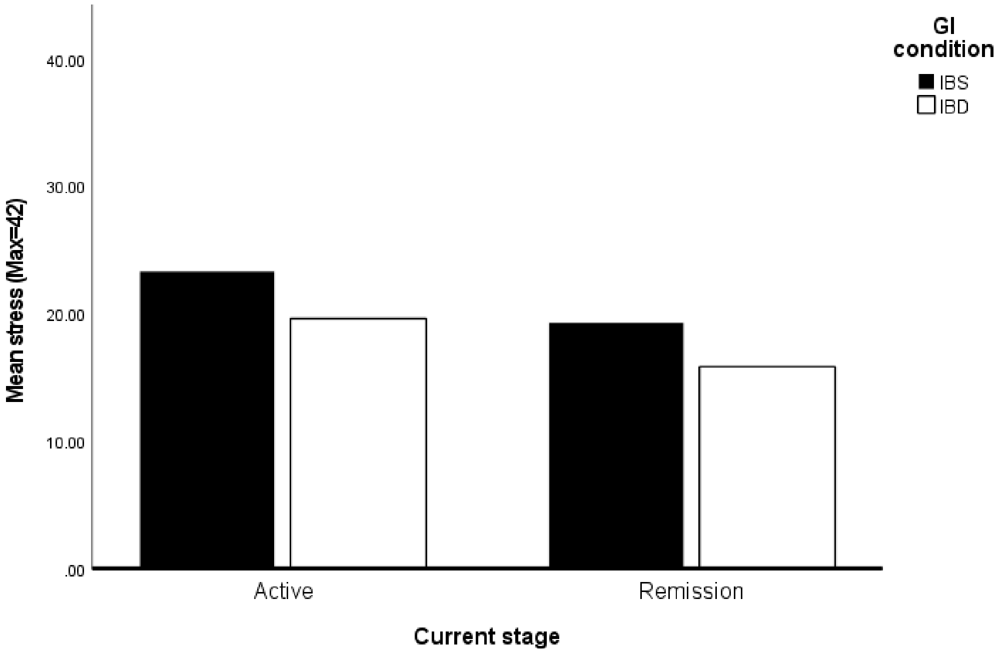
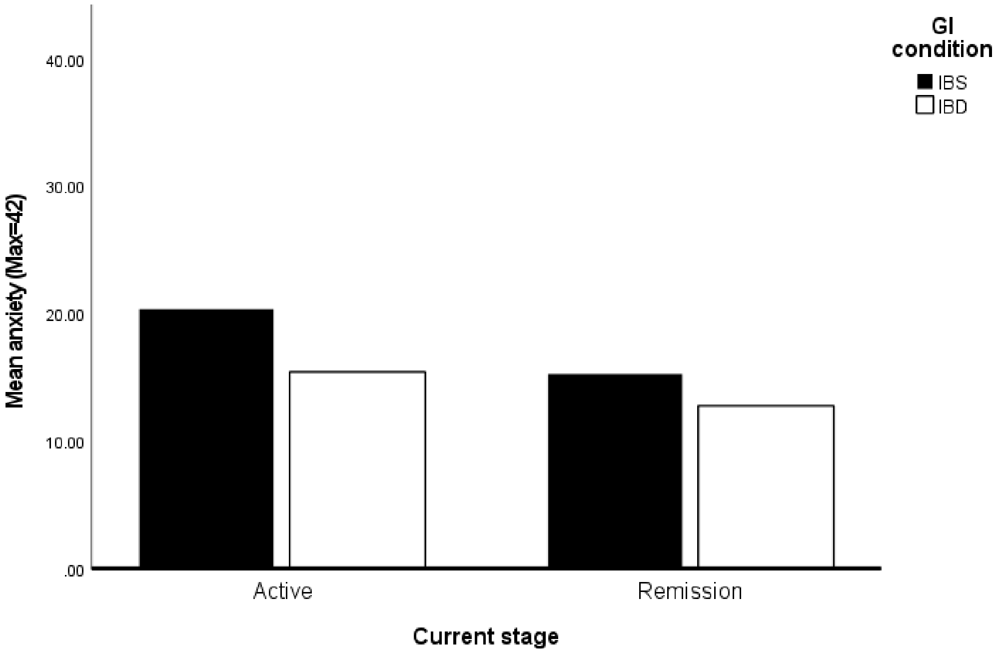


Figure 20

Anxiety by current stage



The effect of current stage on work impairment was explored via an ANOVA, which revealed no significant effect of current stage on work impairment.

Does the ability to recognise one's own emotions differ by GI condition? (HY3)

Hypothesis 3 predicted that the ability to recognise one's own emotions will differ by GI condition.

Hypothesis 3A: Participants with a GI condition will have poorer emotion recognition ability compared to those without a GI condition.

To address hypothesis 3A which proposed that differences in emotion recognition would exist between those with and those without a GI condition, first a one-way ANOVA was conducted which revealed no significant effect of GI condition on alexithymia. Levels of alexithymia were similar for those with IBS (*M*=107.81,

SD=35.09), IBD (*M*=107.69, *SD*=36.66) and those without a GI condition (*M*=110.42, *SD*=27.74).

To explore whether differences in the recognition of positive and negative emotions existed between the groups, a one-way ANOVA was conducted. This revealed no significant differences in the recognition of positive emotions *F*(2, 155)=.29, *p*=.37. There was also no significant difference in the recognition of negative emotions *F*(2, 155)=.94, *p*=.20.

Among those with a GI condition, does the ability to recognise one's own emotions differ by current condition stage? (HY4)

Hypothesis 4 predicted that the ability to recognise one's own emotions will differ across the stages of GI conditions.

Hypothesis 4A: Participants with a GI condition will have poorer ability to recognise one's own emotions when in the active stage compared to those in the remission stage.

To address hypothesis 4, a 2 X 2 ANOVA was conducted but revealed no significant effect of current stage on emotion recognition *F*(1, 120)=.23, *p*=.32, η^2=.00 and no significant interaction effect between GI condition and current stage on alexithymia F(1, 120)=.06, p=.81, n^2=.00. Levels of alexithymia were similar regardless of current stage, as participants with IBS in the active stage had similar levels (*M*=109.73, *SD*=36.49) compared to those in the remission stage (*M*=103.00, *SD*=34.02) and the same was true for those with IBD in the active stage (*M*=109.78, *SD*=35.72) compared to those in the remission stage (*M*=107.55, *SD*=36.52). The mean scores indicated that each of the three samples had an average level of alexithymia, according to normative scoring (Preece et al., 2018). Though levels were slightly higher for those in the active stage for both conditions, this difference was not significant.

The link between alexithymia and social support

To better understand the potential role of emotion recognition in GI conditions, a Pearson correlation analysis was conducted to explore the relationship between alexithymia and social support, $r(122)=.-309$, $p<.001$.This analysis was conducted since it was thought that emotion recognition may be an integral component of social support. The result indicates that as scores of alexithymia increased, perceived social support decreased, which would support that the link between emotion recognition and social support, specifically that poorer social support is associated with poorer emotion recognition.

5.5 Discussion

This study’s primary aim was to explore psychosocial aspects identified as directly relevant to the experience of GI conditions. It was anticipated that this would improve our understanding of the wider experience of these conditions on those diagnosed. There were four hypotheses associated with this aim and each will be discussed in relation to the findings of this study.

5.5.1 Effect of GI condition

Hypothesis 1 stated that participants without a GI condition will report improved life satisfaction and affect balance (SWB), HRQOL (both mental and physical), coping, and social support, and lower levels of employment activity impairment and negative emotions compared to those with a GI condition, irrespective of whether participants had IBS or IBD. The findings only partially supported hypothesis 1. For example, support for this hypothesis included physical HRQOL rated higher among those without a GI condition, which accords with hypothesis 1 and previous research (Nurmi et al., 2013; Pullen & Gale, 2007). Participants without a GI condition also reported decreased work activity impairment than those with a GI condition, as predicted in hypothesis 1. There was an association between GI condition group and employment, which revealed that there were more participants with IBD currently in employment than expected, but fewer participants with IBS and no GI condition in employment than expected. An interpretation of this finding is that individuals with IBD may be better able to maintain employment than previously considered (Bernklev et al., 2006), though 59.62% of the IBD sample were in remission, which could have contributed to this result, as remission has been previously associated with improved employment outcomes among those with CD (Lichtenstein et al., 2004). Participants with IBD had greater overall work impairment compared to the IBS and no GI conditions. This outcome supports the findings of previous research (Bernklev et al., 2006; De Boer et al., 2016; Pare et al., 2006). Collectively, these findings suggest that while IBD may be associated with increased work activity impairment, individuals with this condition should still be able to attend work and maintain employment, suggesting that increased workplace support may be required for these individuals. This study’s findings support the inclusion of employment/work-related issues as a psychosocial factor in a biopsychosocial model of IBS and IBD.

Findings that contradicted the predictions of hypothesis 1 included a non-significant effect of GI condition on aspects of SWB (life satisfaction or affect balance). This finding indicated no differences in SWB (either life satisfaction or affect balance) between those with and without a GI condition, which does not support previous research findings (Farhadi et al., 2018). Differences in mental HRQOL were also not as predicted, as those with IBS reported their mental HRQOL as significantly lower than those with IBD, though this is consistent with the findings of El-serag et al. (2002). Findings also indicated that use of dysfunctional coping strategies was higher among those without a GI condition than those with a GI condition. As such, outcomes related to coping did not support previous research which has reported poorer coping outcomes and increased use of such strategies among those with a GI condition (Fouche et al., 2006; Jones et al., 2006). This finding was not expected but could indicate that individuals with a GI condition in this sample employed more adaptive coping strategies, which could provide an explanation for the lack of observed difference in SWB between those with and without a GI condition. Also, no differences in social support were observed between those with and without a GI condition, which does not support previous literature that has reported decreased social support among individuals with a GI condition (Qualter et al., 2021).

Hypothesis 1B predicted that increased negative emotions (stress, depression and anxiety) would be reported among individuals with a GI condition compared to those without, as has been reported previously (Cho et al., 2011). However, outcomes related to negative emotions in this study were not as predicted, as they existed between those with IBS and those with IBD. Specifically, the result showed increased self-reported stress, anxiety, and depression among participants with IBS. This outcome does not support hypothesis 1 of this study, but it does support the findings of Geng et al. (2018) whose meta-analysis revealed that individuals with IBS report more severe depression and anxiety compared to those with IBD. These findings indicate the mental health of individuals with IBS as an area that could benefit from receiving greater research focus to better support this population.

5.5.2 Effect of current stage

Hypothesis 2 was related to the influence of current stage (active or remission) on psychosocial outcomes. The study findings only partially supported the prediction that psychosocial outcomes would be worse among participants in the active stage compared to those in the remission stage. Current stage was not found to effect problem-focused, emotion-focused coping or social support. Social support was reported as marginally increased by those in the remission stage. This difference was non-significant but does suggest that experiences of social support differ across the course of a GI condition, indicative that social support is an important factor to consider as part of the biopsychosocial expression of IBS and IBD, and as such, requires further exploration.

While no significant effect of GI condition on SWB was observed, upon exploring the subset of participants with a GI condition, life satisfaction and affect balance were rated as higher for those in the remission compared to the active stage for both IBS and IBD. This finding supports the further exploration of SWB among those with IBS and IBD, particularly how this may differ across condition stage, as increased support may be required to support wellbeing during the active stage of these conditions. HRQOL was also increased among those in remission (both the physical and mental components). Previous research has similarly reported that HRQOL is improved among those with IBS in remission (Sierzantowicz et al., 2020). In accordance with the predictions of hypothesis 2A, increased use of dysfunctional coping strategies was reported by participants in the active stage compared to those in remission. Previous research has reported similar outcomes, with increased prevalence of maladaptive coping strategies during the active stage (Sun et al., 2019). Taken together, these findings suggest that the active stage of both IBS and IBD could be associated with greater impairments to psychosocial functioning compared to the remission stage and those with these conditions may have different needs dependent on condition stage.

