

**Judging a Book by its Cover: A Mixed-Methods Exploration of Perceptions of
Inflammatory Bowel Disease**

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ABSTRACT

Inflammatory Bowel Diseases (IBD) are chronic gastrointestinal conditions with fluctuating bowel symptoms. Adjustment to IBD can be impacted by unhelpful behavioural and cognitive factors (e.g., negative illness perceptions). Additionally, individuals with IBD anticipate and report negative reactions from the public. Therefore, views of the public can further impact those with IBD. This program of research had three over-arching aims: (1) to examine the anticipated societal perceptions of those with IBD; (2) to investigate whether anticipating negative societal perceptions contributes to poorer psychological and physical health, and overall quality of life; and, (3) to explore public awareness and perceptions of IBD. These aims were met by conducting four studies.

Study 1: A systematic review of the literature investigating illness perceptions, perceived stigmatisation, and negative emotional reactions toward IBD in those with and without the condition, and the impact of these views on participant outcomes (e.g., psychological health and quality of life) was conducted in Study 1. Article titles and abstracts were screened by two reviewers, and one reviewer extracted data from 82 full-text articles. Key findings of the review were: (1) negative illness perceptions are associated with poorer well-being; (2) individuals with IBD frequently anticipate stigma; (3) fear about disease-related flares occurring in public was the most common emotion reported; and (4) the public appear to direct little enacted stigma towards IBD. Clinical implications include targeting unhelpful perceptions and expectations in treatment.

Study 2: Anticipated societal views of IBD (i.e., how those with IBD view public perceptions of the condition) and their impact on participant well-being were qualitatively explored in Study 2. Semi-structured, individual interviews were

completed with twenty individuals with IBD ($Mage = 32.8$, $SD = 10.54$), and thematic analysis was completed to identify common themes. Four overall themes were identified: (1) poor public awareness of the disease; (2) difficulties with disclosure; (3) reactions of others; and, (4) illness-related self-exclusion. Overall, participants perceived that their physical health and quality of life are *not* impacted by their anticipated views of the public. On the other hand, some participants indicated that their psychological health is affected by their anticipated societal views. These findings translate into social and clinical implications, specifically, public awareness can be increased using campaigns, and concerns about public perceptions can be routinely assessed in clinical settings.

Study 3: Study 3 quantitatively investigated the link between individuals' self-perceptions and their anticipated societal views of IBD, in those with the condition. The impacts of anticipated societal views on well-being was also explored. Individuals with IBD completed an online survey ($N = 132$; $Mage = 32.17$, $SD = 10.41$). Key results of this study were: (1) negative self-perceptions significantly predicted views that the public perceives IBD negatively; (2) anticipating negative public perceptions of IBD significantly contributed to poorer psychological and physical health. Findings indicate a possible mechanism for the formation of meta-perceptions of IBD, via that of self-perceptions. Implications for clinical practice include routinely targeting both self-perceptions and expectations about public views of IBD in assessment and treatment.

Study 4: The final study explored perceptions of IBD in an Australian community sample utilising an experimental design. Participants ($N = 468$; $M = 38.42$, $SD = 14.71$) completed a series of vignettes depicting a hypothetical individual with IBD exhibiting symptoms in a workplace (i.e., bathroom use, flatulence, and faecal incontinence). Participants were randomly allocated to either the disclosure (i.e.,

symptoms were attributed to IBD) or non-disclosure condition. Participants completed affective and avoidance ratings of the IBD symptoms, along with measures of disgust sensitivity, knowledge and familiarity with IBD, and stigmatising attitudes towards IBD. Key findings indicated that: (1) there was greater avoidance of IBD in the non-disclosure condition (i.e., disease-label was not provided), than the disclosure condition, and in the faecal incontinence condition; (2) participants were more willing to have ‘brief’ contact with the target with IBD, in the disclosure condition; (3) those unfamiliar with IBD reported higher stigmatising attitudes and greater avoidance of IBD, in the disclosure condition; (4) higher disgust sensitivity was linked with greater avoidance of IBD, when *no* disease-label was provided (i.e., non-disclosure condition). Overall, findings suggest that disclosure and increased familiarity are linked with lower public stigmatisation and avoidance of IBD. This highlights the benefits of utilising campaigns to increase public awareness of IBD and of collaboratively discussing situations for disclosure with individuals with IBD in clinical settings.

STATEMENT OF ORIGINALITY

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Elia-Jade Edwards

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STATEMENT OF ETHICAL PROTOCOL

I confirm that ethical clearance was granted by the Griffith University Human Research Ethics Committee (GU Ref No: 2016/138; GU Ref No: 2019/046). Further, research from this thesis was supported by an Australian Government Research Training Program (RTP) Stipend Scholarship. I confirm that the research was conducted in accordance with the approved protocols.

Elia-Jade Edwards

March 2020

LIST OF OUTPUTS PRODUCED DURING THE PHD CANDIDATURE

Papers Included in this Thesis

Polak*, E.-J., O'Callaghan, F., & Oaten, M. (2020). Perceptions of IBD within patient and community samples: A systematic review. *Psychology & Health*, 35(4), 425-448. doi:10.1080/08870446.2019.1662014

Edwards, E.-J., O'Callaghan, F., & Oaten, M. “Nobody wants to talk about that stuff”: A qualitative investigation of the anticipated societal perceptions of individuals with inflammatory bowel disease. *Submitted for publication.*

Edwards, E.-J., Oaten, M., & O'Callaghan, F. Exploring self and anticipated societal perceptions of inflammatory bowel disease. *Submitted for publication.*

Edwards, E.-J., Oaten, M., & O'Callaghan, F. Investigating public awareness and perceptions of inflammatory bowel disease: An Australian sample. *Submitted for publication.*

Conference Presentation

Polak*, E.-J., O'Callaghan, F., & Oaten, M. (2018, September). *Perceptions of IBD within patient and community samples: A systematic review.* Poster presented at the Australian Psychological Society Congress, Sydney, Australia.

*Paper submitted/presented using maiden name: Polak

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Included in this thesis are papers in *Chapters 2, 3, 4, and 5*, which are co-authored with other researchers. My contribution to each co-authored paper is outlined at the front of the relevant chapter. The bibliographic details/status for these papers including all authors, are:

Chapter 2: Polak, E.-J., O'Callaghan, F., & Oaten, M. (2020). Perceptions of IBD within patient and community samples: A systematic review. Psychology & Health, 35(4), 425-448. doi:10.1080/08870446.2019.1662014*

Chapter 2 contains a post-peer-review, preprint version of the accepted journal article, in accordance with Taylor & Francis copyright guidelines, respectively. Refer to: <https://authorservices.taylorandfrancis.com/sharing-your-work/>

Chapter 3: Edwards, E.-J., O'Callaghan, F., & Oaten, M. "Nobody wants to talk about that stuff": A qualitative investigation of the anticipated societal perceptions of individuals with inflammatory bowel disease. Submitted for publication.

Chapter 4: Edwards, E.-J., Oaten, M., & O'Callaghan, F. Exploring self and anticipated societal perceptions of inflammatory bowel disease. Submitted for publication.

Chapter 5: Edwards, E.-J., Oaten, M., & O'Callaghan, F. Investigating public awareness and perceptions of inflammatory bowel disease: An Australian sample. Submitted for publication.

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CHAPTER 1

INTRODUCTION AND OVERVIEW

Inflammatory Bowel Diseases (IBD) are conditions that cause chronic inflammation of the gastrointestinal tract (Gill & Bryant, 2019). The course of this disease is extremely unpredictable and is characterised by relapses and remission (M'Koma, 2013). The two major types of IBD are Ulcerative Colitis (UC) and Crohn's Disease (CD; Gajendran, Loganathan, Catinella, & Hashash, 2018). The location of inflammation differs according to an individual's diagnosis (i.e., UC/CD). CD is identified by inflammation occurring anywhere along the gastrointestinal tract (i.e., from the mouth to the anus; Ananthakrishnan, Xavier, & Podolsky, 2017; Gajendran et al., 2018). CD most commonly affects the terminal ileum and perianal areas (Ananthakrishnan et al., 2017; Gill & Bryant, 2019). UC, however, is characterised by superficial inflammation extending from the rectum to the colon (Ananthakrishnan et al., 2017; Gajendran et al., 2019).

The onset of IBD symptoms often occurs during young adulthood (Ananthakrishnan et al., 2017). IBD impacts men and women at equal rates, however, research suggests that CD is slightly more common in females, and UC occurs slightly more in males (Ananthakrishnan et al., 2017; Sonnenberg, 2009). Symptoms may range from mild to severe, but tend to include: frequent, urgent and sometimes bloody diarrhoea, abdominal pain/cramping, swelling or weight gain due to side effects of medication, weight loss and fatigue (Rezapour, Avalos, & Damas, 2020), and extraintestinal symptoms (e.g., skin, eye, liver and musculoskeletal conditions; Gill & Bryant, 2019; Levine & Burakoff, 2011; Rayhorn, 2003). Approximately, one-third of those with IBD experience extraintestinal manifestations (EIMs; Ananthakrishnan et al., 2017), with IBD-associated arthropathy as the most common EIM (Ananthakrishnan et

al., 2017; Gill & Bryant, 2019; Rezapour et al., 2020), occurring in 5-20% of individuals with IBD (Ananthakrishnan et al., 2017). Many individuals with IBD may also be required to undertake a colostomy surgery, resulting in bowel movements being passed through the abdomen and into a pouch which then must be emptied by the individual (Smith, Loewenstein, Rozin, Sherriff, & Ubel, 2007). These types of symptoms can attract negative attention and reactions from the general community and topics pertaining to bowel movements are typically regarded as “taboo”, thus discouraging individuals with IBD from openly discussing their disease with others (Chelvanayagam, 2014; Saunders, 2014; Thompson, 2013).

In Australia, the estimated prevalence rate is 315 per 100,000, with a higher prevalence of CD diagnoses than UC (Studd et al., 2016). Similar prevalence rates are reported for UC and CD in Europe (except for Norway, with reported higher prevalence rates than Australia), North America, and Canada (Ng et al., 2017). Locally, the annual incidence rate of IBD in Australia is estimated to be 29.3 per 100,000 (Wilson et al., 2010). Again, similar incidence rates have been reported in regions of other western countries (Ng et al., 2017) such as, USA (e.g., Shapiro, 2016), Canada (e.g., Bernstein, 2006), New Zealand (e.g., Gearry 2006), and UK (e.g., Rubin, Hungin, Kelly, & Ling 2000). IBD impacts not only developed countries, but research reports that the incidence of IBD has been increasing in newly industrialised countries in Asia, Africa, and South America (Ng et al., 2017). Regarding etiology, it is suggested that a combination of genetic, microbiome and environmental factors (e.g., smoking, diet), along with immune dysfunction, all play a role in the onset of the disease (Ananthakrishnan et al., 2017; Andrews, 2015). The diagnosis of IBD usually occurs through invasive methods such as a colonoscopy and most are diagnosed before the age of 40, with 25% of those as children or adolescents (Andrews, 2015; Lippincott &

Wilkins, 2006). IBD management involves ongoing medical care, which is linked to increasing healthcare costs and utilisation (Lichtenstien et al., 2020; Park et al., 2019). Australian national reports indicated the overall financial costs of IBD to be close to \$500 million in 2005 (\$239 million for CD, \$258 million for UC; Deloitte Access Economics, 2007), and estimate hospital costs for IBD as \$100 million per annum (PricewaterhouseCoopers, 2013). In the USA, research suggests that the lifetime total costs for CD and UC, are \$622,056 and \$405,496, respectively (USD; Lichtenstien et al., 2020). The highest health costs occur within the first year of initial diagnosis and the main factors contributing to healthcare costs include: therapeutics and treatments (e.g., biologics, opioids), emergency department utilisation, and engagement with healthcare services for relapsing symptoms and comorbidities (i.e., mental health and anaemia; Park et al., 2020). Australian-specific data indicates that IBD is associated with productivity costs, and out-of-pocket costs for individuals with IBD (Deloitte Access Economics, 2007). IBD significantly impacts employment via employment separation and early retirement, costing approximately \$204.2 million. Absenteeism costs totalled \$52.3 million in 2005, and on average, employed individuals with IBD had 7.2 days off work per annum. Lastly, individuals with CD and UC are estimated to have out-of-pocket expenses (e.g., travel costs, support with household tasks, and dietary supplements) of \$578.30 and \$594.60 per annum, respectively (Deloitte Access Economics, 2007). IBD is associated with complications and physical morbidities including, an increased risk of developing colorectal cancer (CRC; Ananthakrishnan et al., 2017; Gajendran et al., 2019; Rezapour et al., 2020), metabolic bone disease, malnutrition, and approximately 40% experience Irritable Bowel Syndrome (IBS; Gill & Bryant, 2019). For individuals with UC, severe disease activity can be linked to perforation which requires urgent surgical intervention (Ananthakrishnan et al., 2017).

Regarding CD, individuals with this condition are at an increased risk of experiencing gallstones, thromboembolism, and osteoporosis (Mak, Hart, & Ng, 2019). Further, due to the nature of CD-specific inflammation, 18% of individuals develop strictures, while 35% develop fistulas (Ananthakrishnan et al., 2017). Currently, there is no cure for IBD; therefore, medical treatments are used to induce and maintain remission (Gill & Bryant, 2019; Mak et al., 2019). Surgery is considered when symptoms are unresponsive to medical management or when complications are present (Mak et al., 2019). Due to advances in medical management, the rates of surgery for UC have decreased (Gajendran et al., 2019), however, 10% of individuals with UC require surgical intervention within the first year of diagnosis and 30% require surgery over their lifetime (Andersson & Söderholm, 2009). The most common surgical procedure in UC is a restorative proctocolectomy (Andersson & Söderholm, 2009; Gill & Bryant, 2009). Two-thirds of individuals with CD undergo surgical interventions for either a bowel resection, stricturoplasty or drainage of abscess (Gajendran et al., 2018).

Individuals with IBD are required to adjust to this life-long, chronic disease and this is especially challenging to those diagnosed at younger ages (Andrews, 2015). For young people particularly, the symptoms of IBD can contribute to distress, anxiety and depression (Fuller-Thomson, Lateef, & Sulman, 2015). Further, IBD can significantly impact upon quality of life (Hall, Rubin, Dougall, Hungin, & Neely, 2005; see Knowles, Graff, Wilding, Hewitt, Keefer, & Mikocka-Walus, 2018a, & Knowles, Keefer, Wilding, Hewitt, Graff, & Mikocka-Walus, 2018b for recent reviews of quality of life in IBD). Indeed, research documents that individuals with IBD have higher rates of psychological disorders (e.g., depression and anxiety) than the general population (Bernstein et al., 2019). The lifetime prevalence rates of any anxiety or mood disorder for those with IBD are estimated to be 35.8% (Walker et al., 2008) and there is a higher

comorbidity of elevated psychological distress among those with active symptoms (Graff et al., 2006; Mikocka-Walus et al., 2007; Mikocka-Walus, Knowles, Keefer, & Graff, 2016).

It is evident that IBD is marked by great uncertainty and this can lead to significant challenges for those affected (Cooper, Collier, James, & Hawkey, 2010; Hall et al., 2005). The following extract from an interview with a female UC participant gives an indication of what it is like to live with IBD: *“I can’t tell you, talking about it is terrible because when I’m ill I don’t go out, I can’t face it. Whenever you go to use public toilets you’re never in a contained area. I can’t cope because of what everybody will think,”* (Sally, UC; Cooper et al., 2010, p. 1506). The anguish of living with IBD is apparent in the above quote and it is clear that those with IBD not only find it difficult to talk about the condition, but fear that others will view the disease negatively. This is a common theme throughout the IBD literature with many individuals with IBD reporting reluctance to disclose their disease status to others because they fear their reactions (Dibley, Norton, & Whitehead, 2018; Saunders, 2014; Savard & Woodgate, 2009). Indeed, participants with IBD have experienced negative public reactions when utilising disabled toilets, due to *not* appearing physically unwell or impaired (Piper, 2017). Research also reports that individuals with IBD fear disease-related flares occurring in public (Matini & Ogden, 2016). In this regard, little research has investigated how those with IBD view societal perceptions of their condition, despite the likely ramifications for their psychological functioning. More research is needed to specifically explore this issue and address questions such as: Do individuals with IBD perceive society to have negative perceptions of their condition? Do these views impact upon their psychological and physical functioning and quality of life? Are these views consistent with actual societal perceptions of IBD?

It is surprising then that little research has examined this issue and to our knowledge, there has been no research that has specifically examined anticipated societal perceptions of IBD, in those with the condition, as well as in the wider community. Accordingly, the current program of research aimed to bridge this gap in the IBD literature by investigating three general aims: (1) to examine the anticipated societal perceptions of IBD among those with the condition; (2) to explore if anticipated societal views impact upon the well-being of those with IBD; and lastly, (3) to investigate the extent of the community's awareness and perceptions of IBD.

This chapter introduces and outlines the four studies presented within the thesis. Chapter 2 presents a published manuscript (Study 1), while Chapters 3-5 include three unpublished manuscripts submitted for publication (Studies 2-4). Finally, Chapter 6 presents the General Discussion. References are listed after each chapter. A brief outline of each study is presented below.

Study 1

Study 1 provides a published systematic review of perceptions of IBD in both IBD and community samples (Polak, O'Callaghan, & Oaten, 2020). Study 1 presents a detailed literature review and provides theoretical justification for the empirical investigations conducted in subsequent chapters (i.e., Chapters 3-5). The review addressed a gap in the literature by exploring cognitive and behavioural factors that negatively impact upon illness adjustment: (1) illness perceptions; (2) stigmatisation; (3) emotional reactions. A second aim of the review was to explore the impact of these perceptions and reactions on the psychosocial and physical wellbeing of individuals with IBD. The final aim was to synthesise literature investigating perceptions of IBD within the community, and to investigate the impact of these views on the well-being of individuals with IBD. To complete the review, data was extracted from 82 articles that

met inclusion criteria. Following this, a narrative synthesis was conducted. The findings of the manuscript are presented in two main sections, Section 1: *IBD Participants*, and Section 2: *Community*. For *IBD Participants*, literature indicated that: negative illness perceptions and higher perceived stigma are linked with poorer well-being, and fear about experiencing disease-flares in public is a frequent concern. Regarding the *Community*, little research has explored community perceptions of IBD, however, the extant literature suggests there is little societal stigmatisation of IBD.

Study 2

In Study 2, anticipated societal perceptions of IBD were qualitatively explored. An unpublished manuscript (submitted for publication) is presented, with the following aims: (1) to explore how those with IBD view societal perceptions of their condition; and (2) to investigate the impact of these views on participants' psychological and physical functioning. Little research has investigated in-depth qualitative opinions regarding this issue, and we aimed to bridge this gap in the literature. This was accomplished by completing semi-structured interviews with twenty individuals with IBD. Responses were transcribed verbatim and thematic analysis was utilised to analyse the data. The findings are presented according to four main themes: 1) public awareness of IBD, 2) disclosure, 3) reactions of others, and 4) self-exclusion.

Study 3

Unique to Study 3 was the investigation of the link between self-perceptions and anticipated societal perceptions of IBD, among those with the condition. The second aim was to explore if negative anticipated societal perceptions of IBD contribute to poorer psychological and physical health. Given the gender differences reported in prior IBD research, a further aim was to investigate if demographic factors (i.e., age, gender

and illness severity) moderated participants' views of societal perceptions of IBD. These aims have not been explored in prior research. Findings were obtained utilising quantitative data analysis and key findings are presented in accordance with each research question, that is: there are no differences in anticipated societal perceptions of IBD according to gender, age, and illness severity; negative anticipated societal perceptions of IBD are linked with poorer wellbeing; and, internalising stigmatising attributes of one's IBD predict negative anticipated societal perceptions of IBD.

Study 4

Study 4 presents a manuscript (submitted for publication) investigating awareness and perceptions of IBD in an Australian community sample, a topic that has received little empirical attention. In the extant literature, however, mixed findings have been reported. One study concluded that IBD is at a lower risk of stigmatisation than other conditions (i.e., HIV, obesity; Taft, Bedell, Naftaly, & Keefer, 2017), while another study's findings indicated that IBD is stigmatised even more so than HIV/AIDS, diabetes and alcoholism (Groshek et al., 2017). Study 4 expanded upon prior research by: (1) manipulating IBD symptoms, and proximity and duration of the contact; (2) including 'willingness for contact' (avoidance ratings) and emotion ratings towards the target with IBD; and (3) utilising a community sample of varied ages. Study 4 utilised an experimental design with vignettes depicting a hypothetical individual ('Alex') with IBD exhibiting a range of symptoms in a workplace context. Participants were randomly allocated to receive a disease label for the presented symptoms (i.e., disclosure condition) or no disease label (i.e., non-disclosure condition). Quantitative approaches were used to explore the extent of societal stigmatisation towards IBD, and to identify the variables that moderate stigmatisation. Results are reported in relation to: 1) Willingness for Contact, 2) Emotional Reactions, 3) Type of Contact, 4) Disgust

Sensitivity, and 5) Familiarity and Knowledge of IBD. Study 4 showed that the community appear to display less avoidance and stigmatisation towards IBD when disclosed, and when there is greater awareness of the condition.

General Discussion

Chapter 6 presents the General Discussion, which summarises the overall findings and general conclusions of this program of research. The chapter concludes by discussing the implications of the findings and suggestions for future research.

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CHAPTER 2

STUDY 1

PERCEPTIONS OF IBD WITHIN PATIENT AND COMMUNITY SAMPLES: A SYSTEMATIC REVIEW

Chapter 2 contains Study 1, which presents a post-peer-review, pre-copyedited version of the published journal article (Polak et al., 2020). In the published journal article, all tables and figures are presented as Online Supplementary Materials. For this reason, the original formatting required for this publication was retained and all tables and figures are presented after the conclusion of the article and references. However, the list of database search terms is presented in Appendix A.

Statement of Contribution to Co-authored Published Paper

This chapter includes a co-authored published paper. It consists of a post-peer-review, pre-copyedited version of an article published in *Psychology & Health*. The final authenticated version is available online at: <https://doi.org/10.1080/08870446.2019.1662014>

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My contribution to the paper involved:

- Database searches
- Lead in screening of articles
- Completion of data extraction and synthesis of literature
- Lead in drafting and writing of paper
- Lead in journal submission
- Lead in responding to peer review feedback

(Date) 18 March 2020

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(Date) 18 March 2020

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(Date) 19 March 2020

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Perceptions of IBD within Patient and Community Samples: A Systematic Review

Objective: Inflammatory Bowel Disease (IBD) is a chronic, gastrointestinal condition that involves a range of debilitating bowel symptoms. Adjustment to living with IBD can be negatively impacted by maladaptive cognitive and behavioural factors (e.g., negative illness representations and repressing emotions). Patient samples also report negative reactions from the general public and such perceptions can further negatively impact people living with IBD. Therefore, we aimed to systematically review literature investigating the illness perceptions, perceived stigmatisation, and negative emotional reactions toward IBD within patient and community samples. We also aimed to review how these factors impact those living with IBD (i.e., adjustment, psychological health).

Design: A range of databases (e.g., Psych INFO, PubMed) were searched over two years. One reviewer individually screened titles and abstracts using the specified inclusion criteria, and this process was repeated by a second reviewer. Subsequently, the full text articles were screened and data were extracted for the 82 articles that satisfied the inclusion criteria. Following data extraction, a narrative synthesis was conducted.

Results: The review of 82 studies suggested that negative illness perceptions are linked to poorer psychosocial outcomes, that patient samples frequently anticipate stigmatisation, fear relating to bowel accidents was the most common emotion reported, and that the general public direct little enacted stigma towards IBD. **Conclusion:** For people living with IBD: (i) poorer psychological adjustment was reported by those who held more negative perceptions and reactions toward their illness; and (ii) their concerns regarding public perceptions of IBD warrants further empirical attention. Results emphasise the importance of targeting perceptions, and facilitating education and adaptive responding during treatment.

Inflammatory Bowel Diseases (IBD) are a group of chronic gastrointestinal conditions, most commonly comprised of both Ulcerative Colitis (UC) and Crohn's Disease (CD; Sajadinejad, Asgari, Molavi, Kalantari, & Adibi, 2012). The symptoms of IBD can include urgent and frequent diarrhoea and faecal incontinence (Gearry et al., 2006; Rayhorn, 2003). Not only does IBD impact the physical health of sufferers, but it also negatively affects their quality of life (Hall, Rubin, Dougall, Hungin, & Neely, 2005; Lopez-Sanroman et al., 2017). Specifically, individuals with IBD report a range of daily restrictions, limiting their participation in social activities and employment/education opportunities due to the fear of losing control of bowels in a public setting (Cooper, Collier, James, & Hawkey, 2010; Daniel, 2002; Sammut, Scerri, & Xuereb, 2015; Thompson, 2013).

Like other chronic illnesses, IBD is an incurable, long-term condition that commonly involves adaption to treatment regimens and fluctuating symptoms (Miller, 2000; Moss-Morris, 2013). Moss-Morris (2013) proposed a working model that conceptualises the adjustment to chronic illness. This model defines adjustment as returning to a state of equilibrium (psychosocial and physical adjustment) after experiencing acute or ongoing stressors. Reaching or disrupting this state of equilibrium can be influenced by a number of factors (e.g., personality, illness, and cognitive and behavioural factors). Moss-Morris's model highlights the important influence of cognitive and behavioural factors to illness adjustment. Cognitive factors such as accepting and finding positives within the illness experience, and behavioural factors such as problem-focused coping and healthy expression of emotion, can facilitate adjustment. However, unhelpful factors such as negative cognitions/representations and avoiding emotions can lead to adjustment difficulties.

Current Review

Consistent with this multifaceted conception of adjustment, our review focuses on three factors that can significantly impact those with IBD, in terms of their personal, social, and employment outcomes. These are: (1) illness perceptions or cognitive representations of the disease, (2) stigmatisation, and (3) negative emotional reactions to IBD. Our review expands upon previous reviews by not only examining the effects of these three cognitive and behavioural factors on the quality of life of those with IBD, but also how public perceptions of IBD can impact upon individuals with this condition. Public perceptions regarding this disease have received little attention. This is an important contribution to the literature because of its therapeutic and practical implications for individuals with IBD participating, or attempting to, in social, educational and employment settings. That is, a predominance of negative societal perceptions towards those with IBD may lead to individuals with the disease forming negative illness perceptions about themselves and their disease, further inhibiting adjustment.

Illness Perceptions in IBD

Illness perceptions help individuals to make sense of their illness and have been conceptualised into five themes: identity, timeline, causes, cure-control, and consequences (Meyer, Leventhal, & Gutmann, 1985; Weinman, Petrie, Moss-Morris, & Horne, 1996). The role and influence of illness perceptions is depicted in the Common Sense Model of Illness (CSM; Leventhal, Meyer, & Nerenz, 1980) which suggests that a person's psychological and physical health can be affected by their disease activity (severity of symptoms), how they cognitively represent their disease, and the utilisation of particular coping strategies. In a meta-analysis of the CSM, Hagger and Orbell (2003) reported that a strong illness identity (e.g., viewing one's disease as having

severe consequences and as symptomatic) was associated with negative outcomes such as using maladaptive coping strategies and poorer psychosocial wellbeing. In contrast, perceiving the illness as controllable was associated with problem-focused coping and improved psychological wellbeing. These findings demonstrate the significant impact that negative illness perceptions can have upon an individual's coping and psychological health. Indeed, within the IBD literature, severe IBD symptoms are suggested to be indirectly associated with poorer outcomes (e.g., anxiety and depression), via combinations of negative illness perceptions and maladaptive coping styles (Knowles, Cook, & Tribbick, 2013; Rochelle & Fidler, 2013; Van der Have et al., 2013; Zhang et al., 2016). These findings suggest that individuals with the same disease, but also with different illness perceptions, could utilise varying coping strategies and in turn, experience contrasting quality of life. Illness perceptions therefore represent a cognitive factor that can impact upon an individual's adjustment to IBD, as depicted by Moss-Morris' (2013) model of adjustment. A further issue of concern is that holding negative illness perceptions regarding IBD may also be linked to other negative consequences for patients, such as internalising these negative perceptions towards themselves, and in turn leading to expectations of being stigmatised by those without IBD.

Stigmatisation of IBD

Stigmatisation has been described as the experience of being devalued and/or rejected due to the presence of an undesirable attribute (Goffman, 1968; Joachim & Acorn, 2000). It can be argued that those with IBD possess such attributes insofar as they experience symptoms that are commonly viewed as disgusting (e.g., faecal incontinence; Joachim & Acorn, 2000; Woodward et al., 2016). That is, IBD symptoms are bowel related and many people with IBD perceive their condition as 'taboo', and

consequently anticipate negative reactions from others (Hall et al., 2005; McMullan et al., 2017). For instance, those with IBD report feeling they are different to others (i.e., internalised stigma; Daniel, 2002), that others would perceive them negatively (i.e., perceived/anticipated stigma; Dibley & Norton, 2013) and that employers and colleagues treat them differently at their place of employment (i.e., enacted stigma; Frohlich, 2014; Wyke, Edwards, & Allan, 1988). These studies have also highlighted the harmful effects of stigmatisation on quality of life and psychosocial functioning. A recent review of the aforementioned three domains of stigmatisation in IBD was completed (Taft & Keefer, 2016); however, the current review extends that work by including reports of “no stigmatisation/low stigmatisation” by individuals with IBD and any associated factors (e.g., social support), the categories of stigma sources identified by people with IBD (e.g., colleagues, friends), and concern about the perceptions of the wider community and concealing one’s disease. Additionally, our review extends the extant literature by examining whether the general public does in fact engage in avoidance behaviour (e.g., stigmatisation) toward IBD and its symptoms, as well as people with the disease.

Negative Emotional Reactions towards IBD

Negative emotional reactions refer to an individual’s emotional responses to their symptoms and their disease as a whole. IBD can elicit negative emotional reactions, such as the embarrassment of having a bowel accident in public or fearing surgery (Hall et al., 2005; Lynch & Spence, 2008). Other emotions included in the IBD literature and in this review due to their reported associations with the experience of IBD are anger (e.g., Lynch & Spence, 2008), fear (e.g., Lopez-Sanroman et al., 2017), and shame (e.g., Dibley & Norton, 2013). Due to the ‘taboo’ nature of symptoms that are related to bowel movements and excretion, individuals with IBD may also be susceptible to

experiencing disgust. Research suggests that the emotion of disgust motivates humans to avoid potential source of contamination – e.g., bodily products (Reynolds, McCambridge, Bissett, & Consedine, 2014; Rozin, Haidt, & McCauley, 2000). Surprisingly, limited research has examined the role of disgust in IBD. However there is some evidence that disgust is associated with reduced life satisfaction in individuals with faecal incontinence and a colostomy (Reynolds, Bissett, & Consedine, 2015; Smith, Loewenstein, Rozin, Sherriff, & Ubel, 2007). Faecal disgust is also reported to promote the avoidance of colorectal cancer screening decisions and procedures (Davis, Oaten, Occhipinti, Chambers, & Stevenson, 2017; Reynolds, Consedine, Pizarro, & Bissett, 2013; Reynolds et al., 2014). Relatedly, we are unaware of any research investigating if those with IBD anticipate disgust reactions from the general public. This is one of the first studies to explore the role of disgust in the formation of illness perceptions in this disease, and to examine whether it also operates in public perceptions surrounding the disease. Moreover, this review extends prior research by examining if the general public have broader negative perceptions towards those with IBD.

Community Perceptions of IBD

Whilst few studies have examined societal perceptions of IBD, societal perceptions have been the focus of attention for other conditions (Anagnostopoulos & Spanea, 2005; Kouznetsova, Stevenson, Oaten, & Case, 2012; Smith et al., 2007; Taft, Bedell, Naftaly, & Keefer, 2017). For example, literature suggests that the general population demonstrates negative, stigmatising attitudes towards those with infectious conditions such as human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS; Huskin, Reiser-Robbins, & Kwon, 2018; Katz, Hass, Parisi, Astone, & McEvaddy, 1987; Mak et al., 2006), severe acute respiratory syndrome (SARS; Lau, Yang,

Wong, & Tsui, 2006;), and tuberculosis (TB; Baral, Karki, & Newell, 2007). Huskin and colleagues (2018), for example, found that the public indicated a preference for less contact with individuals with HIV/AIDS, compared to other non-contagious conditions and disabilities, such as physical impairments and mental illness. Within this literature, the public's avoidance and stigmatisation of contagious diseases is plausible, as contamination risk underlies their avoidance. On the other hand, research has also indicated that stigma persists even after a previously infected individual has recovered (Lau et al., 2006). Lau and colleagues (2006) reported that the general population viewed recovered SARS patients as contagious and viewed their health as 'damaged' and thus, indicated avoidance and discrimination towards these individuals. Although IBD is non-contagious, community perceptions are relevant to IBD insofar as the common symptoms of IBD involve faecal matter. These symptoms are often associated with contagious diseases (e.g., gastroenteritis) and therefore, will likely be avoided by the general public. Indeed, Smith and colleagues (2007) found that community members with higher disgust sensitivity were more likely to report avoidance of a person with a colostomy (i.e., pouch that allows bodily waste to enter through the abdominal wall), indicating stronger stigmatising attitudes towards those with this condition. Another study (Taft et al., 2017) also found that a community sample indicated the highest level of enacted stigmatisation towards men with Irritable Bowel Syndrome (IBS), compared to other chronic conditions. IBS shares similar symptoms to IBD, (e.g., diarrhoea), indicating the potential likelihood of those with IBD being subject to avoidance and stigmatisation by the general public, which would, in turn, negatively impact the psychosocial wellbeing of those living with IBD. Finally, these studies suggest that conditions involving bodily products, like that of IBD, are associated with avoidance, stigmatisation and likely, disgust reactions from the general public.