Hypothesis 2B was partially supported, as stress and anxiety were increased among participants in the active stage across IBS and IBD. Yet, no effect of stage was observed with regards to depression, contradicting hypothesis 2B and literature to suggest depression is typically more common during the active stage (Sun et al., 2019). No significant effect of stage was observed on work activity. This finding is supported by research that has reported that there can be negative outcomes associated with the working lives of individuals with IBD during remission (Larussa et al., 2020), indicative that work activity is similarly impaired regardless of condition stage. The findings of this study strongly suggest that increased workplace support would be beneficial for individuals with a GI condition, but that this support should be consistent across the active and remission stages.

There is increasing recognition that, among those with IBD, remission does not always mean absence of symptoms, as some experience IBS-like symptoms during this stage (Teruel et al., 2016). Among these individuals, it is commonly reported that QOL is still impaired (Ozer et al., 2020; Teruel et al., 2016). These findings are interesting when applied to the context of this study, as a large proportion of this study’s sample had IBD, but no information was collected on whether they experienced IBS-like symptoms during remission. This would be a recommended inclusion for similar future research, as this could provide an explanation for the lack of distinction in some of the psychosocial variables between the active and remission stages.

5.5.3 Emotion recognition

Hypotheses 3 and 4 were related to the emotion recognition ability of participants. By way of the gut-brain axis, it was predicted that the previously reported prevalence of alexithymia among individuals with IBS or IBD compared to those without a GI condition (Vigano et al., 2018) would result in poorer emotion recognition ability (Hy3). It was also predicted that scores on the alexithymia measure would be higher among participants during the active stage than the remission stage (Hy4). The findings did not support these hypotheses, as there were no observed differences in alexithymia prevalence between the condition groups or current stage. An encouraging outcome was the correlation between alexithymia and social support among this sample, suggestive that there could be an interplay between emotion recognition ability and social support among individuals with a GI condition. This is an area that requires further exploration, as it could provide important information regarding the psychosocial experience of IBS and IBD which could have practical implications for study and treatment of these conditions.

Exploration of emotion recognition in relation to GI conditions is relatively novel, meaning there is limited information on appropriate measures. An interpretation of the non-significant results seen in this study could be that the PAQ was not sensitive enough to potential differences in emotion recognition between those with and without a GI condition. A limitation of the PAQ is that it only considers the participants own emotions and does not measure how participants recognise the emotions of others, which is an important facet of emotion recognition and social communication (Israelashvili et al., 2019). Other measures could have potentially yielded different results, for example facial emotion recognition using a psychophysical approach measuring reaction times (Chellapa et al., 1995; Davis et al., 2013; Marneweck et al., 2013). Visual psychophysics has previously demonstrated impaired emotion recognition among different samples including individuals with Parkinson’s disease (Bowers et al., 2006; Ho et al., 2020). This method, alongside the use of the PAQ (Preece et al. 2018) would address both recognition of an individual’s own emotions and emotions in others, providing a more comprehensive investigation of emotion recognition among those with a GI condition.

5.5.4 Potential confounding variables

Participants with IBD were significantly older than participants in the IBS and no GI condition. This could explain that those with IBD reported a longer time since diagnosis, as there was a strong correlation between age and time since diagnosis. Those with IBS had a mean age of 28, and a mean time since diagnosis of 6 years, meaning the average age of diagnosis was 22, this is younger than those with IBD who had a mean age of 42 and a mean time since diagnosis of 13, providing a mean age of diagnosis of 29. An interpretation of these findings could be that IBD is diagnosed later in life than IBS. This could be the result of misdiagnosis, as Card et al. (2014) reported that IBD is often misdiagnosed as IBS in the first instance and 3% of their sample had been living with an incorrect IBS diagnosis for over five years.

5.5.5 Strengths and limitations

There were several methodological issues related to the sample and design of this study to address. One issue was that there were unequal sample sizes, with most of the sample made up of those with IBD (66.7%). Recruitment was far more successful from the IBD support groups than the IBS groups. The Crohn’s & Colitis UK support group specifically support researchers and help to disseminate research out to members. There did not seem to be the same level of online support for those with IBS, making it more difficult to recruit this sample. An explanation for the smaller none- GI sample size could be that they did not have the same level of motivation as those with IBS or IBD who could perceive a benefit to their experience, whereas those without a GI condition could not see how their experiences could be improved by providing their responses.

This study had a high rate of drop-out. Approximately 150 participants started but did not complete the study. The points at which individuals stopped completing the study varied- some read the participant information sheet only, others completed the consent form but went no further and others stopped at various points throughout the questions. This could be the result of participant fatigue, since the study took an average of 30 minutes to complete, despite efforts to be economical when selecting measures (for example, by opting for brief measures or including a single measure that addressed multiple factors). This issue could be overcome by reducing the number of measures participants are asked to complete, though this would also reduce the breadth of the study.

The overall sample size was an issue, meaning that this study may not have had sufficient power to detect any differences. A greater number of participants could have been recruited if NHS avenues had been used for recruitment. This is a recommendation for future research to ensure sufficient power. Another issue related to the sample was that it was predominantly female (80%). This study was more successful in recruiting males than study 2, but it is a concern that the experiences of males with IBS or IBD have been under-represented.

As with study 2, the recruitment strategy employed for study 3 could have reduced how representative the sample was, as recruitment was heavily reliant on online technology and social media platforms. This could have resulted in the exclusion of some individuals with a GI condition with no access to the internet. This study also may not be wholly representative of the experiences of indivoduals with a GI condition who are not affiliated with an online support group. Together, these sample issues limit the generalisability of the findings.

5.6 Conclusion

This study explored a wide range of psychosocial variables representative of the lived experiences of those with IBS and IBD and additional variables anticipated to be involved in experiences with these conditions. Limited support for the hypotheses was reported, but outcomes related to employment were of note and suggested a narrative where those with IBD are more likely to be in employment than expected but had increased work activity impairment. It is recommended that this study is repeated, but that future research aims to recruit a larger sample size with more equal group sizes to aid comparison between groups.

5.7 Direction

In response to thesis research question 1, outcomes of this study would suggest that there are differences in psychosocial functioning between IBS and IBD which need to be better understood, as these could result in the need for different, tailored treatments. For example, this study would suggest that increased workplace support is required for individuals with IBD compared to IBS. Based on this finding, it is recommended that future research provides greater focus on the support needs of this population and how they can be met. This study addressed thesis research question 2, increasing knowledge of how (remission or active) influences psychosocial factors and wellbeing outcomes, yet, contrary to this study’s predictions, outcomes on the psychosocial variables were not always more favourable during the remission stage. This suggests that the influence of condition stage still needs to be further explored. Also, while there was no support for a link between GI conditions and impaired emotion recognition ability, there was some evidence that emotion recognition is related to social support among this population, highlighting an avenue of research worthy of further investigation.

Chapter 6

General Discussion

6.0 Introduction

This chapter provides a general discussion of how the suite of studies have addressed the thesis research questions and how this thesis has contributed to existing knowledge. This thesis has expanded upon an existing biopsychosocial model to also include IBD, with additional biopsychosocial factors implicated in the experience of IBS and IBD, supported by the outcomes of the suite of studies. Theoretical implications and practical applications are considered.

6.01 Aims of the thesis

The aim of this thesis was to investigate the influence of having a GI condition (IBS or IBD) on psychosocial wellbeing and health outcomes consistent with the biopsychosocial model of health. The research questions that this thesis examined were:

1. What is the influence of the GI conditions IBS and IBD on psychological and social factors and wellbeing outcomes?

2. What is the influence of GI condition stage on psychological and social factors and wellbeing outcomes?

The following sections are a discussion of how the studies addressed the research aim and questions.

6.1. The influence of GI conditions on psychological and social factors and wellbeing outcomes

Research question 1 was concerned with the influence of having a GI condition (either IBS or IBD) on psychosocial factors and wellbeing outcomes. The initial step in addressing this question was to conduct a scoping review to explore the breadth of existing knowledge and literature on this topic. Biopsychosocial models (Drossman, 2016; Engel, 1977) were employed as overarching frameworks to guide the selection of search terms. This review established a clear evidence base and addressed a gap in the literature for a scoping review aligned with the biopsychosocial model. The increasing awareness and recognition of the role psychological and social factors in GI conditions (Bernstein, 2015) was evident. Outcomes of the review were that HRQOL and QOL have been the most addressed psychosocial wellbeing outcomes, and social support and coping have been the most addressed psychosocial factors related to IBS and IBD. Quantitative methods, primarily surveys, have been the most common research technique, yet, qualitative methods, such as interviews, were preferred when investigating the social support of those with IBS or IBD. Another outcome was that the same psychosocial factors and wellbeing outcomes have been addressed across IBS and IBD, which accords with the argument that they are not as distinct as previously thought (Drossman & Halser, 2016), though there was evidence that IBD is associated with greater impairments in psychosocial functioning, particularly around coping and social support (McCombie et al., 2015; Palant & Himmel, 2019; Vigano et al., 2016), which could contradict this argument. There was also a limited number of studies included in the final narrative that had explored the lived experiences of individuals with IBS or IBD, despite how useful it can be to employ this emic perspective (Sharan & Tisdell, 2015). The outcomes of the review provided a broad, contemporary understanding of the influence of the GI conditions IBS and IBD on psychosocial factors and wellbeing outcomes which increased the depth of explanation and understanding to address research question 1 and 2 further. Specifically, the use of a qualitative, phenomenological methodological approach was appropriate to do this, to further understand the lived experiences of individuals with IBS or IBD. Following this review, it was recommended that future research further should explore the lived experiences of individuals with IBS or IBD using a qualitative, phenomenological approach.

Study 2 provided more depth of focus on research questions 1 and 2, with the aim to further explore the lived experiences of those with IBS or IBD using a series of semi-structured interviews. For example, study 2 afforded additional focus on experiences of remission to provide a more comprehensive overview of the participant's lived experiences. The interviews resulted in five emergent themes which represented the lived experiences of this population: 1) coping, in which participants described their ability to adapt to their condition and the strategies they employ. 2) negative emotional experiences, which encompassed stress, anxiety and depression. Negative emotions were commonly experienced by the participants, demonstrating the affect GI conditions can have on psychological health. 3) addressing a lack of awareness, which highlighted a general lack of awareness and understanding of GI conditions across the general population. Methods by which awareness could be increased were discussed, as these could have implications for improving participant's experiences. 4) the influence on relationships and daily functioning (this included work and education). This theme was centred around participant's experiences of relationships with others and how their daily functioning has been affected. Theme 5) was experiences of remission, which were discussed as largely positive, but discussion did highlight some discrepancy in now remission is defined. These themes were largely consistent with the findings of previous research that had employed a phenomenological approach (Garcia-Sanjuan et al. (2018; Nguyen et al., 2018; Purc-Stephenson et al., 2015; Ung et al.,2013), yet, in this study, remission was discussed in greater depth than expected; indicative that is a more critical aspect of lived experience than previously reported. Overall, the study findings contributed to our knowledge of how GI conditions influence psychosocial factors and wellbeing outcomes and were highlighted as key areas for future research consideration and should be considered in the provision of care and treatment for those with these conditions.

To further explore the influence of GI conditions on psychosocial factors and wellbeing outcomes, study 3 used a quantitative methodology to expand upon the outcomes of study 2 as well as incorporating factors such as SWB and emotion recognition which were hypothesised to be involved in the biopsychosocial expression of IBS and IBD. This study revealed a significant effect of GI condition on the psychosocial factors SWB, negative emotions, dysfunctional coping, social support, HRQOL (both mental and physical components), and work activity. It was expected that differences on these psychosocial variables would exist between those with a GI condition and those without, which was evident for the physical component of HRQOL (those without a GI condition had higher scores than those with IBS or IBD) and work activity impairment (decreased impairment among those without a GI condition compared to those with IBS or IBD). Yet, differences were not in the expected direction for variables such as negative emotions (stress, anxiety and depression) the differences were between participants with IBS and IBD, as those with IBS scored significantly higher on the measure of negative emotions than those with IBD. With regards to research question 1, the findings suggest that IBS and IBD influence psychosocial factors and wellbeing outcomes differently. These findings cannot fully support the argument that IBS and IBD should no longer be classified as distinct conditions (Drossman & Hasler, 2015) since differences in psychosocial wellbeing were evident between the conditions.