Review Questions & Aims

A systematic review of research examining the perceptions and reactions of those with, and without IBD, has not yet been performed. This review is needed in order to examine research investigating the three variables of focus, and to extend prior research by examining whether the perceptions and reactions of those with IBD described in the above sections, are present in the wider community. The review is presented in two main sections (i.e., Section 1: IBD Participants; Section 2: Community) that each focus on the following review questions:

IBD Participants:

RQ1) What are the illness perceptions, and perceptions of stigma and negative emotional reactions of individuals with IBD towards their disease? *RQ2)* What effect do these variables have on the psychosocial and physical wellbeing of individuals with IBD?

Community:

RQ1) What are the illness perceptions, perceptions of stigma and negative emotional reactions that those *without* IBD have towards the disease? *RQ2)* What effect do these variables have on the psychosocial and physical wellbeing of individuals with IBD?

Method

Search Strategy & Terms

Databases were searched over a two-year period from 2015 to 2017 (i.e., PsycINFO, Web of Science, PubMed, Scopus, Informit, CINAHL, ProQuest, and MEDLINE). A final database search was conducted in 2018. Search terms involved utilising a combination of terms for IBD (e.g., Inflammatory Bowel Disease OR IBD OR Ulcerative Colitis OR UC OR Crohn's Disease OR CD), along with alternating terms to

search for the psychological variables of interest (Illness perceptions OR cognitions OR representations; Stigma* OR discrimination* OR stigmatisation* OR excluded* OR ostracised* OR prejudiced* OR avoidance*; Negative Emotions OR Feelings), along with patient outcomes (e.g., Psychosocial health OR psychosocial wellbeing; Quality of life OR Health Related Quality of Life). For a full list of search terms used for both research questions, please refer to Appendix A.

Inclusion & Exclusion Criteria

Studies were included in the current review if they: 1) examined illness perceptions, perceptions and experiences of stigma, and negative emotional reactions and their impact upon patient outcomes, within both patient or community samples; 2) were published in English, from 1950 onwards; 3) were published and peer-reviewed (however, dissertations were included); 4) used intervention, experimental and observational designs (longitudinal or cross-sectional; both quantitative and qualitative designs were included); 5) used reliable and valid scales and methods to measure variables; 6) included participants from 12 years of age with an IBD diagnosis (CD/UC). We excluded paediatric IBD due to complexities and other confounding factors that can arise during childhood development. Studies were also excluded if they were: (1) editorials, news reports or commentaries; (2) pilot studies or case studies; (3) existing meta-analyses or reviews; and (4) conference abstracts.

Data Extraction & Synthesis

One reviewer individually screened titles and abstracts using the specified inclusion criteria and this process was repeated by a second reviewer. If studies met the inclusion criteria, then the full text versions were obtained and again screened. The necessary data were extracted and tabulated (e.g., study sample, design, methods and key results) and following this a narrative synthesis was completed. The Preferred Reporting Items for

Systematic Reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009) flow diagram for the review is presented in Figure 2.1 (some studies reported findings on multiple variables and if so, were only counted once in Figure 2.1).

Quality Assessment

The methodological quality of each included study was assessed by the lead author, along with four independent research assistants/reviewers. The lead author and two research assistants independently evaluated the quality of quantitative studies by using a quality assessment tool used in two published reviews exploring psychological correlates of IBD (Jordan, Sin, Fear, & Chalder, 2016) and rheumatoid arthritis (Matcham, Ali, Hotopf, & Chalder, 2015). Studies were given a quality rating out of seven, using the following criteria, each of which was scored as Yes (Score 1) or No (Score 0): (1) whether the psychological variable was measured using validated/reliable tools; (2) whether the outcome variable(s) (i.e., anxiety and depression, quality of life, physical health, treatment adherence, healthcare engagement, quality of social relationships and family and sexual functioning) were measured using validated/reliable tools; (3) whether a random or consecutive recruitment strategy was used; (4) whether participants were recruited from multiple locations (e.g., recruited from clinics/centres in multiple locations, or research was advertised to multiple locations); (5) whether eligibility criteria were specified; (6) whether the participation rate was $N > 75\%$; (7) whether the study indicated it had adequate power. If studies did not report anything for a particular criterion, they were scored as “No”.

Each qualitative study was assessed by the lead author and two research assistants using the Critical Appraisal Skills Programme (CASP) Checklist for qualitative research (2018; refer to <https://casp-uk.net/casp-tools-checklists/>). Studies were given a quality score out of nine that was calculated using nine questions from the

CASP checklist. Each question was scored using the following: ‘Yes’ (Score 1), ‘Can’t tell’ (Score 0), ‘No’ (Score 0). The final question (i.e., ‘How valuable was the research?’) was excluded from quality assessment due to its subjectivity and inability to be scored using the method above. At the completion of quality assessment, the authors and research assistants reached an agreement for studies with discrepant quality ratings. The results of this quality assessment are summarised in Tables 2.1a and 2.1b.

Results

The results are divided into two sections, 1) IBD Participants, and 2) Community. A total of 82 studies were included in the review, with 73 studies in the IBD Participants section, and nine studies in the Community section. More studies used quantitative designs (48 studies; primarily cross-sectional designs used) than qualitative designs (34 studies).

IBD Participants

Illness Perceptions

The illness perceptions of adults with IBD were examined in 21 studies (see Table 2.2). The majority of studies included both IBD types, while four studies included those with CD and two studies focused on ulcerative colitis exclusively (refer to Table 2.2). Across all studies, the outcomes examined were: psychological health, quality of life, physical health, non-adherence to treatments, and family and sexual functioning. Assessment of study quality, in Table 2.1a, indicates that quantitative studies examining illness perceptions are of mixed quality. Overall, the majority of studies used validated measures and stated eligibility criteria. However, less than half of studies used a random/consecutive recruitment strategy and multi-centre recruitment. Only a small number of studies specifically reported adequate power or had a participation rate of

>75%. Refer to Table 2.1b for the quality summary of the two qualitative studies in this category.

Illness Perceptions and Outcomes. Fifteen studies investigated the relationship between illness perceptions and outcome variables (see Table 2.2; e.g., Tribbick et al., 2017). At a bivariable level, 14 of the 15 studies consistently suggested that negative illness perceptions are associated with poorer outcomes (refer to Table 2.3). The most common outcomes influenced by illness perceptions were increased psychological distress (i.e., anxiety and depression), and reduced quality of life. Specifically, a stronger illness identity, viewing one's disease as having severe consequences, and feeling emotionally affected by IBD, were frequently reported to be associated with poorer outcomes.

At a multivariable level, 11 studies used more sophisticated statistical techniques such as regression and structural equation modelling to determine if negative illness perceptions significantly predicted poorer outcomes (Dorrian, Dempster, & Adair, 2009; Han et al., 2005; Knowles, Cook, & Tribbick, 2013; Knowles, Gass, & Macrae, 2013; Knowles, Wilson, Connell, & Kamm, 2011; Rochelle & Fidler, 2013; Tribbick et al., 2017; van der Have, Brakenhoff, et al., 2015; van der Have, Fidler, et al., 2015; van der Have et al., 2013; Zhang et al., 2016). In the seven studies using regression analyses, the most common outcome measured was quality of life (refer to Table 2.2). Across these studies, there was variability in the unique contribution that illness perceptions accounted for in outcomes, with percentages ranging from 4% to 32%. The most frequent unique predictors of outcomes were illness identity and consequences. Specifically, a stronger illness identity (attributing all symptoms to IBD) and perceiving that IBD has serious consequences for one's daily life, predicted poorer quality of life and psychological wellbeing. Across studies using structural equation modelling

(Knowles, Cook, et al., 2013; Knowles, Gass, et al., 2013; Knowles et al., 2011; Zhang et al., 2016), illness perceptions accounted for 7% to 52% of the percentage of variance in outcomes. Depression and anxiety were the most common outcomes explored. When examining outcomes separately, illness perceptions uniquely accounted for 9% to 30% in the explanation of anxiety, 10% to 52% in the explanation of depression, and 7% of the variance in QOL.

Common Sense Model of Illness. Conflicting evidence exists within the IBD literature regarding the CSM (refer to Table 2.2). Overall, three studies found support for this model (Knowles et al., 2011; van der Have, Brakenhoff, et al., 2015; van Erp et al., 2016), three studies found disconfirming evidence (Dorrian et al., 2009; van der Have et al., 2013; Zhang et al., 2016), and one study reported mixed findings (Knowles, Cook, et al., 2013). Studies that corroborated the CSM reported that participant outcomes were influenced by disease status/activity via illness perceptions and coping strategies. The majority of results found that that illness perceptions had a significant, direct influence on participant outcomes (Knowles, Cook, et al., 2013; Knowles, Gass, et al., 2013; Knowles et al., 2011; van Erp et al., 2017; Zhang et al., 2016) and indirectly mediated the relationship between disease activity and coping (Knowles, Cook, et al., 2013; Knowles et al., 2011; van Erp et al., 2017). However, an inconsistent finding was reported by one study in which the relationship between months since surgery and emotion-focussed coping, was not mediated by illness perceptions (Knowles, Cook, et al., 2013).

Disease Activity. The influence of disease activity (the extent of the severity of one's disease) on illness perceptions and participant outcomes was also investigated. Consistently, results indicated that those with increased disease activity held more negative illness perceptions (Knowles, Wilson, et al., 2013; Knowles et al., 2011;

Tribbick et al., 2017; van Erp et al., 2018; Zhang et al., 2016) and experienced poorer outcomes (Han et al., 2005; Knowles, Cook, et al., 2013; Knowles et al., 2011; Levy et al., 2014; Tribbick et al., 2017; van der Have, Brakenhoff, et al., 2015; van der Have, Fidder, et al., 2015; van der Have et al., 2013; van Erp et al., 2018; Zhang et al., 2016). Additionally, those who have had IBD for a longer time reported having a poorer quality of life (van der Have et al., 2013).

Gender & Age Differences. Mixed evidence was reported for the impact of gender differences on illness perceptions and participant outcomes in IBD. Females reported significantly lower quality of life, and increased anxiety and depression, compared to males in four studies (Knowles, Gass, et al., 2013; Tribbick et al., 2017; van der Have, Fidder, et al., 2015; van der Have et al., 2013). In addition, females with active symptoms significantly reported more negative illness perceptions, in relation to themes of illness identity, chronicity and emotional response, than male participants (Tribbick et al., 2017). However, two studies (Han et al., 2005; Knowles, Wilson, et al., 2013) found no significant gender differences on participant outcomes, despite the fact that all of these studies used similar measures, sample sizes, and analyses. Further to this, disease types (e.g., CD and UC only groups) also varied across both groups. Age differences were investigated, in which older participants were more likely to view their disease as chronic and as having serious consequences (Rochelle & Fidler, 2013), and that older age was associated with increased emotional concerns, however, this association was weak (Han et al., 2005).

Qualitative Studies. Only two studies have examined illness perceptions qualitatively (Dibley, Norton, & Whitehead, 2018; Matini & Ogden, 2016). Common themes presented were concerns about being at fault for causing the condition and perceiving IBD as uncontrollable. Many participants also stated their subjective reasons

for the onset of their disease, which were generally psychological in nature. Other hypothesised causes for the onset of IBD were: infections, the use of the contraceptive pill, issues with one's immune system, and genetic factors (Dibley et al., 2018).

Stigma

Thirty-eight studies investigating stigma in IBD were included in this review (refer to Table 2.4). Qualitative designs (N=23) were utilised more than quantitative designs (N=15). All but five studies used participants with both IBD types (CD only samples: Mayberry, Probert, Srivastava, Rhodes, & Mayberry, 1992; Norton, Thomas, Lomax, & Dudley-Brown, 2012; UC only samples: McMullan et al., 2017; Sammut et al., 2015; Savard & Woodgate, 2009). Most studies utilised an adult sample, while one study utilised a sample of both adults and adolescents (Moser et al., 1995), and another study that investigated participants' activity on an online social media platform was unable to specify the exact age of their sample (Frohlich, 2016). Gamwell and colleagues (2018) used a sample of primarily adolescents (Mean age: 14.96, age range: 10 to 18), however they also included some 10- to 11-year-old children. Given the study's recency and relevance, it was included in the current review. The outcomes investigated across these studies were: psychological health, quality of life, treatment adherence, and physical health. Examination of study quality in Table 2.1a shows that quantitative studies exploring stigma in IBD are of mixed quality. Most studies used validated measures and half of the included studies recruited participants from multiple centres. Few studies satisfied the criterion of being adequately powered. Comparatively, qualitative studies in this category are of a relatively high quality, with the majority satisfying the quality assessment criteria. However, only 35% of studies adequately considered the relationship between the researcher and the participants (refer to Table 2.1b).

Stigma Domains & Outcomes. A common theme across these studies was that perceptions of stigma did not match the actual experiences of those with IBD. Participants were more likely to anticipate stigma, than to experience stigmatisation by others. Overall, participants reported that they felt supported by the people around them. The most studied stigma domain was perceived or anticipated stigma (investigated in 34 studies; displayed in Table 2.4), finding that individuals with IBD perceive that others (i.e., family, friends, healthcare professionals, and the community) do not understand their illness (Dibley & Norton, 2013; Jordan, Ohlsen, Hayee, & Chalder, 2018; Lesage, Hagege, Tucut, & Gendre, 2011; Matini & Ogden, 2016; Piper, 2017), or take their complaints seriously (Frohlich, 2016; Sammut et al., 2015). Internalised stigma was explored in 16 studies (refer to Table 2.4) finding that participants had internalised a sense of ‘uncleanliness’ towards themselves. This led many to feel alienated and withdraw themselves in social situations (Daniel, 2002; Hall et al., 2005; McMullan et al., 2017; Norton et al., 2012; Sammut et al., 2015; Taft, Ballou, & Keefer, 2013; Woodward et al., 2016) and participants would avoid talking about their symptoms to others (Daniel, 2002; Frohlich, 2016; Saunders, 2014).

Sixteen studies considered enacted stigma, where those with IBD were treated differently by others (shown in Table 2.4). Enacted stigma was most commonly experienced in employment. However, three studies found that ‘being treated differently’ was ranked as least important out of a list of IBD-related concerns, by both newly and established diagnosed groups (Canavan, Abrams, Hawthorne, Drossman, & Mayberry, 2006), and by those with both CD and UC (Jelsness-Jørgensen, Moum, & Bernklev, 2011; Levenstein et al., 2001). Eleven studies in Table 2.4 found low stigma or stigma resistance behaviours (i.e., resisting internalised stigma; refer to Ritsher, Otilingam, & Grajales, 2003). Preliminary evidence suggests that social support,

disclosure of IBD, positive cognitive appraisal and having IBD for a longer time, as well as awareness of IBD in the general public, are all factors that contribute to stigma resilience (Cooper et al., 2010; Dibley et al., 2018; Frohlich, 2014; Krause, 2003; Larsson, Loof, & Nordin, 2017; Norton et al., 2012).

At both bivariable and multivariable levels, evidence suggests that increased stigma is associated with, and predictive of, negative outcomes (e.g., higher depression; de Rooy et al., 2001; Gamwell et al., 2018; Taft et al., 2013; Taft, Keefer, Artz, Bratten, & Jones, 2011; Taft, Keefer, Leonhard, & Nealon-Woods, 2009). There is substantial variability across studies in the amount of variance accounted for in outcomes (ranging from 2% to 52%). Qualitatively, four studies found that perceptions and experiences of stigma resulted in poorer psychosocial health and other adverse outcomes (Jordan et al., 2018; Norton et al., 2012; Piper, 2017; Purc-stephenson, Bowlby, & Qaqish, 2015).

Categories of People. Little research has examined the specific groups of people by whom those with IBD feel stigmatised. Within the research that has investigated this, individuals with IBD felt most stigmatised by employers (see Table 2.4; e.g., Wyke et al., 1988). All but two studies reported that family members directed stigma towards participants (e.g., Woodward et al., 2016), with many reporting their family had little understanding of their disease. This was followed by healthcare professionals (9 studies; e.g., Chiapponi, Witt, Dlugosch, Gülberg, & Siebeck, 2016) finding that individuals with IBD felt that healthcare professionals have a poor understanding of the impact of IBD and that they are not always treated with empathy. A small number of studies reported stigmatisation by colleagues (Czuber-Dochan, Dibley, Terry, Ream, & Norton, 2013; Frohlich, 2014; Lesage et al., 2011; Piper, 2017; Taft et al., 2009) and only one study reported stigmatisation from a partner (Taft et al., 2009).

Concealing IBD. A common theme in the literature is that many participants report a desire to, or instances of, concealing their disease, so that their IBD would not be revealed to others and they would not be judged negatively (e.g., Hall et al., 2005; refer to Table 2.4). Concealing IBD from colleagues and employers was frequently reported, with Dibley and colleagues (2018) noting that participants preferred to not inform colleagues of their disease, as this would affect how their colleagues perceived their abilities. Additionally, participants also utilised many strategies to conceal their disease such as, avoiding public bathrooms (Norton et al., 2012), packing spare rolls of toilet paper and a change of clothes when in public (Hall et al., 2005; Thompson, 2013).

Stigmatisation by the General Public. Many studies reported concerns about public perceptions of IBD (see Table 2.4; e.g., Dibley et al., 2018). Those with IBD were most concerned with the social unacceptability or ‘taboo’ of IBD reporting that poor bowel control does not adhere to societal norms of public hygiene (e.g., Dibley et al., 2018; Woodward et al., 2016). Individuals with IBD also perceived that the general public has little awareness or understanding of their disease compared to other well-known conditions (Dibley et al., 2018; Frohlich, 2016; Matini & Ogden, 2016; Purcstephenson et al., 2015). Five studies indicated concern about the reactions of the general public while in public bathrooms due to the smells and sounds that can occur, along with their frequent visits to bathrooms (Cooper et al., 2010; Daniel, 2002; Larsson et al., 2017; Norton et al., 2012; Piper, 2017).

Demographic & Disease Differences. A small number of studies have investigated age, gender and disease differences in stigma. Some evidence highlighted that women are more likely to be affected by stigma, compared to men. For example, women reported more concerns about stigmatisation than men (Moser et al., 1995). In the only study that examined both age and gender differences, de Rooy and colleagues

(2001) found that in females, older age was associated with more concern about disease stigma. Mixed findings were reported regarding the length of disease duration and stigma, with one study finding that those who have had the disease for a longer time reported higher perceived stigma (Taft et al., 2011). In contrast, two studies reported that those who have had IBD for a longer time report lower stigma (Dibley et al., 2018; Frohlich, 2014). However, two studies found that the length of disease duration has no impact upon stigma concerns (Canavan et al., 2006; Gamwell et al., 2018).

Negative Emotional Reactions

Negative emotional reactions were explored in 34 studies (presented in Table 2.5) in those with IBD. The most common emotion reported was fear, followed by embarrassment, shame, anger and lastly, disgust. A large majority of studies involved samples with both IBD types (CD samples: Lynch & Spence, 2008; Norton et al., 2012; UC samples: Lopez-Sanroman et al., 2017; McMullan et al., 2017; Rubin et al., 2009; Sammut et al., 2015; Savard & Woodgate, 2009). Most of the studies used adult samples (31 studies), one study utilised an adolescent sample (Cervesi, Battistutta, Martelossi, Ronfani, & Ventura, 2013), and two studies used combined adolescent and adult samples (Lynch & Spence, 2008; Wolfe & Sirois, 2008). Further, the majority of studies used qualitative research designs. Only a small number of studies have investigated the effect of these emotions on participant outcomes (see Table 2.5).

Overall, quality assessment indicated that quantitative studies examining emotional reactions were of poor quality (refer to Table 2.1a). Only half of studies used validated measures, and 60% of studies used multi-centre recruitment. A small number of studies had a participation rate of >75% and none of the studies reported sufficient power (refer to Table 2.1a for other quality criteria). On the other hand, the majority of qualitative studies satisfied assessment criteria (refer to Table 2.1b). However, only 63% used

rigorous data analysis methods and few studies considered the relationship between the researcher and the participants.

Fear. Fear was the most frequently reported emotion across all studies. Overall, participants indicated multiple fears about IBD in 29 studies (refer to Table 2.5). The most common fears described by those with IBD were in relation to losing control of their bowels in social situations, in addition to experiencing ostomy/colostomy leakages, and fears about bathroom availability (e.g., Larsson et al., 2017). These fears affected participants' quality of life, psychological wellbeing, as well as their social and healthcare engagement (see Table 2.5).

Embarrassment. Embarrassment was explored in 23 studies (displayed in Table 2.5). Overall, participants were embarrassed most by the likelihood of experiencing bowel symptoms in public, such as not being able to gain access to a toilet when symptoms are urgent and when experiencing bowel incontinence (e.g., Dibley & Norton, 2013). Seven qualitative studies reported on the effects of embarrassment on participant outcomes (Daniel, 2002; Dibley et al., 2018; Hall et al., 2005; McMullan et al., 2017; Purc-stephenon et al., 2015; Sephton, Kemp, & Ridgway, 2016; Thompson, 2013). The most common outcome affected was avoiding potential embarrassment by not attending social situations or discussing one's disease.

Shame, Anger and Disgust. Ten studies indicated that participants experienced shame in relation to IBD (see Table 2.5). Few studies specified reasons underlying this, and these studies reported that those with IBD felt ashamed of their symptoms (Krause, 2003; Larsson et al., 2017; Thompson, 2013). Qualitatively, shame has been reported to lead to lower health care engagement (Dibley & Norton, 2013) and quantitative studies suggested that shame is predictive of poorer psychological wellbeing (Trindade,

Ferreira, & Pinto-Gouveia, 2017a; Trindade, Ferreira, & Pinto-Gouveia, 2017b; refer to Table 2.5).

The emotion of anger was reported in nine studies (presented in Table 2.5). Similarly to shame, few studies provided a context for the participants' anger. However, studies reported that those with IBD feel angry about other people attributing their physical pain to psychological causes (Sammur et al., 2015) and not understanding their condition (Daniel, 2002). Factors that elicited anger in participants are presented in Table 2.5. There has been limited research on the role of disgust in IBD, with only seven studies reporting on this emotion, as shown in Table 2.5 (Dibley & Norton, 2013; Dibley et al., 2018; Jordan et al., 2018; Norton & Dibley, 2013; Piper, 2017; Purcstephenson et al., 2015; Woodward et al., 2016). Preliminary evidence highlighted that participants regard their symptoms as disgusting, as these symptoms encompass body excretion (Dibley et al., 2018; Woodward et al., 2016) and typically smell unpleasant (Dibley & Norton, 2013; Dibley et al., 2018). The influence of disgust on participant outcomes is displayed in Table 2.5.

Demographic and Disease Differences. A small number of studies reported on demographic and disease activity differences in relation to negative emotional reactions towards IBD. In regards to age differences, two studies (Scholmerich, Sedlak, Hoppe-Seyler, & Gerok, 1987; Trindade et al., 2017a) suggested that older participants are more likely to fear the side effects of medications, whereas younger participants are more afraid of surgical operations, and more likely to experience increased feelings of shame. Five studies explored disease severity/activity differences in emotional reactions (Dibley et al., 2018; Farrell, McCarthy, & Savage, 2016; Jelsness-Jørgensen et al., 2011; Trindade et al., 2017a; Trindade et al., 2017b). Experiencing a higher frequency of IBD symptoms was related to feelings of inferiority and inadequacy (i.e., shame;

Trindade et al., 2017a; Trindade et al., 2017b) and more fears in relation to IBD (Jelsness-Jørgensen et al., 2011). Farrell and colleagues (2016) found that those with active IBD symptoms were significantly more likely to feel embarrassed, fearful and angry than those in remission.

Community

Overall, few studies have investigated the perceptions and reactions of those without IBD (refer to Table 2.6). While some studies included IBD samples, along with non-IBD participants, *none of these studies reported on how the views and reactions of the community impact upon those with IBD*. Based on this, the second review question (i.e., what effect do these variables have on the psychosocial and physical wellbeing of individuals with IBD?) is not explored in the following sections, as no findings have been reported in the literature. Assessment of study quality indicates that most quantitative studies exploring illness perceptions of IBD within the community, satisfied the assessment criteria (refer to Table 2.1a), and notably, all studies used multi-centre recruitment. However, only 25% of studies both had a participation rate of >75% and reported adequate power. In regards to stigma, over half of studies reported an adequate participation rate and recruited participants from multiple centres, although analyses revealed lower percentage rates for the remaining quality assessment criteria for studies exploring stigma (refer to Table 2.1a). Finally, Tables 2.1a and 2.1b present the quality assessment of the remaining two studies that have explored community perceptions of stigma (qualitative study, Table 2.1b) and emotional reactions (quantitative study, Table 2.1a) in IBD.

Illness Perceptions, Stigma and Negative Emotional Reactions

Four studies have investigated the illness perceptions of IBD in persons who do not have the disease (see Table 2.6; Dickman et al., 2011; Levy et al., 2014; Rubin et al., 2009; Sevcik, 2005). All studies utilised adult samples and quantitative designs. Overall, two studies reported that health care professionals (i.e., nurses and gastroenterologists) viewed IBD as a chronic disease (Dickman et al., 2011; Levy et al., 2014). One study investigated perceptions of curability of IBD (Sevcik, 2005). Perceptions of personal control were examined in two studies, suggesting that gastroenterologists view the personal control of patients to impact the course of IBD (Levy et al., 2014; Rubin et al., 2009).

Regarding stigma, one study found results regarding both internalised stigma, and perceived/anticipated stigma in IBD (Czuber-Dochan et al., 2014). Four studies reported on enacted stigma (Czuber-Dochan et al., 2014; Moody, Probert, Jayanthi, & Mayberry, 1992; Rohde et al., 2018; Taft et al., 2017) and preliminary findings suggested that the general population directs little enacted stigma towards IBD. Research evidence suggested factors that contribute to higher levels of enacted stigma towards IBD, these were: lower familiarity and knowledge of IBD, being male, possessing low levels of empathy, and the condition resulting in lower work performance (Moody et al., 1992; Rohde et al., 2018; Taft et al., 2017). Lastly, only one study investigated societal emotional reactions towards IBD (refer to Table 2.6; Magro et al., 2009).

Discussion

IBD Participants

Overall, we conclude that those who perceive their disease negatively are more likely to experience a poorer quality of life and psychological/physical health. Illness perceptions were consistently suggested to be directly and indirectly associated with participant outcomes in studies investigating the CSM of illness. However, firm conclusions could not be reached about the unique contribution of illness perceptions to the explanation of outcomes. Relationships between illness perceptions and participant outcomes were variable. Variabilities in research designs, measures, and recruitment methods and overall, mixed study quality, are all factors that contributed to these inconsistent findings. Despite this, it appeared that specific facets of illness perceptions, specifically that of strong illness identity and perceiving IBD to have serious consequences, were consistently reported to be linked with poorer participant outcomes. This has been corroborated by previous reviews (Hagger & Orbell, 2003; Jordan et al., 2016), with Jordan and colleagues (2016) reporting that beliefs about the seriousness of consequences of IBD were associated with poorer adjustment, even when demographic and illness factors were taken into consideration. Hagger and Orbell's review highlighted that having a strong illness identity, and perceptions of IBD as having severe consequences, were associated with the use of maladaptive coping strategies, as well as poor psychosocial functioning. Lastly, findings also indicated that those living with IBD for a longer time and experiencing a higher number of symptoms, are more likely to have more negative illness perceptions towards their condition, resulting in a lower quality of life and higher psychological distress.

Those with IBD reported experiencing anticipated/perceived, internalised, and enacted stigma. Stigma impacted upon participants' psychological and physical

functioning, and their overall quality of life. It can be inferred from this review that those with IBD seem to overestimate the likelihood of being stigmatised, in that participants anticipated stigmatisation more than it was actually experienced. This is consistent with Taft and Keefer's review (2016), as instances of being directly stigmatised were less common than reports of anticipated or perceived stigma. This pattern evidenced in the IBD literature, indicates the possibility that anticipating or perceiving stigmatisation from others may contribute to individuals internalising stigmatising attributes to themselves and thus, engaging in self-stigmatising behaviours as a result (e.g., socially withdrawing from others, avoiding public places). Relatedly, many participants with IBD reported a desire to conceal their disease from others, and many anticipated that the general public would stigmatise them due to the taboo surrounding the discussion or public display of bowel functions. Concerns about the social taboo of faeces are also present in those considering colorectal cancer screening procedures (Palmer, Thomas, Von Wagner, & Raine, 2014), in that participants indicated that the taboo surrounding the collection and posting of one's own faeces does not conform to social norms. Societal concerns have also been explored in conditions not involving bowel symptoms, like that of TB. A qualitative review of stigma in TB found that patients perceived society to consider TB as a 'dirty disease' and expressed concerns about how the general public view them (Juniarti & Evans, 2011). Therefore, those with TB reported that they actively conceal their condition from their community and wider society. These findings indicate the impact that societal views and norms can have on those with a condition that patients regard as 'taboo', like that of IBD. Along with concerns about the general public, those with IBD also reported concerns about stigmatisation within the employment context, such that those with IBD felt most

stigmatised by their employers and reported more instances of enacted stigma occurring in their place of employment than other settings.

Overall, psychological wellbeing, quality of life, social relationships, and healthcare and engagement were impacted by the emotions experienced by those with IBD. Fear was the most commonly reported emotion, followed by feelings of embarrassment. Both fear and embarrassment related to bowel accidents occurring in public and the subsequent reactions of the general public, if and when bowel symptoms are exposed. These findings again relate to the violation of social norms of appropriate adult defecation that were outlined earlier in this review. In conditions that involve faecal incontinence (such as IBD), the bodily function of excretion is shifted from a private to a public matter due to the uncontrollable nature of symptoms (Chelvanayagam, 2014; Timmermans, 2016; Williams, 2008) and highlights the context for fear and embarrassment for those with IBD. Along with those with IBD, patients with a stoma also face this same issue, and a review of stressors following stoma surgery reported that patients feared their stoma leaking while in public, along with the smells and noises accompanied with a stoma (Ang, Chen, Siah, He, & Klainin-Yobas, 2013). These fears resulted in the avoidance of social outings, again emphasising the impact that the fear of public body excretion can have on those with conditions involving bowel symptoms. Furthermore, shame and anger were less commonly reported in the IBD literature, compared to fear and embarrassment. Few studies have explored the role of disgust in IBD, however, it seems that those with IBD inherently view their symptoms as disgusting and internalise this by labelling themselves as disgusting. Lastly, those experiencing a higher number of IBD symptoms were more likely to report increased feelings of shame, fear, and embarrassment.

Community

Research most commonly explored healthcare professionals' illness perceptions of IBD. All healthcare professionals perceived IBD as a disease that is chronic. However, contrasting illness perceptions of IBD were found between patients and healthcare professionals. This disparity may be due to poor communication between the patient and the healthcare professional and is suggested to lead to poor patient outcomes, such as impacting the patient-healthcare professional relationship (Levy et al., 2014; Rubin et al., 2009). Generally, little enacted stigma towards those with IBD was reported by the general population. Taft and colleagues' (2017) findings indicated that the public direct more enacted stigma towards those with IBS than those with IBD. Additionally, the level of familiarity of IBD was found to be an important contributor to enacted stigma, as community members who were more familiar with IBD, displayed lower enacted stigma (Rohde et al., 2018; Taft et al., 2017). However, it should be noted that Taft and colleagues' study design used vignettes that described the symptoms of IBD to their participants (2017). Therefore, participants attributed the symptoms described to that of IBD. However, Rohde and colleagues (2018) used scenarios which included disclosure and non-disclosure conditions and found that college students attributed more enacted stigma in scenarios whereby IBD was not disclosed. Therefore, this finding suggests that higher levels of stigma are present when a disease-label is not provided. Overall, only a few studies have explored community perceptions of stigma towards IBD, however, it seems that for those with IBD, there is a lower risk of being stigmatised by the public than anticipated. Lastly, only one study investigated the emotional reactions of carers towards IBD, concluding that carers fear consequences that can occur with IBD (i.e., IBD affecting employment opportunities; Magro et al., 2009). No other research has examined the community's emotional response to IBD.

Gender

A pattern emerged in which females had poorer quality of life and mental health outcomes, more negative illness perceptions towards their condition and appeared to be more concerned about being stigmatised, than males. However, it should be noted that only a small number of studies investigated gender differences, and more research is needed to reach firm conclusions about these findings.

Limitations & Future Directions

A major limitation across the literature reviewed was that most studies utilised cross-sectional designs, impacting the ability to infer causal relationships between variables. More longitudinal research is needed within the IBD literature, and this is especially warranted to confirm if the hypothesised causal relationships in the CSM of illness exist for those with IBD. Overall, limited research has investigated the community's perceptions of IBD, and research that has explored this has primarily focused on the perceptions of healthcare professionals. While this is important, there is a need for further research to address the gap in this field relating to the wider community's perceptions and awareness of IBD. Further to this, our review found that prior research has failed to investigate how the community's perceptions of IBD impact those with the condition, and thus, we were unable to answer the second review question for this topic. This presents an important challenge for future research. The role of disgust in IBD has not been sufficiently explored in the IBD literature reviewed, despite the disgust-eliciting symptoms that can occur in IBD. It would be helpful for future research to investigate the extent to which an individual's disgust sensitivity impacts upon how one perceives or responds to their IBD, and in turn, how this influences their quality of life and psychosocial wellbeing. Research could further explore whether the community displays disgust towards the symptoms of IBD and ultimately, those with IBD. Lastly,

research could explore demographic, disease activity and gender differences across all variables.

Implications

The findings of our review have clinical implications for those with IBD. Education could be provided to healthcare professionals regarding the impact that negative illness perceptions, stigma and negative emotional responses towards IBD have on patients' wellbeing and overall health. Healthcare professionals could integrate an assessment of these factors into routine care of the patient to target negative illness perceptions and facilitate adaptive responses to emotions during treatment. It is also important for those with IBD to be informed about the tendency to over-anticipate stigmatisation, to reduce or minimise withdrawing from and avoiding social situations due to the expectation of being treated differently by others.

Conclusions

Importantly, the results of our review suggest that unhelpful cognitive and behavioural factors can impact upon adjustment to IBD. Within patient samples, those who viewed their disease negatively, anticipated negative reactions from the public, and those who feared bowel accidents occurring in public, reported poorer mental health and quality of life. Patients frequently reported concerns related to public perceptions of IBD, however little research has investigated the perceptions of IBD within the community. Future research should focus on investigating other people's views of IBD and determining how this impacts upon those with the condition.

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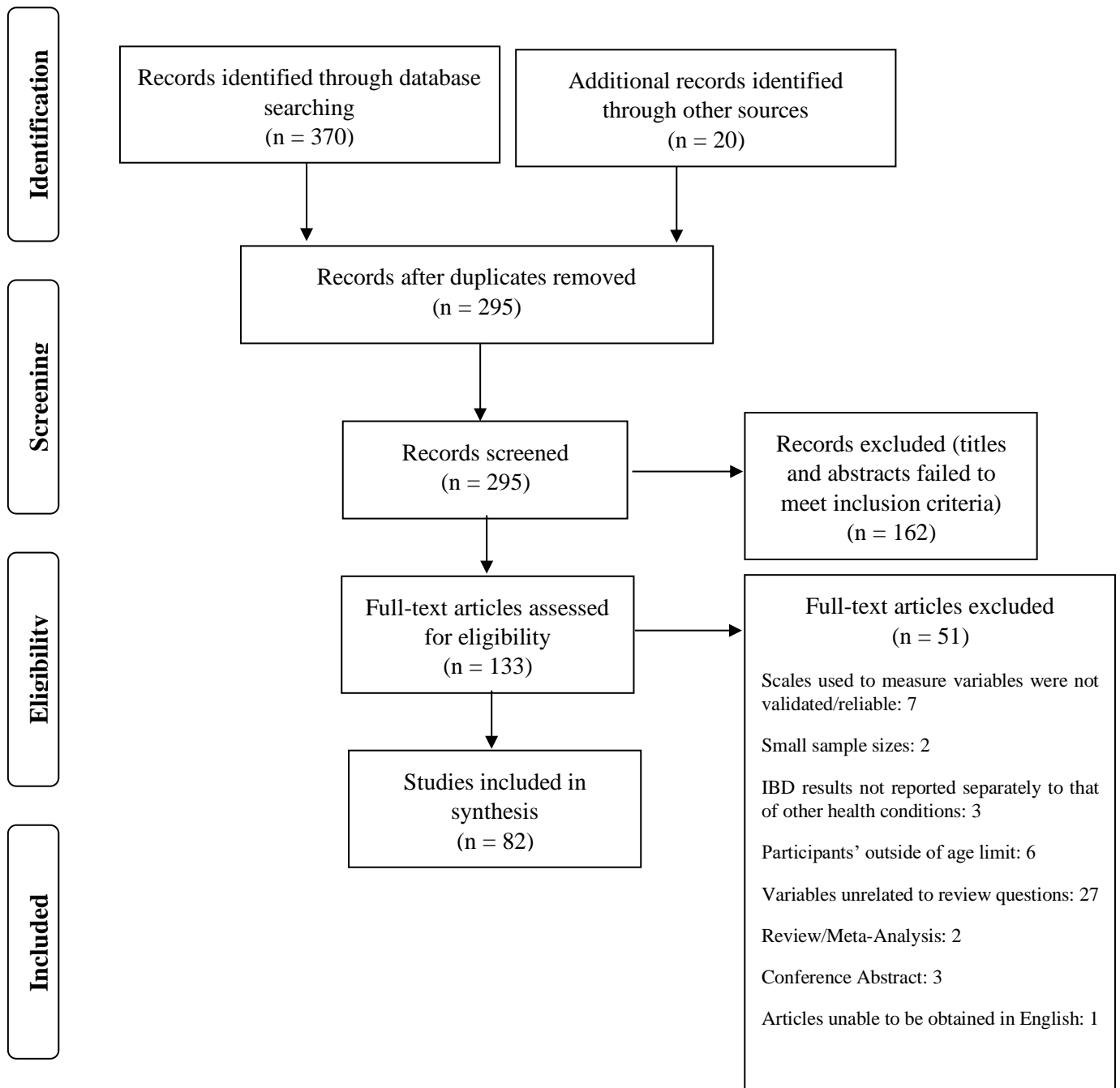


Figure 2.1. PRISMA Flow Diagram for Study Selection and Extraction.

Table 2.1a. Combined Quality Assessment of Categories Present in Quantitative Studies

Category	Validated measure of psychological variable?	Validated measure of outcome variable?	Randomised/consecutive recruitment strategy?	Multi-Centre?	Eligibility criteria specified?	Participation rate >75%	Adequately Powered?
	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<i>IBD Participants</i>							
Illness Perceptions (N = 19)	95%	95%	42%	42%	74%	37%	16%
Stigma (N = 15 studies)	80%	80%	20%	53%	47%	33%	13%
Negative Emotional Reactions (N = 10)	50%	50%	40%	60%	40%	20%	0
<i>Community</i>							
Illness Perceptions (N = 4)	75%	75%	75%	100%	75%	25%	25%
Stigma (N = 3)	33%	33%	33%	67%	33%	67%	0
Negative Emotional Reactions (N = 1)*	No	No	No	Yes	Yes	No	No

*Only one study is included in this category and responses are recorded as either Yes or No

Table 2.1b. Combined Quality Assessment of Categories Present in Qualitative

Category	Clear stated aim?	Qualitative methodology appropriate?	Appropriate research design?	Appropriate recruitment strategy?	Data collection addressed research issue?	Considered the relationship between the researcher and the participants?	Considered ethical issues?	Rigorous data analysis?	Clear statement of findings?
	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<i>IBD Participants</i>									
Illness Perceptions (N = 2)	100%	100%	50%	50%	50%	50%	100%	50%	50%
Stigma (N = 23 studies)	96%	100%	70%	83%	83%	35%	78%	70%	87%
Negative Emotional Reactions (N = 24)	96%	100%	71%	88%	75%	29%	88%	63%	83%
<i>Community+</i>									
Stigma (N = 1)*	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes

+Only one category included in this section. *Only one study included in this category and responses are recorded either as Yes or No.

Table 2.2 Summary of Studies Examining Illness Perceptions in Patients with IBD

Author(s)/Country	Sample/Recruitment	Design/Statistical Methods	Results
<i>Quantitative Studies</i>			
Dorrian et al., (2009). Ireland.	N = 80 (CD: 26; UC: 54). Outpatient clinic.	Cross-Sectional. Hierarchical Regression Analyses.	Illness perceptions significantly contributed to the variance explained in adjustment to IBD. Viewing one's IBD as having serious consequences was a unique predictor of poorer adjustment to IBD. Coping did not mediate the r/ship between illness perceptions and adjustment. <i>The CSM of illness was not supported.</i>
Han et al., (2005). United Kingdom.	N = 111 (UC only). General hospital.	Cross-Sectional. Hierarchical Regression Analyses.	Domains of Illness Identity and Consequences were significant predictors of QOL.
Knowles et al., (2011). Australia.	N = 96 (CD only). Tertiary hospital IBD outpatient clinic.	Cross-Sectional. Structural Equation Modelling.	Disease activity has an indirect impact on anxiety and depression, via illness perceptions and coping strategies. <i>Found support for the CSM of illness.</i>
Knowles, Cook, & Tribbick (2013). Australia	N = 83 (CD: 31; UC: 52, with a stoma) Online advertisements.	Cross-Sectional. Structural Equation Modelling.	The relationship between health status and depression and anxiety was indirectly explained by illness perceptions and maladaptive coping. Illness perceptions did not mediate the relationship between months since surgery and emotion-focused coping. <i>Mixed findings in relation to the CSM of illness.</i>
Knowles, Gass, & Macrae (2013). Australia	N = 74 (CD: 44; UC: 34). Advertisements on IBD online support forums and national IBD associations.	Cross-Sectional. Structural Equation Modelling.	Illness perceptions directly explained depression, anxiety and family functioning. Mediating pathways were found in which sexual problems, sexual satisfaction, explained relationships between illness perceptions and marital functioning.
Knowles, Wilson, et al., (2013). Australia.	N = 31 (CD only, with ostomy). Two teaching hospitals.	Cross-Sectional. Correlations & Mann-Witney U test.	Found no gender differences for anxiety, depression and stoma-related HRQOL. Those with a temporary ostomy reported more negative illness perceptions. Those with negative illness perceptions indicated higher levels of depression and anxiety and lower QOL.
Levy, et al., (2014). Israel.	N = 31 (CD only). University medical centre.	Cross-Sectional. Factorial ANOVAs.	Patients rated IBD as severe, benefits from medical treatment, and viewed that psychological factors and accidents/injuries have a contributory role in the causation of IBD.
Moser et al., (1995). Austria.	N = 105 (CD: 72; UC: 33). University outpatient clinic.	Cross-Sectional. Multiple Linear Regression Analyses.	Those who perceive psychosocial factors to cause the onset of the disease are more likely to be concerned about the uncertain nature of the disease.

Table 2.2 (Continued).

Author(s)/Country	Sample/Recruitment	Design/Statistical Methods	Results
Rochelle & Fidler (2013). United Kingdom.	N = 102 (CD: 67; UC: 46). Outpatient clinic in a teaching hospital.	Cross-Sectional. Hierarchical Regression Analyses.	Individual illness perceptions significantly predicted outcomes. Beliefs that medication controls symptoms (treatment control) was predictive of QOL. Having more understanding of one's IBD (illness coherence) significantly predicted higher depression.
Rubin et al., (2009). United States of America.	N = 451 (UC only). Research surveying panel of US citizens.	Cross-sectional. Multiple linear regression analyses.	79% of the sample perceived that their disease was not under control, 81% rated that IBD did impact upon their life, and just over half stated that IBD interrupted their daily activities (58%).
Sevcik (2005). United States of America.	N = 31 (number per diagnosis not provided). Crohn's & Colitis Foundation of America.	Cross-Sectional. One-Way ANOVAs and Multiple Comparisons.	Illness representations were not significantly associated with illness intrusiveness. Those with IBD viewed their condition as serious, viewed IBD as incurable and indicated that they are not personally responsible for the onset of the disease.
Tribbick et al., (2017). Australia.	N = 81 (CD: 56; UC: 25). University hospital outpatient clinic.	Cross-Sectional. Hierarchical Regression Analyses.	Illness perception domain of identity was a significant predictor of both depression and QOL. Emotional response was a significant predictor of anxiety.
Van Der Have et al., (2013). Netherlands.	N = 82 (CD only). Tertiary Referral Centre.	Cross-Sectional. T-tests & Hierarchical Regression Analyses	Illness perceptions significantly contributed variance explained in HRQOL: Systemic symptoms (9%), Emotional Symptoms (27%), and Social Symptoms (7%). Coping did not indirectly explain the relationship between illness perceptions and HRQOL and <i>the CSM of illness was not supported</i> .
Van Der Have, Brakenhoff et al., (2015). Netherlands.	N = 204 (CD: 146; UC: 58). Medical Centre.	Longitudinal. Student's T-Test, Univariate analyses, & Step-Wise Regression Analyses.	Stronger beliefs about the seriousness and emotional impact of IBD significantly contributed to lower QOL. Coping (decreasing activity) mediated the relationship between illness identity and consequences and QOL. <i>This supported the CSM of illness</i> . Those with IBD who experienced back/joint pain reported poorer QOL and lower work productivity compared to those without pain.
Van Der Have, Fidler et al., (2015). Netherlands.	N = 1108 (CD: 554; UC: 424). Data collected from the, 'Costs Of Inflammatory bowel disease: In the Netherlands' cohort.	Longitudinal Hierarchical Regression Analyses.	For those with CD, 12% of the variance in self-reported disability was explained by illness perceptions. For those with UC, 7.5% of the variance in self-reported disability was explained by illness perceptions.
Van Der Have et al., (2016). Netherlands.	N = 128 (CD: 104; UC: 24). Three university and three general hospitals.	Longitudinal. Spearman's correlation analyses & Univariate Logistic Regression Analysis.	A stronger emotional response towards IBD and viewing IBD as an acute condition were significantly associated with non-adherence to anti-TNF therapy.

Table 2.2 (Continued).

Author(s)/Country	Sample/Recruitment	Design/Statistical Methods	Results
Van Erp et al., (2017). Netherlands.	N = 211 (CD: 154; UC: 57). Outpatient clinic.	Cross-Sectional. Multiple Mediation Analyses.	Coping (decreasing activity) indirectly explained the relationship between illness perceptions and outcomes (poorer mental health and physical health, and more activity impairment). <i>This supported the CSM of illness.</i>
Van Erp et al., (2018). Netherlands.	N = 204, with arthropathies: (n= 123; CD: 95; UC: 28), without arthropathies: (n= 81; CD: 51; UC: 30). Longitudinal cohort data ('JOINT cohort').	Longitudinal. Descriptive statistics. Independent t-test and a χ^2 -test. Linear regression models.	Participants with IBD with arthropathies (i.e., back pain, joint complains) had more negative illness perceptions and experienced higher levels of activity impairments, and poorer physical and psychological health, than those without arthropathies. At a 12 month follow-up, patients with IBD and arthropathies were less likely to perceive medical treatment as effective.
Zhang et al., (2016). China.	N = 159 (CD only). Tertiary hospital outpatient clinic.	Cross-Sectional. Structural Equation Modelling	Illness perceptions indirectly explained the relationship between disease severity and stress. Stress mediated the relationship between illness perceptions and outcomes. Maladaptive coping was not a mediator. <i>This did not support the CSM of illness.</i>
<i>Qualitative Studies</i>			
Dibley, Norton, & Whitehead (2018). United Kingdom.	N = 40 (CD: 22; UC: 13; Both: 4; Proctitus: 1). National IBD association - Crohn's & Colitis United Kingdom.	Unstructured interviews. Diekelmann's hermeneutic method.	Some participants perceived they did not have control of their disease. Many tried to find a cause for their disease.
Matini & Ogden (2016). United Kingdom.	N = 22 (CD: 10, UC: 12). Online support networks and IBD support forums.	In-depth semi-structured interviews. Thematic Analysis	Participants reported that IBD is their fault or could have been prevented. Some reported that stressful life events triggered the cause of the onset of IBD.
QOL, Quality of Life; CSM, Common Sense Model of Illness; HRQOL, Health-related quality of life.			

Table 2.3. Correlations between Illness Perceptions and Outcomes

Author (year) /IBD Diagnosis	Illness Perception Domain (Measure)	Emotional/Mental Health (Measure)	Physical Health (Measure)			QOL (Measure)	
<i>Domains of Illness Perceptions & Outcomes</i>							
Dorrian et al., (2009). Both UC & CD.	IPQ-R	Psych Distress (HADS)				QOL (UK IBDQ-)	HRQOL (FLP)
	Identity	0.37**				0.50***	0.44***
	Acute/chronic Timeline	0.17 (NS)				0.33**	0.14 (NS)
	Cyclical Timeline	0.39***				0.42***	0.18 (NS)
	Consequences	0.64***				0.58***	0.59***
	Personal Control	−0.09 (NS)				0.01 (NS)	0.28*
	Treatment Control	−0.09 (.NS)				−0.08 (.NS)	−0.08 (NS)
	Illness Coherence	−0.35**				−0.15 (NS)	−0.16 (NS)
	Psychological Cause	0.34**				0.03 (NS)	0.08 (NS)
Rochelle & Fidler (2013). Both UC & CD.	IPQ-R	Emotion Function (UK IBDQ)	Bowel Function I (UK IBDQ)	Bowel Function II (UK IBDQ)	Systemic Function (UK IBDQ)	Social Function (UK IBDQ)	
	Timeline	.24*	NR	.57**	NR	.24*	
	Cyclical						
	Consequences	−.35***	NR	NR	−.31**	−.35***	
	Personal Control	−.29**	NR	.37***	−.20*	−.29**	
	Treatment Control	0.23*	NR	0.55**	0.22*	0.23*	
	Illness Coherence	NR	NR	0.31***	NR	NR	

Table 2.3. (Continued).

Author (year) /IBD Diagnosis	Illness Perception Domain (Measure)	Emotional/Mental Health (Measure)	Physical Health (Measure)		QOL (Measure)	
Sevcik, (2005). Both UC & CD.	Emotional Representation	-.43***	-.22*	NR	-.40***	-.43***
	Illness Representations (IMIQ)					Illness Intrusiveness (IIRS)
	Consequences					0.31 (NS)
	Symptom Variability					-0.02 (NS)
	Curability					0.1 (NS)
Tribbick et al., (2017). Both UC & CD.	Personal Responsibility					-0.01 (NS)
	Brief IPQ	Dep (HADS)	Anxiety (HADS)			QOL (WHOQOL-BRIEF)
	Identity	0.63***	0.45***			- 0.72***
	Timeline	0.31**	0.23*			- 0.56**
	Concern	0.50***	0.57***			- 0.59***
	Consequences	0.42***	0.44***			- 0.51***
	Personal Control	0.34**	0.23*			- 0.52***
	Treatment Control	0.31**	0.26*			- 0.42***
	Understanding	0.04	0.12			- 0.19
	Emotional response	0.60***	0.66***			- 0.63***
Van Der Have et al., (2013). CD only.	IPQ-R					HRQOL (IBDQ-32)
	Illness Identity					-0.41**
	Consequences Acute/chronic					-0.54** 0.00 (NS)

Table 2.3. (Continued).

Author (year) /IBD Diagnosis	Illness Perception Domain (Measure)	Emotional/Mental Health (Measure)	Physical Health (Measure)		QOL (Measure)
Van Der Have, Fidder et al., (2015). Both UC & CD.	Cyclical				−0.39**
	Personal control				0.10 (NS)
	Treatment control				0.07 (NS)
	Illness coherence				0.25*
	Emotional representations				−0.41**
	Psychological factors				−0.19 (NS)
	Risk Factors				−0.11 (NS)
	Brief IPQ		IBD Disability (IBD Disability Index)		
			CD	UC	
	Consequences		−0.59***	−0.56***	
	Timeline		−0.02 (NS)	−0.01 (NS)	
	Personal Control		0.36***	0.28***	
	Treatment Control		0.16***	0.19***	
	Identity		−0.64***	−0.60***	
	Concerns		−0.49***	−0.47***	
	Understanding		0.16***	0.13**	
	Emotional Response		−0.54***	−0.49***	

Table 2.3. (Continued).

Author (year) /IBD Diagnosis	Illness Perception Domain (Measure)	Emotional/Mental Health (Measure)	Physical Health (Measure)	QOL (Measure)	
Van Erp et al., (2017). Both UC & CD.	IPQ-R	Mental Health (SF-36)	Physical Health (SF-36)	Activity Impairment (WPAI)	Work Impairment (WPAI)
	Identity	−.25***	−.36***	.34***	.22**
	Timeline Chronic	−.10	0.04	−.02	−.18*
	Timeline cyclical	−.18**	−.34***	.31***	.29***
	Consequences	−.41***	−.48***	.49***	.39***
	Personal control	.21**	.23**	−.19**	−.09
	Treatment control	.17*	.28***	−.29***	−.18*
	Illness coherence	.44***	.19**	−.26***	−.22*
	Emotional representations	−.54***	−.22**	.32***	.24**
Author (year) /IBD Diagnosis	Illness Perception (Measure)	Emotional/Mental Health (Measure)	Physical Health (Measure)	QOL (Measure)	
Illness Perception Total Score & Outcomes					
Knowles et al., (2011). CD only.		Anxiety (HADS)	Dep (HADS)		
	Brief IPQ	0.43***	0.47***		
Knowles, Cook, & Tribbick. (2013). Both CD & UC, with stoma.		Anxiety (HADS)	Dep (HADS)		
	Brief IPQ	0.63***	0.54***		

Table 2.3. (Continued).

Author (year) /IBD Diagnosis	Illness Perception (Measure)	Emotional/Mental Health (Measure)			Physical Health (Measure)			QOL (Measure)				
Knowles, Gass, & Macrae (2013). Both CD & UC.		Anxiety (HADS)	Dep (HADS)					Body Image (BISC)	Sexual Problems (SPS)	Sexual Satisfaction (SSS)	Marital Functioning (MFS)	Family Functioning (FFS)
	Brief IPQ	0.47***	0.65***					0.28*	0.32**	−0.29*	−0.05	−0.22
Knowles, Wilson et al., (2013). CD only, with stoma.		Anxiety (HADS)	Dep (HADS)					QOL: sexuality body image (SQOL)	QOL: work/ social (SQOL)	QOL: stoma function (SQOL)	QOL: financial concerns (SQOL)	QOL: skin irritation (SQOL)
	Brief IPQ	0.43*	0.43*					− 0.40*	− 0.68**	− 0.40*	− 0.52**	− 0.30 (NS)
Zhang et al., (2016). CD only.		Stress (PSQ)	Anxiety (HADS)	Dep (HADS)				QOL (IBDQ)				
	Brief IPQ	0.69***	0.62***	0.57***				−0.73***				

* $p < .05$, ** $p < .01$, *** $p < .001$; NR, Not Reported; NS, Non-Significant.

HRQOL, Health-related quality of life; QOL, Quality of Life. Brief IPQ, Brief Illness Perception Questionnaire; HADS, Hospital Anxiety and Depression Scale; WHOQOL-BRIEF, World Health Organization Brief Quality of Life Scale; IPQ-R, Revised Illness Perceptions Questionnaire; SF-36, Short-Form 36; WPAI, Work Productivity and Activity Impairment Questionnaire; UK IBDQ, United Kingdom Inflammatory Bowel Disease Questionnaire; IBDQ-32, Inflammatory Bowel Disease Questionnaire; FLP, Functional Limitations Profile; IMIQ, Implicit Models of Illness Questionnaire; IIRS, Illness Intrusiveness Rating Scale; PSQ, Perceived Stress Questionnaire; BISC, Body Image and Self-Consciousness During Intimacy Scale; SPS, Sexual Problems Scale; SSS, Sexual Satisfaction Scale; MFS, Marital Functioning Scale; FFS, Family Functioning Scale; SQOL, Stoma Quality of Life Scale.

Table 2.4. Summary of Studies Examining Stigma in Patients with IBD

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Perceived/Anticipated Stigma	Internalised Stigma	Enacted Stigma	Stigma Resilience	Outcomes
<i>Quantitative</i>							
Argyriou et al., (2017). Greece.	N = 200 (CD: 96; UC: 104). Tertiary referral centre.	Cross-sectional. Chi-square test, Mann-Whitney-Wilcoxon test, step-wise linear regression analysis.			More than half of the sample stated that they could not participate in social events due to other people.		
Canavan et al., (2006). United Kingdom.	N = 152 (CD only). Database and outpatient clinics.	Cross-Sectional Design. Correlation and stepwise multiple linear regression analyses.		Participants rated that they experience body stigma.	Least concerned about, 'being treated differently.'		
Chiapponi et al., (2016). Germany.	N = 121 (CD: 92; UC: 29). University hospital.	Cross-Sectional. Welch's, Mann-Whitney U test.	Participants perceived that physicians don't take them seriously or lack interest.		Reported negative experiences with physicians.		
De Rooy et al., (2001). Canada.	N = 259 (CD: 120; UC: 121). IBD Centre in hospital.	Cross-sectional. Student t-tests, MANOVA and Step-wise regression analyses.	Older aged women were concerned about disease stigma.				Disease stigma significantly contributed to the explanation of current wellbeing.
Gamwell et al., (2018). United States of America.	N = 90 (CD: 49; UC: 31; Mean age: 14.96). Gastroenterology clinic at children's hospital.	Cross-Sectional. Multiple regression and mediation analyses.	Participants with depressive symptoms in the clinically elevated range had significantly higher perceived stigma scores.				Increased illness stigma was associated with higher levels of depression, via thwarted belongingness (indirect path found).

Table 2.4. (Continued).

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Perceived/Anticipated Stigma	Internalised Stigma	Enacted Stigma	Stigma Resilience	Outcomes
Jelsness- Jørgensen et al., (2011). Norway.	N = 140 (CD: 48; UC: 92). Three outpatient clinics.	Longitudinal. One-way ANOVAs, correlations, and linear regression analyses.			'Being treated differently' was ranked as least important out of a list of concerns.		
Lesage et al., (2011). France.	N = 2424 (CD: 1494; UC: 741; Undetermined Colitis: 189). National IBD association or gastroenterologist office.	Cross-sectional. Descriptive Statistics, Chi- square test or student's t-test, Cohen non- parametric test.	Participants perceived that friends and colleagues were not aware that the disease impacts them.		9% of sample dismissed from work.		
Levenstein, et al. (2001). Italy.	N = 2002 (CD: 1141; UC: 861). Data collected from survey completed by prior longitudinal study, and analysed cross-sectionally.	Cross-sectional. Descriptive statistics and ANOVAs.	Patients across multiple countries perceive they are a burden to others.	Patients across multiple countries rated that they have body stigma.	Being 'treated differently' was rated as one of the least five most unimportant concerns.		
Mayberry et al., (1992). Wales.	N = 58 (CD only). Recruited from database.	Cross-sectional. Student's t-test.	Perceived stigmatisation from employers and teachers.		50% of patients with CD had difficulties finding work.		
Moser et al., (1995). Austria.	N = 105 (CD: 72; UC: 33). University outpatient clinic.	Cross-sectional Wilcoxon test, Kruskal-Wallis test, X^2 -test. Correlations and multiple linear regression.	Females had concerns about being treated differently.				

Table 2.4. (Continued).

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Perceived/Anticipated Stigma	Internalised Stigma	Enacted Stigma	Stigma Resilience	Outcomes
Pittet et al. (2017). United Kingdom.	N = 1102 (CD: 595; UC = 507). Swiss IBD Cohort (SIBDC).	Cross-sectional. Linear multiple regressions analyses.	Perceived stigmatisation a concern for participants, especially those using treatments and with a history of resection and surgery.				Increased anxiety and depression.
Taft et al., (2009). United States of America.	N = 211 (CD: 156; UC: 55). Crohn's & Colitis Foundation of America, and online adverts.	Cross-Sectional. T-tests, One-way ANOVAs, MANOVA, Hierarchical Regression.	84% of sample reported perceived stigma (mostly low to moderate levels). Perceived the most stigmatisation from employers.			Low stigma was reported.	Perceived stigma significant predictor of the following outcomes: HQOL, self-esteem, self-efficacy and psychological distress.
Taft et al., (2011). United States of America.	N = 227 with IBD (number per diagnosis not provided). Outpatient clinic and online adverts.	Cross-Sectional. Linear regression and step-wise regression analyses.	8% reported moderate to high perceived stigma. 44% reported mild perceived stigma.				Higher stigma associated with higher depression, and lower self-efficacy and QOL.
Taft et al., (2013). United States of America.	N = 191 (CD: 126; UC: 65). Outpatient clinic or online advertisements.	Cross-Sectional. One-Way ANOVAs, Tukey's HSD post-hoc, and step-wise regression analyses.		36% of participants reported internalised stigma. Most commonly experienced alienation and social withdrawal.		88% of the sample reported a moderate level of stigma resistance behaviours.	Internalised stigma was a significant predictor of self-esteem, HRQOL, and psychological distress.
Wyke et al., (1998). United Kingdom.	Initial: N = 170 (CD: 95; UC: 75). Follow up: N = 144 (CD: 83; UC: 61). General hospital.	Longitudinal. Descriptive statistics.	Perceived that the attitudes of employers and colleagues were stigmatising.		Seven participants reported direct experiences of stigmatisation (e.g., refused work).	Most participants indicated that their colleagues and employers were helpful.	

Table 2.4. (Continued).

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Perceived/Anticipated Stigma	Internalised Stigma	Enacted Stigma	Stigma Resilience	Outcomes
<i>Qualitative Studies</i>							
Bernhofer et al., (2015). United States of America.	N = 16 (CD: 12; UC: 4). Hospitalised patients in academic medical centre.	Individual interviews. Interpretive phenomenological design.	Patients with IBD perceived that they were labelled negatively by healthcare professionals.				
Cooper et al., (2010). United Kingdom.	N = 24 (UC: 12; CD: 12). Outpatient clinic.	Individual semi-structured interviews. Systematic framework analysis approach.	Perceived lack of societal awareness of IBD and stigma towards IBD. Perceived stigma would occur when using public toilets.		Direct stigmatisation experiences with employers.		
Czuber-Dochan, et al., (2013). United Kingdom.	N = 46 (CD: 28; UC: 18). Crohn's and Colitis United Kingdom member database.	Focus groups. Inductive thematic framework.	Participants perceived stigma from healthcare providers and employers/colleagues.				
Daniel (2002). Canada.	N = 5 (number per diagnosis not provided). Advertised to local paper.	In-depth semi-structured interviews. Phenomenological descriptive research method.	Perceive others do not understand their IBD.	Experienced alienation and 'felt different.' Beliefs about non-disclosure of IBD to others.			
Dibley & Norton (2013). United Kingdom.	N = 28 interviews (CD: 14; UC: 12); N = 583 free-text responses (CD: 269; UC: 288). Crohn's & Colitis United Kingdom.	Free-text responses and interviews. Pragmatic thematic approach.	Expressed concerns about how others perceive them and understand their illness.				

Table 2.4. (Continued).

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Perceived/Anticipated Stigma	Internalised Stigma	Enacted Stigma	Stigma Resilience	Outcomes
Dibley, Norton, & Whitehead (2018). United Kingdom.	N = 40 (CD: 22; UC: 13; Both: 4; Proctitis: 1). National IBD association - Crohn's & Colitis United Kingdom.	Unstructured interviews. Diekelmann's hermeneutic method.	Participants expected others to perceive them in a negative way.	Participants reported they could not meet social norms of cleanliness.	Treated differently by other people and excluded in social situations.	60% of the sample reported not feeling stigmatised.	
Frohlich, (2014). United States of America.	N = 14 (CD: 7; UC: 7). IBD Facebook support groups.	Individual interviews. Thematic analysis.	Participants perceived they would be stigmatised by others.		Reported direct experiences of stigmatisation.	Despite initially perceiving stigmatisation, most participants felt supported.	
Frohlich, (2016). United States of America.	14 online communities involving IBD. Social websites: e.g., Facebook, Twitter.	Ethnographic and interviews with community leaders of websites. Searched for patterns and themes within the data.	Perceived others do not take IBD seriously.	Due to nature of symptoms being taboo, did not want to talk about disease due to fear of others making, 'poop jokes.'	Received stigmatising comments on social media.		
Hall et al., (2005). United Kingdom.	N = 31 (CD: 14; UC: 17). Recruited from previous study.	Individual interviews and focus groups. Grounded theory.	Participants perceive that they should remain positive as this is more socially acceptable to others.	Conceal disease from others and withdraw.			
Jordan et al., (2018). United Kingdom.	N = 25 (CD: 11; UC: 14). IBD clinical service.	In-depth semi- structured individual interviews. Template analysis.	Perceive others do not understand IBD and anticipate others will alienate them due to bowel symptoms.				Avoidance of others, non-disclosure of IBD and minimising impact of IBD.