6.1.1 The influence of GI condition stage on psychological and social factors and wellbeing outcomes.

Research question 2 aimed to address the influence of stage (active or remission) on psychosocial factors and wellbeing outcomes aligned with biopsychosocial models of health (Drossman, 2016; Engel, 1977). An unexpected insight from study 1 was that remission has not received the same level of research focus as the active stages of IBS and IBD. The limited research included in the final review narrative that had addressed remission acknowledged it to be an important stage in IBS or IBD, but only two out of the eight studies addressed the psychosocial influence of the remission stage, reporting that among those with CD in remission, HRQOL is still affected (Iglesias et al., 2010) and that there is a risk of developing a depressive-anxious comorbidity (Vigano et al., 2016). This study highlighted the importance of considering remission in greater depth, which was a focus of studies 2 and 3. Remission was also added as a biological factor to the biopsychosocial model developed as part of this thesis.

Study 2 provided an understanding of the influence of current stage on the lived experiences of individuals with IBS and IBD. Most of the participants viewed remission as a period of relief, with decreased physical and psychological symptoms associated with their condition- this was true across IBS and IBD. Only one participant could not describe their experience of remission, as according to their definition, their IBS had never entered the remission stage. This was a similar finding to that of Kitchen et al. (2020) and could indicate some discrepancy with how individuals with GI conditions understand and define remission. Most characterised remission as a period where symptoms (both physical and psychological) are less severe, though this does not accord with the clinical definition of remission as a period where symptoms are absent (Teruel et al., 2016).

Outcomes of study 3 were mixed with regards to the influence of remission on psychosocial factors and wellbeing outcomes. There was a significant effect of stage on SWB, with increased SWB among those with IBS and IBD in the remission stage compared to those in the active stage. Participants in the active stage also rated their stress and use of dysfunctional coping as higher than those in the remission stage but rated their physical HRQOL as lower during the active stage than those in the remission stage. These findings provide evidence to indicate that psychosocial functioning is improved during the remission compared to the active stage of IBS and IBD and contribute to the understanding of the influence of stage on psychosocial functioning. These findings can be further built on by future research and have implications for how GI conditions are addressed across their course.

6.2 Theoretical implications

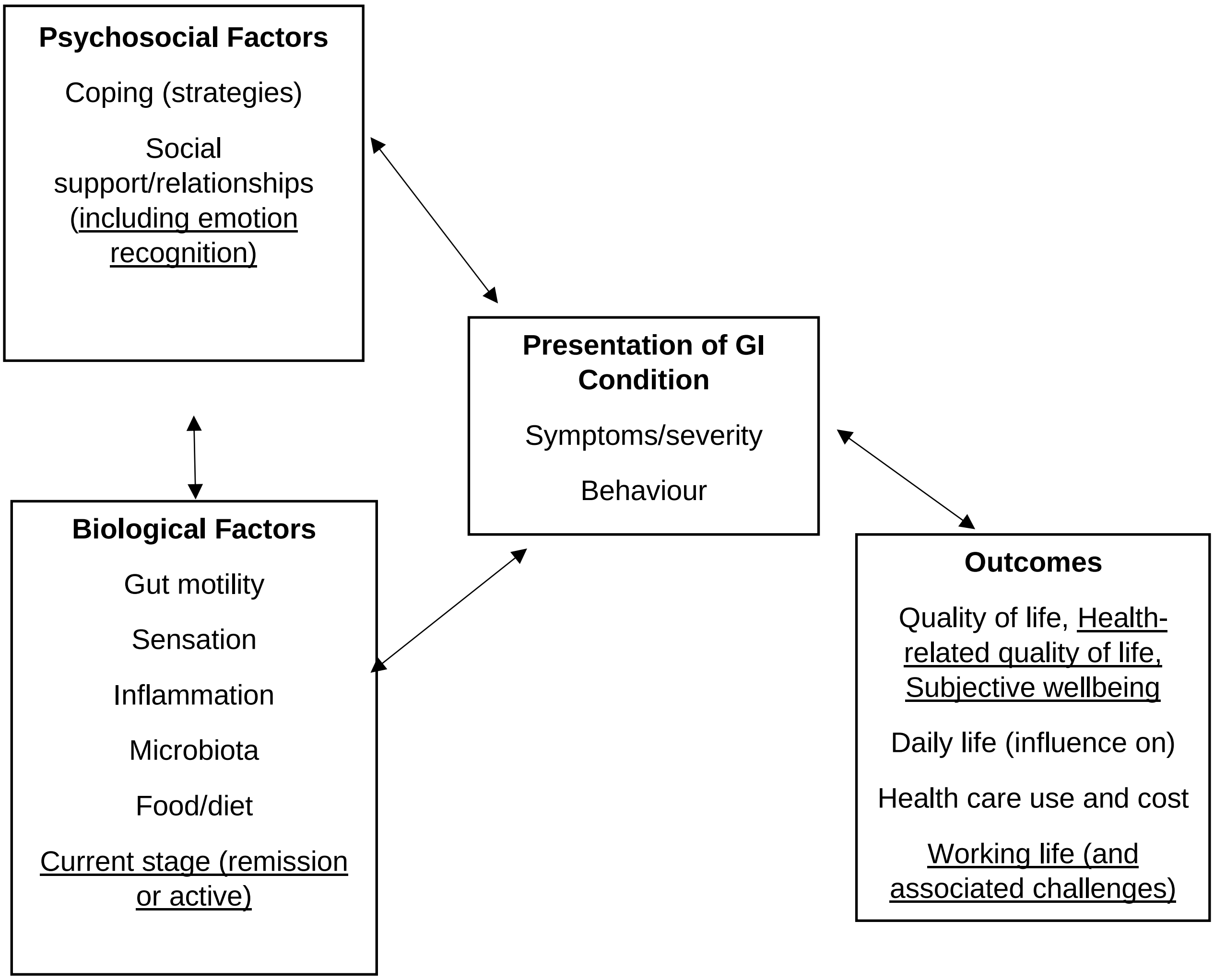
Despite past dominance, the biomedical model has reached the limit to its application, since it cannot sufficiently explain complicated chronic conditions (Havelka et al., 2009). Rather, the biopsychosocial model is increasingly preferred within health research, due to its acknowledgment of health conditions and the need to extend beyond a biomedical approach (Pilgrim, 2015; Wade & Halligan, 2017). The biopsychosocial model is favoured for the exploration of GI conditions, particularly IBS (Soares, 2014) due to the complex symptoms associated with this condition. This section provides an evaluation of how successfully biopsychosocial models (Drossman, 2016; Engel, 1977) were applied to this research.

In trying to understand the psychosocial aspects asspociated with GI conditions, a key element was to explore the lived experiences of individuals with IBS or IBD. Biopsychosocial models (Drossman, 2016; Engel, 1977) are highly appropriate as frameworks for this approach as they emphasise the importance of the individual and their experiences and actions (Farre & Rapley, 2017), and, as such, the model appeals to phenomenologists (Wade & Halligan, 2017). Overall, the results of studies 1, 2 and 3 support the argument that GI conditions are biopsychosocial in nature, solidifying the link between physical and psychological health. Yet, in response to the previous dominance of the biomedical model, there needs to be further investigation into psychosocial aspects of GI conditions. The findings of this thesis support the continued application of biopsychosocial models (Drossman, 2016; Engel, 1977) to the exploration of IBS and IBD.

To ensure this, this research sought to extend the application of Drossman's (2016) biopsychosocial model to also consider IBD, in support of the current rhetoric that the two share enough similarities that they should be explored together (Drossman & Hasler, 2016). It has been proposed that IBS may be a milder form of IBD (Rani et al., 2016). The research conducted within this thesis was indicative that the same psychosocial factors and wellbeing outcomes are associated with both IBS and IBD. As such, a biopsychosocial model that could be applied to both conditions would be beneficial moving forward. This led to the development of the following model (Figure 21). Factors underlined are additions to Drossman's (2016) model based on the outcomes of research conducted within this thesis.

Figure 21

A biopsychosocial model of factors implicated in the experience of IBS and IBD.



Note: Terms underlined are new additions to Drossman's (2016) biopsychosocial model.

The conclusion that the biopsychosocial model is appropriate as a model to explain IBS and IBD is consistent with research that has reported this model to be highly applicable to the study of chronic conditions, since it accounts for their complex and highly integrated nature (Kusnanto et al., 2018). For example, the biopsychosocial model has proven effective to the application of other health conditions including diabetes, where the combination of psychosocial and biological factors associated with this condition including depression and anxiety (Kusnanto et al., 2018). It is recommended that psychosocial and biological treatments for diabetes should be used in combination to tackle the diverse range of difficulties faced, ultimately improving quality of life (Portelli, 2021). Additional to IBS, the biopsychosocial model has been successfully applied to other functional conditions, such as fibromyalgia which is characterised by chronic pain, mood disorders and sleep disturbances (Bellato et al., 2012). Treatments for fibromyalgia are recommended to align with the biopsychosocial model (Turk & Adams, 2016). Central to the application of the biopsychosocial model to any health conditions is that the person/patient is actively engaged with managing their illness (Kusnanto et al., 2018), which was a concept important in this thesis.

6.3 Implications for future research

Overarchingly, it is recommended that biopsychosocial models continue to be applied when researching IBS and IBD as this model best acknowledges their complexity and the need to stress the importance of an individual’s experiences. In this way, research can be co-produced alongside those living with a specific health condition, which should result in mutual benefit for the research participants (their experiences are acknowledged and can result in targeted change) and for the researcher (their research is directly relevant to areas of concern, ensuring it will have great influence).

The application of the biopsychosocial model to the exploration of IBS and IBD within this research resulted in important implications for future research. For example, work absenteeism and presenteeism were reported to be issues for individuals with IBS or IBD. Following this research, it was recommended that future research should focus on workplace support, with a proposed model (Figure 22) highlighting the importance and relevance of work-related issues in the experience of IBS and IBD. Research should particularly aim to address lacking workplace support by exploring methods by which workplace support can be increased for individuals with IBS or IBD. One suggestion is to implement flexible working, with strategies including the option to work from home when needed and adjustable working hours (Hill et al., 2008; Ray & Pana-Cryan, 2021). Among the general population, employing flexible work policies has resulted in decreased stress, fewer instances of absence, and increased wellbeing (Halpern, 2005; Ray & Pana-Cryan, 2021). The same benefits could be available to those with IBS and IBD. It is also suggested that future research should consider whether additional support is required for individuals who perceive their GI condition as preventing them from working. Researchers could investigate methods to support their introduction or re-introduction to employment, as this could be overwhelming.

Study 1’s scoping review revealed a potential issue related to terminology used to explore wellbeing. It was evidenced that QOL and HRQOL have been commonly addressed in the literature on IBS and IBD, but are often used interchangeably (Karimi & Brazier, 2016). This is suggestive of two things; the first being that there needs to be better distinction between the two terms, and secondly that other wellbeing concepts have been comparatively under-investigated. This research addressed SWB due to its associations with social relationships, work and physical health, as “happier” individuals are more likely to have successful relationships, have improved work outcomes (more likely to be in employment and have higher job satisfaction), and have fewer work absences (Armenta et al., 2015). It was therefore surprising that only two out of the 68 studies included in the final narrative addressed SWB. Both these studies reported negative SWB outcomes associated with IBS (Farhadi et al., 2018; Lackner et al., 2010), which suggests that further exploration of SWB among this population is warranted as well as expanding focus to IBD.