Table 2.4. (Continued).

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Perceived/Anticipated Stigma	Internalised Stigma	Enacted Stigma	Stigma Resilience	Outcomes
Krause, (2003). Chile.	N = 19 (number per diagnosis not provided). IBD support group.	Individual interviews. Grounded theory.	Participants perceived that their family viewed them as, 'ill and handicapped'.		Participants described that they were treated by family as, 'ill and handicapped'.	After intervention: perceived and experienced less stigma.	
Larsson et al., (2017). Sweden.	N = 15 (CD: 8; UC: 7). Gastroenterology department at a university hospital.	Individual Interviews. Content Analysis.	Worried about the reactions of other people.	Concerned about the smells and sounds their bodies produce.			
Lesnovska et al., (2017). Sweden.	N = 26 (CD: 10; UC: 16). Hospital clinic.	Focus groups and individual interviews. Identified common themes.	Perceived not treated with respect by healthcare professionals and that they had a negative view of IBD.		Healthcare providers treated IBD as a joke.		
Matini & Ogden, (2016). United Kingdom.	N = 22 (CD: 10, UC: 12). Online support networks and IBD support forums.	In-depth semi- structured interviews. Thematic Analysis	Perceive that others do not understand IBD.		Reports of being treated differently compared to other people.		
McMullan et al., (2017). United Kingdom.	N = 28 (UC only). Four hospitals.	Semi-structured interviews. Framework analytical approach.		Alienation and social withdrawal.		Reported receiving support from employers, friends and family.	
Norton et al., (2012). United States of America.	N = 87 (CD only). From specialist office.	Video diaries and focus groups. Identified common themes.	Perceive a lack of understanding and blame from friends and family.	Isolation and avoidance.		Upon disclosure of disease, many found support from others.	Resulted in feelings of depression and loneliness.

Table 2.4. (Continued).

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Perceived/Anticipated Stigma	Internalised Stigma	Enacted Stigma	Stigma Resilience	Outcomes
Piper (2017). United Kingdom.	N = 15 (CD: 9; UC: 4). Outpatient IBD clinics.	Individual semi- structured interviews. Thematic analysis.	Anticipate that others will perceive them negatively and others do not understand IBD.	Feel different to other people and internalised that they were a burden to others.	Reported experiences of discrimination while using disabled toilets and 'can't wait cards'.		Avoidance, use of humour, justifying behaviour, delayed healthcare, absence from work and reduced confidence.
Purc- Stephenson et al., (2015). Canada.	N = 378 (CD: 251; UC: 127).Online adverts.	Open-ended survey questions. Grounded theory: identifying key themes.	Perceive others do not understand IBD and judge those with the disease.				Resulted in low self- esteem.
Sammut, Scerri, & Xureb (2015). Malta.	N = 10 (UC only). Outpatient clinic of general hospital.	Semi-structured individual interviews. Interpretive Phenomenological Analysis (IPA).	Perceived family did not take complaints seriously.	Reports of alienation and withdrawal.	Experienced direct stigmatisation from employer.		
Saunders (2014). United Kingdom.	N = 16 (number per diagnosis not provided). Four United Kingdom universities and IBD clinic.	Interviews. Discourse analysis.	Perceive stigmatisation due to taboo of IBD symptoms.	Participants felt they needed to hide and not disclose that they had the condition.	Friends made stigmatising comments and would laugh.		
Savard & Woodgate (2009). Canada.	N = 6 (UC only, with ostomy). Treatment outpatient centre.	Individual interviews. Identified common themes.	Participants perceive stigma is associated with IBD.	Conceal disease from others and, 'feel different'.			
Thompson (2013). United States of America.	N = 12 (interviews; number per diagnosis not provided). IBD support groups.	Participant- Observer in IBD support groups and individual interviews. Content analysis.	Perceive stigmatisation due to the unacceptability of symptoms.	Conceal conditions from others.			

Table 2.4. (Continued).

[illegible]

Table 2.5. Summary of Studies Examining Negative Reactions in Patients with IBD

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Fear	Embarrassment	Shame	Anger	Disgust	Outcomes
<i>Quantitative</i>								
Cervesi et al., (2013). Italy.	N = 28 patients (CD: 17; UC: 11). Hospital.	Cross-sectional survey design. Mann-Whitney Test, and X^2 test.	43% feared surgery and 36% feared being hospitalised.					
Denters et al., (2013). Netherlands.	N = 146 with IBD (number per diagnosis not reported). Two teaching and two regional hospitals.	Longitudinal. ANOVAs, Chi-Squared tests and student t-tests.		Those with IBD indicated significantly more embarrassment during colonoscopy than other groups (e.g., IBS).				
Farrell et al., (2016). Ireland.	N = 247 (CD: 162; UC: 85). Teaching Hospital.	Cross-sectional, Descriptive statistics, Mann-Whitney U-tests and χ^2 .	In those with active IBD: 30.8% felt fearful	In those with active IBD: 49.3% felt embarrassed		In those with active IBD: 39.7% indicated feelings of anger.		
Jelsness-Jørgensen et al., (2011). Norway.	N = 140 (CD: 48; UC: 92). Three outpatient clinics.	Longitudinal. One-way ANOVAs, t-tests, bivariate correlations, and linear regression analyses.	Requiring an ostomy bag, loss of bowel control, and low energy.					
Lesage et al., (2011). France.	N = 2424 (CD: 1494; UC: 741; Undetermined Colitis: 189). National IBD association/gastroenterologist.	Cross-sectional. Descriptive Statistics, Chi-square test or student's t-test, Cohen non-parametric test.	Risk of surgery, ostomy bag, cancer, and incontinence.					

Table 2.5. (Continued)

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Fear	Embarrassment	Shame	Anger	Disgust	Outcomes
Lopez-Sanroman, et al. (2017). Spain.	N = 436 (UC only). Hospital.	Cross-sectional Descriptive statistics, student t-tests, chi-squared or Fisher exact tests.	Risk of colon cancer, colostomy, faecal incontinence in public and surgery.	37% of the sample reported feelings of embarrassment.		60% of the sample reported feelings of anger.		
Rubin et al., (2009). United States of America.	N = 451 (UC only). Research surveying panel of US citizens.	Cross-sectional. Multiple linear regression analyses.	84% of the sample indicated a fear of the long-term effects of UC.	70% of sample indicated feeling embarrassment.				
Scholmerich et al., (1987). Germany.	N = 80 (CD: 60; UC: 19). University IBD outpatient clinic.	Cross-sectional. Descriptive Statistics.	Risk of cancer.					
Trindade et al., (2017a). Portugal.	N = 161 (CD: 89; UC: 70). Portuguese Association for IBD.	Cross-sectional Path analyses.			Shame had a direct influence on poorer psychological health and social relationships.			Shame is associated with poorer psychological health and poorer quality of social relationships.
Trindade et al., (2017b). Portugal.	N = 161 (CD: 89; UC: 70). Portuguese Association for IBD.	Cross-sectional Path analyses.			IBD symptoms and patients' depressive symptoms were indirectly mediated by shame. Shame was a predictor of depression.			Shame may explain the relationship between severity of symptoms and depression.

Table 2.5. (Continued)

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Fear	Embarrassment	Shame	Anger	Disgust	Outcomes
<i>Qualitative</i>								
Allison et al., (2013). United Kingdom.	N = 24 (CD: 17; UC: 7). Tertiary referral centre.	Semi-structured interviews. Narrative. Data analysis: 1. Story mapping 2. Restorying.	Fear of surgery and ostomy.					Increased concern and anxiety.
Daniel (2002). Canada.	N = 5 (number per diagnosis not provided). Advertised to local paper.	In- depth semi-structured interviews. Phenomenological descriptive research method	Losing control of bowel in public situations, requiring surgery or colostomy.	Uncontrollable bowel sounds, incontinence and urgency, and having to talk about the disease.	Described being ashamed in relation to disease.	Family members and professionals do not understand the disease.		Impacts upon quality of social relationships and goals for travel and education.
Devlen et al., (2014). United States of America.	N = 27 (CD: 6; UC: 21). IBD tertiary clinical site.	Focus groups and individual interviews. Grounded Theory.	Flare and incontinence, risk of cancer, future course of disease and shortened lifespan.	By their symptoms and of soiling themselves in public.				
Dibley & Norton (2013). United Kingdom.	N = 28 interviews (CD: 14; UC: 12). N = 583 free-text responses (CD: 269; UC: 288). Crohn's & Colitis United Kingdom.	Free-text responses and interviews. Pragmatic thematic approach.	Incontinence	Incontinence and flatulence occurring in public	Soiling self.	Angry about the impacts it has on families.	Participants reported they feel disgusting, dirty and smelly.	Impacts upon quality of social relationships.
Dibley et al., (2018). United Kingdom.	N = 40 (CD: 22; UC: 13; Both: 4; Proctitis: 1). National IBD association - Crohn's & Colitis United Kingdom.	Unstructured interviews. Diekelmann's hermeneutic method.	Concealed disease for fear of not being able to find employment.	Embarrassed about nature of symptoms.			Regard IBD as a 'dirty disease'. Self-directed disgust and public would display disgust towards IBD.	Embarrassment hinders developing relationships with others and seeking healthcare.

Table 2.5. (Continued)

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Fear	Embarrassment	Shame	Anger	Disgust	Outcomes
Hall et al., (2005). United Kingdom	N = 31 (CD: 14; UC: 17). Recruited from previous study.	Semi-structured interviews and focus groups. Grounded Theory.	Bowel control.	Bowel control and symptoms of IBD.				Avoiding public outings.
Hall et al., (2007). United Kingdom.	N = 31 (CD: 14; UC: 17). Recruited from previous study.	Semi-structured interviews and focus groups. Grounded Theory.	Dependency to medication and effects of medications.					Concerns about treatment could lead to delayed healthcare.
Jordan et al., (2018). United Kingdom.	N = 25 (CD: 11; UC: 14). IBD clinical service.	In-depth semi- structured individual interviews. Template analysis.	Fearful of judgement and stigmatisation, and bowel accidents.				Other people would perceive them as, 'unclean.'	Choose not to have intimate relationships. Other people would want to avoid them due to their, 'uncleanliness.'
Keeton et al., (2015). Australia.	N = 294 (Number per diagnosis not provided). Teaching hospital.	Open-ended survey question. Thematic Analysis.	Risk of cancer, body image issues, family life, mortality & fearing embarrassment.	Experience embarrassment in relation to IBD.				
Krause (2003). Chile.	N = 19 (number per diagnosis not provided). IBD support group.	Individual interviews. Grounded theory.	Developing cancer and passing disease onto offspring.	Losing control of bowels in public.	Towards symptoms (e.g., incontinence).			Following intervention, participants reported experiencing less fear and shame.
Larsson et al., (2016). Sweden.	N = 15 (CD: 8; UC: 7). Gastroenterology department at a university hospital.	Individual Interviews. Content Analysis.	Feared losing control of bowels.		Described feeling ashamed of disease and symptoms			
Lynch & Spence, (2008). New Zealand.	N = 4 youth (CD only). Support groups and gastroenterologists.	Semi-structured interviews. Thematic Analysis.	Having a colostomy or surgery, fear of dying and being in pain.	Having an ostomy and using public toilets.		Having IBD and anger at parents for passing on IBD.		Avoided using public toilets due to embarrassment.

Table 2.5. (Continued)

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Fear	Embarrassment	Shame	Anger	Disgust	Outcomes
Matini & Ogden (2016). United Kingdom.	N = 22 (CD: 10, UC: 12). Online support networks and IBD support forums.	In-depth semi-structured interviews. Thematic Analysis	Fearful of symptoms occurring at social events.					
McMullan et al., (2017). United Kingdom.	N = 28 (UC only). Four hospitals.	Semi-structured interviews. Framework analytical approach.	Locating a toilet when needed.	Described feeling embarrassed in relation to IBD.				Restrictions to daily life, isolation and avoidance.
Norton & Dibley, (2013). United Kingdom.	N = 617 (CD: 279; UC: 310; Other IBD: 28). Crohn's & Colitis United Kingdom.	Free-text responses. Pragmatic thematic approach.		Felt embarrassment.	Felt ashamed about disease.		Reported feeling 'dirty.'	Feeling ashamed and dirty were given as reasons for delayed healthcare.
Norton et al., (2012). United States of America.	N = 87 (CD only). From specialist office.	Video diaries and focus groups. Identified common themes.	Soiling self.	Frequent trips to the bathroom, soiling self and flatulence.		Having a chronic disease at a young age.		
Piper, (2017). United Kingdom.	N = 15 (CD: 9; UC: 4). Outpatient IBD clinics.	Individual semi-structured interviews. Thematic analysis.	Fearful of being judged negatively by others.	Embarrassed of IBD symptoms (e.g., wind) and being a burden to others.	Ashamed of bowel accidents, using disabled toilets. Experience shame in intimate relationships.	Angry about others questioning their use of disabled toilets and 'can't wait cards.'	Facial expressions from other people in response to IBD, appeared to reflect disgust.	
Purc-Stephenson et al., (2015). Canada.	N = 378 (CD: 251; UC: 127). Online Adverts.	Open-ended survey questions. Grounded theory: identifying key themes.	Passing IBD onto their children.	Embarrassed when having to discuss IBD with acquaintances.	Reporting feeling shame.		Feel dirty.	Social isolation, reduced self-esteem and difficulties initiating new social relationships.

Table 2.5. (Continued)

Author(s)/ Country	Sample/ Recruitment	Design/Statistical Methods	Fear	Embarrassment	Shame	Anger	Disgust	Outcomes
Sammut et al., (2015). Malta.	N = 10 (UC only). Outpatient clinic of general hospital.	Semi-structured individual interviews. Interpretive Phenomenological Analysis (IPA).	Fearful that initial symptoms were caused by cancer.	Embarrassed when unable to reach a toilet in time.		Angry that others attributed cause of pain to be psychological.		Isolation and alienation. Others not taking participants' disease seriously.
Savard & Woodgate (2009). Canada.	N = 6 (UC only, with ostomy). Treatment outpatient centre.	Individual interviews. Identified common themes.	Fears about ostomy leakage, locating the nearest bathroom, and taking medication.	Having an ostomy, side effects of medications and embarrassed by symptoms.				
Sephton et al., (2016). United Kingdom.	N = 8 (CD: 3; UC: 5). Crohn's Colitis United Kingdom and clinics.	Semi-structured interviews. Thematic analysis.	Having an ostomy bag, loss of bowel control, and reduced energy levels.	After education programme participants qualitatively reported they were less embarrassed about discussing their condition.				Desire to conceal and not discuss disease.
Thompson, (2013). United States of America.	N = 12 (interviews; Number per diagnosis not provided). IBD support groups.	Participant- Observer in IBD support groups and individual interviews. Content analysis.		Reported embarrassment due to the nature of symptoms.	Ashamed about the symptoms of IBD.			Embarrassment leads to using humour and modifying language when discussing IBD.
Wolfe et al., (2008). Canada.	N = 282 (CD: 187; UC: 79; other IBD: 16). Online support groups and gastroenterologist offices.	Responses to open-ended question. Qualitative Content Analysis	Losing control of bowels and having to use the bathroom urgently.	Possibility of having to pass a bowel movement on the side of the road.				

Table 2.6. Summary of Studies Examining Illness Perceptions, Stigma and Negative Emotional Reactions in Community Samples

Author(s)/ Country	Sample/ Recruitment	Design/ Statistical Methods	Identity	Timeline	Causes	Cure-Control	Consequences
<i>Illness Perceptions</i>							
Dickman et al., (2011). Israel.	Nurses (N = 43) and Gastroenterologists (N = 55). Questionnaires were posted to healthcare professionals.	Quantitative, Cross-sectional. Descriptive methods, two-way ANOVAs, two-way multivariate ANOVAs.		Nurses and gastroenterologists viewed IBD as chronic. Nurses perceived that IBD may improve over time and Gastroenterologists disagreed.		Both groups viewed medical treatment as beneficial for the control of symptoms.	Both groups rated IBD as having serious consequences.
Levy et al., (2014). Israel.	Gastroenterologists (N = 55). Clinics and hospitals.	Quantitative, cross-sectional. Factorial ANOVA and T-tests.		Viewed as chronic	Gastroenterologists less likely to view psychological factors as a cause of IBD, than patients.	View medical treatment and personal control to influence course of disease.	IBD has severe consequences and has an emotional impact on patients.
Rubin et al., (2009). United States of America.	Gastroenterologists (N = 300). Recruited from a list of certified gastroenterologists.	Quantitative, cross-sectional. Multiple linear regression analyses.				Physicians rated those with IBD as more in control of their condition, compared to that of patients.	Rated IBD has having less serious consequences than that of patients.

Table 2.6. (Continued)

Author(s)/ Country	Sample/ Recruitment	Design/ Statistical Methods	Identity	Timeline	Causes	Cure-Control	Consequences
Sevcik (2005). Dissertation. United States of America.	Friends and family (N = 48; SN). US (N = 48; not familiar with IBD participants).	Quantitative, Cross-Sectional. One-Way ANOVAs and Multiple Comparisons.				US viewed IBD as curable and IBD subjects as responsible. SN rated IBD as incurable and IBD subjects as responsible.	SN viewed IBD as a serious disease. US viewed IBD as a less serious disease.
Author(s)/ Country	Sample/ Recruitment	Design/ Statistical Methods	Perceived/ Anticipated Stigma	Internalised Stigma	Enacted Stigma	Stigma Resilience	
Stigma							
Czuber- Dochan et al., (2014). United Kingdom.	Multiple health professions (N = 20).	Qualitative. In- depth semi- structured interviews. Descriptive phenomenology.	Perceive that IBD patients may not be satisfied with healthcare professional's response to their fatigue.	Healthcare professionals reported that those with IBD could view themselves negatively because of their fatigue.	Fatigue may be interpreted as 'laziness' in a workplace.		
Moody et al., (1992). United Kingdom.	Employers (N = 53). Questionnaires sent to employers throughout Cardiff and Leicester, UK.	Quantitative, cross-sectional. Descriptive statistics.			A quarter of employers reported they would not hire those with IBD and 30% would not provide time off to attend appointments.	Views towards those with IBD were mostly positive.	

Table 2.6. (Continued)

Author(s)/ Country	Sample/ Recruitment	Design/ Statistical Methods	Perceived/ Anticipated Stigma	Internalised Stigma	Enacted Stigma	Stigma Resilience	Author(s)/ Country
Rohde et al., (2018). United States of America.	College students (N = 127). Undergraduate course at a university.	Quantitative, experimental. Independent samples t-test, ANOVAs, linear regression.			Higher enacted stigma present towards IBD in scenarios in the non-disclosure condition.	Less enacted stigma present in non-disclosure condition, higher familiarity and perceived knowledge of IBD.	
Taft et al., (2017). United States of America.	Online Sample (N = 392; general population). Social media and a research-dedicated website.	Quantitative, experimental. Independent samples t-tests, ANOVA, correlations, step- wise linear regression, ANCOVA.			Higher levels of enacted stigma reported towards those with IBS, compared to those with IBD and Adult-Onset Asthma.	Those with IBS more likely to be stigmatised than those with IBD.	
Author(s)/ Country	Sample/ Recruitment	Design/ Statistical Methods	Fear	Embarrassment	Shame	Anger	Disgust
<i>Negative Emotional Reactions</i>							
Magro et al., (2009). Portugal.	Caregivers (N = 324, 93% Caregivers).	Quantitative, cross-sectional. Descriptive Statistics, Chi- square test and Fisher's Exact Test.	Developing cancer, limited knowledge about IBD and effects on employment and education opportunities.				

SN, Social Network; US, University Students.

CHAPTER 3

STUDY 2

“NOBODY WANTS TO TALK ABOUT THAT STUFF”: A QUALITATIVE INVESTIGATION OF THE ANTICIPATED SOCIETAL PERCEPTIONS OF INDIVIDUALS WITH INFLAMMATORY BOWEL DISEASE

Chapter 3 contains Study 2, presented in the form of an unpublished manuscript that has been submitted for publication. The formatting required by the publisher for submission was retained. All tables are presented following the presentation of the references.

Statement of Contribution to Co-authored Paper

This chapter includes a co-authored paper, which has been submitted for publication. The bibliographic details of this co-authored paper, including all authors, are:

Edwards, E.-J., O'Callaghan, F., & Oaten, M. “Nobody wants to talk about that stuff”: A qualitative investigation of the anticipated societal perceptions of individuals with inflammatory bowel disease. *Submitted for publication.*

My contribution to the paper involved:

- Review of the literature
- Applying for ethical approval
- Co-development of research questions and interview schedule
- Recruitment of participants
- Lead in the completion of semi-structured interviews with participants
- Lead in transcription of interview responses
- Co-developing the final list of themes/subthemes and their interpretation
- Lead in drafting and writing of paper
- Corresponding author of the journal submission

(Date) 18 March 2020

Elia-Jade Edwards

(Date) 18 March 2020

Supervisor: A/Prof Frances O'Callaghan

(Date) 19 March 2020

Supervisor: A/Prof Megan Oaten

See Appendix B for the information and consent from

Abstract

Individuals with Inflammatory Bowel Disease (IBD) report concerns about being subject to negative reactions towards their condition when in public. Little research has explored in-depth qualitative opinions on anticipated public views of IBD among those with the condition, and the potential impact of these views on wellbeing. This study explored the perceptions and reactions anticipated by those with IBD from the general public in relation to their condition, and the impact these anticipated perceptions have on participants' physical and psychological health, and their overall quality of life. Semi-structured interviews were completed by two authors with twenty participants with IBD (*Mean age* = 32.8; *% female* = 75%; *Years diagnosed* = 13.69; *SD* = 10.79). Two independent data coders utilised thematic analysis on the interview transcripts, in order to reduce potential researcher bias. The themes identified by both coders were further examined and reported. Four themes were identified: (1) poor public awareness of IBD; (2) difficulties with disclosure; (3) emotional and social public reactions; and lastly, (4) 'self-exclusion'. Participants indicated that their physical health and quality of life are not impacted by their anticipated views, however their psychological health is impacted.

The difficulties faced by those with IBD when interacting in public settings highlight an overarching theme reflecting the taboos surrounding bowel functions and the adverse impact of anticipated public views on psychological health. There is therefore a need to focus attention on implementing public IBD awareness campaigns, and routinely assessing self-excluding behaviours in clinical practice.

Keywords: Keywords: Anticipated Societal Perceptions; IBD; Disclosure; Public Awareness; Emotions; Disgust; Mental Health; Quality of Life.

“Nobody wants to talk about that stuff”: A Qualitative Investigation of the Anticipated Societal Perceptions of Individuals with Inflammatory Bowel Disease

Inflammatory Bowel Diseases (IBDs) are chronic, gastrointestinal conditions that typically comprise Ulcerative Colitis (UC) and Crohn’s Disease (CD; Gajendran, Loganathan, Catinella, & Hashash, 2018). Common symptoms of IBD include diarrhoea (often bloody), abdominal cramps, and fatigue (Gill & Bryant, 2019; Jordan, Ohlsen, Hayee, & Chalder, 2018). Individuals with IBD experience fluctuating episodes of remission and active symptoms, negatively impacting upon engagement in social activities with close others (i.e., family and close friends; Jordan et al., 2018; Purc-Stephenson, Bowlby, & Qaqish, 2015). IBD researchers have extensively investigated the concerns of those with IBD regarding their social network, and their perceptions of the views of close others (e.g., Norton, Thomas, Lomax, & Dudley-Brown, 2012; Saunders, 2014; Taft, Keefer, Leonhard, & Nealon-Woods, 2009). For instance, some participants described that friends and family perceived that IBD was caused by lifestyle and diet factors or believed that IBD was an eating disorder (Norton et al., 2012). Those with IBD have also described feeling rejected by the reactions of friends towards their condition (Piper, 2017; Saunders, 2014). In a qualitative study involving young adults with IBD (Saunders, 2014), a 19-year-old male described that his friends made negative remarks (e.g., “Right, you’re not ever gonna use our toilet again,” p. 1025) about the smells accompanied by his diarrhoea when experiencing a disease flare. As a result, the participant chose to conceal his condition due to the shame he experienced (Saunders, 2014). This provides further evidence of the impact of IBD in daily interactions with one’s social network, and the shame that can be felt within these interactions.

Little research, however, has specifically explored how those with IBD view public perceptions of the condition, despite having to function in public settings (e.g., public bathrooms, shopping centres) with symptoms that would cause embarrassment if they became

outwardly perceptible. In our recent systematic review of perceptions of IBD among those who have the disease (Polak, O'Callaghan, & Oaten, 2020), we found that in studies investigating stigmatisation of IBD, participants reported concerns about societal perceptions of the disease. Most of these concerns related to the societal taboo surrounding bowel conditions and beliefs that participants cannot meet societal expectations of cleanliness that are reinforced and encouraged in society (Cooper, Collier, James, & Hawkey, 2010; Dibley, Norton, & Whitehead, 2018; Woodward et al., 2016). Other qualitative studies report that those with IBD experience fears about exposing their symptoms in public (Daniel, 2002; Hall, Rubin, Dougall, Hungin, & Neely, 2005; Jordan et al., 2018; Larsson, Lööf, & Nordin, 2017; Matini & Ogden, 2016). Another everyday occurrence within the public domain is the use of public bathrooms. Those with IBD report concerns about the reactions of other people when having to use public bathrooms and also report situations whereby the public have questioned the use of their 'can't wait cards' when needing to skip a bathroom queue or when urgently requiring to use a toilet within a department store (Cooper et al., 2010; Daniel, 2002; Larsson et al., 2017; Norton et al., 2012). Many participants attribute these public perceptions to the fact that they often do not outwardly appear unwell (Piper, 2017). Preliminary qualitative findings also indicate that those with IBD perceive poor awareness and knowledge of IBD among the general public, especially compared to other health conditions (Dibley et al., 2018; Matini & Ogden, 2016; Purc-Stephenson et al., 2015).

The aforementioned findings indicate some of the concerns expressed by individuals with IBD regarding the general public. However, to the best of our knowledge, no IBD research to date has specifically explored anticipated societal perceptions of IBD and their impact on the wellbeing of those with IBD. In the current study, we gathered in-depth qualitative opinions of individuals with IBD in order to address the following research questions: *RQ1*: What perceptions and reactions (i.e., perceived societal illness perceptions of

IBD, stigmatisation experiences, and emotional reactions towards IBD) do individuals with IBD think the general public have towards their condition? *RQ2*: What impact do these anticipated societal perceptions of IBD have on participants' physical and psychological health, and their overall quality of life?

Method

Study design

A qualitative design involving individual, semi-structured interviews was used to investigate participants' in-depth opinions in relation to the research questions.

Recruitment

Participants were recruited via advertising an online survey link on Crohn's & Colitis Australia's Facebook page, and online IBD support groups and forums (e.g., Facebook support groups). Many studies have used this purposive recruitment strategy to recruit a suitable number of research participants with IBD (e.g., Knowles, Cook, & Tribbick, 2013; Knowles, Gass, & Macrae, 2013; Matini & Ogden, 2016; Rubin et al., 2009; Taft, Ballou, & Keefer, 2013; Taft, Keefer, Artz, Bratten, & Jones, 2011; Taft et al., 2009). After completing the survey, participants were given the option to elaborate on their views further in a subsequent individual interview. Consenting participants were redirected to a URL to provide their contact details separately to their survey responses. Ethical approval to conduct this study was obtained from the University's Human Research Ethics Committee.

Procedure

Participants were contacted to organise the time and mode of preference for their interview (i.e., face-to-face, skype, or phone). Interviews lasted approximately 45 to 60 minutes and most were conducted via telephone. The lead author (E. E.) conducted 18 interviews, while another author (F. O.) conducted the remaining two interviews (i.e., to ensure confidentiality as these interviewees were known to EE). An interview guide was prepared (see below in

‘data collection’) and reviewed prior to interviewing to ensure consistency across interviewers. Prior to commencing interviews, each participant had the study information and consent sheet read to them; once consent was obtained, the interview proceeded. Participant consent was also obtained to audio-record the interviews and to include the participant’s age, gender and diagnosis with their responses. The interviewer reviewed the definition of the ‘general public’ (i.e., strangers or acquaintances) to ensure that each participant had the same understanding of this term before proceeding with the interview. The interview audio recordings were transcribed verbatim by each interviewer.

Data collection

The authors were guided by the literature searched and synthesised in their systematic review (i.e., Polak et al., 2020) to derive the interview questions. The interview guide was organised into five key areas: (1) perceptions and reactions of the general public to IBD; (2) the general public’s emotional responses to IBD; (3) anticipated societal illness perceptions of IBD; (4) perceptions and experiences of stigmatisation from the general public; and (5) the impact of these views on participants’ physical and psychological health, and quality of life. Key interview questions are presented in Table 3.1.

Data Analysis

Two independent and experienced data coders utilised thematic analysis to examine the transcripts and were blind to each other’s findings. The consolidated criteria for reporting qualitative research (COREQ; Tong, Sainsbury, & Craig, 2007) specifies that the use of multiple data coders can demonstrate further understanding of the topic being explored and therefore, the current study utilised this approach in order to improve the credibility and rigour of the findings and to reduce subjectivity. Further to this, as the authors of this study were involved in both conducting the interviews and transcription, it was deemed appropriate to have independent coders examine the transcripts to reduce potential researcher bias.

The data coders utilised the following five phases as outlined by Braun and Clarke (2006, 2012). These are: (1) ensure familiarity with the data by reading transcripts, (2) develop preliminary codes for the data, (3) search for commonalities between codes to develop initial themes, (4) evaluate and assess themes, and (5) define and give a name to the constructed themes. The data coders generated the preliminary codes using the interview transcripts and recorded their themes and sub-themes. The final list of themes and subthemes were examined further by the research team. Major similarities between each set of final themes and subthemes indicated that the coders independently validated each other's findings. The themes that were identified by both coders were adopted by the research team for the purpose of analysis.

Results

Participants

Twenty individuals with IBD diagnoses (12 with CD, 7 with UC, 1 with Indeterminate Colitis) completed qualitative interviews. Participants were 15 females and 5 males between the ages of 18 and 56 years ($Mage = 32.8$, $SD = 10.54$; $Myears\ diagnosed = 13.69$). Eight participants reported experiencing active disease symptoms, while 12 interviewees reported that they were in remission (three of these participants were experiencing medication side effects and bouts of urgency). Despite one participant residing in the United States (refer to Table 3.2), the Australian clinical guide to best practice for IBD (Gastroenterological Society of Australia, 2018) complements guidelines from the leading gastroenterological societies of other developed countries/regions such as the United States, the United Kingdom and Europe. These include guidelines from the American Gastroenterological Association (Ko et al., 2019), the British Society of Gastroenterology (Lamb et al., 2019) and the European Crohn's and Colitis Organisation (Harbord et al., 2017; Magro et al., 2017). Further demographic information is presented in Table 3.2.

Findings

Four overall themes were identified by both coders: 1) public awareness of the disease; 2) disclosure; 3) reactions of others; and, 4) illness-related self-exclusion. Each theme is discussed below, with illustrative quotes (refer to Table 3.3 for more participant quotes corresponding to each theme). Results regarding the impact of anticipated societal views on participants' physical and psychological health, and quality of life are also presented.

Public Awareness of the Disease

Participants reported that the general public has a lack of knowledge and awareness of IBD, in that the public do not know of the term 'IBD' or what the condition involves, – e.g., “...*I would say that not many people would actually know what it is.... people that have heard of it, they don't really know the details about it, so I'd say they don't know too much.*” (P2 - female, age 28, CD). Participants reported that IBD is not as well-known as more prevalent conditions, such as cancer. One participant compared public knowledge of her brother's treatment for cancer to her own condition: “...*So for example, my little brother went through cancer treatment for lymphoma and if he had walked up to a stranger and said, “I have a type of cancer, which I'm having treatment for,” there would be a level of understanding of that and what that implies. As opposed to me walking up to a stranger on the street and saying, I have a kind of bowel disease and I'm undergoing treatment for that.*” (P17 - female, age 29, CD).