An aim of this thesis was to investigate emotion recognition as a psychosocial factor aligned with the biopsychosocial model (Figure 1). For example, considering psychosocial explanations such as social relationships and the role they may have in emotion recognition and biological explanations such as the increased prevalence of alexithymia among those with a GI condition (Porcelli et al., 1995; Porcelli et al., 2017; Vigano, et al., 2018). Study 3 identified an inverse relationship between social support and recognition of one’s own emotions that suggests that seeking to increase the social support available to those with a GI condition could be associated with improved recognition of one’s own emotions This was encouraging, but further research in this area is both warranted and potentially beneficial. The high prevalence rates of alexithymia among those with a GI condition requires improved understanding. This could be an outcome of the gut-brain axis, but there needs to be further exploration of the mechanisms by which this occurs. It was proposed in Chapter 5 that a different measure of emotion recognition could be employed. Potentially, a psychophysical methodology would provide a more robust method by which to explore the emotion recognition of this population and could investigate the negative emotional bias in more depth. If a causal link between GI conditions and differences in emotion recognition ability was found, this could lead to the development of an early intervention tool or tracker to determine when a flare-up is imminent. Visual psychophysics has proved useful in detecting impaired emotion recognition ability among other health conditions, for example Parkinson's disease (Bowers et al., 2006; Ho et al., 2020).

6.5 Original contributions

This research was novel in its application of the biopsychosocial model. Firstly, existing frameworks were combined with additional key factors to provide a more holistic overview of IBS and IBD. While Drossman's (2016) biopsychosocial model is well-established and often applied to the study of IBS (Tanaka et al., 2011), there are important psychosocial aspects missing from this model that have been identified by this thesis. For example, factors such as work-related challenges and remission do not feature, despite research reporting their involvement in the biopsychosocial expression of GI conditions (Berknlev et al. 2006; La Berre et al., 2019; Ueno et al., 2017). This research acknowledged that condition stage (active or remission) could influence lived experiences and wellbeing outcomes, and so aimed to consider IBS and IBD across their course. Another amendment to Drossman's (2016) model was to replace life stress and psychologic state with SWB, since the terms are conceptually similar. SWB is increasingly acknowledged as a factor affected by IBS and IBD (Emerson et al. 2021) and its links to health (Larson, 1978; Steptoe et al., 2014), social support (Saphire-Bernstein & Taylor, 2015; Umberson & Karas Montez,

2010) and quality of life (Lex et al., 2019), further support its inclusion in a biopsychosocial model.

This research also extended the application of Drossman's (2016) model to address IBD. Currently there is no biopsychosocial model of IBD, despite the potential for such a model to increase our understanding of IBD (Mikocka-Walus et al., 2012). Ensuring IBD had been explored using a biopsychosocial model was an important aspect of this research, as there is increasing recognition that IBS and IBD share biological and psychosocial similarities which warrant their joint investigation (Drossman & Hasler, 2016). Certainly, studies 1 and 2 were suggestive that the same psychosocial factors and wellbeing outcomes are involved across both conditions. A unified model would provide a comprehensive framework to aid further exploration of the argument that IBS and IBD should no longer be classified as distinct conditions. These amendments led to the development of a biopsychosocial model (Figure 1) that can be employed in future research.

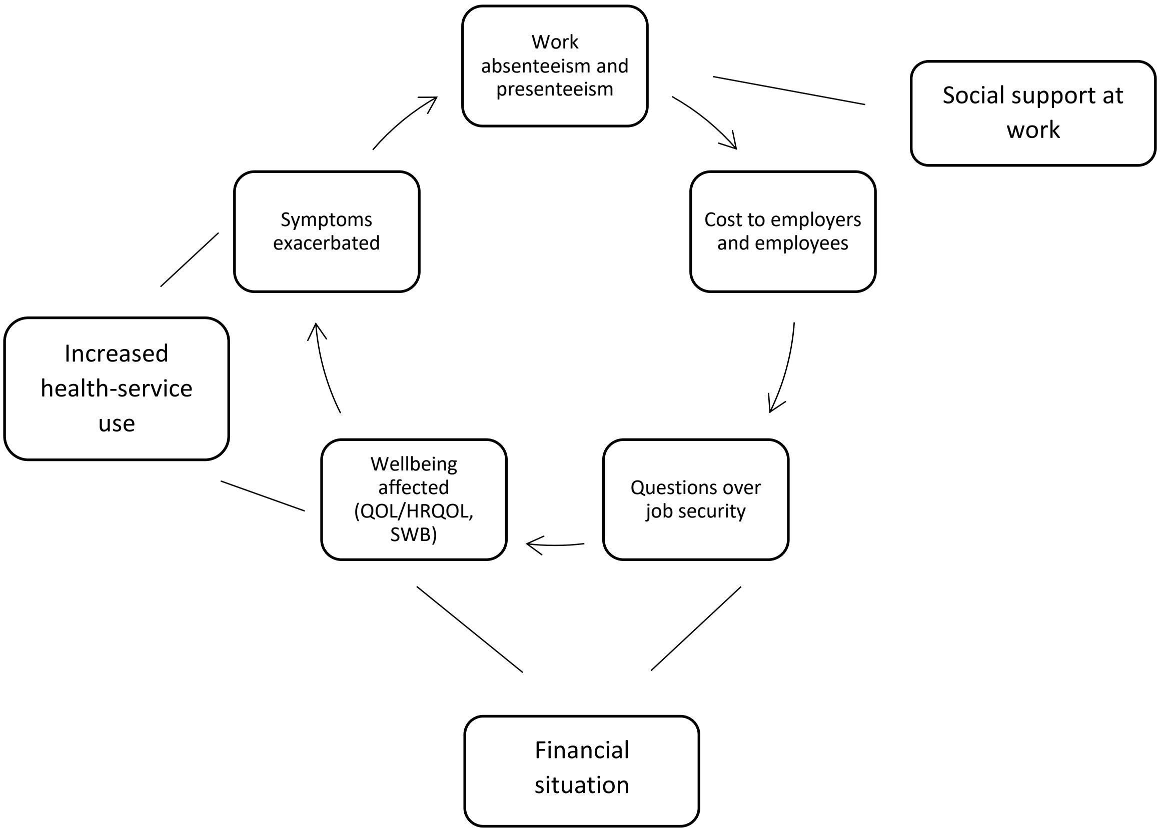
The potential role of emotion recognition in IBS and IBD was a novel area explored within this thesis. Study 3 sought to investigate were, if anywhere, emotion recognition would best fit in the biopsychosocial expression of GI conditions. Emotion recognition was explored via the PAQ (Preece et al., 2018), but no significant differences between those with a GI condition and those without were observed. A negative correlation (of medium strength) between social support and alexithymia was reported, suggesting an inverse relationship between the two variables, which was expected. This result was encouraging and suggests that the link between social support and emotion recognition among those with IBS and IBD is worth further exploration. The use of more comprehensive methods to study emotion recognition are advised, as alexithymia only explored emotion recognition in oneself, thus ignoring how emotions are recognised in others. This research explored a novel area and could act as a catalyst to inspire researchers to consider emotion recognition further in the context of GI conditions.

Theoretical implications of this work include the development of a biopsychosocial model capable to explaining IBS and IBD, which has provided a novel conceptualisation of these conditions and how they should be explored. Application of this model to future research could result in enhanced support for individuals across the course of their condition, since condition stage is now formally acknowledged as an important aspect of IBS and IBD experience. The identification of emotion recognition as an area of investigation and its links to social support among those with a GI condition could have practical applications. For example, it has been reported that, with training, emotion recognition ability can improve (Döllinger et al., 2021) which could have implications for social communication and social support. This would be beneficial to the wider population, not only those with a GI condition. Were future research to report differences in emotion recognition ability between the active and remission stages of IBS and IBD, another potential application could be to employ emotion recognition as a method to predict an imminent transition from remission to the active stage.

This work could also prove useful in supporting individuals with IBS or IBD more successfully, for example in employment. The complex challenges often faced by those with these conditions were highlighted in this thesis, leading to work-related challenges being included as an integral part of the biopsychosocial model (Figure 1). A preliminary model has been developed to approach this, which could be adapted for application to other chronic health conditions.

Figure 22

Complex systems illustrating work-related challenges as a psychosocial factor involved in IBS and IBD



An important aspect of this research was that it sought to voice and highlight the experiences of those who live with IBS and IBD, as this research could have the biggest implications for this population. To do this, an inductive approach was adopted throughout to ensure research was focused on directly relevant aspects. In this way, the research was co-produced with those affected by GI conditions. It is recommended that future researchers adopt a similar approach, acknowledging the input of those at the centre of their work.

6.6 Concluding remarks

This thesis aimed to investigate the influence of having a GI condition (IBS or IBD) on psychosocial wellbeing and health outcomes consistent with the biopsychosocial model of health. Presently, the most addressed psychosocial factors are social support and the most addressed wellbeing outcomes are HRQOL and QOL, but less researched outcomes such as SWB should receive increased focus. Coping and social support are integral aspects of the lived experiences of individuals with IBS and IBD alongside experiences of remission, negative emotional experiences, and a wish to increase awareness of these conditions. Succinctly, the outcomes of this research support the continued use of the biopsychosocial model to explore IBS and IBD and the co-production of research with those most affected. The outcomes of this research provide avenues for future research and highlight areas that require additional support from health care workers and policy makers.

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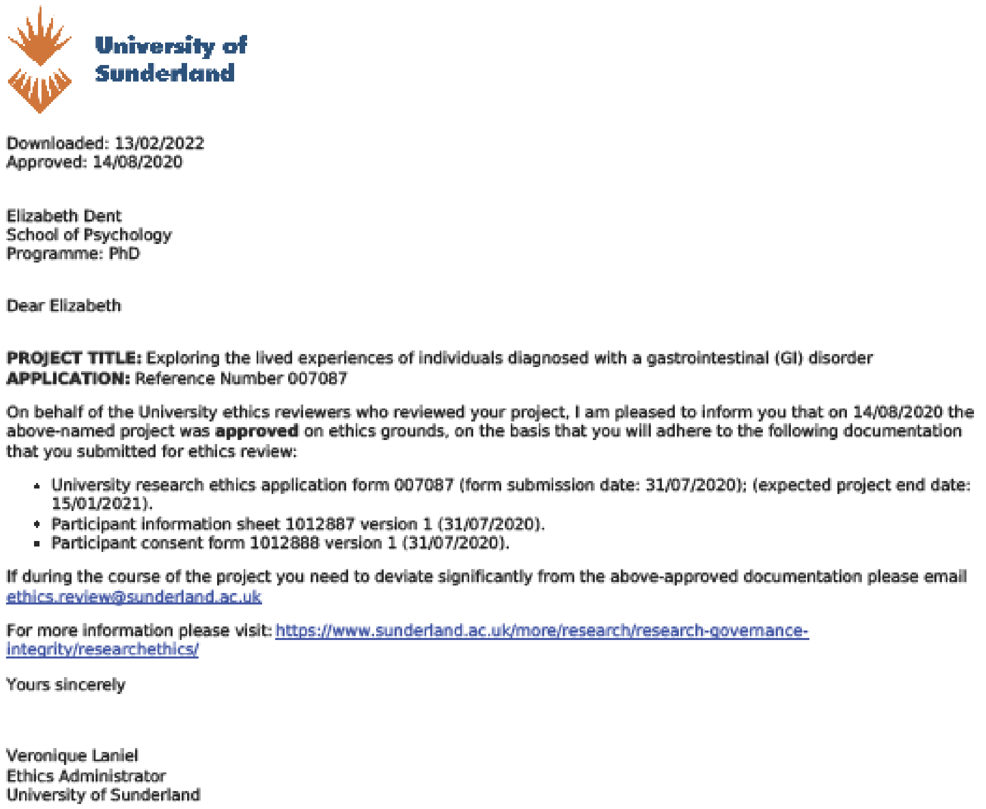
Appendices

Appendix A



University of
Sunderland

Downloaded: 13/02/2022
Approved: 14/08/2020

Elizabeth Dent
School of Psychology
Programme: PhD

Dear Elizabeth

PROJECT TITLE: Exploring the lived experiences of individuals diagnosed with a gastrointestinal (GI) disorder
APPLICATION: Reference Number 007087

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 14/08/2020 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 007087 (form submission date: 31/07/2020); (expected project end date: 15/01/2021).
- Participant information sheet 1012887 version 1 (31/07/2020).
- Participant consent form 1012888 version 1 (31/07/2020).