The public's confusion between IBD and Irritable Bowel Syndrome (IBS) was also noted by participants. For example, “*Some people that do know stuff still get mixed up between like IBS and the other conditions like CD and what not. They don't really understand the difference. They might see like ads on TV about IBS, like health products and think that everything is the same and take a probiotic and you're good to go... Yeah they just think*

everything to do with the bowel is kind of the same. If you are kind of having problems with it then you have IBS....” (P6 - male, age 30, CD).

Due to the general public’s poor knowledge of IBD, many participants reported that the public underestimate the severity of the condition and do not take it seriously. Participants often attributed this to the invisible nature of IBD; that is, the symptoms are commonly not outwardly visible or apparent to the public. For example, one participant commented,

“...Because you appear [healthy] on the outside – unless you have dramatic weight loss or something – you appear normal, so when I explain it to them, I don’t feel like they realise how severe it actually is...” (P19 - female, age 24, UC). Another participant stated, *“I don’t think they realise how extreme it [IBD] can actually get.”* (P8 - male, age 49, CD).

Participants reported that poor public awareness of IBD leads them to feel misunderstood, excluded, and not believed by others.

Disclosure

Participants described a number of barriers to disclosing their condition to people with whom they were unfamiliar. For example, participants often felt uncomfortable, nervous and embarrassed to tell members of the public about their condition – e.g., *“...but sometimes I get a little bit nervous explaining it to the general public...I’m reluctant to talk about the symptoms with them...”* (P19 - female, age 24, UC). Participants were also reluctant to disclose their condition due to the possibility of being perceived negatively by others or being reacted to in a negative manner. For instance, a participant reported: *“I find...even myself down playing because I’ve had negative reactions in the past so you know when you just dumb it down and say basically...you go to the toilet a lot, you might get obstructions, and you don’t put on weight because you can’t eat...depending on what information you give them is depending on what reaction they will give you.....yeah varied reactions depending on what you tell them... I’ve never ever with people I barely know, I’ve never ever gone into the*

nitty-gritty and... there is an embarrassment in there for me as well as a protective measure. I guess you just dumb it down a bit so that people don't view you differently." (P3 - Female, Age 49, CD). The preceding quote further illustrates concerns regarding participants' reluctance to talk about IBD symptoms with the general public, which was linked to excluding details about bowel symptoms when disclosing.

The reluctance to disclose one's condition was attributed to the taboo nature of IBD symptoms, as participants perceived that the general public do not want to discuss bodily functions and would alter their explanation of IBD as a result. On the other hand, some participants kept their condition private, as they described that the signs of IBD are often not visible to others: *"...because I feel that I am able to keep my disease and my symptoms well hidden from the general public,"* (P18 - female, age 30, UC). P2 also stated, *"No... I wouldn't tell anyone you know. It's not like a physical thing...not like I have a big rash or something... no one needs to know,"* (female, age 49, CD). Some participants reported that disclosure occurs when they have a necessary reason or purpose for doing so, such as disclosing their condition to their employer when unwell. For example, the following participant stated, *"I think it's a personal medical condition that only needs to be discussed in situations where it's important. I would only ever discuss it with someone if I felt they needed to know. Like my boss. Or if I'm suffering from [laughs] if I'm suffering badly in like a workshop or something and I'm running to the toilet all the time [laughs] if I need to inform someone in that instance then that's fine..."* (P7 - female, age 32, UC).

Reactions of others

This theme encompasses two sub-themes: negative emotional reactions of others and social reactions.

Negative Emotional Reactions of Others

According to participants, the general public display three main emotional reactions towards their condition: disgust, pity/sympathy, and fear.

Disgust. Participants reported instances where members of the public reacted in disgust towards their condition, such as when using public bathrooms. One participant described the reactions of a shop assistant after having to urgently use a bathroom located within a store, “...they [the staff] sort of had a look of disgust and things like that on their face when I came back out..., so yeah it made me feel extremely uncomfortable.” (P9 - male, age 34, UC). Another participant also described disgust reactions from members of the public while using a public bathroom, “I have had a number of incidents where people have actually walked in [to the bathroom] who know nothing obviously about these sorts of conditions and they actually acted with a verbal sort of...this is just incredible, who’s died in here? You know, actually saying things out loud,” (P8 - male, age 49, CD). Participants reported that members of the general public are also disgusted by IBD bowel symptoms, procedures and colostomy bags, with one participant stating, “...and then you’ve gotta add in the surgeries and stuff like that. We’re left all scarred and hacked up, bits missing and of course you’ve got people who have a bag [colostomy bag] and the general public are just horribly disgusted by them.” (P11 - female, age 33, CD with Fistula). Lastly, a female participant reflected that she felt disgusted by her own condition and assumed that members of the public would react in the same manner, “So I think if you put it in that context, if you’re disgusted with yourself why couldn’t you imagine some, you know, stranger being disgusted...?” (P3 - female, age 49, CD).

Pity/Sympathy. Participants reported receiving pity or sympathy after disclosing their condition to a member of the public. For example, a participant stated, “They feel pity for you. Yeah like, say you meet someone and you get to chatting and they say something about

it, the general consensus is - oh poor you, that must be hard.” (P11 - female, age 33, CD with Fistula). Participants described that they typically receive sympathy rather than empathy. One participant described his dislike for other people displaying sympathy towards him: *“But the thing is I’m pretty against sympathy, like I will say I’m alright and people will still feel sorry for you. Like they see what you can’t do and they sympathise with it but doesn’t really bother me like I just get on with life and go with it.”* (P6 - male, age 30, CD).

Fear. Participants had mixed opinions about whether the general public are fearful of IBD. Some participants reported that members of the public are not fearful due to poor awareness of the condition. For instance, a participant stated, *“I don’t think that the general society would be fearful of Crohn’s because they really have no idea about it.”* (P3 - female, age 49, CD). On the other hand, some participants have been asked if IBD is contagious and it was perceived that this reflected a level of fear or apprehension towards IBD – e.g., *“If they hear CD and they think it’s something contagious, so they don’t want to be around you because they are afraid they will catch it.”* (P1 - female, age 30, CD).

Social Reactions

Several other reactions from the general public were reported by participants: judgement, support, discomfort, and curiosity.

Judgement. Participants described feeling judged for their frequent bathroom use, their appearance, the taboo nature of their condition and food intolerances that result from IBD. One participant reported an instance where she felt negatively judged after losing weight from IBD: *“...I went down to 39 kilos, people thought that I had anorexia and they judged me on that, when you’re six feet tall, 39 kilos, that’s pretty bad.... Oh, yeah you could see ribs, backbones the works....so in the general public, yeah you could see the looks. They looked at you twice. And I heard one lady at the shop say to her little girl, “See that’s what happens when you don’t eat.”* (P3 - female, age 49, CD). Another participant described

anticipating judgement in the event that she had a bowel accident in public, *“But yeah, I think the general public in that instance would just be like, ‘Oh my god, what is wrong with that person?’ And wouldn’t ever think like it was a chronic medical condition,”* (P14 - female, age 26, UC).

Support. Despite the negative reactions experienced by those with IBD, participants also reported feeling supported and understood by people they are unfamiliar with. For instance, a participant reported, *“I was working in a job and I was working in the shopping mall...with a couple of old ladies who I had never worked with before and I just suddenly got a really bad flare up and so had to go to the bathroom and I was really sick and I tried to explain to them that I had CD and that I would have to go home. It was, yeah, it was pretty bad but... they understood and heard about it before and so they were quite understanding.”* (P2 - female, age 28, CD). Participants described that members of the public have shown genuine concern upon hearing about their IBD, and have experienced positive reactions. For instance, a participant stated (P15 - female, age 27, Indeterminate Colitis), *“Usually it’s concern...they don’t realise that it is like long-term and they seem sort of shocked and concerned about you, yeah,”* while another participant stated, *“Most people that you tell either don’t know what it is or they seem impressed that you have been able to hold it together so well....so.”* (P5 - male, age 34, UC).

Discomfort. Participants perceived that members of the public appear to experience discomfort when hearing about IBD symptoms. A participant described this discomfort: *“I would just say maybe, it’s just uncomfortable. They seem uncomfortable with the conversation. I don’t know how to – what emotion to put with that – just discomfort...”* (P19 - female, age 24, UC). Participants felt that the public’s unease stems from the nature of IBD symptoms, insofar as they relate to the bowels. For instance, a participant stated, *“Yeah, so when I’m in a big flare and symptoms include ulcers and like bloody diarrhoea, those are the*

things that people sort of get turned off by and not wanting to talk about it,” (P15 - female, age 27, Indeterminate Colitis). In response to hearing about IBD, members of the public were reported to avoid further discussion of IBD – e.g., by changing the topic or discontinuing with questions. One participant reflected: *“So they’ll either go quiet, they change the topic or it will be their facial reactions of like ohhh...they’ll pull back from you,”* (P13 - female, age 43, CD).

Curiosity. Another reported public reaction towards IBD was curiosity. Participants reported that members of the public were curious upon hearing of their condition and were genuinely interested in learning more about IBD; for example: *“...Get somebody who genuinely wants to learn, wants to know even if it’s someone you just met on the bus and you’re just talking coz you got a long bus trip or whatever. So some of them genuinely want to know and will ask questions,”* (P1 - female, age 30, CD).

Illness-Related Self-Exclusion

Rather than feeling excluded by other people, participants instead described how they excluded themselves from public settings involving social occasions and events. Two key factors were identified as barriers to participating in public activities, and these factors formed two subthemes: self-exclusion – illness; and self-exclusion – functional.

Self-Exclusion – Illness

Participants felt uncomfortable leaving their homes when experiencing bowel symptoms and reported frequently cancelling their plans. In response to being asked if she ever felt excluded, a participant stated, *“If I have its usually on my end and not their end...umm...it’s usually because I can’t participate or I committed to do something and then I can’t because I’m in the hospital or I’m too sick,”* (P1 - female, age 30, CD). Another participant described being unable to attend social events due to symptoms: *“Yeah, so once again, going back to when I was first diagnosed, and once again prior, it was something where I didn’t like being*

out in the public, because I knew that I was still having those severe symptoms, I knew the ramifications of that, so yeah, there was a lot of times where there were different events and things and like that being hosted in the public, that I would have liked to have gone along to, but, didn't feel comfortable going... I felt embarrassed with what I had. I thought that if people notice me going to the bathroom quite often, they would have the wrong impression and things like that..." (P9 - male, age 34, UC). This quote illustrates the impact of severe IBD symptoms on an individual's ability to attend social events, as well as concerns about others making judgements about toilet habits.

Self-Exclusion – Functional

Participation in social activities was also limited due to functionality, in that participants often avoided public settings due to difficulties accessing public toilets and food intolerances that result from IBD. Participants reported they are unable to eat the food available at restaurants or cafes and therefore, would avoid attending these types of social occasions. For example, a participant stated, *"Oh well, lots of restaurants don't have foods that I can eat so, I would just have to sit there and like yeah this is fun [laughs]. I feel like sort of...I don't see the point in sitting there and going there to not eat..."* (P6 - male, age 30, CD).

A frequent concern for participants was avoiding events with difficult access to public toilets. This commonly occurred in settings with large crowds queuing to use public toilets, such as in shopping centres, music concerts/festivals and in bars/nightclubs.

Participants preferred to not attend public settings where the location of the toilets was unknown. For instance, a participant reported, *"If I don't know where the toilets are, sounds terrible, but if it's really bad, if you don't know where the toilet is, there is a very low chance, if I'm going to an event, there's a very low chance that I'll go,"* (P7 - female, age 32, UC).

The ease of access to public bathrooms was a source of concern and fear for participants and is illustrated by the following quote, *"I avoid things that I know will make me really nervous.*

I avoid things where I know I'm going to be really uncomfortable. I avoid things where I don't know like the location of bathrooms. That sometimes stops me from doing things," (P19 - female, age 24, UC). Another participant described frequently avoiding public events when he was first diagnosed due to being unwell and reported that this impacts him when he considers attending future social occasions:

"...even though these days I'm a lot better, there's still certain social situations that I won't include myself in, so once again where there's major community events and things like that, it's just that, there were things that I had to avoid for so long, that now being with sort of that many people, not having a bathroom by me and things like that, that fear just comes rushing back, and yeah, it's still something that I just can't do," (P9 - male, age 34, UC).

Physical and Psychological Health, and Quality of Life

Overall, participants denied that their physical health is impacted by their anticipated societal views of IBD, with one participant stating, *"...Physical health, no not at all. I can do whatever my body allows regardless of what people think,"* (P12 - male, age 19, CD). A few however, endorsed that these views impact their physical health. For instance, a participant discussed that avoiding public toilets would often lead to cramps, *"...I would try and like hold things in. Like hold going to the toilet or something like that and that would start cramps or something like that. Yeah that's happened where I've tried to like avoid [using the toilet] and you know that's probably worked out worse for me,"* (P14 - female, age 26, UC).

Mixed findings were reported about the impact of anticipated negative public reactions on psychological health. Some participants reported that their anticipated negative public reactions affect their psychological health. Participants described concerns about the risk of bowel accidents occurring in public, negative comments about weight loss, and lack of public knowledge of IBD as factors that impact their psychological health. One participant commented, *"...having an accident when you're out can affect you psychologically..."* (P10 -

female, age 56, CD). Another participant elaborated on a factor that impacts her psychological health, *“Yeah, it does because I guess the general public, I feel, doesn’t have a lot of information about it and they don’t understand how severe it is...It sometimes gets me down a little bit because people don’t know how bad it can be and... yeah, it has affected my psychological health,”* (P19 - female, age 24, UC). However, other participants felt that these views do not impact their mental health, as depicted by the following quote, *“Well no, like, not me personally.... I’m pretty tough-minded. I don’t really care what people think...so no, it does not affect my psychological health”* (P2 – female, age 28, CD).

Lastly, participants considered that their quality of life is *not* impacted by their anticipated public perceptions of IBD, but rather by the symptoms of IBD and having to take medications and attend regular medical appointments. Some participants described persevering despite having IBD. For instance, after being asked if these views impacted her quality of life, a participant stated, *“No, not in the slightest. It’s just who I am now, so it’s part of my life and if people don’t like it, then they don’t have to. I was told by my doctors not to go to study, or work, just take care of it but I didn’t accept that. It was hard getting my strength back but I just kept doing the things I wanted to do.”* (P16 - female, age 20, CD).

Discussion

We explored in-depth qualitative opinions of how those with IBD view societal perceptions of the condition (RQ1), as well as investigating the potential impact of these views on participant wellbeing (RQ2). In answering *RQ1*, participants identified the following concerns about societal views and reactions towards IBD: 1) public awareness of the disease; 2) disclosure; 3) reactions of others; and, 4) illness-related self-exclusion.

To the best of our knowledge, this is the first study to specifically question participants with IBD about societal perceptions of their condition. Participants reported that the general public do not understand what the term ‘IBD’ is, or what the condition involves. This point

was further illustrated when participants compared poor public knowledge of IBD and its treatment to that of more prevalent conditions such as cancer. Qualitative reports also indicated that poor public awareness and knowledge of IBD contributes to poor public understanding of the severity of the disease and leads to it being confused with other conditions with similar symptoms (e.g., IBS). Our results, in conjunction with findings from other studies (Dibley et al., 2018; Frohlich, 2016; Matini & Ogden, 2016; Purc-Stephenson et al., 2015) highlight the concerns of many individuals with IBD that there is poor public awareness and knowledge of the disease.

Our results provide important new insights for those with IBD facing disclosure to unfamiliar others. Participants reported that they would feel uncomfortable and embarrassed to disclose their condition to the general public and fear they will be judged negatively upon disclosure. Findings also revealed that explanations about bowel symptoms are often omitted when disclosing one's IBD and this appears to serve a self-protective function, in that participants perceive that this reduces the negative perceptions and reactions from others. Our findings, along with prior literature, suggest that the reluctance to discuss their IBD symptoms is because topics concerning faecal matter are largely taboo (Woodward et al., 2016) and are considered an inappropriate subject for conversation (Dibley et al., 2018). It is important to note that interviewees reported that they often keep their condition private as their IBD symptoms are not physically visible to others. Further insight into this finding is provided by early research by Goffman (1963) who noted that individuals living with 'invisible' chronic conditions can either openly discuss or conceal their condition, with the latter associated with the risk of being 'found out' and experiencing stigma as a result. This suggests that the invisible nature of IBD provides individuals with some flexibility regarding disclosure. However, in the current sample, some interviewees appeared to engage in protective disclosure – insofar as they choose when and how they disclose to specific

individuals (Joachim & Acorn, 2000), by disclosing when there is a necessary purpose to do so (e.g., disclosing to their employers). Therefore, this indicates a complex decision-making process for those with IBD, who need to decide whether to disclose their condition, or risk others finding out about their condition, a concern reported in previous qualitative studies (Hall et al., 2005; Woodward et al., 2016). While reluctance to disclose IBD has been reported previously (e.g., Dibley et al., 2018; Hall et al., 2005; Jordan et al., 2018; McMullan et al., 2017; Woodward et al., 2016), our findings extend the literature by exploring concerns about disclosing to the general public and other unfamiliar persons.

Furthermore, those with IBD reported experiencing a range of emotional and social reactions from the public: disgust, pity, sympathy, fear, support, curiosity, judgement and discomfort. Little research has investigated the role of disgust in IBD (Polak et al., 2020). Some research has suggested that individuals with IBD are disgusted by their symptoms and infer that other people would be similarly disgusted (Dibley et al., 2018; Piper, 2017; Woodward et al., 2016). The current study, however, provides insight into the aspects of IBD that can elicit public disgust. For instance, a common theme identified was that participants reported that the public have reacted in disgust in response to their use of public bathrooms, as indicated by facial expressions exemplifying disgust or by making negative comments about smells. Qualitative reports also indicated that the public are disgusted by colostomies. Participants also reported that they dislike receiving pity and sympathy from the public, which is congruent with prior literature (Saunders, 2014). Mixed findings were reported in relation to fear, with some perceiving that the public are unable to fear a condition that they are unaware of, while others stated that the public fear that IBD is contagious.

This is the first study in which participants reported the public to show genuine curiosity and interest in learning more about their condition. Further to this, participants reported instances of feeling supported by the public. Prior research has reported that participants have

felt supported by close others such as family, and in work settings by employers and colleagues (Frohlich, 2014), however, our findings highlight that strangers and unfamiliar others also show support to those living with IBD. We also found that participants experienced negative social reactions such as judgement and discomfort from the general public. This included stigmatising comments about the appearance and the frequency of bathroom use by those with IBD. The public also displayed discomfort upon hearing of this condition, exemplified by facial expressions and avoidance (e.g., changing the topic, pulling back). These behaviours are consistent with reactions of disgust, which can include withdrawal from a disgust-eliciting stimulus (Oaten, Stevenson, & Case, 2009; Rozin, Haidt, & McCauley, 2000).

Further to this, we found that participants withdrew and excluded themselves from situations due to their illness and other functional reasons like food intolerances and difficulties accessing public toilets. Difficulties accessing bathrooms at events with large crowds was a cause of fear and anxiety for participants. Concerns about toilet availability have also been noted in previous studies (McMullan et al., 2017; Sammut, Scerri, & Xuereb, 2015; Savard & Woodgate, 2009). We propose that participants' self-exclusion is motivated by fears or concerns about accidents occurring in public, and so in order to prevent accidents, individuals choose to exclude themselves from social situations due to anticipating or experiencing urgent bowel symptoms, as well as accessing public toilets. In our recent review (Polak et al., 2020), fears of losing control of bowels was the most common emotional response reported by individuals with IBD. These concerns resulted in participants avoiding public outings. Therefore, this highlights that the symptoms and other related concerns (e.g., food intolerances) caused by IBD are a barrier to participating in social events and contribute to self-imposed exclusion for individuals with IBD.

In relation to *RQ2*, this was the first qualitative study to investigate the impact of anticipated societal views of IBD on wellbeing. Most participants perceived that their physical health and quality of life are not impacted by their anticipated societal views of IBD. Qualitative reports suggested that these interviewees prefer not to focus or ruminate on the opinions of other people, but rather choose to focus on their physical health and pursuing their goals. Themes of personal growth and identifying new life goals due to IBD have been reported previously by participants with IBD (Purc-Stephenson et al., 2015). In the current study, however, mixed findings were reported for psychological health, with some feeling that their mental wellbeing was adversely affected and others feeling that IBD had resulted in positive growth. Concerns about misconceptions of IBD and that potential partners will not find those with IBD attractive were linked to low mood in a previous study (Jordan et al., 2018). The current findings, therefore, highlight the negative impact of concerns about the views of others on psychological health.

Strengths, Limitations and Future Research

This is the first qualitative investigation of anticipated societal perceptions of IBD. We devised and utilised a comprehensive interview guide to gather responses and used this guide consistently across interviews. Additionally, we utilised protocols consistent with COREQ to examine the data and our sample was representative of varied ages and IBD diagnoses. However, potential limitations can also be identified. Those who consented to participate in interviews may have differed from others in terms of their views on the topic being explored, their psychological and physical health, and their concerns about the impact of public perceptions on their own wellbeing. Additionally, as the interview related to psychological constructs, consenting participants may be more likely to express their concerns to others or engage in support (Jordan et al., 2018). Most participants resided in Australia and identified as female, and this may further impact the generalisability of our findings. Despite this, our

findings appear to be consistent with prior IBD literature. Future research could extend these findings by recruiting a larger and more culturally diverse sample to explore consistencies and differences in concerns across different ethnic groups. Researchers could also interview members of the public to explore their perceptions and knowledge of IBD and compare findings across patient and public samples.

Implications

The findings of this study have practical and clinical implications. Limited public awareness of IBD could be addressed by relevant organisations utilising advertising campaigns to increase public knowledge of IBD, such as educational signage in public areas, or online, television and radio advertisements. Public advertising campaigns may assist in debunking the public's myths and misconceptions of IBD, which in turn, may contribute to those with IBD feeling better understood by the general public and less reluctant to disclose their condition to others (Saunders, 2014). In relation to clinical practice, these findings can be used to inform health professionals of other concerns held by individuals with IBD. Concerns about public perceptions of IBD can be included as components of assessment and treatment. Further to this, the impact of these concerns on patient wellbeing can also be assessed and treated. This may involve a collaborative discussion to consider decision making for disclosure and to evaluate patient preferences regarding how they disclose their condition in these circumstances. Given the prevalence of self-exclusion from public settings, this could be included as a routine assessment question. This would assist in identifying those who are withdrawing from social occasions and other rewarding activities (e.g., hobbies, physical activity), as well as those that are hypervigilant towards possible signs of urgent bowel symptoms (Jordan et al., 2018). Identifying and decreasing restrictive behaviours may, in turn, improve wellbeing (Jordan et al., 2018).

Conclusions

Overall, participants reported: 1) the public have little knowledge and understanding of IBD; 2) difficulties disclosing their condition to unfamiliar others; 3) experiencing both positive and negative reactions from the public, and 4) few concerns about feeling excluded by others, but instead reporting instances of withdrawing themselves from public settings due to symptoms and other functional reasons. We propose that the findings are connected to an overarching theme concerning the taboos surrounding bowel functions and the adverse impact of anticipated societal views on psychological health and behaviour (e.g., non-disclosure and concealment of one's condition).

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Table 3.1. Examples of Interview Questions

Topic and Questions
<p>1. Perceptions and Reactions of Others</p> <p><i>"What perceptions/views do you think the general public has of IBD or the specific symptoms of IBD?"</i></p> <p><i>"How do you think a close friend or a person in your social circle would react if you told them about the symptoms of IBD?"</i></p>
<p>2. Illness Perceptions</p> <p><i>"How much do you think the general public knows about IBD and its symptoms?"</i></p> <p><i>"Does the general public have awareness that IBD is a chronic disease?"</i></p>
<p>3. Emotional Responses</p> <p><i>"If you think about all the different emotions we can have, what emotions do you think the general public may have in response to IBD?"</i></p>
<p>4. Stigmatisation</p> <p><i>"Have you ever been excluded or felt stigmatised by the general public because of Ulcerative Colitis/Crohn's Disease?"</i></p>
<p>5. Quality of life, Physical and Psychological Health</p> <p><i>"Do these views, perceptions and reactions from the general public influence your.... "</i></p> <p><i>a. physical health?</i></p> <p><i>b. psychological health?</i></p> <p><i>c. quality of life?</i></p>

Table 3.2. Participant Demographics ($N = 20$)

	Total ($n =$ 20)	%	M (SD)
Female	15	25%	
<i>Age</i>			32.80 (10.54)
18-29	8	40%	
30-39	7	35%	
40-49	4	20%	
50-56	1	5%	
<i>Country of Residence</i>			
Australia	19	95%	
USA	1	5%	
<i>Diagnosis</i>			
Crohn's Disease	12	60%	
Ulcerative Colitis	7	35%	
Indeterminate Colitis	1	5%	
<i>Disease Duration</i>			13.69 (10.79)
<1 yr	1	5%	
1-5 yrs	6	30%	
6-10 yrs	2	10%	
11-15 yrs	5	25%	
16-25 yrs	2	10%	
26-36 yrs	4	20%	
<i>Age at Diagnosis</i>			19.60 (3.87)
15-17 yrs	6	30%	
18-23 yrs	11	55%	
24-28 yrs	3	15%	
<i>Disease Status</i>			
Active Symptoms	8	40%	
Remission	12	60%	

Table 3.3 Example Quotes for each Theme

Theme/Subtheme	Example Quotes
1) Public Awareness of the Disease	<i>"I don't think that they understand that there is a difference of say irritable bowel syndrome or Crohn's and Colitis. I think from judging from my... from the responses that I get you know they immediately say, 'what's that?' So there's not a lot of knowledge out there."</i> (P3 - Female, age 49, CD).
2) Disclosure	<i>"I try to be careful with what I say....like just...general...like you know it hurts a lot or it makes me feel tired...I try not to say...you know it also causes horrible diarrhoea and you know....nobody really wants to talk about that stuff..."</i> (P5 - male, age 34, UC).
3) Reactions of others	
Negative emotional reactions:	
disgust	<i>"I think there would be some members of the general public that would have a negative reaction to it, of basically again just being grossed out by it. Like there would be lots of people out there who would have never experienced any problems or issues, like gastrointestinal issues and so to them they would think it's quite gross..."</i> (P18 - female, age 30, UC).
pity/sympathy	<i>"I have noticed that I get a lot of pity, and they'll go, 'oh you poor thing, that's awful'."</i> (P14 - female, age 26, UC).
fear	<i>"I get asked a lot like how common is it, is it contagious, what are the odds that I would suddenly get this...um...a little of fear but no more so than the fear of getting cancer or developing MS or Lupus. There would be fear but I don't think overwhelmingly so,"</i> (P1 - female, age 30, CD).
Social reactions:	
judgement	<i>"So more like people thinking your weird going to the toilet all the time...sort of why are you doing this?"</i> (P6 - male, age 30, CD).
support	<i>"Usually the first response is concern"</i> (P16 - female, age 20, CD).
discomfort	<i>"I think the bowel, anything to with poo, anything coming out of that end, if you mention anything to do with the bowel, it's very uncomfortable for them,"</i> (P13 - female, age 43, CD).
curiosity	<i>"I have recently had contact in that regard to someone that I would class as an acquaintance that I don't know. And they were quite shocked but very interested,"</i> (P8 - male, age 49, CD).
4) Illness-Related Self-Exclusion:	
Self-Exclusion-Illness	<i>"Well when I had my flares I just didn't feel like doing anything, I stayed at home all the time,"</i> (P12 - male, age 19, CD).
Self-Exclusion-Functional	<i>"...or if I know I might not be able to get to bathroom, I probably won't go or if I'm going to be out for a really long time and be stuck there for a while, I'll probably not go,"</i> (P4 - female, age 18, UC).

CHAPTER 4**STUDY 3****EXPLORING SELF AND ANTICIPATED SOCIETAL PERCEPTIONS OF
INFLAMMATORY BOWEL DISEASE**

Chapter 4 contains Study 3, presented in the form of an unpublished manuscript that has been submitted for publication. The formatting required by the publisher for submission was retained. All tables are presented within the paper and all references are listed at the end of the chapter. The supplementary materials are presented in Appendix C.

Statement of Contribution to Co-authored Paper

This chapter includes a co-authored paper, which has been submitted for publication. The bibliographic details of this co-authored paper, including all authors, are:

Edwards, E.-J., Oaten, M., & O'Callaghan, F. Exploring self and anticipated societal perceptions of inflammatory bowel disease. *Submitted for publication.*

My contribution to the paper involved:

- Review of the literature
- Co-development of research questions
- Co-development of measure
- Applying for ethical approval
- Recruitment of participants
- Data management, co-selection of data analyses, and lead in conducting data analyses
- Lead in drafting and writing of paper
- Corresponding author of the journal submission

(Date) 18 March 2020

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(Date) 19 March 2020

Supervisor: A/Prof Megan Oaten

(Date) 18 March 2020

Supervisor: A/Prof Frances O'Callaghan

See Appendix B for the information and consent from

Abstract

Background: Inflammatory Bowel Diseases (IBDs) are lifelong, gastrointestinal conditions.

Much research has investigated the concerns of those with IBD regarding their social network. However, little research has explored the anticipated societal perceptions of those with IBD and their impact on individual well-being. Therefore, the following research questions were explored: Are there demographic differences (i.e., according to age, gender and illness severity) in the societal perceptions of IBD in those experiencing the disease?

Do anticipated societal perceptions of IBD negatively impact mental and physical functioning? Do negative self-perceptions regarding one's IBD contribute to negative anticipated societal perceptions of IBD?

Methods: A cross-sectional, survey design was utilised. Individuals with IBD completed online surveys, incorporating the following measures: Anticipated societal perceptions of IBD, Brief Illness Perceptions Questionnaire, perceptions of internalised stigma, Three-Domain Disgust Scale, and the The Short-Form 12-version 2.

Results: The sample consisted of 132 participants with IBD ($M_{age} = 32.17$, $SD = 10.41$; % *Female* = 68%; $M_{years\ diagnosed} = 9.33$, $SD = 8.44$). Anticipated societal views of IBD did not differ according to demographic factors. Anticipating negative societal perceptions of IBD significantly contributed to poorer physical and mental health. Internalising negative attributes regarding one's IBD significantly contributed to perceptions that the public will view IBD negatively.

Conclusion: Anticipating negative public perceptions towards IBD impacts upon participant wellbeing and has implications for clinical practice in light of the important link identified between self and public perceptions of IBD.

Key Words: Inflammatory Bowel Disease, societal perceptions, psychological health, illness perceptions, stigmatisation and disgust

Exploring Self and Anticipated Societal Perceptions of Inflammatory Bowel Disease

Inflammatory Bowel Diseases (IBDs) are conditions with ongoing bowel symptoms. The two prominent types of IBD are Crohn's Disease (CD) and Ulcerative Colitis (UC). These are lifelong, global diseases that commonly involve inflammation of the colon, rectum or anywhere along the gastrointestinal tract [1]. IBD is characterised by fluctuating episodes of disease flares (active symptoms) and remission that can often be unpredictable. Symptoms include frequent diarrhoea, urgency to move bowels, flatulence, faecal incontinence, abdominal pains, and skin conditions. IBD adversely affects physical health (e.g., extreme fatigue) [2], and mental health (e.g., low mood) [3]. It also leads to social difficulties for an individual with IBD, such as frequently missing out on social events with members of their social network [4].

Demographic Factors Impacting Anticipated Societal Views

It is yet to be explored if those of varying demographics have different anticipated societal views of IBD, compared to other demographic groups. This issue was addressed by the following research question: *Are there demographic differences (i.e., according to age, gender and illness severity) in the societal perceptions of IBD in those experiencing the disease?* In our recent review, a pattern emerged whereby females with IBD appeared to have poorer quality of life, more negative illness perceptions towards IBD, and increased anxiety, depression and concerns about being stigmatised, relative to males [5]. Earlier research reported that older females reported more concerns about disease stigma relative to younger females [6]. Research evidence also suggests that older age groups with IBD are more likely to perceive IBD as chronic and as having severe consequences [7], and experience increased emotional concerns relative to younger individuals with IBD [8]. In regards to illness severity, females with active IBD symptoms reported more negative illness perceptions in facets of illness identity, emotional response and timeline (i.e., viewed IBD as chronic), than

males [9], and those with active symptoms are also more likely to experience increased feelings of embarrassment, fear and anger, compared to those in remission [10]. Experiencing a higher number of IBD symptoms has also been linked to increased feelings of shame [11, 12]. These findings indicate possible differences in perceptions and reactions in IBD, according to an individual's gender, age and illness severity. Consequently, we hypothesised that females, older individuals, and those with active IBD symptoms, would be more likely to anticipate negative public perceptions of IBD.

The Impact of Anticipated Societal Perceptions of IBD on Mental and Physical Functioning

A number of studies have explored the concerns of those with IBD regarding their social network (e.g., friends, family and employers). For instance, research has reported that those with IBD feel stigmatised by their social network [13, 14]. Two studies suggested that perceiving stigma from members of one's social network is predictive of poorer self-esteem, and higher rates of depression [13, 15]. In relation to family members, those with IBD report that their families do not fully comprehend their condition, or blame them for their condition [16-18]. These concerns can lead to feelings of isolation and rejection (Piper, 2017, unpublished dissertation). In addition, individuals with IBD also express concern regarding the views of their employers and colleagues [2, 19], believing they have a limited understanding of IBD and the extent of its impact on daily life [2, 16].

However, not only do those with IBD have to interact within their social network, they also have to regularly interact with community members in public settings (e.g., using public bathrooms in a shopping centre). Therefore, it is also important to understand community awareness and opinion regarding IBD, although little research has explored this. IBD is relevant in a societal context insofar as bowel symptoms, like bloody diarrhoea, are not openly discussed in public, but rather are considered a private matter [20, 21].

Preliminary research indicates those with IBD report concerns about experiencing a disease flare in public and exposing their bowel symptoms [4, 16, 22-24]. They feel that in this circumstance, the public will view themselves, as disgusting [19, 25]. Further to this, those with IBD perceive that there is poor public awareness of IBD, compared to that of other conditions [16, 19, 24, 26].

Unsurprisingly, for those with IBD, anticipating negative perceptions from the public, coupled with low public awareness of IBD, is likely to have negative implications. Potential consequences reported in the literature are avoidance of situations where there is a likelihood of exposing one's symptoms [4, 24, 27], minimising one's condition and/or symptoms (Piper, 2017, unpublished dissertation), and actively concealing one's condition [16], as well as embarrassment when bowel symptoms occur in public [18, 28, 29]. Despite the likely negative impact of public perceptions on those with IBD, little research has investigated the anticipated societal views of those with IBD and how such concerns impact self-reported wellbeing. This gap within the IBD literature was investigated in the current research by seeking to answer the following research question: *Do anticipated societal perceptions of IBD negatively impact mental and physical functioning?*

Research investigating anticipated views of individuals with another condition – a colostomy – suggests that those who view and respond to their colostomy in a maladaptive manner, anticipate that other people will also view their condition negatively [30]. Findings revealed that individuals with higher disgust sensitivity were more likely to anticipate negative reactions to their colostomy, and this was, in turn, associated with poorer adjustment and well-being [30]. This finding is important as it suggests a possible mechanism for how individuals with bowel conditions, like that of IBD, may construct or form societal views of themselves and their condition; for example, through that of their own personal perceptions and reactions to their condition.

Indeed, research findings exploring social processes indicate that people tend to overestimate the extent to which others have the same beliefs and characteristics as themselves [31, 32]. To date, IBD literature has not yet explored whether individuals with more negative perceptions and reactions towards their IBD, also infer that the general public has similar views towards IBD. To investigate this further, the following research question was addressed: *Do negative self-perceptions regarding one's IBD contribute to negative anticipated societal perceptions of IBD?* Specifically, this study focused on three factors that are theorised to impact upon illness adjustment [33]: 1) the emotion of disgust, 2) illness perceptions, and 3) internalised stigma. Based upon the aforementioned findings by Smith and colleagues [30], we expect that individuals with IBD who (i) possess higher levels of disgust sensitivity, (ii) have more negative illness perceptions, and (iii) internalise stigmatising attributes towards themselves, will in turn, anticipate more negative societal views towards their condition. Research findings regarding the emotion of disgust, illness perceptions, and internalised stigma are presented below.

Self-Perceptions and Reactions Impacting Anticipated Societal Views of IBD

Disgust

The emotion of disgust is considered to prevent contact with potential sources of contamination [34-36]. The extant literature suggests there are stable individual differences in one's propensity to experience disgust and this is referred to as disgust sensitivity [37, 38]. Research indicates that an individual's disgust sensitivity can influence life satisfaction and adjustment of those with faecal incontinence [39] and colostomy [30] – both conditions also involve bowel symptoms similar to IBD. Disgust sensitivity can also influence engagement in health screening behaviours such as colorectal cancer screening, which involves the collection of one's faeces [34, 40]. Disgust motivates individuals to avoid contact with faecal matter, however, those with bowel conditions, like IBD, have unavoidable contact with their

faecal matter due to experiencing urgent bowel symptoms. Despite this, little research has explored the role of disgust in IBD. However, one qualitative study reported that a participant with IBD labelled her symptoms involving blood and mucus as disgusting, and assumed that other people would also be disgusted by her condition [19]. Given the impact of disgust on patient outcomes in other conditions involving bowel symptoms, its potential role in the formation of societal perceptions of IBD warrants investigation.

Illness Perceptions

Illness perceptions are cognitive theories of one's condition that, in turn, assist individuals in comprehending their condition [41, 42]. Illness perceptions play a role in influencing the psychological and physical functioning of those with health conditions [43, 44]. They guide the use of coping behaviours utilised by the individual, which in turn influences their illness outcomes (i.e., psychological and physical health) [43, 44]. Severe IBD disease activity indirectly influences poorer psychological health via combinations of negative illness perceptions and maladaptive coping strategies [45-47]. The accumulation of research on illness perceptions in IBD suggests that individuals can utilise either adaptive or maladaptive coping behaviours or experience different outcomes (e.g., anxiety or positive well-being), depending on their illness perceptions [5].

Although some research has explored the illness perceptions of those with IBD, the question of whether or not individuals with IBD expect other people to cognitively perceive their illness in a similar manner to themselves has not been investigated. Indeed, research suggests that the formation of meta-perceptions (i.e., individuals' beliefs about how others view them) [48], are biased and influenced by automatic and implicit processes, in that individuals project their own attributes and beliefs onto others [49, 50]. If projection of one's illness perceptions onto others occurs, this may impact an individual's psychological

functioning, similarly to the manner in which negative illness perceptions regarding IBD are predictive of poorer psychological wellbeing.

Internalised Stigma

Another factor that may impact illness outcomes in IBD is stigmatisation. Recent research has delineated stigma into three domains – internalised (e.g., labelling oneself as ‘dirty’), perceived/anticipated (e.g., perceiving one will be treated differently upon disclosure of condition), and enacted (or experienced) stigma [51-53]. As noted previously, stigma in IBD is linked with poor patient outcomes such as depression [13, 15]. Those with IBD have also reported experiencing discrimination (i.e., enacted stigma) in their workplaces (e.g., refused work) [18, 26, 54, 55], and being excluded in social situations [19, 56]. However, the current study focused on internalised stigma, which refers to internalising negative stereotypes and stigmatising attributes of one’s condition [57]. In a quantitative study exploring internalised stigma in IBD [57], researchers found that approximately one-third of the sample experienced internalised stigma. Most participants endorsed items related to alienation and social withdrawal. Results indicated that internalised stigma significantly predicted poorer quality of life, and higher psychological distress for individuals with IBD, highlighting the impact of attributing negative characteristics towards oneself. However, IBD research has not yet investigated how internalised stigma contributes to anticipated societal views of IBD, an issue addressed in the current research.

Methods

Participants

Of 192 participants who completed the survey, 139 completed all measures (completion rate: 72%). Seven participants were excluded from analyses due to providing a diagnosis other than IBD. The final, online sample consisted of 132 participants with self-reported IBD diagnoses ($Mage = 32.17$, $SD = 10.41$). The majority were females with CD who resided in Australia and were married/living with a partner (refer to Table 4.1). Over half of the sample

Table 4.1. Demographic and Clinical Information ($N = 132$)

<i>Demographic Variables</i>	<i>N = 132</i>	<i>%</i>
Age (<i>M, SD</i>)	32.17	10.41
Gender		
Male	41	31%
Female	90	68%
Other	1	0.8%
Place of Residence		
Australia	78	59%
USA	34	25%
Canada	8	6%
Europe	6	4.5%
UK	2	1.5%
South Africa	2	1.5%
New Zealand	1	0.8%
South America	1	0.8%
Employment		
Employed	97	73%
Unemployed	12	9%
Other (e.g., home duties, student)	23	17%
Education		
University/College Degree	85	64%
Certificate/Diploma	23	17%
Secondary (High School)	23	17%
Other (e.g., Trade)	1	0.8%
Relationship Status		
In a Relationship	83	63%
Not in a Relationship	49	37%
<i>Clinical Variables</i>		
IBD Diagnosis		
CD	60	45%
UC	57	43%
Other (e.g., Indeterminate Colitis)	15	11%
Disease Duration (years)	9.52	8.7
Experiencing Onset of Disease		
Yes	17	12.8%
No	115	87.1%
Remission		
Yes	44	33.3%
No	88	66.6%

indicated they were experiencing relapse or active symptoms, or early onset of IBD symptoms. One-third of the sample indicated that their symptoms were in remission.

Procedure

Participants were recruited by advertising an online link through: 1) Crohn's and Colitis Australia's Facebook page; 2) social networking sites (e.g., IBD support groups on Facebook); and (3) internet health forums. This recruitment method was utilised to recruit the required number of participants for analyses. Advertising a survey link on various online platforms has been used by a number of studies investigating IBD [13, 15, 24, 45, 57-59] due to the challenges in obtaining a sample with a chronic disease. Participants completed the questionnaire on an online-survey platform that was available from March 2017 to December 2017. At the end of the survey, participants could opt to complete an individual interview to provide their opinions on the research topic in more depth (these findings are reported elsewhere). Ethical approval to conduct this research was granted by the University's Human Research Ethics Committee.

Measures

Demographic and Clinical Information. Participants were asked to provide their demographic and clinical information (e.g., their IBD diagnosis and duration, and their relapse/remission information).

Anticipated Societal Views of IBD. Currently, there is no publicly available scale to measure the anticipated societal perceptions of individuals with IBD. Therefore, the authors developed eight items to assess this construct (refer to Electronic Supplementary Material 1, Appendix C). Items were informed by IBD literature and were piloted by three individuals with confirmed diagnoses of IBD. Pilot participants rated the items on coherency and relevance, and also provided qualitative feedback. The eight items were modified based on pilot feedback.

The eight items did not reach adequate reliability (Cronbach's Alpha = .67) and upon further investigation, two items were excluded (i.e., Items 1 and 2), as it was found that they did not correlate highly with the other items. The remaining six items showed good internal consistency (Cronbach's Alpha = .71). Item 1 (i.e., an excluded item) was examined independently as a measure of perceived public awareness of IBD (i.e., '*I think other people would know what IBD is*'; 1 = *Strongly Disagree*; 7 = *Strongly Agree*).

The six-item scale asked: how those with IBD consider the general public to cognitively perceive IBD; how those with IBD perceive they would be stigmatised by the general public, how those with IBD consider the general public to emotionally react to their condition; and perceived expectations of members of the general public. These items were measured on a seven-point Likert scale (1 = *Strongly Disagree*; 7 = *Strongly Agree*; e.g., '*I think other people would treat me differently if they knew about my IBD*'). In calculating the final score, the six items were averaged, with higher scores indicating that participants anticipated more negative public perceptions of their condition. A Principal Components Analysis (PCA) was performed to examine the component structure of this measure, and all assumptions of the analysis were met. The PCA indicated that all six items loaded on a single factor (factor loadings > .463; refer to Table 4.2), accounting for 43.09% of the total variance (Eigenvalue = 2.585). This indicates that the six items appear to be measuring the same construct.

Illness Perceptions. The Brief Illness Perceptions Questionnaire (Brief IPQ) is a 9-item scale that measures cognitive and emotional representations of illness: consequences, timeline, personal control, treatment control identity coherence, concern, emotional response, and causal attributions [60]. Eight items are measured on an 11-point Likert scale (e.g., 0 = *No effect at all*; 10 = *Severely affects my life*; e.g., "*How concerned are you about your illness?*"). To calculate the total score, three items were reverse-coded and all eight items

were averaged, with a higher score indicating more negative illness perceptions. The ninth item (i.e., causal attribution) has an open-ended response and asks respondents to list three perceived causes of their illness, and therefore was not included in the total score. The Brief IPQ demonstrates good internal consistency in an IBD sample (Cronbach's Alpha = 0.83) [45] and within the current sample (Cronbach's Alpha = 0.72).

Internalised Stigma. Three items reflecting internalised stigma were adapted from a seven-item scale measuring stigma in colostomy patients [30] (refer to Electronic Supplementary Material 2, Appendix C). The items were modified by changing the term, 'ostomy' to 'IBD' (e.g., *I feel embarrassed by my IBD*). Additionally, some of the items were modified based on feedback from pilot reviewers. The scale utilised a 7-point Likert scale (*1 = Strongly Disagree; 7 = Strongly Agree*; e.g., *My IBD makes me feel socially uncomfortable*), and the total score was calculated by averaging all items. Higher scores indicated higher internalised stigma. This scale demonstrated acceptable internal reliability within this sample (Cronbach's Alpha = .67).

Disgust Sensitivity. The 21-item Three-Domain Disgust Scale [61] conceptualises and measures disgust as three domains: pathogen disgust (e.g., *stepping on dog poo*), sexual disgust (e.g., *finding out that someone you don't like has sexual fantasies about you*), and moral disgust (e.g., *deceiving a friend*). It is rated from *0 = Not at all disgusting; 6 = Extremely disgusting*. A total score was calculated for each domain and for the overall score. A higher score indicates higher moral, sexual and pathogen disgust, and overall higher disgust sensitivity. Prior research has demonstrated a high Cronbach's alpha for each domain of this scale (pathogen: .83; sexual: .86; moral: .89) [61]. These items demonstrated excellent internal reliability in the current sample (i.e., total score; Cronbach's Alpha = .88).

Quality of Life. The Short-Form 12 version 2 (SF-12v2) [62] was used to measure mental health functioning (Mental Component Summary; MCS) and physical functioning

(Physical Component Summary; PCS). The SF-12v2 consists of 12 questions, with a higher score indicating better functioning. Scoring was completed utilising software provided by the licensor of the SF12v2 (Quality Metric Incorporated; converts MCS and PCS raw scores to T Scores), to compare results to that of prior research and established US norms [63].

Australian norms for the SF12v2 are currently not available. Previous reliability analyses indicated that the SF-12 has adequate internal consistency (MCS = .88; PCS = .92) [63] and analyses indicated that this scale also has good internal consistency within the current sample (Cronbach's Alpha = .89).

Results

Screening analyses indicated no significant differences between disease type (i.e., CD or UC), participant location (e.g., Australia, USA, or Canada), or gender across all outcome variables (refer to Table 4.3). Similarly, there were no significant differences between illness severity levels across outcome variables, except for physical health (see Table 4.3).

Participants experiencing symptom onset or active symptoms reported poorer physical functioning than those in remission.

Descriptive statistics are presented in Table 4.4. Fifty-two percent ($n = 69$) of the sample indicated that they anticipated negative public perceptions of their condition (i.e., scores at and above the 50th percentile). Regarding perceived public awareness of IBD, 70% of the sample *disagreed* that the general public has knowledge of the condition ($n = 92$). Additionally, 71% ($n = 136$) of the sample's scores for MCS fell below the general population norm, indicating that the majority were experiencing poorer mental health functioning than the general population (calculated by using all participants who attempted the survey, $N = 192$) [63]. In comparison, 37% ($n = 71$) of the sample's scores for PCS fell below the general population norm ($N = 192$) [63].

Correlational analyses revealed that anticipated societal perceptions of IBD were significantly, positively correlated with illness perceptions and internalised stigma (refer to Table 4.4). Anticipated societal perceptions also had a significant, negative association with mental and physical health functioning. Finally, with the exception of pathogen disgust and disease duration, associations between disgust sensitivity and other variables were not significant. These two variables were significantly, negatively correlated ($r = -.19, p = <.05$) suggesting that having IBD for a longer time is associated with lower disgust for pathogens (i.e., bodily products).

Research Questions

In relation to demographic factors, there were no significant differences between participants' scores on anticipated societal views of IBD according to their age, gender, or illness severity (refer to Table 4.3), and therefore these variables were not controlled for in the regression analyses below. In answering the research question concerning the impact of anticipated societal perceptions on mental and physical functioning, two linear regression analyses were conducted. Firstly, anticipated societal perceptions of IBD significantly predicted physical functioning $F(1, 129) = 11.60, p = .001$, with 7.5% of the variance in PCS being explained by anticipated views ($\beta = -.287; N = 131$). Analyses further revealed that anticipated societal perceptions significantly accounted for 8.3% of the variance in MCS $F(1, 129) = 12.81, p = <.001$ ($\beta = -.301; N = 131$). This suggests that anticipating more negative views from the public towards IBD significantly contributes to poorer mental and physical health functioning for those with IBD.

To investigate if negative self-perceptions about IBD contribute to negative anticipated societal perceptions, a multiple linear regression analysis was completed, by entering all predictors (i.e., disgust, illness perceptions and internalised stigma)

Table 4.2. Factor Loadings and Variance of Items developed to measure Anticipated Societal Perceptions ($N = 132$)

Item no.	Item content	Factor Loadings	Variance explained by Item
5	"I think other people would be uncomfortable discussing my IBD symptoms with me."	.80	.64
7	I think other people would be revolted by my IBD symptoms."	.79	.62
6	"I think other people would feel embarrassed if I experienced IBD symptoms on a social occasion."	.76	.58
4	"I think other people would treat me differently if they knew about my IBD."	.55	.30
8	"I think other people would expect things from me that I cannot do because of my IBD."	.48	.23
3	"I think other people would view me as being responsible for my IBD."	.46	.22

Table 4.3. Screening Analyses for Outcome Variables

Demographic Variable	Outcome Variable	Statistical Analyses	Statistics	M (SD)
	<i>Anticipated Societal Perceptions</i>			
Age*		Pearson's Correlation	$r = .09, p = .283$	
Gender		independent samples t-test	$t(129) = -.91, p = .365$	Males: 4.97 (1.11) Females: 5.15 (1.02)
Illness Severity		independent samples t-test	$t(103) = .40, p = .693$	Active Symptoms: 5.21 (1.12) Remission: 5.13 (.92)
		one-way ANOVA	$F(3, 128) = .87, p = .457$	Symptom Onset: 5.31 (1.06) Active Symptoms: 5.17 (1.15) Remission: 5.13 (9.92) Other: 4.83 (1.10)
Disease Type		independent samples t-test	$t(115) = -.54, p = .591$	UC: 5.03 (1.09) CD: 5.13 (1.06)
Participant Location		one-way ANOVA	$F(7, 124) = .21, p = .982$	Australia: 5.15 (.99) USA: 5.10 (1.21) Canada: 4.79 (1.31) Europe: 5.03 (1.05) UK: 4.67 (1.89) South Africa: 5.08 (.35) New Zealand: 5.33+ South America: 5.67+

Physical Functioning				
Gender		independent samples t-test	$t(129) = .54, p = .593$	Males: 47.84 (9.91) Females: 46.84 (9.83)
Illness Severity		independent samples t-test	Welch's $t(102.98) = -4.64, p = <.001$	Active Symptoms: 44.95 (9.55) Remission: 52.34 (6.77)
		one-way ANOVA	$F(3, 128) = .747, p = <.001$	Symptom Onset: 45.48 (7.18) Active Symptoms: 44.77 (10.32) Remission: 52.34 (6.77) Other: 43.29 (11.34)
Disease Type		independent samples t-test	$t(115) = 1.63, p = .105$	UC: 48.54 (10.33) CD: 45.59 (9.20)
Participant Location		one-way ANOVA	$F(7, 124) = .60, p = .759$	Australia: 47.43 (9.35) USA: 46.14 (11.73) Canada: 47.17 (8.11) Europe: 47.68 (7.41) UK: 49.74 (8.13) South Africa: 49.34 (13.50) New Zealand: 29.81+ South America: 53.95+
Mental Functioning				
Gender		independent samples t-test	$t(129) = .33, p = .742$	Males: 39.78 (8.12) Females: 39.18 (10.20)
Illness Severity		independent samples t-test	$t(103) = -1.87, p = .065$	Active Symptoms: 37.04 (9.38) Remission: 40.63 (10.16)

	one-way ANOVA	$F(3, 128) = 2.17, p = .095$	Symptom Onset: 36.06 (10.90) Active Symptoms: 37.39 (8.90) Remission: 40.63 (10.16) Other: 41.90 (8.61)
Disease Type	independent samples t-test	$t(115) = -.86, p = .394$	UC: 38.04 (10.37) CD: 39.53 (8.47)
Participant Location	one-way ANOVA	$F(7, 124) = 1.79, p = .095$	Australia: 40.69 (9.28) USA: 35.80 (9.24) Canada: 38.64 (10.32) Europe: 33.54 (12.14) UK: 40.17 (6.37) South Africa: 36.89 (11.66) New Zealand: 52.84+ South America: 48.94+

*Pearson's correlation was completed as age is a continuous variable; +n = 1

Table 4.4. Pearson's Correlations and Descriptive Values of Study Variables ($N = 132$)

	ASP ^a	Illness Perceptions	Internalised Stigma	Disgust Sensitivity	MCS	PCS	Mean (SD)	Min-Max Score
ASP ^a							5.11 (1.06)	2-7
Illness Perceptions	.40*						47.90 (9.84)	20-73
Internalised Stigma	.62*	.51*					15.47 (8.02)	3-33
Disgust Sensitivity	.09	.12	-.03				3.39 (0.95)	1-6
MCS	-.27*	-.39*	-.36*	.07			50 (10) ^b	11-63
PCS	-.25*	-.57*	-.28*	-.09	-.05		50 (10) ^b	21-67

* $p < .01$, a = Anticipated Societal Perceptions of IBD, b = T Scores

simultaneously. Together, the three predictors significantly accounted for 40.6% of the variance in anticipated societal perceptions $F(3, 124) = 28.23, p = <.001, (N = 128)$. When the predictors were considered individually, neither disgust ($p = .21$) nor illness perceptions ($p = .51$) uniquely explained anticipated societal perceptions. Internalised stigma was the only predictor to make a significant, unique contribution to anticipated societal perceptions ($\beta = .530, p = <.001$), explaining 20.16% of the variance in anticipated societal perceptions. This suggests that internalising stigmatising attributes towards oneself, contributes significantly to negative anticipated societal perceptions towards IBD.

Discussion

This study investigated the anticipated societal views of those with IBD and the impact of these views on participants' psychological and physical health. It also explored whether participants with negative self-perceptions and reactions to IBD, also perceive the public to have similar views of this condition. Among participants with IBD, anticipating negative public perceptions of IBD was associated with negative illness perceptions, higher internalised stigma, and poorer mental and physical health. A negative relationship was observed between illness duration and pathogen disgust, suggesting that participants may habituate to core disgust elicitors typically present in IBD (e.g., body products). To date, habituation to disgust-eliciting stimuli has not yet been explored within health conditions. However, Rozin [64] reported that medical students showed reductions in disgust sensitivity to body envelope violations (e.g., blood) and to touching cold dead bodies (e.g., cadavers) across training. Similar findings have been reported for nursing students [65]. When applied to the current study, these findings suggest that individuals with the greatest exposure to IBD symptoms demonstrate resilience to disgust-eliciting symptoms (e.g., faecal matter) not observed in those with a short illness time-course.

Firstly, the research question regarding anticipated societal perceptions and participant demographic factors showed that those with IBD across different age groups, gender and varying levels of illness severity, do not significantly differ in their anticipated societal views of IBD. Another research question concerned the impact of societal perceptions on wellbeing, with results indicating that anticipating negative public perceptions of IBD contributed to poorer psychological and physical health in the current sample. Smith and colleagues [30] also reported that concerns about the perceptions of others negatively impacted upon colostomy adjustment, which, in turn, was associated with poorer life satisfaction. Similar findings have been reported in other conditions. For example, a qualitative review investigating perceptions of living with Parkinson's disease found that participants commonly experienced social anxiety and that this was linked to thoughts about what others thought of them (i.e., anticipated societal views), contributing to social withdrawal and poorer well-being [66].

In relation to self- and societal perceptions of IBD, preliminary evidence suggested that together, higher levels of disgust sensitivity, negative illness perceptions and internalising stigma contribute to perceptions that the public will view IBD negatively. However, internalised stigma was the only variable to uniquely explain anticipated societal perceptions, suggesting that the relationships between that of disgust sensitivity, illness perceptions and societal perceptions are accounted for by internalised stigma. This finding suggests that perceptions of one's self-image in relation to IBD, impacts upon how individuals form societal views of their condition. Specifically, internalising negative attributes in relation to IBD appears to be linked with views that the public will also perceive IBD negatively and in turn, this appears to impact physical and mental wellbeing. Further, it can be inferred that anticipating negative public perceptions of IBD would likely impact upon daily interactions with members of the public. To date, no prior research has explored this

research question, and these findings extend IBD literature by exploring how self-perceptions are linked to the formation of anticipated public perceptions of IBD. However, these findings are consistent with previous studies reporting that individuals tend to overestimate that others will have similar views to them [19, 30, 49, 50]. These findings are also consistent with the idea that individuals project their own views onto others [31, 49], providing an explanation for the current findings, in that those with IBD infer that the public have similar views to their own.

Strengths, Limitations and Future Research

This is the first study to quantitatively explore anticipated societal views of IBD from the perspective of those with the condition, and their impact on individual wellbeing. Other strengths include recruiting a diverse sample representing the views of multiple nationalities and that our findings have translatable implications for health professionals working in clinical settings. As a cross-sectional design was utilised in this study, the direction of the findings cannot be inferred. Additionally, utilising a convenience online sample can increase sampling bias and is reliant on self-reports for clinical information (e.g., diagnosis). Another limitation of this study was that clinical details regarding how the participants' diagnosis was made and by whom (e.g., Gastroenterologist) was not collected. The outcome variables of focus were physical and mental functioning; however, this study did not measure or account for psychological distress (e.g., specific measure of anxiety/depression). The scale developed to measure anticipated societal perceptions of IBD has not been validated. However, analyses indicated that this measure was internally consistent and correlated with the study variables. Future research could validate and publish this scale with an IBD sample. Further to this, a validated measure of disease activity (e.g., Manitoba Index) was not utilised and future studies should aim to utilise a specific measure of IBD disease activity. Research can further extend our findings by using a longitudinal design to explore the direction of these findings

(e, g., to examine whether negative self-perceptions predict negative anticipated societal perceptions of IBD, and whether these views predict poor functioning or vice-versa).

Implications

The current findings have implications for clinical practice. Firstly, individuals with IBD could be screened in clinical settings by administering measures to identify those with higher internalised stigma towards their condition. Once identified, this can be targeted in clinical practice by firstly educating individuals that internalising stigma towards oneself predicts negative perceived societal perceptions, and that these societal views likely impact upon their physical and psychological health. Internalised stigma can be targeted in therapy by facilitating individuals to critically evaluate and reframe their negative self-perceptions, with the aim of reducing the impact of these self-perceptions on their overall mental health and quality of life.

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CHAPTER 5

STUDY 4

INVESTIGATING PUBLIC AWARENESS AND PERCEPTIONS OF INFLAMMATORY BOWEL DISEASE: AN AUSTRALIAN SAMPLE

Chapter 5 contains Study 4, presented in the form of an unpublished manuscript that has been submitted for publication. The formatting required by the publisher for submission was retained. The reference list is presented at the conclusion of the manuscript, followed by the tables and figure. The supplementary materials are presented in Appendix E.

Statement of Contribution to Co-authored Paper

This chapter includes a co-authored paper, which has been submitted for publication. The bibliographic details of this co-authored paper, including all authors, are:

Edwards, E.-J., Oaten, M., & O'Callaghan, F. Investigating public awareness and perceptions of inflammatory bowel disease: An Australian sample. *Submitted for publication.*

My contribution to the paper involved:

- Review of the literature
- Applying for ethical approval
- Co-development of hypotheses
- Co-development of vignettes and measures
- Recruitment of participants and management of pilot testing
- Data management, selection and conduction of data analyses

- Lead in drafting and writing of paper
- Corresponding author of the journal submission

(Date) 18 March 2020

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(Date) 19 March 2020

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See Appendix D for the information and consent form

Abstract

Inflammatory Bowel Diseases (IBD) are conditions with chronic bowel symptoms. Individuals with IBD anticipate and report direct experiences of stigmatisation. Research suggests the public avoids those with medical conditions, as disease cues activate disgust and contamination risk. Our study provided the first examination of: (i) public awareness of IBD in an Australian sample; (ii) any emotional reactions and avoidance of specific IBD symptoms (e.g., faecal incontinence); and (iii) whether proximity and duration of contact mitigates stigmatisation of IBD. Participants ($N = 468$; $M = 38.42$, $SD = 14.71$; % *Female* = 71%) read vignettes of a hypothetical individual with IBD exhibiting symptoms in a workplace context. Participants were randomly allocated to disclosure (of the disease) or non-disclosure conditions and completed ratings of avoidance and emotional reactions. Findings indicated that: (1) over half of the sample had poor awareness of IBD (53%, $n = 248$); (2) greater avoidance of IBD occurred in the non-disclosure condition, $F(1,462) = 4.68$, $p = .03$, $\eta_p^2 = .01$; (3) greater avoidance was linked with prolonged contact, $F(2.62, 1208) = 1148.04$, $p < .001$, $\eta_p^2 = .71$; (4) emotional reactions did not differ according to disclosure, $p = .771$; and (5) higher disgust was associated with avoidance of IBD symptoms (i.e., when IBD was *not* disclosed; correlations ranging from $r = -.15$ to $r = -.17$; all p 's $\leq .02$). Greater stigmatisation of IBD appears to be linked with non-disclosure and prolonged contact. Implications for clinical practice include exploring possible benefits of disclosing one's IBD in order to reduce stigmatising attitudes.

Investigating Public Awareness and Perceptions of Inflammatory Bowel Disease: An Australian Sample

Inflammatory Bowel Diseases (IBD) are a group of chronic gastrointestinal conditions that consist of two main types, Crohn's Disease and Ulcerative Colitis. IBD involves inflammation of the gastrointestinal tract (Gajendran, Loganathan, Catinella, & Hashash, 2018). Symptoms of IBD are episodic, in that individuals with IBD experience periods of remission and active symptoms such as: a sense of urgency to empty bowels, diarrhoea, rectal bleeding, abdominal pain, and fatigue (Ananthakrishnan, Xavier, & Podolsky, 2017; Jordan et al., 2018). Individuals with IBD are at risk of experiencing poor mental health due to fluctuating, unpredictable symptoms and their disruptions to employment, education, and social activities (Jordan et al., 2018; Kemp et al., 2012; Restall et al., 2016).

Many individuals with IBD report concerns about interacting with others in their daily environment, especially within public settings. For instance, participants report concerns when utilising public/shared bathrooms, for fear of negative reactions to smells and sounds that occur (Cooper et al., 2010; Lynch & Spence, 2008). Those with IBD are fearful of disease-related flares occurring in public, which is linked with preventative behaviours (e.g., planning trips around toilet availability) and anxiety (Jordan et al., 2018). Those with IBD report efforts to conceal their condition (e.g., 'holding on' to avoid the use of bathrooms; Thompson, 2013) and are reluctant to disclose information about their condition (Barned et al., 2016). A recent review indicated that those with IBD are most concerned about the societal taboos attached to bowels and faecal symptoms (Polak et al., 2020). This is further complicated by views that the public have little knowledge and awareness of IBD (Cooper et al., 2010), and often hold misconceptions about the condition (Matini & Ogden, 2016). Such factors

therefore provide a context for individuals' withholding of information regarding their IBD and fears about experiencing disease-related flares in public settings. Much research has documented self-reported concerns regarding stigmatisation in those with IBD (e.g., Dibley et al, 2018; Saunders, 2014; Taft et al., 2009). However, little research has explored public awareness and perceptions of IBD and to date, no research has explored this in an Australian sample. Such findings would provide important information regarding the Australian public's perceptions of IBD and the challenges faced by individuals living with IBD. We addressed this gap in the literature by exploring an Australian sample's awareness and perceptions of IBD using an experimental design. In addition, we investigated community ratings of preferred social distance from a hypothetical individual with IBD, thus reflecting the degree of enacted stigmatisation towards IBD.