If during the course of the project you need to deviate significantly from the above-approved documentation please email ethics.review@sunderland.ac.uk

For more information please visit: https://www.sunderland.ac.uk/more/research/research-governance-integrity/researchethics/

Yours sincerely

Veronique Laniel
Ethics Administrator
University of Sunderland

Appendix B

Advert to be used to recruit participants online

Participants Required

Study title: Exploring the lived experiences of individuals diagnosed with a gastrointestinal (GI) disorder.

Study aim: To explore and better understand the lived experiences of individuals diagnosed with irritable bowel syndrome (IBS) or inflammatory bowel disease (IBD).

Interviewing those who have been diagnosed with a GI disorder (either IBS or IBD) about their direct and lived experiences will increase our understanding and knowledge of these conditions as well as helping to better inform the focus of future research.

Individuals who are aged 18 and over, a fluent English speaker, and have been diagnosed with irritable bowel syndrome (IBS) or inflammatory bowel disease (IBD) are invited to take part in an interview exploring their experiences living with these conditions.

The interview will last approximately 1 hour and would take place using Microsoft Teams (you do not have to have an account with this software to take part).

For more information please contact:

Bg51eg@student.sunderland.ac.uk

This study has been approved by the University of Sunderland Research Ethics Committee.

Thank you.

Elizabeth Dent.

Appendix C

University of Sunderland

Participation Consent Form

Study title: Exploring the lived experiences of individuals diagnosed with a gastrointestinal (GI) disorder.

Participant code: ________________

	Please initial here
I am over the age of 18.	
I have read and understood the attached study information.	
I understand that I have the right to withdraw from the study without giving a reason at any time during the study itself.	
I understand that I also have the right to withdraw my data for a short period after I have participated, i.e., 2 weeks after attending the interview.	
I understand that the interview will be audio recorded.	
I understand that data may be used for publication, but that any quotes/ excerpts will be anonymized using pseudonyms.	

I consent to participate in this study.

Print Name: ……………………………………………………… Signature: ……………………………………..

Date: ……………………………………………..

Appendix D

University of Sunderland

Participant Information Sheet

Study Title

Exploring the lived experiences of individuals diagnosed with a gastrointestinal (GI) disorder.

What is the study's purpose?

The purpose of this study is to better understand the experiences of individuals with GI disorders. GI disorders such as irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) are increasing in prevalence, and it is becoming clear that a better understanding of GI disorders and their impact is needed. One of the best methods for this is to enquire about the experiences of those most affected, as these individuals can provide keen insight and first-hand knowledge.

Why have I been approached to take part?

You have been approached because you have either IBS or IBD and are over the age of 18.

Do I have to take part?

Participation is voluntary, so you are under no obligation to take part in this study. You have the right to withdraw from the research (without providing a reason). In this case, your data will be destroyed and thus not used in the final analysis. If you wish to withdraw, contact the researcher (contact information is provided). You can withdraw up to two weeks after taking part.

What will happen to me if I take part?

A date and time will be arranged for you to take part in an interview. It is anticipated that the interview will last approximately 60 minutes. The interview will be audio recorded and take place via Microsoft Teams. You do not need to have a Microsoft Teams account, as an invitation to join the interview will be sent via email. You do not need to turn your webcam on if you would prefer not to have your face visible. You will not be video recorded.

You will be asked general questions regarding your GI disorder, including questions around how your disorder impacts your daily life and what you find challenging about your disorder. You are under no obligation to provide details of your experiences if you do not wish to do so. While there are topics the researcher wishes to cover, you are free to discuss anything you wish if you feel it is relevant to your experience. There are no right or wrong answers to the questions you will be asked, they are designed to better understand your experiences living with a GI disorder.

What are the possible disadvantages of taking part?

Some participants may find it upsetting to discuss their GI disorder. There is no pressure for you to do so. If you feel this would cause you concern, you do not have to participate. There is also the option to disable your webcam, so your face is not visible.

If you feel upset or concerned at any point, there are services/resources the researcher can direct you to. For example, included at the end of this document is a short list of available resources (should you need them).

What if something goes wrong?

It is not anticipated that anything will go wrong. However, if anything should go wrong, you can exercise your right to withdraw by contacting the researcher. Similarly, if you are unhappy with the conduct of this research, you can contact the research supervisor Dr. Nicola Davinson, or the Chair of the University of Sunderland Research Ethics Group Dr. John Fulton. Contact details are included below.

Will my taking part be kept confidential?

Yes. Pseudonyms will be used in the transcripts to protect participant's identities. Upon completion of the interview, only the researcher and supervisors listed on this document will have access to raw data. In accordance with the Data Protection Act 2018, data will be stored on a password protected computer for a minimum of 1 year after the completion of the researcher's PhD, and up to 3 years after any papers associated with this research are accepted for publication. Audio recordings may be deleted sooner than this.

What will happen to the results of the research study?

The result of this study will be written up by the researcher as part of their PhD thesis. Results could also be used for publication but that any quotes/ excerpts will be anonymized using pseudonyms.

Who is organizing and funding the research?

This study is being organized by Elizabeth Dent (PhD student at the University of Sunderland, School of Psychology) and her supervisors. This project has not received external funding.

Who has reviewed this study?

A departmental subcommittee of the University of Sunderland Research Ethics committee has reviewed and approved this study.

Contact for further information

Researcher: Elizabeth Dent

Email: bg51eg@student.sunderland.ac.uk

Supervisor 1: Dr. Nicola Davison

Email: nicola.davinson@sunderland.ac.uk

Supervisor 2: Dr. Stephanie Wilkie

Email: stephanie.wilkie@sunderland.ac.uk

Chairperson of the University of Sunderland Research Ethics Committee: Dr. John Fulton

Email: john.fulton@sunderland.ac.uk

Examples of resources available should you experience distress as a result of discussing your GI disorder:

https://www.nhs.uk/conditions/irritable-bowel-syndrome-ibs/further-help-and-support/ provides information and links to dietician information and psychological services.

https://www.crohnsandcolitis.org.uk/support provides similar support for those with IBD, with information on emotional and financial support as well as tips for everyday life with IBD.

https://ibduk.org/resources-for-ibd-services also provides resources and support for those with IBD.

Your GPs are available to offer extra support and advice if necessary.

Appendix E

Interview Schedule

Topic for interview: the lived experiences of individuals with the GI conditions IBS or IBD. Range of topic areas: daily life, experiences during periods of remission, challenges faced as a result of participant's condition, and thoughts on what participants would like others to be aware of regarding their condition.

Introduction: Thank you for indicating your interest in participating in this study. My name is Elizabeth Dent, I'm a PhD student investigating the lived experiences of individuals who have been diagnosed with IBS or IBD. The interview will last approximately one hour, and you are free to discuss anything you feel is relevant to your experience. Can I just check you are still happy to participate?

Would you be happy to introduce yourself?

Questions: I am going to ask you some questions about your condition to better understand your experiences.

1) First, please tell me about your GI condition and the symptoms you typically experience?
2) When were you diagnosed with your GI condition? (if not covered in answer to question 1)
    a. Can you tell me about the process you went through to get diagnosed?
3) Let's talk about how your condition impacts your daily life.
    a. What specific ways of coping with physical symptoms have you developed?
    b. Are there social or psychological symptoms that you have experienced, and if so, how do you address these?
        i. For example, your work and social life?
4) Could you describe your experiences of remission with your condition?
    a. If participants indicate that they have not previously experienced a period of remission, perhaps because their condition is severe or they are more recently diagnosed, I will try and clarify why this is the case, and could ask what they would expect of a period of remission.
5) What aspects of your experience with a GI condition would you view as most challenging, and why?
    a. Conversely, are there any aspects of your experience that have been positive?
6) How have those around you responded to your diagnosis, be it family, loved ones, colleagues?
7) What would you want others to know about your GI condition?
    a. For example, to address misconceptions or better inform others.

Questions 1, 2 and 3 will be asked first, but the remaining questions do not have a set order in which they have to be asked. This will be determined by the flow of conversation and any spontaneous points participants raise.

Probes and follow-up questions for clarification and extra detail:

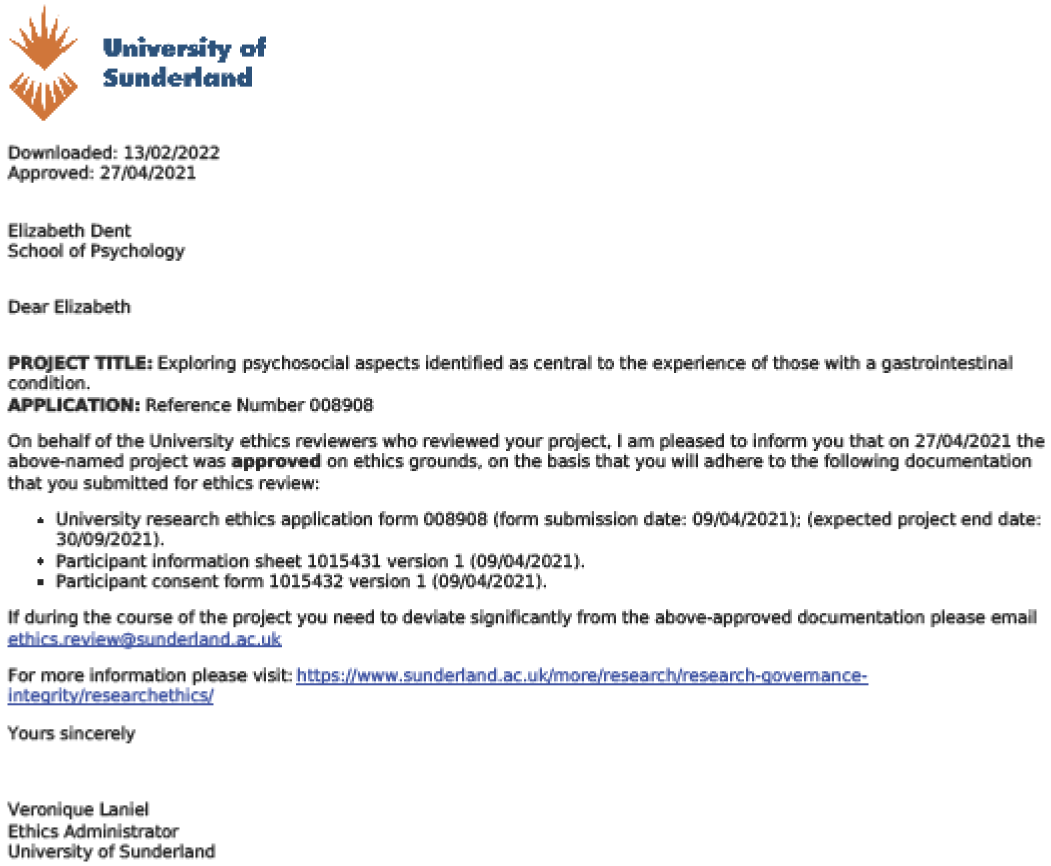
- Can you explain that further?
- Why do you think that?
- How does that make you feel?
- What do you mean by that?

Bringing the interview to a close: Is there anything we haven't covered today that you would like to mention or discuss that you feel is relevant to your experience living with a GI condition?

Debrief: Just to recap, the purpose of this study was to explore the lived experiences of individuals who have been diagnosed with either IBS or IBD. This data will be kept confidential, with names changed, and will be written up and analysed as part of my PhD thesis and there is a possibility that a paper may be submitted to an academic journal.

Thank you for your time.