Disease Avoidance and Stigmatisation

Research suggests that stigmatisation occurs on the basis of disease avoidance (Oaten et al., 2011), as those with visible medical conditions are avoided and commonly excluded in interpersonal and social contexts. Documented examples include the avoidance of people with infectious conditions such as HIV/AIDS (Huskin et al., 2017) and SARS (Mak et al., 2006), and even individuals with non-infectious conditions such as acne (Kouznetsova et al., 2012; Papadopoulos et al., 2000), eczema (Hong et al., 2008; Kouznetsova et al., 2012), and facial birthmarks and burns (Clarke, 1999). Oaten et al. (2011) proposed a disease-avoidance system comprised of: 1) an emotional component: visible disease cues activate disgust, contamination, and avoidance; and 2) cognitive components: disease labels access disease-related semantic knowledge, activate mental images of disease cues, resulting in disgust, contamination, and avoidance. Research suggests that disgust functions to promote the avoidance of pathogen sources, such as

animals (e.g., cockroaches), rotten food (e.g., spoiled milk), or body products (e.g., faeces), etc. (Rozin et al., 2000).

A study investigating disease-avoidant behaviour (Kouznetsova et al., 2012) also found that community members indicated a preference for greater social distance as the prospect for contact, symptom visibility and contagion risk increased, and that this avoidance was associated with higher disgust sensitivity (i.e., an individual's propensity to experience disgust reactions; Rozin et al., 2000). Relatedly, another study (Smith et al., 2007) reported that community members high in disgust sensitivity indicated greater avoidance of individuals with a colostomy. In another study, community participants with high state disgust (i.e., induced disgust vignette) made greater socially-avoidant decisions regarding a meeting with a friend planning to, "share details of their bowel troubles," (Reynolds et al., 2015, p. 102). Thus if we perceive someone to be sick, whether on the basis of a disease cue or disease label, we may avoid them as potential carriers of infectious disease (Kouznetsova et al., 2012; Oaten et al., 2011). These findings highlight the importance of investigating disease avoidant behaviour and the implications for those with bowel conditions, given the role of bodily products in inducing disgust. Therefore, the current study explored whether the public implicitly avoid IBD based upon disease cues presented within vignettes, thus indicating the degree of stigma directed towards IBD.

Public Perceptions and Stigmatisation of IBD

Few studies have explored public stigmatisation and perceptions of IBD. In the extant literature, however, mixed findings have been reported. One study investigated the degree of enacted stigma directed towards IBD in a US online community sample (Taft et al., 2017). It was concluded that individuals with Irritable Bowel Syndrome (IBS) are more at risk of stigmatisation than those with IBD, as community members directed

significantly higher levels of enacted stigma towards those with IBS than those with IBD (Taft et al., 2017). Another study using a large, US online sample (N=1200; Groshek et al., 2017) reported different findings, with participants rating IBD, on average, as having the highest degree of social stigma compared to other conditions (e.g., alcoholism, diabetes, and HIV/AIDS). Participants also rated stomas and bloody diarrhoea as the most embarrassing IBD symptoms. An experimental study explored stigmatisation of IBD in a sample of college students and reported alternative findings (Rohde et al., 2018). Participants were randomly allocated to vignettes depicting college classmates working on a group project. In the vignettes, participants were either informed that the target had IBD (disclosure condition) or did not have IBD (non-disclosure condition). Severity of disease was operationalised as the frequency of bathroom use per hour (i.e., low, moderate and high). Results indicated that participants directed higher enacted stigma towards IBD in the non-disclosure condition, than the disclosure condition. However, levels of enacted stigma did not significantly differ according to disease severity, suggesting that this could be operationalised differently, by including the presence of symptoms (e.g., diarrhoea; Rohde et al., 2018).

The variability in research findings could be accounted for by different operationalisations of stigma. Taft et al. (2017) included a description of IBD prior to completing questionnaires, thus providing a context for the symptoms described with participants attributing symptoms to IBD (Polak et al., 2020). However, Rohde et al. (2018) found that participants stigmatised IBD when symptoms were not attributed to a disease-label (i.e., non-disclosure-condition) and participants are more likely to perceive the individual as responsible or to blame for frequent bathroom use (Saunders, 2014). Lastly, our systematic review concluded that further research is needed to explore community perceptions of IBD (Polak et al., 2020). The current study aimed to extend

prior literature, including Rohde and colleagues' research (2018) by: (1) utilising an alternative method for operationalising symptoms of IBD; (2) including ratings of 'willingness for contact' (i.e., avoidance ratings) with a hypothetical individual with IBD; (3) rating the extent of negative emotional reactions directed towards IBD; and (4) manipulating duration and proximity of contact within vignettes; (5) exploring the link between disgust sensitivity and avoidance of IBD and lastly, (6) utilising a community sample of varying ages.

Based upon literature presented above, the following hypotheses were examined:

H1: Participants in the non-disclosure condition will be more likely to rate symptoms negatively and avoid the target, relative to participants in the disclosure condition (i.e., where a disease label is included).

H2: The general public will be most likely to avoid the target and rate symptoms negatively in the incontinence condition, followed by the flatulence condition, and bathroom use condition.

H3: Participants will be more likely to avoid the target, as the proximity and duration of contact increases, regardless of whether they in the disclosure or non-disclosure condition.

H4: Higher disgust sensitivity will be associated with greater avoidance of the target.

Knowledge, Familiarity, and IBD

Few studies have investigated public awareness of IBD, and how familiarity and knowledge moderate stigmatisation. The first published study to investigate public awareness of IBD found that most of an Austrian sample had never heard of IBD (Angelberger et al., 2009). More recent studies present similar findings, with a US online sample answering two-thirds of questions about IBD knowledge incorrectly

(Groshek et al., 2017) and 42.4% of a college sample reporting no familiarity with IBD (Rohde et al., 2018). Further to this, the extant literature suggests that factors such as IBD knowledge and familiarity moderate enacted stigma of IBD. Findings indicate that higher knowledge of IBD is associated with lower stigma (Groshek et al., 2017; Rohde et al., 2018), and that those familiar with IBD are more likely to exhibit reduced stigma (Rohde et al., 2018; Taft et al., 2017). Familiarity was reported to be the most important contributor to enacted stigma, even more so than emotional empathy (Taft et al., 2017). Based upon these research findings, the following hypotheses were formed:

H5: Participants familiar with IBD will rate greater willingness to have contact with the target, and will report lower stigmatising attitudes towards IBD, relative to participants who are unfamiliar with IBD.

H6: Participants with higher knowledge of IBD will rate greater willingness to have contact with the target, and will report lower stigmatising attitudes towards IBD, relative to participants with lower knowledge of IBD.

Method

Participants

Of 749 participants who commenced the online survey, 480 completed all measures (i.e., a completion rate of 64%). Twelve participants had diagnoses of IBD and were excluded from analyses, resulting in a final sample size of 468. Ages ranged from 18 to 65 ($M = 38.42$, $SD = 14.71$), with 71% being female ($n = 330$) and all residing in Australia. Fifty-six percent ($n = 260$) of participants reported having a medical condition.

Procedure

Participants were recruited via advertisements on Facebook from March to May 2019. We utilised a 2 (disclosure condition: disclosure, non-disclosure; between-subjects IV)

x 3 (symptoms: bathroom use, flatulence, and incontinence; within-subjects IV) mixed groups, experimental vignette design. Participants were randomly allocated to either the disclosure or non-disclosure condition for a series of three vignettes. Initially, the true purpose of the survey was masked from potential participants and therefore, recruitment advertisements stated that the study was investigating, ‘community perceptions of health and wellbeing.’ As participants progressed through the survey, they were made aware that it related to IBD and were provided with a medical explanation of the disease. Participants were provided with a statement explaining the true purpose of the study at completion. The online survey took approximately 15 minutes to complete.

Ethical approval was granted by the University’s Human Research Ethics Committee.

Measures

Vignettes. The authors developed a series of six vignettes involving a target (i.e., ‘Alex’) experiencing typical IBD symptoms within a workplace context, based upon the IBD vignettes developed by published research (i.e., Rohde et al., 2018; vignette design described above). Rohde et al.’s vignette design was adapted and extended in the current study by including a range of IBD symptoms, assessing willingness for contact and emotional reactions towards IBD, and manipulating proximity/duration of contact with the target. However, the current study utilised randomisation to either a disclosure or non-disclosure condition, similarly to that of Rohde et al. The vignettes were modified and improved based upon the feedback of 20 individuals who piloted the items.

Vignettes were set in a workplace context to simulate regular interpersonal contact. In the non-disclosure condition, the vignettes included symptoms of IBD without a disease label, while the disclosure condition provided both, thereby allowing the participants to attribute the symptoms to IBD. Further, after random allocation to

either the disclosure or non-disclosure condition, participants were presented with a series of three vignettes describing the following symptoms: (1) bathroom use; (2) flatulence and; (3) incontinence. The order of these vignettes was counterbalanced. Participants then completed a series of questions to explore their willingness for contact with Alex (e.g., *‘In the situation presented above, how likely is it that most people would be comfortable to’*; 1 = *Not at all Likely*; 7 = *Extremely Likely*). Higher scores indicated greater willingness for contact and lower scores reflected avoidance. Participants then indicated their emotional reactions in response to the scenario: embarrassment, fear, sympathy (reversed), disgust, happiness (reversed), anger and sadness (e.g., *‘In the situation presented above, which emotion(s) would most people likely feel?’*; 1 = *Not at all Likely*; 7 = *Extremely Likely*). Higher scores reflected increased negative emotional reactions. Items assessing willingness for contact were further categorised according to: (1) duration of contact: short, long or sustained; and (2) distance of contact: close or not close. Refer to the supplementary materials in Appendix E for a copy of the six vignettes and willingness for contact/emotional reactions items.

Knowledge and Awareness of IBD. The five items assessing participants’ knowledge of IBD were adapted from Sevcik (2005, p. 138). The first item was adapted from Sevcik by asking participants to identify the two major types of IBD from a list of ten conditions (i.e., Sevcik asked participants to recall the two types of IBD). The percentage of participants that correctly identified UC and CD as the main types of IBD were then calculated. Three of the true/false items were created by Sevcik (2005) and included questions about symptoms, treatment, and whether IBD occurs in children. The final true/false item was developed by the authors and asked participants about the chronicity of IBD (e.g., *“IBD is not a chronic disease”*). A score of 1 was given for

each correct true/false response option. The final score ranged from 0 to 4. A higher score reflected higher knowledge of IBD. A further question was adapted from Angelberger et al. (2009) to assess participants' awareness of IBD: "*Have you ever heard or read about Inflammatory Bowel Disease?*" Responses were measured on a four-point Likert Scale (e.g., *1 = I have never heard or read about this disease; 4 = I have already dealt with it myself or with someone I know who has this disease*).

Participants with higher scores had more awareness of IBD.

Familiarity with IBD. Participants were asked if they themselves have been diagnosed with IBD or whether they know someone who has been diagnosed with IBD. These questions were adapted from Rohde et al. (2018) and were scored as a binary variable (i.e., *1 = Yes, 2 = No*). Participants who self-reported that they had an IBD diagnosis were excluded from analyses.

Stigma. We adapted the Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CS; The International Federation of Anti-Leprosy Associations and Netherlands Leprosy Relief, 2011; Van Brakel et al., 2012; Weiss, 1997) to assess participants' agreement with stigmatising attitudes towards individuals with IBD. The EMIC-CS measures 15 items on a four-point Likert scale (e.g., *Would the symptoms of IBD make members of the general public feel disgusted? 2 = Yes, 1 = Possibly, 0 = No, 0 = Don't Know*). We modified these items to suit IBD and shortened the measure to 11 items (refer to Table 5.1 for items). Higher scores reflected agreement with stigmatising attitudes towards IBD. Total scores were calculated by summing the 11 items. These items demonstrated good internal reliability in the current community sample (Cronbach's Alpha = .82).

Disgust. The Three-Domain Disgust Scale (Tybur et al., 2009) was utilised to measure participants' disgust sensitivity. This 21-item scale measures the following

domains of disgust: sexual disgust, pathogen disgust, and moral disgust (measured on a 7-point Likert scale; 0 = *Not all Disgusting*; 6 = *Extremely Disgusting*). One item was excluded as it referenced sexual orientation preferences. An overall total score was calculated by summing the items. Within the current sample, this scale had adequate internal reliability (Cronbach's Alpha = .88).

Demographic and Clinical Information. Participants provided their gender and age. They were asked whether they had been formally diagnosed with a medical condition(s) and if so, were given the option of providing the diagnosis.

Results

Over half the sample (53%, $n = 248$) reported poor awareness of IBD (i.e., had not heard/read about IBD or had somewhere heard the term), compared to 29% ($n = 136$) who have read information about IBD, and 17.9% ($n = 84$) who have, or know someone with, IBD. Most participants answered true or false knowledge questions about IBD correctly (refer to Table 5.2a). However, 74% ($n = 347$) of participants incorrectly identified Irritable Bowel Syndrome as a type of IBD. Regarding stigmatising attitudes, many agreed that an individual with IBD would not disclose their condition, and the symptoms of IBD would make others feel pity and embarrassment. In comparison, many participants *disagreed* that others would avoid, or refuse to visit the home of an individual with IBD (see Table 5.1). Refer to Table 5.2a for descriptive statistics. Lastly, screening tests indicated no significant differences between the randomised groups (i.e., disclosure/non-disclosure) across age, gender, knowledge of IBD and personal medical history (see Table 5.3).

Associations between Variables

Correlational analyses revealed significant, negative correlations between willingness for contact and emotional reactions, for both the disclosure and non-disclosure

conditions. Stigma had significant, negative correlations with willingness for contact and a significant, positive correlation with emotional reactions, regardless of disclosure. Refer to Table 5.2b for correlations.

Willingness for Contact

A 3 (symptoms: bathroom use, flatulence, and incontinence) \times 2 (disclosure condition: disclosure, non-disclosure) mixed-factorial ANOVA was completed to examine willingness for contact in both *H1* and *H2* (see Table 5.4). Four participants were excluded from analyses due to biased responding (i.e., extreme values; $N = 464$). The main effect of symptoms was significant and comparisons were conducted between each symptom condition (see Table 5.4 for statistics). Participants were more willing to have contact with the target in the: 1) bathroom use condition compared to the flatulence condition; 2) flatulence condition compared to the incontinence condition; and 3) bathroom use condition compared to the incontinence condition. There was a significant effect of disclosure, as willingness for contact was higher in the disclosure condition, than the non-disclosure condition (see Table 5.4). The interaction between symptom and disclosure was *not* significant ($p = .52$).

Emotional Reactions

Another 3 (symptoms: bathroom use, flatulence, and incontinence) \times 2 (disclosure condition: disclosure, non-disclosure) mixed factorial ANOVA was completed to examine emotional reactions, in both *H1* and *H2*. Three participants were excluded from analyses due to biased responding ($N = 465$). A significant main effect was found for symptoms. Comparisons revealed that negative emotional reactions were higher for: 1) flatulence compared to bathroom use; and 2) incontinence compared to bathroom use. However, no significant differences were found between the flatulence and incontinence conditions on emotional reactions. Further, there was no significant effect for disclosure

(see Table 5.4), and the interaction between symptoms and disclosure was *not* significant ($p = .154$).

Type of Contact

A 4 (type of contact: sustained close contact, short, close contact, short, *not* close contact, and long close contact) \times 2 (disclosure: disclosure, non-disclosure) mixed factorial ANOVA was completed to investigate willingness for contact in *H3* (see Table 5.5). Five participants had biased patterns of responding and were excluded from analyses ($N = 463$). Analyses indicated that the assumption of sphericity was violated and so the Huynh-Feldt correction was applied when interpreting and reporting the findings. There was a significant main effect found for type of contact and comparisons were conducted between each type of contact. Willingness for contact was higher for: 1) short, *not* close contact compared to short, close contact; 2) long, close contact compared to sustained, close contact; and 3) short, *not* close contact compared to both long and sustained contact conditions. A significant main effect was found for disclosure. Willingness for contact was higher in the disclosure condition, than the non-disclosure condition.

The Type of Contact \times Disclosure interaction was significant, $F(2.62, 1208) = 23.17, p = .<001, \eta_p^2 = .05$. Follow up F -tests indicated that willingness for contact was higher for short, close contact in the disclosure condition, than the non-disclosure condition, $F(1, 461) = 13.05, p = .<001, \eta_p^2 = .03$. Further, willingness for contact was higher for short, *not* close contact in the disclosure condition, than the non-disclosure condition, $F(1, 461) = 11.94, p = .001, \eta_p^2 = .03$ (see Figure 5.1).

Disgust Sensitivity and Willingness for Contact

Bivariate correlations were analysed to explore *H4*. No associations were present in relation to contact in the disclosure condition (all p 's $= >.410$). However, in the non-

disclosure condition, disgust sensitivity had significant, negative correlations with willingness for contact across all symptom conditions - bathroom use ($r = -.15, p = .02$), flatulence ($r = -.17, p = .01$), and incontinence ($r = -.16, p = .01$). Follow up analyses were conducted by completing three linear regressions for each symptom in the *non-disclosure* condition. Results indicated that higher disgust sensitivity significantly contributed to lower willingness for contact with the target in the bathroom use, $F(1, 242) = 5.38, p = .02, (R^2 = .022, \beta = -.148; N = 243)$, flatulence $F(1, 242) = 7.28, p = .007, (R^2 = .029, \beta = -.171; N = 243)$, and incontinence $F(1, 242) = 6.54, p = .01, (R^2 = .026, \beta = -.163, N = 243)$ conditions. In the *disclosure* condition, however, disgust sensitivity did not predict willingness for contact, (all p 's $> .410$).

Familiarity and Knowledge of IBD

Familiarity with IBD. A series of independent samples t -tests were completed to investigate $H5$. In the *disclosure* condition, those familiar with IBD were more willing to have contact with the target across all symptoms (bathroom use: $M = 54.98, SD = 16.38$; flatulence: $M = 50.38, SD = 17.28$; incontinence: $M = 50.66, SD = 18.01$), than those unfamiliar with IBD (bathroom use: $M = 48.88; SD = 16.12, t(222) = 2.81, p = .005$; flatulence: $M = 45.91, SD = 16.68, t(222) = 1.97, p = .049$, incontinence: $M = 42.88, SD = 17.63, t(222) = 3.27, p = .001$). However, there were no significant differences in willingness for contact scores between familiar vs unfamiliar participants in the *non-disclosure* condition (all p 's $> .096$). Further, those unfamiliar with IBD reported higher stigmatising attitudes towards IBD ($M = 11.13, SD = 4.14$), than those familiar with IBD ($M = 10.14, SD = 4.16$), $t(466) = -2.58, p = .01$.

Knowledge of IBD. Bivariate correlations were conducted to answer $H6$.

Analyses revealed a positive correlation between knowledge of IBD and willingness for contact in the bathroom use condition only (across both disclosure and non-disclosure

conditions; $r = .10$, $p = .03$). These associations were not found in the flatulence or incontinence conditions. No significant associations were found between knowledge of IBD and stigma.

Discussion

To date, this is the first study to explore public awareness and ratings of avoidance and emotional reactions towards IBD symptoms in an Australian sample. Other unique aspects included utilising an alternative approach to operationalising IBD symptoms, exploring the link between disgust sensitivity and stigmatisation of IBD, and manipulating duration and proximity of contact within vignettes. Findings indicated that community members were more likely to *avoid* the target, but not more likely to *rate symptoms negatively*, when symptoms were presented without a disease label (i.e., non-disclosure condition). Therefore, *H1* was partially supported. Findings are consistent with prior literature (Rohde et al., 2018; Taft et al., 2017), particularly Rohde and colleagues' findings. Indeed, this suggests that knowledge of a disease label moderates avoidance, which contrasts with other findings in this field (Kouznetsova et al., 2012). However, Kouznetsova et al. (2012) found that avoidance of non-infectious conditions was linked to increased symptom visibility and contagion risk, whereas in the current study, two of the three symptoms were not visible to the eye (i.e., bathroom use, flatulence), in comparison to the incontinence condition – which was a faecal symptom that was easily apparent. Further, the presence of a disease label for symptoms in the disclosure condition could be linked to participant appraisals of decreased contagion risk. Thus, the public are more likely to avoid non-infectious conditions that are highly visible – particularly on the face, and that *appear* to be contagious (Kouznetsova et al., 2012). It is also possible that providing a disease label reduces blame for the responsibility of symptoms (Saunders, 2014). Saunders (2014) proposed that young

adults with IBD experienced blame and judgements from others of being morally culpable, as a result of non-disclosure. Further, disclosing IBD in vignettes may have resulted in increased emotional empathy towards the target. Moreover, the non-significant finding regarding ratings of emotion highlights that across both conditions (i.e., disclosure and non-disclosure), the public rated symptoms similarly. It appears then, that the community directs negative emotions towards bowel symptoms, regardless of knowledge of symptoms being linked to IBD.

Again, the general public were more likely to *avoid* the target with faecal incontinence, followed by flatulence and bathroom use, however, this pattern did not emerge for *emotion ratings* – partially supporting *H2*. This is consistent with prior literature suggesting that greater avoidance occurs for stimuli with the greatest contamination risk (Oaten et al., 2009; Stevenson et al., 2009). Faecal incontinence was the only visible symptom condition, again corroborating that there is greater avoidance for more visible disease signs (Kouznetsova et al., 2012). This is a unique finding as previous research has not explored direct public stigmatisation/avoidance of specific IBD symptoms. Public avoidance and negative affective ratings directed towards flatulence and faecal incontinence are consistent with the concerns of those with IBD regarding negative public reactions to disease-flares or accidents. In regard to emotion ratings, the public rated symptoms of both faecal incontinence and flatulence similarly.

Participants in the non-disclosure condition indicated greater avoidance of the target in the ‘short’ contact scenarios, than those in the disclosure condition. Therefore, *H3* was supported as similar avoidance ratings were reported for more prolonged contact, indicating greater avoidance of the target, regardless of whether IBD was disclosed. This is the first IBD study to explore if proximity and duration of contact

moderate public stigmatisation of IBD. This suggests that disclosure may only be helpful for reducing stigmatisation for situations involving brief contact.

Higher disgust sensitivity was linked with greater avoidance of IBD in the non-disclosure condition, providing partial support for H4. However, disgust sensitivity was not associated with avoidance when IBD was known. Prior research has reported that those with high disgust indicate greater avoidance and stigmatisation towards those with bowel symptoms (Reynolds et al., 2015; Smith et al., 2007) as well as health conditions generally (Kouznetsova et al., 2012). It is important to note that we compared disgust separately in each of the disclosure and non-disclosure conditions, in which those in the disclosure condition attributed symptoms to a non-contagious, chronic condition with no disease threat/contagion risk. In contrast, participants in the non-disclosure condition were not provided with a context for symptoms and these symptoms likely brought disease labels to mind, subsequently activating disgust and avoidance (Oaten et al., 2011).

Moreover, participants familiar with IBD were more willing to have contact with the target than those with no prior experience of IBD. However, this finding only emerged in the disclosure condition. These participants also reported lower stigmatising attitudes towards IBD. Therefore, H5 was partially supported. Prior research has consistently reported that greater familiarity with IBD is linked with lower enacted stigma (Rohde et al., 2018; Taft et al., 2017), however, our findings highlight that familiarity moderates the stigmatisation of IBD, when IBD is disclosed. This suggests that even knowing someone with IBD does not lower stigma directed towards symptoms, if no confirmation of IBD is provided. Again, this is consistent with disease avoidance mechanisms, that disease signs are interpreted and avoided if deemed contagious (Oaten et al., 2011). Lastly, H6 was not supported, as those with more

knowledge of IBD were not more willing to have contact with the target exhibiting flatulence and faecal incontinence. However, increased IBD knowledge was associated with willingness to have contact with the target in the bathroom use condition, which is consistent with previous findings (i.e., Rohde et al., 2018). Our findings indicate that increased knowledge of IBD does not mitigate avoidance of faecal symptoms in IBD, which also elicit disgust. Finally, IBD knowledge was not associated with lower stigmatising attitudes towards the condition.

Strengths, Limitations & Future Research

Our study extended previous research by manipulating IBD symptoms to measure affective and avoidance ratings of IBD. We recruited a large community sample, with participants of varying ages. Potential limitations of our study include an unequal representation of males, which may limit the generalisability of the findings to the wider IBD population. Additionally, a large percentage of the sample answered ‘true and false’ IBD knowledge questions correctly (despite over half of the sample indicating low awareness of IBD), suggesting online participants may have accessed answers via the internet. Another limitation is that participants in the disclosure condition, may have responded in a socially desirable and empathic manner, influencing participants to rate lower avoidance of IBD. Further, participants randomised to the disclosure condition may have become aware of the true purpose of the research (i.e., exploring IBD) and this may have influenced their responses. Participant occupation (e.g., counsellor, nurse) and familiarity with chronic illness (e.g., has a partner with a chronic illness) may have also influenced the findings, as those familiar with chronic illness or employed in ‘helping’ roles may be more empathic or compassionate in their responses. Additionally, participant mental health and online response bias may have also influenced the results. Lastly, a control condition (e.g., a vignette depicting an

individual with another chronic condition) was not included and may limit the conclusions made. Future research could extend our findings by utilising vignettes with a wider range of IBD symptoms (e.g., unintentional weight loss, abdominal pain, and facial swelling). Vignettes manipulating disclosure could also depict scenarios with multiple chronic health conditions (e.g., diabetes, irritable bowel syndrome, asthma, HIV/AIDS) to compare the stigmatisation of IBD to other health conditions.

Implications

Results suggest that disclosing IBD and increased familiarity with the condition may be linked with reduced avoidance/stigmatisation of IBD. In clinical settings, health professionals could incorporate discussions about possible benefits of disclosure in treatment and collaboratively rehearse scripts that individuals can utilise in settings where disclosure may be appropriate. Our findings also highlight the importance of implementing public awareness campaigns (e.g., advertising via television, social media) to increase awareness and knowledge of IBD and reduce stigmatisation of the condition.

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Table 5.1. Number and Percentage of the Sample Endorsing Stigmatising Attitudes (*N* = 468)

Stigmatising Attitudes - Item	Yes		Possibly		No/Unsure	
	%	n	%	n	%	n
1. Would a person with IBD keep others from knowing about their illness, if possible?	47.60%	223	47.60%	223	4.70%	22
2. Would the symptoms of IBD make other people feel embarrassed?	56.60%	265	38.50%	180	4.90%	23
3. Would others think less of a person with IBD?	7.90%	37	49.40%	231	42.70%	200
4. Would knowing that somebody has IBD make others feel uncomfortable to be around them?	11.50%	54	56.80%	266	31.60%	148
5. Would others avoid a person affected by IBD?	8.30%	39	48.50%	227	43.20%	202
6. Would others refuse to visit the home of a person with IBD?	7.50%	35	34.80%	163	57.70%	270
7. Would the symptoms of IBD make others feel disgusted?	19.70%	92	63.50%	297	16.90%	79
8. Would IBD be a problem for a person to find a partner?	20.10%	94	59.60%	279	20.30%	95
9. Would the symptoms of IBD make others feel pity?	37%	173	54.50%	255	8.50%	40
10. Would having IBD cause difficulty for a person to find work?	22.20%	104	51.90%	243	25.90%	121
11. Would others dislike buying food from a person with IBD?	19.40%	91	47.20%	221	33.30%	156

Table 5.2a Descriptive Statistics of Study Variables*

Variable	M (SD)	Min-Max Scores
Disclosure - Willingness for Contact ($n = 224$)	48.81 (15.79)	11-77
Non-Disclosure - Willingness for Contact ($n = 244$)	45.96 (15.98)	13-77
Disclosure - Emotional Reactions ($n = 224$)	26.56 (4.59)	15-44
Non-Disclosure - Emotional Reactions ($n = 244$)	26.60 (4.43)	9-43
Stigmatising Attitudes ($N = 468$)	10.68 (4.18)	0-22
Disgust Sensitivity ($N = 465$)	71.03 (19.56)	0-120
Knowledge of IBD ($N = 468$)	3.64 (.62)	1-4

*Disclosure and Non-Disclosure variables have been totalled across all symptom conditions

Table 5.2b Pearson's Correlations across Disclosure & Non-Disclosure⁺

<i>Disclosure Condition</i>		
	Disclosure - Willingness for Contact	Disclosure - Emotional Reactions
Disclosure - Emotional Reactions	-.35*	
Stigmatising Attitudes	-.36*	.42*
<i>Non-Disclosure Condition</i>		
	Non-Disclosure - Willingness for Contact	Non-Disclosure - Emotional Reactions
Non-Disclosure - Emotional Reactions	-.48*	
Stigmatising Attitudes	-.42*	.34*

* $p = < .01$; ⁺Disclosure and Non-Disclosure variables have been totalled across all symptom conditions

Table 5.3. Screening Analyses for the Disclosure ($n = 224$) and Non-Disclosure Conditions ($n = 244$)

Demographic Variable	Statistical Analyses	Statistics	$M (SD)$
Age	Independent samples t-test	$t(466) = .26, p = .796$	Disclosure Condition: 38.60 (14.54) Non-Disclosure Condition: 38.25 (14.89)
Knowledge of IBD	Independent samples t-test	$t(466) = .06, p = .952$	Disclosure Condition: 3.64 (.61) Non-Disclosure Condition: 3.64 (.64)
Personal Medical History (i.e., Yes/No)	Chi-square test	$X^2(1, N = 468) = .41, p = .521$	
Gender (i.e., Male, Female, Other)	Chi-square test	$X^2(2, N = 468) = 1.25, p = .536$	

Table 5.4. Results for the 3 (symptoms: bathroom use, flatulence, and incontinence) \times 2 (disclosure condition: disclosure, non-disclosure) mixed-factorial ANOVA for Willingness for Contact ($N = 464$) and Emotional Reactions ($N = 465$; including comparisons; F statistics).

Variable	BU	F	I		Dis	Non-Dis	
Willingness for contact	M (SD) 49.81 (16.38)	M (SD) 46.53 (17.59)	M (SD) 45.30 (18.55)	<i>F Statistics</i> $F(2, 924) = 28.68, p < .001, \eta_p^2 = .06$	M (SD) 48.86 (15.54)	M (SD) 45.71 (15.79)	<i>F Statistics</i> $F(1, 462) = 4.68, p = .03, \eta_p^2 = .01$
<i>Comparisons (F Statistics)</i>	<i>BU vs F</i> $F(1, 462) = 30.55, p < .001, \eta_p^2 = .06$	<i>F vs I</i> $F(1, 462) = 4.16, p = .042, \eta_p^2 = .01$	<i>BU v I</i> $F(1, 462) = 48.64, p < .001, \eta_p^2 = .09$				
Emotional Reactions	26.15 (4.94)	26.66 (5.07)	26.82 (5.04)	$F(2, 962) = 5.93, p = .003, \eta_p^2 = .01$	26.48 (4.44)	26.60 (4.17)	$p = .771$
<i>Comparisons (F statistics)</i>	<i>F vs BU</i> $F(1, 463) = 6.06, p = .014, \eta_p^2 = .01$	<i>I vs BU</i> $F(1, 463) = 10.76, p = .001, \eta_p^2 = .02$	<i>F vs I</i> $p = .401$				

*BU = Bathroom Use; F = Flatulence; I = Incontinence; Dis = Disclosure Condition; Non-Dis = Non-Disclosure Condition

Table 5.5. Results for the 4 (type of contact: sustained close contact, short, close contact, short, *not* close contact, and long close contact) \times 2 (disclosure: disclosure, non-disclosure) mixed factorial ANOVA for Willingness for Contact ($N = 463$; including comparisons; F statistics).