Appendix F



University of Sunderland

Downloaded: 13/02/2022
Approved: 27/04/2021

Elizabeth Dent
School of Psychology

Dear Elizabeth

PROJECT TITLE: Exploring psychosocial aspects identified as central to the experience of those with a gastrointestinal condition.
APPLICATION: Reference Number 008908

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 27/04/2021 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 008908 (form submission date: 09/04/2021); (expected project end date: 30/09/2021).
- Participant information sheet 1015431 version 1 (09/04/2021).
- Participant consent form 1015432 version 1 (09/04/2021).

If during the course of the project you need to deviate significantly from the above-approved documentation please email ethics.review@sunderland.ac.uk

For more information please visit: https://www.sunderland.ac.uk/more/research/research-governance-integrity/researchethics/

Yours sincerely

Veronique Laniel
Ethics Administrator
University of Sunderland

Appendix G

Recruitment Advert for General Population

Participants required.

Study title: Exploring psychosocial aspects identified as central to the experience of those with a gastrointestinal condition.

Study aim: To further explore psychosocial aspects identified as directly relevant to the lived experiences of individuals with irritable bowel syndrome (IBS) or inflammatory bowel disease (IBD).

You must be aged 18 and over to take part in this research. You do not have to have a GI condition to take part as participation is open to individuals with a diagnosis of IBS or IBD as well as individuals with no GI conditions. Individuals with a diagnosis of autism spectrum disorder or any GI condition other than IBS or IBD are not eligible to take part.

You will be asked to disclose your gender, age, condition duration (only applicable to those with IBS or IBD), and any diagnoses of alexithymia, depression and/or anxiety. You will then be asked to complete a series of survey measures. Participation in this research will take around 30-45 minutes.

If you are interested in taking part, please click the link below.

Study link to go here.

If you would like more information, please contact:

Bg51eg@student.sunderland.ac.uk

This study has been approved by the University of Sunderland Research Ethics Committee.

Thank you.

Elizabeth Dent (PhD student).

Appendix H

Recruitment Advert for IBS/IBD Support Groups.

Participants required.

Study title: Exploring psychosocial aspects identified as central to the experience of those with a gastrointestinal condition.

Study aim: To further explore psychosocial aspects identified as directly relevant to the lived experiences of individuals with irritable bowel syndrome (IBS) or inflammatory bowel disease (IBD).

Individuals who are aged 18 and over with a diagnosis of IBS, IBD are invited to take part in this research. Individuals with a diagnosis of autism spectrum disorder or any GI condition other than IBS or IBD are not eligible to take part.

You will be asked to disclose your gender, age, condition duration and any diagnoses of alexithymia, depression and/or anxiety. You will then be asked to complete a series of survey measures. Participation in this research will take around 30-45 minutes.

If you are interested in taking part, please click the link below.

Study link to go here.

If you would like more information, please contact:

Bg51eg@student.sunderland.ac.uk

This study has been approved by the University of Sunderland Research Ethics Committee.

Thank you.

Elizabeth Dent (PhD student).

Appendix I

University of Sunderland

Participation Consent Form

Study title:

Exploring psychosocial aspects identified as central to the experience of those with a gastrointestinal condition.

Please enter a unique and memorable six-digit participant code:

Please tick the following boxes to indicate your consent to each statement.

	Please tick here
I am over the age of 18.	☐
I have read and understood the attached study information.	☐
I understand that I have the right to withdraw from the study without giving a reason at any time during the study itself.	☐
I understand that I also have the right to withdraw my data for a short period after I have participated, i.e., 2 weeks after participation.	☐
I understand that data may be used for publication, but data will be completely anonymized.	☐
I confirm I do not have a diagnosis of autism spectrum disorder	☐
I consent to participate in this study.	☐

Appendix J

University of Sunderland

Participant Information Sheet

Study Title

Exploring psychosocial aspects identified as central to the experience of those with a gastrointestinal condition.

What is the study's purpose?

The purpose of this study is to better understand the psychosocial impact of gastrointestinal (GI) conditions on those diagnosed. GI conditions such as irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) are increasing in prevalence, and it is becoming clear that a better understanding of GI disorders and their impact is needed. This study aims to build upon the findings of a prior exploration into the lived experiences of individuals with IBS or IBD. Survey measures will be used to investigate areas reported as central to these participants lived experiences.

Why have I been approached to take part?

You have been approached because you have been diagnosed with IBS or IBD and are over the age of 18. Individuals with no gastrointestinal conditions are also invited to take part. As emotion recognition/identification will be investigated as part of this study, individuals with autism spectrum disorder are not eligible to take part. Individuals with GI conditions other than IBS or IBD are also not eligible to take part.

Do I have to take part?

Participation is voluntary, so you are under no obligation to take part in this study. You have the right to withdraw from the research (without providing a reason). In this case, your data will be destroyed and thus not used in the final analysis. You can withdraw when completing the survey by closing your web browser at any time. After completing the survey, if you wish to withdraw, contact the researcher (contact information is provided) with your unique participant code. You can withdraw up to two weeks after taking part.

What will happen to me if I take part?

You will be asked to provide some demographic information including your gender, age and whether you have IBS, IBD or no GI condition. If you have IBS or IBD, you will be asked to disclose your condition duration (in years) and whether you are currently in the remission or active stage of your condition. You will be asked to disclose any diagnoses of alexithymia, depression and/or anxiety. You will then be asked to complete a series of survey measures investigating specific psychosocial aspects. There are no right or wrong answers to these survey measures, and you are under no obligation to answer any question(s) that make you feel distressed. This study will take approximately 30-45 minutes.

What are the possible disadvantages of taking part?

Some participants may find it upsetting to answer questions related to their GI disorder or mental health. There is no pressure for you to do so. If you feel this would cause you concern, you do not have to participate.

If you feel upset or concerned at any point, there are services/resources the researcher can direct you to. For example, included at the end of this document is a short list of available resources (should you need them).

What if something goes wrong?

It is not anticipated that anything will go wrong. However, if anything should go wrong, you can exercise your right to withdraw by contacting the researcher. Similarly, if you are unhappy with the conduct of this research, you can contact the research supervisor Dr. Nicola Davinson, or the Chair of the University of Sunderland Research Ethics Group Dr. John Fulton. Contact details are included below.

Will my taking part be kept confidential?

Yes. Only the researcher and supervisory team will have access to raw data. In accordance with the Data Protection Act 2018, data will be stored on a password protected computer for a minimum of 1 year after the completion of the researcher’s PhD, and up to 3 years after any papers associated with this research are accepted for publication.

What will happen to the results of the research study?

The result of this study will be written up by the researcher as part of their PhD thesis. If suitable, the results may also be presented at academic conferences and/or written up for publication in peer reviewed academic journals, but data will be anonymized.

Who is organizing and funding the research?

This study is being organized by Elizabeth Dent (PhD student at the University of Sunderland, School of Psychology) and her supervisors. This project has not received external funding.

Who has reviewed this study?

A departmental subcommittee of the University of Sunderland Research Ethics committee has reviewed and approved this study.

Contact for further information

Researcher: Elizabeth Dent

Email: bg51eg@student.sunderland.ac.uk

Supervisor 1: Dr. Nicola Davison

Email: nicola.davinson@sunderland.ac.uk

Supervisor 2: Dr. Stephanie Wilkie

Email: stephanie.wilkie@sunderland.ac.uk

Chairperson of the University of Sunderland Research Ethics Committee: Dr. John Fulton

Email: john.fulton@sunderland.ac.uk

Examples of resources available should you experience distress as a result of discussing your GI disorder:

https://www.nhs.uk/conditions/irritable-bowel-syndrome-ibs/further-help-and-support/ provides information and links to dietician information and psychological services.

https://www.crohnsandcolitis.org.uk/support provides similar support for those with IBD, with information on emotional and financial support as well as tips for everyday life with IBD.

https://ibduk.org/resources-for-ibd-services also provides resources and support for those with IBD.

Your GPs are available to offer extra support and advice if necessary.

For students at the University of Sunderland, you are free to contact the Wellbeing Service if necessary.

Appendix K

University of Sunderland

Study Debriefing

Thank you for your participation in this study. The aim of this study was to better understand the psychosocial impact of GI conditions on those diagnosed. Previously, a series of interviews with those diagnosed with irritable bowel syndrome (IBS) or inflammatory bowel disease (IBD) identified several psychosocial areas as directly relevant to their lived experiences. You were asked to complete a series of survey measures to further explore some of these areas, specifically coping, negative emotional experiences and the social impact of GI conditions.

It is expected that differences in responses to the survey measures you completed will be observed between those with and without GI conditions. We expect to see differences in self-reported quality of life, subjective wellbeing, relationships, work and activities, coping and alexithymia between the groups. It is also anticipated that age, gender, condition duration, and any comorbidities will also impact research outcomes.

Should you wish, you can withdraw from this study up to two weeks after participation. To withdraw contact the researcher using the email provided with your participation code. Your data will then be removed and destroyed.

This data will be written up as part of my PhD thesis and may be prepared as an article for publication. All data is anonymized and confidential.

If participating in this study has caused you any distress, you may wish to contact someone, such as your GP, but University of Sunderland students can also contact the University’s wellbeing service using the details below.

Website: https://sj.sunderland.ac.uk/wellbeing/

Telephone:0191 515 2933

Email: wellbeing@sunderland.ac.uk

Address: 1st Floor, Edinburgh Building,

City Campus,

Sunderland,

SR1 3SD.

For those with a GI condition, the following resources may also be helpful if you have felt distressed as a result of this study.

https://www.nhs.uk/conditions/irritable-bowel-syndrome-ibs/further-help-and-support/ provides information and links to dietician information and psychological services.

https://www.crohnsandcolitis.org.uk/support provides similar support for those with IBD, with information on emotional and financial support as well as tips for everyday life with IBD.

https://ibduk.org/resources-for-ibd-services also provides resources and support for those with IBD.

To request further information about this study, or to be made aware of the results upon the study's completion, please contact the researcher or supervisor using the following details.

Elizabeth Dent (Researcher): bg51eg@student.sunderland.ac.uk

Dr. Nicola Davinson (Supervisor): nicola.davinson@sunderland.ac.uk

Appendix L

Opening demographic and condition questions.

1. What is your age?

2. What is your gender?

Male Female Other

3. Which of the following describes your gastrointestinal health status?

IBS IBD No gastrointestinal conditions (skip to question 6)

4. How long have you had your condition (in years)?

5. What stage of your condition are you currently experiencing?

Active stage Remission stage

6. Have you been diagnosed with the following conditions?

Depression Anxiety Alexithymia

36-ITEM SHORT FORM SURVEY INSTRUMENT
(SF-36)

RAND 36-Item Health Survey 1.0 Questionnaire Items

Choose one option for each questionnaire item.

1. In general, would you say your health is:

○ 1 - Excellent

○ 2 - Very good

○ 3 - Good

○ 4 - Fair

○ 5 - Poor

---

2. **Compared to one year ago**, how would you rate your health in general **now**?

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

○ 1 - Much better now than one year ago

○ 2 - Somewhat better now than one year ago

○ 3 - About the same

○ 4 - Somewhat worse now than one year ago

○ 5 - Much worse now than one year ago

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
3. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	○ 1	○ 2	○ 3
4. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○ 1	○ 2	○ 3
5. Lifting or carrying groceries	○ 1	○ 2	○ 3
6. Climbing **several** flights of stairs	○ 1	○ 2	○ 3
7. Climbing **one** flight of stairs	○ 1	○ 2	○ 3
8. Bending, kneeling, or stooping	○ 1	○ 2	○ 3
9. Walking **more than a mile**	○ 1	○ 2	○ 3
10. Walking **several blocks**	○ 1	○ 2	○ 3
11. Walking **one block**	○ 1	○ 2	○ 3
12. Bathing or dressing yourself	○ 1	○ 2	○ 3

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

	Yes	No
13. Cut down the **amount of time** you spent on work or other activities	○	○
14. **Accomplished less** than you would like	○	○
15. Were limited in the **kind** of work or other activities	○	○
16. Had **difficulty** performing the work or other activities (for example, it took extra effort)	○	○

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	Yes	No
17. Cut down the **amount of time** you spent on work or other activities	○	○
18. **Accomplished less** than you would like	○	○
19. Didn't do work or other activities as **carefully** as usual	○	○

---

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

○ 1 - Not at all

○ 2 - Slightly

○ 3 - Moderately

○ 4 - Quite a bit

○ 5 - Extremely

---

21. How much **bodily** pain have you had during the **past 4 weeks**?

○ 1 - None

○ 2 - Very mild

○ 3 - Mild

○ 4 - Moderate

○ 5 - Severe

○ 6 - Very severe

---

22. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

○ 1 - Not at all

○ 2 - A little bit

○ 3 - Moderately

○ 4 - Quite a bit

○ 5 - Extremely

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
23. Did you feel full of pep?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
24. Have you been a very nervous person?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
25. Have you felt so down in the dumps that nothing could cheer you up?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
26. Have you felt calm and peaceful?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
27. Did you have a lot of energy?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
28. Have you felt downhearted and blue?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
29. Did you feel worn out?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
30. Have you been a happy person?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
31. Did you feel tired?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6

---

32. During the **past 4 weeks**, how much of the time has **your physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?
How TRUE or FALSE is **each** of the following statements for you.

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false

○ 1 - All of the time

○ 2 - Most of the time

○ 3 - Some of the time

○ 4 - A little of the time

○ 5 - None of the time

33. I seem to get sick a little easier than other people	○ 1	○ 2	○ 3	○ 4	○ 5
34. I am as healthy as anybody I know	○ 1	○ 2	○ 3	○ 4	○ 5
35. I expect my health to get worse	○ 1	○ 2	○ 3	○ 4	○ 5
36. My health is excellent	○ 1	○ 2	○ 3	○ 4	○ 5

NovoPsych

Brief-COPE (Brief-COPE)

(Carver, 1997)

Instructions:

The following questions ask how you have sought to cope with a hardship in your life. Read the statements and indicate how much you have been using each coping style.

		I haven't been doing this at all	A little bit	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.	**1**	**2**	**3**	**4**
2	I've been concentrating my efforts on doing something about the situation I'm in.	**1**	**2**	**3**	**4**
3	I've been saying to myself "this isn't real".	**1**	**2**	**3**	**4**
4	I've been using alcohol or other drugs to make myself feel better	**1**	**2**	**3**	**4**
5	I've been getting emotional support from others.	**1**	**2**	**3**	**4**
6	I've been giving up trying to deal with it.	**1**	**2**	**3**	**4**
7	I've been taking action to try to make the situation better.	**1**	**2**	**3**	**4**
8	I've been refusing to believe that it has happened.	**1**	**2**	**3**	**4**
9	I've been saying things to let my unpleasant feelings escape.	**1**	**2**	**3**	**4**
10	I've been getting help and advice from other people.	**1**	**2**	**3**	**4**
11	I've been using alcohol or other drugs to help me get through it.	**1**	**2**	**3**	**4**
12	I've been trying to see it in a different light, to make it seem more positive.	**1**	**2**	**3**	**4**
13	I've been criticizing myself.	**1**	**2**	**3**	**4**
14	I've been trying to come up with a strategy about what to do.	**1**	**2**	**3**	**4**
15	I've been getting comfort and understanding from someone.	**1**	**2**	**3**	**4**
16					

	I've been giving up the attempt to cope.	**1**	**2**	**3**	**4**

		I haven't been doing this at all	A little bit	A medium amount	I've been doing this a lot
17	I've been looking for something good in what is happening.	**1**	**2**	**3**	**4**
18	I've been making jokes about it.	**1**	**2**	**3**	**4**
19	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	**1**	**2**	**3**	**4**
20	I've been accepting the reality of the fact that it has happened.	**1**	**2**	**3**	**4**
21	I've been expressing my negative feelings.	**1**	**2**	**3**	**4**
22	I've been trying to find comfort in my religion or spiritual beliefs.	**1**	**2**	**3**	**4**
23	I've been trying to get advice or help from other people about what	**1**	**2**	**3**	**4**
24	I've been learning to live with it.	**1**	**2**	**3**	**4**
25	I've been thinking hard about what steps to take.	**1**	**2**	**3**	**4**
26	I've been blaming myself for things that happened	**1**	**2**	**3**	**4**
27	I've been praying or meditating	**1**	**2**	**3**	**4**
28	I've been making fun of the situation.	**1**	**2**	**3**	**4**

Satisfaction With Life Scale

(Diener., Emmons., Larsen &Griffin, 1985)

Below are five statements that you may agree or disagree with. Using the 1 - 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

- 7 - Strongly agree
- 6 - Agree
- 5 - Slightly agree
- 4 - Neither agree nor disagree
- 3 - Slightly disagree
- 2 - Disagree
- 1 - Strongly disagree

____ In most ways my life is close to my ideal.

____ The conditions of my life are excellent.

____ I am satisfied with my life.

____ So far I have gotten the important things I want in life.

____ If I could live my life over, I would change almost nothing.

Scale of Positive and Negative Experience (SPANE)

(Diener., Wirtz., Tov., Kim-Prieto., Choi., Oishi., & Biswas-Diener, 2009)

Please think about what you have been doing and experiencing during the past four weeks. Then report how much you experienced each of the following feelings, using the scale below. For each item, select a number from 1 to 5, and indicate that number on your response sheet.

1. Very Rarely or Never
2. Rarely
3. Sometimes
4. Often
5. Very Often or Always

Positive

Negative

Good

Bad

Pleasant

Unpleasant

Happy

Sad

Afraid

Joyful

Angry

Contented

The Social Provisions Scale
(Cutrona & Russel, 1987)

Instructions

In answering the next set of questions I am going to ask you, I want you to think about your current relationship with friends, family members, co-workers, community members, and so on. Please tell me to what extent you agree that each statement describes your current relationships with other people. Use the following scale to give me your opinion. (Hand a response card.) So, for example, if you feel a statement is very true of your current relationships, you would tell me "strongly agree". If you feel a statement clearly does not describe your relationships, you would respond "strongly disagree". Do you have any questions?

Strongly Disagree	Disagree	Agree	Strongly Agree
1	2	3	4

1. There are people I can depend on to help me if I really need it. ______

2. I feel that I do not have close personal relationships with other people. ______

3. There is no one I can turn to for guidance in times of stress. ______

4. There are people who depend on me for help. ______

5. There are people who enjoy the same social activities I do. ______

6. Other people do not view me as competent. ______

7. I feel personally responsible for the well-being of another person. ______

8. I feel part of a group of people who share my attitudes and beliefs. ______

9. I do not think other people respect my skills and abilities. ______

10. If something went wrong, no one would come to my assistance. ______

11. I have close relationships that provide me with a sense of emotional security and well-being.

______

12. There is someone I could talk to about important decisions in my life. _____
13. I have relationships where my competence and skills are recognized. _____
14. There is no one who shares my interests and concerns. _____
15. There is no one who really relies on me for their well-being. _____
16. There is a trustworthy person I could turn to for advice if I were having problems. _____
17. I feel a strong emotional bond with at least one other person. _____
18. There is no one I can depend on for aid if I really need it. _____
19. There is no one I feel comfortable talking about problems with. _____
20. There are people who admire my talents and abilities. _____
21. I lack a feeling of intimacy with another person. _____
22. There is no one who likes to do the things I do. _____
23. There are people I can count on in an emergency. _____
24. No one needs me to care for them. _____

Work Productivity and Activity Impairment Questionnaire: General Health V2.0 (WPAI:GH)

(Reily, Zbrozek, & Dukes, 1993)

The following questions ask about the effect of your health problems on your ability to work and perform regular activities. By health problems we mean any physical or emotional problem or symptom. *Please fill in the blanks or circle a number, as indicated.*

1. Are you currently employed (working for pay)? ____ NO ____ YES *If NO, check "NO" and skip to question 6.*

The next questions are about the **past seven days**, not including today.

2. During the past seven days, how many hours did you miss from work because of your health problems? *Include hours you missed on sick days, times you went in late, left early, etc., because of your health problems. Do not include time you missed to participate in this study.*

   _____HOURS

3. During the past seven days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off to participate in this study?

   _____HOURS

4. During the past seven days, how many hours did you actually work?

   _____HOURS *(If "0", skip to question 6.)*

5. During the past seven days, how much did your health problems affect your productivity <u>while you were working</u>?

   Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual. If health problems affected your work only a little, choose a low number. Choose a high number if health problems affected your work a great deal.

Consider only how much <u>health problems</u> affected productivity <u>while you were working</u>.

Health Health problems problems had
______________________________ completely
no effect on my 0 1 2 3 4 5 6 7 8 9 10 prevented me
work from working

CIRCLE A NUMBER

6. During the past seven days, how much did your health problems affect your ability to do your regular daily activities, other than work at a job?

   By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If health problems affected your activities only a little, choose a low number. Choose a high number if health problems affected your activities a great deal.

Consider only how much <u>health problems</u> affected your ability to do your regular daily activities, other than work at a job.

Health problems Health problems
had no effect on ______________________________ completely
my daily 0 1 2 3 4 5 6 7 8 9 10 prevented me activities from doing my
daily activities

CIRCLE A NUMBER

Depression, Anxiety and Stress Scale

(Lovibond & Lovibond, 1995)

DAS S 21

Name:

Date:

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time 3 Applied to me very much, or most of the time

1 I found it hard to wind down 0 1 2 3

2 I was aware of dryness of my mouth 0 1 2 3

3 I couldn't seem to experience any positive feeling at all 0 1 2 3

4 I experienced breathing difficulty (e.g, excessively rapid breathing breathlessness in the absence of physical exertion) 0 1 2 3

5 I found it difficult to work up the initiative to do things 0 1 2 3

6 I tended to over-react to situations 0 1 2 3

7 I experienced trembling (eg, in the hands) 0 1 2 3

8 I felt that I was using a lot of nervous energy 0 1 2 3

9 I was worried about situations in which I might panic and make a fool of myself 0 1 2 3

10 I felt that I had nothing to look forward to 0 1 2 3

11 I found myself getting agitated 0 1 2 3

12 I found it difficult to relax 0 1 2 3

13 I felt down-hearted and blue 0 1 2 3

14 I was intolerant of anything that kept me from getting on with what I was doing 0 1 2 3

15 I felt I was close to panic 0 1 2 3

16 I was unable to become enthusiastic about anything 0 1 2 3

17 I felt I wasn't worth much as a person 0 1 2 3

18 I felt that I was rather touchy 0 1 2 3

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) 0 1 2 3

20 I felt scared without any good reason 0 1 2 3

21 I felt that life was meaningless 0 1 2 3

Perth Alexithymia Questionnaire

(Preece, Becerra, Robinson, Dandy,& Allan, 2018a)

PAQ

Name:

Date:

This questionnaire asks about how you perceive and experience your emotions. Please score the following statements according to **how much you agree or disagree that the statement**

is true of you. Cicle one answer for each statement.

Some questions mention *bad* or *unpleasant* emotions, this means emotions like sadness,

anger, or fear. Some questions mention *good* or *pleasant* emotions, this means emotions like

happiness, amusement, or excitement.

		Strongly disagree	**----**	**----**	**Neither agree nor disagree**	**----**	**----**	**Strongly agree**
1	When I'm feeling *bad* (feeling an unpleasant emotion), I can't find the right words to describe those feelings.	1	2	3	4	5	6	7
2	When I'm feeling *bad*, I can't tell whether I'm sad, angry, or scared.	1	2	3	4	5	6	7
3	I tend to ignore how I feel.	1	2	3	4	5	6	7
4	When I'm feeling *good* (feeling a pleasant emotion), I can't find the right words to describe those feelings.	1	2	3	4	5	6	7

5	When I’m feeling *good*, I can’t tell whether I’m happy, excited, or amused.	1	2	3	4	5	6	7
6	I prefer to just let my feelings happen in the background, rather than focus on them.	1	2	3	4	5	6	7
7	When I’m feeling *bad*, I can’t talk about those feelings in much depth or detail.	1	2	3	4	5	6	7
8	When I’m feeling *bad*, I can’t make sense of those feelings.	1	2	3	4	5	6	7
9	I don’t pay attention to my emotions.	1	2	3	4	5	6	7
10	When I’m feeling *good*, I can’t talk about those feelings in much depth or detail.	1	2	3	4	5	6	7
11	When I’m feeling *good*, I can’t make sense of those feelings.	1	2	3	4	5	6	7
12	Usually, I try to avoid thinking about what I’m feeling.	1	2	3	4	5	6	7

		Strongly disagree	----	----	**Neither agree nor disagree**	----	----	**Strongly agree**
13	When something *bad* happens, it’s hard for me to put into words how I’m feeling.	1	2	3	4	5	6	7
14	When I’m feeling *bad*, I get confused about what emotion it is.	1	2	3	4	5	6	7
15	I prefer to focus on things I can actually see	1	2	3	4	5	6	7

	or touch, rather than my emotions.							
16	When something *good* happens, it’s hard for me to put into words how I’m feeling.	1	2	3	4	5	6	7
17	When I’m feeling *good*, I get confused about what emotion it is.	1	2	3	4	5	6	7
18	I don’t try to be ‘in touch’ with my emotions.	1	2	3	4	5	6	7
19	When I’m feeling *bad*, if I try to describe how I’m feeling I don’t know what to say.	1	2	3	4	5	6	7
20	When I’m feeling *bad*, I’m puzzled by those feelings.	1	2	3	4	5	6	7
21	It’s not important for me to know what I’m feeling.	1	2	3	4	5	6	7
22	When I’m feeling *good*, if I try to describe how I’m feeling I don’t know what to say.	1	2	3	4	5	6	7
23	When I’m feeling *good*, I’m puzzled by those feelings.	1	2	3	4	5	6	7
24	It’s strange for me to think about my emotions.	1	2	3	4	5	6	7

Appendix M

Specifics of search strategy for scoping review

This scoping review sought to explore the breadth of existing literature and knowledge around the influence of GI conditions on psychosocial factors and wellbeing outcomes. The following databases were selected for use in this review: PsycARTICLES, PubMed, Cochrane Library and Web of Science. These databases were selected as they were available to access through the University's library services and have received praise for their scope of coverage and multidisciplinary nature (Burnham, 2006; Charbonneau, 2005; Li et al., 2018; Williamson & Minter, 2019) making them appropriate choices for inclusion in a scoping review. It was felt that this combination of databases would provide a comprehensive overview of the literature, covering biomedical (Falagas et al., 2008) and psychosocial aspects (APA PsycARTICLES, n.d; Birkle et al., 2019). The initial search was concluded in August 2019 but was updated in June 2021 to ensure the review was up to date.

Search Terms

Search terms were identified with reference to Drossman's (2016) model with some additions/modifications. These terms fell under either the categories of "gastrointestinal health" or "biopsychosocial factors" and are included in Table 3 of this thesis which is also included again below for convenience. This table provides information on the source of these terms.

Table 3

Indicative Search Terms

Gastrointestinal health	Biopsychosocial factors	Source
Irritable bowel syndrome	Subjective wellbeing/life satisfaction/positive affect/negative affect	Farhadi et al. (2018)
Inflammatory bowel disease/Crohn's'/Ulcerative colitis	Social support/relationships/support network/isolation/loneliness	Drossman (2016)
Gut microbiota	Wellbeing	WHO (2013)
Gut flora	Coping	Drossman (2016)
Gastrointestinal condition	Quality of life/health-related quality of life	Drossman (2016)
Healthy gut	Work absence	Cosnes et al. (2011)/Kawalec et al. (2017)
	Daily function	Drossman (2016)
	Medical visits/health service use/medications	Adapted from Drossman (2016) terms health care use and health care costs

Note: The gastrointestinal health search terms gut microbiota, gut flora and healthy gut were included to provide a wider overview of gut health in the context of the GI conditions IBS and IBD. The only GI conditions explored in this review were IBS and IBD as per the inclusion/ exclusion criteria.

Search terms were combined using a pre-determined search strategy that saw each GI health term combined with each biopsychosocial factor. For example, one search would be (irritable bowel syndrome) AND (subjective wellbeing). The Boolean operator AND was either typed into the search bar of the database or selected from a drop-down menu to combine search terms.

The following is an overview of this search strategy applied to each database.

(irritable bowel syndrome) AND (subjective wellbeing)

(irritable bowel syndrome) AND (life satisfaction)

(irritable bowel syndrome) AND (positive affect)

(irritable bowel syndrome) AND (negative affect)

(irritable bowel syndrome) AND (social support)

(irritable bowel syndrome) AND (relationships)

(irritable bowel syndrome) AND (support network)

(irritable bowel syndrome) AND (isolation)

(irritable bowel syndrome) AND (loneliness)

(irritable bowel syndrome) AND (wellbeing)

(irritable bowel syndrome) AND (coping)

(irritable bowel syndrome) AND (quality of life)

(irritable bowel syndrome) AND (health-related quality of life)

(irritable bowel syndrome) AND (work absence)

(irritable bowel syndrome) AND (daily function)

(irritable bowel syndrome) AND (medical visits)

(irritable bowel syndrome) AND (health service use)

(irritable bowel syndrome) AND (medications)

(inflammatory bowel disease) AND (subjective wellbeing) (inflammatory bowel disease) AND (life satisfaction)

(inflammatory bowel disease) AND (positive affect)

(inflammatory bowel disease) AND (negative affect)

(inflammatory bowel disease) AND (social support)

(inflammatory bowel disease) AND (relationships)

(inflammatory bowel disease) AND (support network)

(inflammatory bowel disease) AND (isolation)

(inflammatory bowel disease) AND (loneliness)

(inflammatory bowel disease) AND (wellbeing)

(inflammatory bowel disease) AND (coping)

(inflammatory bowel disease) AND (quality of life)

(inflammatory bowel disease) AND (health-related quality of life)

(inflammatory bowel disease) AND (work absence)

(inflammatory bowel disease) AND (daily function)

(inflammatory bowel disease) AND (medical visits)

(inflammatory bowel disease) AND (health service use)

(inflammatory bowel disease) AND (medications)

(Crohn’s) AND (subjective wellbeing)

(Crohn’s) AND (life satisfaction)

(Crohn’s) AND (positive affect)

(Crohn’s) AND (negative affect)

(Crohn’s) AND (social support)

(Crohn’s) AND (relationships)

(Crohn’s) AND (support network)

(Crohn’s) AND (isolation)

(Crohn’s) AND (loneliness)

(Crohn’s) AND (wellbeing)

(Crohn’s) AND (coping)

(Crohn’s) AND (quality of life)

(Crohn’s) AND (health-related quality of life)

(Crohn’s) AND (work absence)

(Crohn’s) AND (daily function)

(Crohn’s) AND (medical visits)

(Crohn’s) AND (health service use)

(Crohn’s) AND (medications)

(Ulcerative colitis) AND (subjective wellbeing)

(Ulcerative colitis) AND (life satisfaction)

(Ulcerative colitis) AND (positive affect)

(Ulcerative colitis) AND (negative affect)

(Ulcerative colitis) AND (social support)

(Ulcerative colitis) AND (relationships)

(Ulcerative colitis) AND (support network)

(Ulcerative colitis) AND (isolation)

(Ulcerative colitis) AND (loneliness)

(Ulcerative colitis) AND (wellbeing)

(Ulcerative colitis) AND (coping)

(Ulcerative colitis) AND (quality of life)

(Ulcerative colitis) AND (health-related quality of life)

(Ulcerative colitis) AND (work absence)

(Ulcerative colitis) AND (daily function)

(Ulcerative colitis) AND (medical visits)

(Ulcerative colitis) AND (health service use)

(Ulcerative colitis) AND (medications)

(gut microbiota) AND (subjective wellbeing)

(gut microbiota) AND (life satisfaction)

(gut microbiota) AND (positive affect)

(gut microbiota) AND (negative affect)

(gut microbiota) AND (social support)

(gut microbiota) AND (relationships)

(gut microbiota) AND (support network)

(gut microbiota) AND (isolation)

(gut microbiota) AND (loneliness)

(gut microbiota) AND (wellbeing)

(gut microbiota) AND (coping)

(gut microbiota) AND (quality of life)

(gut microbiota) AND (health-related quality of life)

(gut microbiota) AND (work absence)

(gut microbiota) AND (daily function)

(gut microbiota) AND (medical visits)

(gut microbiota) AND (health service use)

(gut microbiota) AND (medications)

(gut flora) AND (subjective wellbeing)

(gut flora) AND (life satisfaction)

(gut flora) AND (positive affect)

(gut flora) AND (negative affect)

(gut flora) AND (social support)

(gut flora) AND (relationships)

(gut flora) AND (support network)

(gut flora) AND (isolation)

(gut flora) AND (loneliness)

(gut flora) AND (wellbeing)

(gut flora) AND (coping)

(gut flora) AND (quality of life)

(gut flora) AND (health-related quality of life)

(gut flora) AND (work absence)

(gut flora) AND (daily function)

(gut flora) AND (medical visits)

(gut flora) AND (health service use)

(gut flora) AND (medications)

(gastrointestinal condition) AND (subjective wellbeing)

(gastrointestinal condition) AND (life satisfaction)

(gastrointestinal condition) AND (positive affect)

(gastrointestinal condition) AND (negative affect)

(gastrointestinal condition) AND (social support)

(gastrointestinal condition) AND (relationships)

(gastrointestinal condition) AND (isolation) (gastrointestinal condition) AND (loneliness)

(gastrointestinal condition) AND (wellbeing)

(gastrointestinal condition) AND (coping)

(gastrointestinal condition) AND (quality of life)

(gastrointestinal condition) AND (health-related quality of life)

(gastrointestinal condition) AND (work absence)

(gastrointestinal condition) AND (daily function)

(gastrointestinal condition) AND (medical visits)

(gastrointestinal condition) AND (health service use)

(gastrointestinal condition) AND (medications)

(healthy gut) AND (subjective wellbeing)

(healthy gut) AND (life satisfaction)

(healthy gut) AND (positive affect)

(healthy gut) AND (negative affect)

(healthy gut) AND (social support)

(healthy gut) AND (relationships)

(healthy gut) AND (support network)

(healthy gut) AND (isolation)

(healthy gut) AND (loneliness)

(healthy gut) AND (wellbeing)

(healthy gut) AND (coping)

(healthy gut) AND (quality of life)

(healthy gut) AND (health-related quality of life)

(healthy gut) AND (work absence)

(healthy gut) AND (daily function)

(healthy gut) AND (medical visits)

(healthy gut) AND (health service use)

(healthy gut) AND (medications)

When searching using PsycARTICLES advanced search function, the search field TX All Text was selected for each search term. A limit placed on this search was to only include full text articles. Using PubMed's advanced search builder, all fields were selected as the search field for each term. The search field All Fields was selected for SCOPUS. For Web of Science, the advanced search function was used and the search field All Fields was selected for each search term. When searching using Cochrane Library the search field ALL Text was selected for each search term. Across each database, a custom date rate of 2000-2019 was initially applied to each search, which limited the number of returned results. When the search was updated the date range was entered as 2019-2021.

Inclusion and Exclusion Criteria

To ensure relevance, inclusion and exclusion criteria (listed in Table 2) were adhered to throughout the review process.

Table 2

Inclusion and Exclusion Criteria Applied to Scoping Review

Inclusion criteria	Exclusion criteria
At least one wellbeing outcome consistent with the biopsychosocial model of health	No wellbeing outcomes consistent with the biopsychosocial model of health
Focus on GI conditions including IBD, IBD, CD and UC	Animal/lab studies
Quantitative, qualitative, mixed methods and case-studies	No relevance to GI conditions (e.g. concerned with other health issues)
Completed studies or in development	
Published after 2000	