Variable	Short, Not Close	Short, Close	Long	Sustained		Dis	Non-Dis	
Willingness for contact	M (SD) 43.04 (13.43)	M (SD) 39.49 (13.65)	M (SD) 34.19 (13.54)	M (SD) 25.16 (8.90)	<i>F Statistics</i> $F(2.62, 1208) = 1148.04$, $p = <.001$, $\eta_p^2 = .71$.	M (SD) 36.77 (11.52)	M (SD) 34.28 (11.84)	<i>F Statistics</i> $F(1, 461) = 5.24$, $p =$.02, $\eta_p^2 = .01$
<i>Comparisons(F Statistics)</i>	<i>Short, Close vs Short, Not Close</i> $F(1, 461) =$ 214.26, $p =$ <.001, $\eta_p^2 =$.32	<i>Short Not Close vs Long</i> $F(1, 461) =$ 629.41, $p =$ <.001, $\eta_p^2 =$.58	<i>Short Not Close vs Sustained</i> $F(1, 461) =$ 2400.09, p $= <.001$, $\eta_p^2 = .84$	<i>Long vs Sustained</i> $F(1, 461)$ $= 735.51$, $p = <.001$, $\eta_p^2 = .62$				

*Dis = Disclosure Condition; Non-Dis = Non-Disclosure Condition

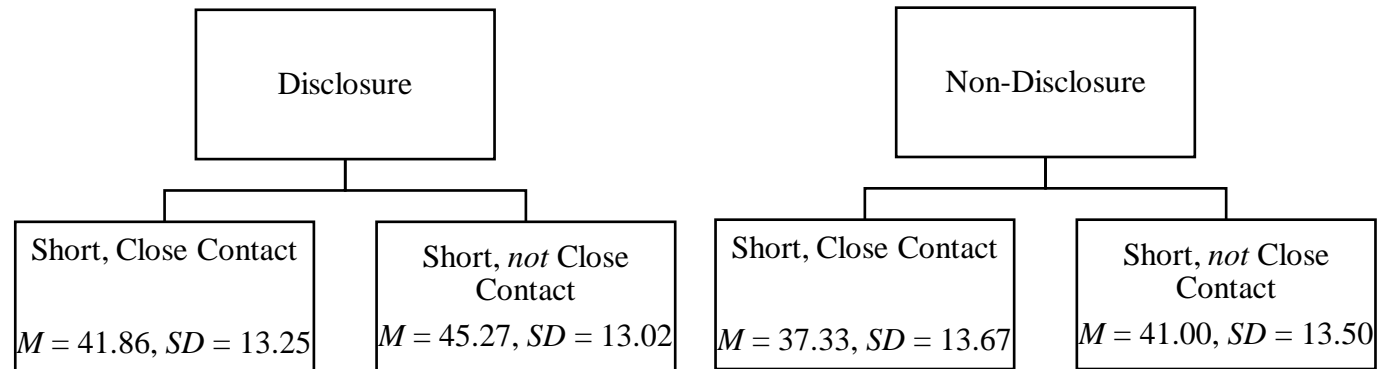


Figure 5.1. Simple effects analysis – means presented for each group according to disclosure and non-disclosure ($N = 463$).

CHAPTER 6

GENERAL DISCUSSION

This thesis extended previous literature by exploring anticipated societal perceptions of IBD, in those with the condition and in an Australian community sample. The aims of this research were three-fold: 1) to investigate how those with IBD view societal perceptions of their condition; 2) to explore if anticipated societal perceptions are linked with poorer wellbeing; and, 3) to examine the extent of societal awareness and stigmatisation of IBD. Chapter 1 presented the rationale for the current research and briefly introduced each study. A published manuscript was presented in Chapter 2 and Chapters 3-5 contained three empirical studies that have been submitted for publication.

Study 1 consisted of a published systematic review of IBD literature exploring illness perceptions, perceptions of stigma, and emotional reactions in those with and without IBD (Polak, O'Callaghan, & Oaten, 2020). Data was extracted from 82 studies and for individuals with IBD, results indicated: (i) having negative illness perceptions in regards to one's IBD is linked with poorer psychological well-being; (ii) participants frequently anticipate stigmatisation from others; and (iii) fear (i.e., about faecal symptoms occurring in public) was the most frequent emotion reported. Regarding public perceptions of IBD, the extant literature suggests that the public directs little stigma towards IBD. However, more research is needed to explore public perceptions of IBD and this provided a clear rationale for undertaking Study 4 to further investigate this issue.

In Study 2, qualitative views on anticipated societal perceptions of IBD and their potential impacts on health and quality of life were explored. Twenty individuals with IBD diagnoses completed semi-structured interviews. Overall, the participants' responses reflected four common themes: (1) poor public awareness of IBD, (2)

difficulties with disclosure, (3) reactions from others towards IBD, and (4) excluding oneself from public events due to experiencing symptoms and other functional reasons (e.g., accessibility of public bathrooms). Participants generally perceived that their health and quality of life are not impacted by these views. However, some participants viewed that their anticipated societal perceptions of IBD impact them psychologically. Outcomes from this study highlighted important implications for working with those with IBD in clinical settings, and this is discussed in more detail below (see ‘Implications: Societal and Clinical’).

Study 3 explored the link between negative self-perceptions and anticipated societal perceptions of IBD. A further aim of the study was to investigate if anticipating negative societal perceptions of IBD contributes to poorer psychological and physical health. Finally, Study 3 explored whether females, older individuals, and those with active symptoms possess more negative anticipated societal views of IBD. This study also involved a sample of individuals with IBD. Key findings that emerged were: (i) greater internalisation of negative attributes regarding one’s IBD was linked with anticipating negative public perceptions; (ii) anticipating the public to have negative views of IBD contributed to poorer psychological and physical health for individuals with IBD; and (iii) there were no differences in anticipated societal perceptions according to age, gender and illness severity. Findings suggest the formation of anticipated societal perceptions of IBD occurs via self-perceptions of one’s condition. Overall, both Studies 2 and 3 suggest that anticipating negative societal perceptions of IBD is linked with poorer psychological health for individuals with IBD.

In Study 4, awareness and perceptions of IBD in an Australian community sample were investigated. This study also investigated factors that moderate stigmatisation of IBD. Study 4 extended prior research and uniquely added to the

literature by: (i) obtaining affective and avoidance ratings of specific IBD symptoms - separately for disclosure and non-disclosure of the condition, (ii) by exploring the role of disgust sensitivity in regards to avoidance of IBD, and lastly, (iii) by manipulating proximity and duration of contact within vignettes. The sample consisted of community members residing in Australia and all participants completed an online survey. A key finding of Study 4 was that community members indicated greater avoidance of IBD in the *non-disclosure* condition, whereby participants did *not* attribute the symptoms to IBD. Secondly, participants indicated negative emotional reactions towards faecal symptoms, irrespective of disclosure. Results indicated that the following are linked with greater public stigmatisation of IBD: 1) non-disclosure of IBD, 2) presence of faecal symptoms, 3) situations involving prolonged contact with IBD, and 4) lower familiarity with IBD and higher disgust sensitivity (i.e., when IBD is *not* disclosed). These findings have societal and clinical implications, and these are further explored below. Additionally, these findings from community members in Study 4 can be compared to the findings obtained from individuals with IBD in Studies 2 and 3. In subsequent sections, general conclusions are inferred from overall findings and by comparing findings from Studies 2 and 3 (individuals with IBD), to that of Study 4 (community sample).

Comparing Findings: Individuals with IBD and the Wider Community

Utilising findings from this program of research, conclusions can be inferred about whether the concerns of those with IBD are consistent with those of the general community. Namely, do these individuals need to fear negative evaluation from those without IBD? This topic will be discussed throughout the following paragraphs, by comparing the findings reported by those with and without IBD on these pertinent

factors: 1) Disclosure; 2) IBD Symptoms; 3) Familiarity and Awareness of IBD; and 4) Disgust.

Disclosure

Qualitative reports in Study 2 indicated that individuals with IBD are hesitant to disclose their condition due to a number of barriers, one of which is the expectation of negative reactions from others upon disclosure. However, this contrasts with Study 4 findings which indicated that disclosure mitigates stigmatisation. Specifically, lower stigma was directed towards IBD when disclosed, and community members were more willing to have brief contact with the target when confirmation of IBD was provided. Indeed, this suggests that disclosing one's IBD to others may reduce stigmatising attitudes and negative judgements of IBD. Therefore, disclosure may work to provide a cause/condition to attribute symptoms to, thereby reducing personal blame for symptoms (Saunders, 2014). Disclosure may also increase familiarity with IBD and elicit empathy from others towards the individual with IBD, thus resulting in lower stigmatising attitudes towards IBD. Further, findings from our systematic review (Polak et al., 2020) indicated that social support and disclosure of one's IBD are linked with stigma resilience (e.g., Dibley, Norton, & Whitehead, 2018; Frohlich, 2014). It can be inferred, then, that in some circumstances (e.g., employment settings) disclosure may be helpful for those with IBD to increase understanding and support from others. For instance, a report by the UK Work Foundation group found that employees with IBD reported benefits of disclosing their condition to their employer when requiring sick leave or time off to attend hospital appointments (Bajorek, Summers, & Bevan, 2015, as cited in Guo, Rohde, & Farraye, 2020). Employees also reported that their employers were appreciative of their self-disclosure and that this promoted open communication. Consequently, employers were able to offer flexible work arrangements for some

employees. Similarly, Crohn's and Colitis Australia's (CCA) guide for employees with IBD (2013, see pg. 8) recommend disclosing one's condition to employers for the following reasons: (1) to request flexible working arrangements or modifications; (2) the employer has "equal opportunity" policies in place; (3) to demonstrate that IBD does not impact upon work productivity; and (4) to increase the employer's understanding/empathy when required to take sick leave or attend medical appointments. This guide also outlines key advantages for disclosing one's condition to immediate co-workers such as to increase cooperation and understanding of reasons for flexible work arrangements, leave, or re-allocation of work responsibilities. Regarding public settings, CCA (2020) discuss the use of 'can't wait cards' as a method to disclose one's IBD to businesses if urgently requiring the use of their bathroom facilities (refer to https://www.crohnsandcolitis.com.au/site/wp-content/uploads/can_t_wait_card.jpg for an example of the 'can't wait card'). Lastly, CCA's Crohn's and Colitis Hub (2020) recommends that individuals with IBD seek support from a trusted person (e.g., family member or friend).

The above information outlines some recommendations or benefits of disease disclosure in employment and public settings. However, the current findings need to be considered with caution as individuals with IBD may still need to evaluate the appropriateness to disclose given the context/situation (e.g., when first meeting someone), the impacts or consequences of disclosing, and their relationship to the person(s) in question. Rohde et al. (2018) highlighted that situations such as a first date or job interview may not be appropriate situations to disclose one's condition. CCA's guide for employees with IBD (2013, see pg. 9) also suggests limits to disclosing to an employer, for example, if one's IBD is in remission and if IBD has no impact on work performance or attendance. As noted in previous research (Rohde et al., 2018), further

research is needed on this topic, before the full implications for clinical practice are known. Lastly, those with IBD may also consider potential negative emotional reactions towards the symptoms of their condition, and this issue is explored below.

IBD Symptoms

Individuals with IBD anticipate stigmatisation and negative emotional reactions in response to the symptoms that they experience (as reported in Studies 1 and 2). Further to this, participants also reported direct experiences of public stigmatisation of IBD symptoms (e.g., negative verbal remarks made about smells in public bathrooms – Study 2). These concerns appear consistent with the findings revealed in Study 4, where community members indicated the greatest avoidance of faecal symptoms, and directed similar negative emotional reactions towards IBD symptoms, irrespective of disclosure. Therefore, even when community members attributed symptoms like that of flatulence and faecal incontinence to a chronic disease, they still directed negative emotional responses to these symptoms, similarly to those who were unaware that IBD was the cause of symptoms (i.e., non-disclosure group). It appears then, that IBD individuals' concerns regarding negative judgements of individual symptoms of IBD are consistent with findings indicated by the general community, further corroborating the occurrence of the negative reactions that are, in fact, feared by those with IBD. These reactions likely occur in the context of the social unacceptability of private bowel symptoms being made public (Dibley et al., 2018). Additionally, these findings are consistent with participant reports of excluding themselves from public events due to fears of being unable to access bathrooms, or when experiencing active flares (Study 2). In light of the findings discussed above regarding disclosure and IBD symptoms, the public may respond negatively to individual symptoms of IBD, but on the other hand appear to display increased willingness to have contact with IBD upon disclosure of the condition.

In other words, the public appear to respond to faecal symptoms negatively, rather than the disease label of “IBD”. Moreover, familiarity and awareness of IBD were additional factors that mitigated stigmatisation of IBD.

Familiarity and Awareness

Individuals with IBD perceived the general community to have little awareness of IBD (as reported in Study 2). This appeared to be consistent with findings reported by the community in Study 4, with just over half the sample indicating poor awareness of IBD and most indicating that they do not know someone with the condition. Based upon the collective findings, it can be inferred that the majority of the general community have little awareness of IBD and in turn do not associate disgust-eliciting behaviours such as diarrhoea to a chronic disease, further providing insight into the mechanisms underlying negative public reactions towards IBD symptoms. Moreover, if there was greater awareness of IBD in the wider community, then those with the condition may be more comfortable openly disclosing their condition with others (Saunders, 2014). Relatedly, Study 4 indicated that greater public familiarity with IBD was linked with lower stigmatisation, when IBD was disclosed. This suggests that disclosure of one’s IBD may increase familiarity with IBD within the community, and potentially reduce negative reactions to IBD over time. Another variable of focus among those with IBD and in the community, was that of disgust.

Disgust

Those with IBD anticipate and perceive disgust reactions from the wider community in response to their condition and symptoms (i.e., as reported in Study 2). Consistent with this, community members with high disgust sensitivity indicated greater avoidance of IBD symptoms when the condition was *not* disclosed. It is likely then, that upon presentation of symptoms without a disease label, community members interpreted

symptoms as signs of infectious disease resulting in greater avoidance. However, when there was confirmation of IBD, disgust sensitivity was not linked with avoidance of IBD, and this is inconsistent with the above concerns of those with IBD. Therefore, providing a ‘disease label’ and cause for symptoms may have lowered disgust and reduced judgements of contagion risk, in turn increasing willingness for contact. Indeed, accurate contagion knowledge has mitigated prejudicial attitudes towards HIV/AIDS, an often stigmatised condition (Chan, Yang, Li, Stooze, & Reidpath, 2009). In the current research, these findings imply that accurate knowledge about a condition’s contagion risk is linked with reduced avoidance and thus, lower stigmatisation (Kouznetsova, Stevenson, Oaten, & Case, 2012). This highlights that disclosure may increase knowledge of the condition, and moderate stigmatising attitudes and disgust.

Summary: Comparing Findings

Collectively, findings indicated that for:

- 1) *Disclosure*: it appears that individuals with IBD have mostly negative perceptions of disclosure and expect negative reactions in this circumstance, however, findings indicated that disclosure may elicit support and empathy from others, in turn lowering stigmatisation of IBD. However, further research is needed to explore this topic further.
- 2) *IBD symptoms*: there were consistent responses between those with IBD and the community regarding negative reactions to IBD symptoms. Negative public reactions to IBD symptoms likely occur based upon the taboo attached to bowels.
- 3) *Familiarity and Awareness*: there seems to be poor awareness of IBD in the community, as hypothesised by those with the condition.

- 4) *Disgust*: those with IBD anticipate the general community to respond to their condition with disgust, however, according to findings, disgust was not linked with avoidance when IBD was disclosed. This suggests a mechanism whereby disclosure moderates disgust.

Implications: Societal and Clinical

Findings that emerged from this program of research have implications for clinical settings, and for the wider community. At a societal level, awareness and knowledge of IBD can be increased by utilising advertising campaigns. This can be achieved through introducing a national campaign to major shopping centres, by placing flyers with information about IBD in public bathrooms. Other mediums like social media, television and radio advertisements could also be utilised. For instance, the Foundation of Crohn's and Colitis America released a TV/print public awareness campaign in 2013 titled, 'Escape the stalls.' The campaign featured a celebrity spokesperson with Ulcerative Colitis, along with print ads (e.g., in public bathrooms, billboards) depicting feet of different people under bathroom stalls with accompanying captions that were developed to generate conversations and discussions about IBD. A similar advertising campaign could be utilised within Australia. Additionally, advertising campaigns could utilise celebrities or members of the community to share their story with IBD. In turn, campaigns such as these could increase awareness of IBD among thousands of people in the community, and facilitate those with IBD to openly discuss their condition and to feel more comfortable engaging with the community.

Clinically, findings highlighted a number of implications for healthcare professionals working with individuals with IBD, specifically, within: 1) assessment, 2) education, and 3) therapy. Mental health professionals can routinely *assess* the following factors: illness perceptions, perceptions of stigma (particularly internalised

stigma), emotional reactions towards IBD (Polak et al., 2020), self-excluding behaviours, and concerns regarding public perceptions of IBD. These factors could be assessed using standardised measures that can be completed in clinic waiting rooms prior to appointments, and via clinical interviewing. Outcomes of these assessments (i.e., scores over cut-offs or endorsing clinical interview questions) can inform treatment planning, with the aim of reducing the impact of these factors on psychological functioning and quality of life. Secondly, based upon the collective findings, mental health professionals can provide *education* to those with IBD regarding the pattern in IBD literature, whereby those with IBD tend to anticipate negative reactions and stigmatisation from others, and in turn, avoid social situations due to these expectations (Polak et al., 2020). Lastly, within *therapy*, mental health professionals can explore adaptive responses to emotions (Polak et al., 2020), and assist in reframing negative self-perceptions and anticipated public views of the condition. Regarding disclosure, professionals can engage individuals in collaborative discussions regarding decision-making for when and how to disclose one's condition if required and the potential benefits in doing so in the appropriate circumstances. Lastly, 'scripts' to disclose one's condition with others can be collaboratively written and rehearsed.

Future Research and Recommendations

To further extend the current findings, future research could examine anticipated societal perceptions of those with IBD cross-culturally, to explore similarities and differences in concerns across different cultures and countries. Furthermore, the current research extended prior literature by specifically exploring if those with IBD perceive the public to be disgusted by their condition, and if disgust sensitivity impacts public stigmatisation of IBD. Research could expand upon this work by exploring the role of disgust in IBD and the impacts on clinical outcomes. Specifically, research could

investigate if high disgust sensitivity is linked with maladaptive coping mechanisms and responses to one's condition, and in turn, the influence of disgust sensitivity on mental health and quality of life (Polak et al., 2020). On the other hand, research could explore if lower disgust sensitivity is linked with adaptive coping and improved functioning (e.g., reduced anxiety/depression and improved quality of life). Lastly, the cross-sectional nature of this research limited the ability to draw conclusions about the direction of the effects and causation. Therefore, it is recommended that future research utilise longitudinal designs to explore the direction of the findings. For instance, researchers could utilise a longitudinal design to investigate if concerns regarding public perceptions change over time and to explore the relationships investigated in Study 3, namely, if anticipating negative societal perceptions predicts poorer physical and psychological functioning, and if internalising negative attributes of one's disease contributes to the formation of negative anticipated societal perceptions of IBD. This could be conducted by following a cohort of individuals with IBD at different time points and collecting data via online questionnaires to measure the variables of focus – e.g., when first diagnosed in adolescence/early adulthood (Time 1), in mid adulthood (Time 2) and late adulthood (Time 3). Moreover, outcomes from the published systematic review (Study 1; Polak et al., 2020) indicated that more research is needed to explore public awareness and perceptions of IBD, and this presents an important task for future research. Additionally, the qualitative design in Study 2 could be replicated utilising a community sample to explore qualitative opinions regarding public perceptions of IBD, particularly whether the public display disgust towards the condition. Based upon the findings of interviews, further conclusions could be inferred regarding consistencies or differences between those with IBD and community samples. Lastly, research can extend the current work on community perceptions of IBD by

utilising a vignette design to explore reactions to a wider range of IBD symptoms, and to compare perceptions of IBD to other chronic health conditions.

Conclusion

This research presented preliminary findings regarding societal perceptions of IBD in those with the condition and in the wider community. The current findings contributed to understanding how individuals with IBD view societal perceptions of their disease. Additionally, this thesis provided important and valuable information about the awareness and knowledge of this disease in an Australian community sample, and factors that can moderate the extent of stigmatisation towards IBD. Outcomes from Studies 1 to 3 suggested that for individuals with IBD: (i) negative self-perceptions of the condition negatively impact upon wellbeing, and are linked to anticipating negative societal perceptions of IBD; (ii) viewing the community to have negative perceptions of IBD, impacts upon the psychological health of those with the condition; and (iii) common concerns exist regarding difficulties with disclosing one's condition and functioning within public settings due to anticipated negative reactions. These findings highlight the importance of considering concerns regarding self and public perceptions of IBD, along with the impact of these concerns on overall wellbeing. Study 4 findings indicated that disclosure of IBD may increase familiarity with the condition, elicit support and empathy from others, and reduce disgust and stigmatisation towards IBD. Based upon findings from Study 4, it is suggested that, once disclosed, the community views the 'disease label' of IBD positively, rather than the individual symptoms of IBD. It also appears that due to poor awareness of IBD in the community, the public, in turn, do not attribute bowel symptoms to that of a chronic condition. However, further research in this area is needed to infer stronger conclusions. Furthermore, societal implications were highlighted, namely, that of developing awareness campaigns to

generate discussion about IBD and its impacts. Other clinical implications were also discussed regarding factors (e.g., illness perceptions, internalised stigma, concerns about public perceptions) to include in assessment, education and therapy within clinical settings. Finally, it would be helpful to utilise longitudinal designs to extend the current findings, with the aim of improving well-being and everyday life for individuals with IBD.

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APPENDIX A

SEARCH TERMS USED IN STUDY 1, CHAPTER 2

Search Terms for IBD Participants:

Inflammatory Bowel Disease OR IBD OR Ulcerative Colitis OR UC OR Crohn's Disease OR CD

AND

Adults OR Adolescents, AND (Combination of the following)

Perceptions

Illness perceptions OR cognitions OR representations

Stigma* OR discrimination* OR stigmatisation* OR excluded* OR ostracised* OR prejudiced* OR avoidance*

Negative Emotions OR Feelings

Concerns

Psychological reactions OR Emotional reactions

Embarrassment* OR Humiliated*

Fear* OR Afraid

Disgust*

Shame* OR Ashamed

Anger OR Frustration

Psychological Outcomes OR Psychological wellbeing

Psychosocial health OR psychosocial wellbeing

Physical Health

Psychological distress OR Anxiety OR Depression OR Stress

Quality of life OR Health Related Quality of Life

Self-esteem

Self-efficacy

Medication Adherence OR Treatment Adherence

Observational Study

Experimental Study

Interventional Study

Correlate

Predict

Qualitative OR Quantitative

Search Terms for Community:

Inflammatory Bowel Disease OR IBD OR Ulcerative Colitis OR UC OR Crohn's Disease OR CD

AND

Adults OR Children OR Adolescents

AND

General Population* OR Community OR Community Members OR Lay Sample OR Community Sample

Public Awareness

Medical Professionals OR Gastroenterologists OR Nurses OR General Practitioners OR GPs

Carers OR Loved Ones OR Partners OR Parents

AND (Combination of the following)

Perceptions

Illness perceptions OR cognitions OR representations

Stigma* OR discrimination* OR stigmatisation* OR excluded* OR ostracised* OR prejudiced* OR avoidance*

Negative Emotions OR Feelings

Psychological reactions OR Emotional reactions

Embarrassment* OR Humiliated*

Fear* OR Afraid

Disgust*

Shame* OR Ashamed

Anger OR Frustration

Psychological Outcomes OR Psychological wellbeing

Psychosocial health OR psychosocial wellbeing

Physical Health

Psychological distress OR Anxiety OR Depression OR Stress

Quality of life OR Health Related Quality of Life

Self-esteem

Self-efficacy

Medication Adherence OR Treatment Adherence

Observational Study

Experimental Study

Interventional Study

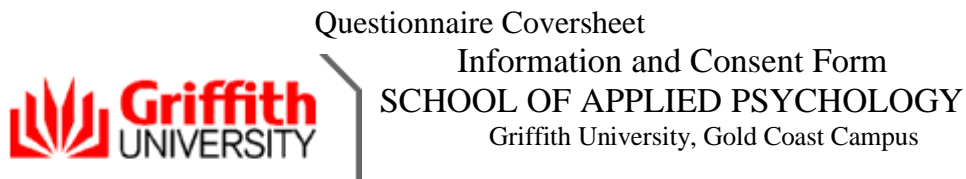
Correlate

Predict

Qualitative OR Quantitative

APPENDIX B

INFORMATION AND CONSENT FORM FOR CHAPTERS 3-4



INFORMATION & CONSENT Societal Perceptions of Inflammatory Bowel Disease

(GU Ref No: 2016/138)

Who is conducting the research?

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Office Phone: (07) 5678 0831

Clinical Psychology

PhD researcher: Elia-Jade Polak
School of Applied Psychology, Griffith University
Email: elia-jade.polak@griffithuni.edu.au

Why is the research being conducted?

The research is being conducted as part of the requirements of the Doctor of Philosophy in Clinical Psychology being undertaken by Elia-Jade Polak and supervised by Associate Professor Fran O'Callaghan and Dr Megan Oaten. The aim of the study is to explore how individuals with IBD view the general public's perceptions and reactions (thoughts and feelings) towards their disease and the influence these perceptions have on their quality of life.

What you will be asked to do

You will be asked to complete the attached survey. The survey is anonymous and all responses given will remain confidential. The survey will take approximately 20 minutes to complete. In return for completing the survey, you are eligible to enter a draw to win one of three \$30 Amazon eGift Cards. Upon completion of data collection, the winners will be randomly selected by a person not involved with the research project, and will be contacted via email.

You will also be given the option to complete an individual interview at a later date (*either online - using an audio or video Skype chat, telephone or in person*) to allow you to share your perspectives in greater depth. It will take no more than 40 minutes to complete the interview and **you will receive a \$25 Amazon eGift Card to thank you for your participation** (refreshments will be provided at in person interviews). Additionally, sharing one's story can be healing, empowering and therapeutic. Upon completion of the interview, your voucher will be emailed to you.

Eligibility for participation

Participation is open to all individuals who have been medically diagnosed with Inflammatory Bowel Disease (including those in remission), aged between 18 to 60 years.

The expected benefits of the research

The research is expected to contribute to our knowledge and understanding of the anticipated societal perceptions of individuals with IBD and their influence on quality of life.

Risks to you

There are no anticipated risks involved with participating in the survey. However, the survey includes questions in relation to opinions/reactions about sexual acts/situations. *You do not need to answer every question and if you become uncomfortable when completing the survey, you can exit the survey at any time without penalty.* Minimal risks may also be associated with participating in the interview. It is possible that you may experience low levels of distress as a result of discussing your condition. If so, you will be encouraged to contact your GP or Lifeline Australia (i.e., 13 11 14). Additionally, you can choose to stop the interview at any time without providing an explanation. *If you suspect that answering the survey and/or interview questions about societal perceptions of IBD may cause you to feel distressed, then it is recommended that you do not take part in this research.*

Your confidentiality

No identifiable information will be collected during the completion of the online questionnaires so you may be assured that the information you provide will remain completely confidential. If you wish to enter the prize draw, you will be asked to record your email address **separately** to the questionnaire responses. You will be directed to a different link where you can provide this information. This information cannot be linked to your responses.

If you agree to participate in an individual interview you will be asked to click on a link that will redirect you to another internet page, where you can provide your name and contact information (i.e., preferred phone number and email address). Your confidentiality will be maintained, as your contact information will be recorded **separately to the questionnaire responses**. Additionally, with your consent, the responses that you provide to interview questions will be audio recorded and deleted immediately after the completion of the study. Your responses will remain completely confidential as all identifiable information (such as your name) will be deleted and will not be recorded with your responses. However, with your permission we would like to keep your age, gender and IBD diagnosis linked to the responses. As required by Griffith University, all research data (survey/interview responses and analysis) will be retained in a locked cabinet and/or a password protected electronic file at Griffith University for a period of five years before being destroyed.

Please note: Any information that has been sent to you by an organisation, has been sent on the researchers' behalf. The researchers of this study have not been given the names or contact details of any members.

Your participation is voluntary

Your participation is entirely voluntary and there will be no penalty if you decide not to complete the questionnaire or the interview. You may stop both the questionnaire and the interview at any time without providing an explanation.

Mechanism for distribution and return

Questionnaires will be made available and returned online. As previously stated, all responses are confidential.

Questions / further information

If you have any further questions regarding this project please do not hesitate to contact any member of the research team on the contact details provided above.

The ethical conduct of this research

Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research* (2007). If you have any concerns or complaints about the ethical conduct of the research project please contact the Manager, Research Ethics on (07) 3735 4375 or research-ethics@griffith.edu.au.

Feedback to you

If you wish to obtain a summary of the results, please contact one of the investigators as shown above. Additionally, a summary of the main findings of this study will be emailed/posted to each of the organisations that the study was advertised from, so that the organisations can disseminate them to you. These summaries will not contain any identifiable information but rather aggregated results, such as the average scores on quantitative measures and the main themes found within the qualitative data.

Expressing consent

You will be deemed to have understood the terms and conditions and have consented to participate in this research project by completing the questionnaire. Please keep this informed consent letter for future reference.

If you choose to participate in the interview, you will indicate informed consent for this at the end of the online questionnaire. Specifically, the final item of questionnaire will be, "Would you be willing to participate in a follow-up individual interview?" You will then be able to choose between "Yes" or "No" response options. Therefore, consent for the individual interview will be indicated if you select the "Yes" response option. You will further indicate consent by typing your name and the date when entering your contact details into the new internet page, to participate in the interview (this information will not be connected to your survey responses).

Terms and Conditions of Entry into the Draw

1. The prize draw is being run by Associate Professor Frances O'Callaghan, Dr Megan Oaten and Elia-Jade Polak of Griffith University to encourage participation in our study exploring how individuals with IBD view the general public's perceptions and reactions (thoughts and feelings) towards their disease and the influence these perceptions have on their quality of life.
2. By electing to participate, you accept these terms and conditions as governing the prize draw. Instructions on how to enter the prize draw and details advertising the survey form part of the conditions. Any personal information you provide to us in the course of entering the prize draw will be dealt with by us in accordance with our privacy policy (published at: <http://www.griffith.edu.au/about-griffith/governance/plans-publications/griffith-university-privacy-plan>).
3. Three (3) prizes will be awarded in prize draw, each prize being an Amazon eGift Card and being worth \$30. Should the advertised prize become unavailable as a result of circumstances beyond our control, we are free (at our sole discretion) to substitute a cash prize equivalent to the value of the prize advertised.
4. Entry is free (other than the cost of accessing the website which is your responsibility). Entry is open between March 2017 and December 2017. Entries received after the closing date will not be accepted.
5. To enter the prize draw, you must:
 - (a) be aged between 18 to 60 years ;
 - (b) have been medically diagnosed with Inflammatory Bowel Disease (including those in remission); and
 - (c) provide a valid email address.
6. You may not enter the prize draw if you are: i) a member of the research team, ii) employed by the research team; iii) an immediate family member (i.e. a spouse-partner, child or sibling) of someone identified at 1 or 2 above.
7. You may only submit one entry in the prize draw.
8. All survey and other materials provided by you become our property. No responsibility is taken for late, lost or misdirected surveys or entries.

9. Following the closing date, the prize winners will be selected randomly from valid entries received. Each entry can only be drawn once.
10. Subject to system malfunction, the draw will occur on Friday 10th of December, 2016. If the systems supporting the draw are not functioning as they should when the draw is due, the draw will be held as soon as possible once the systems become functional again. Prize winners do not need to be present at the time of the draw.
11. Prize winner names will not be published.
12. The relevant prize will be sent to each prize winner at the email address captured within the survey instrument. If an address has not been supplied, the entry will be treated in accordance with clause 14. The majority of prizes will be emailed within two weeks of the draw.
13. The right to a prize is not transferable or assignable to another person.
14. If any prize winner cannot be contacted within three (3) months of the draw, then that person's right to the prize is forfeited and the prize will be treated as an unclaimed prize.
15. Only one redraw of unclaimed prizes will take place, and other existing prizes are not affected. The redraw prize winner(s) will be randomly selected from remaining valid entries and notified within two (2) weeks of the redraw. If the redraw prize winner(s) cannot be contacted within three (3) months of the redraw, then we may determine that the relevant prize(s) will not be awarded.
16. Prizes cannot be substituted for another prize at the election of the prize-winner.
17. We are not liable for any loss, expense, damage or injury sustained by any entrant in connection with this prize draw, the prize or redemption of the prize, except for any liability which cannot be excluded by law (in which case, that liability is limited to the minimum allowable by law).
18. We may suspend the promotion if we determine that the integrity or administration of the promotion has been adversely affected due to circumstances beyond its control. We may disqualify any individual who tampers with the entry process.

Your assistance with this research is greatly appreciated

A/Professor Fran O'Callaghan
School of Applied Psychology
Griffith University
Gold Coast Campus

Dr Megan Oaten
School of Applied Psychology
Griffith University
Gold Coast Campus

Elia-Jade Polak
School of Applied Psychology
Griffith University
Gold Coast Campus

APPENDIX C

SUPPLEMENTARY MATERIALS FOR CHAPTER 4

Electronic Supplementary Material 1

Items utilised to measure Anticipated Societal Perceptions of IBD:

The questions below will ask you how you think other people view your disease. For the purpose of these questions, “other people” refer to people in the general public. Please choose the number that best corresponds to your views (1 = strongly disagree; 7 = strongly agree).

1. I think other people would know what IBD is.
2. I think other people would believe that IBD negatively affects my life.
3. I think other people would view me as being responsible for my IBD.
4. I think other people would treat me differently if they knew about my IBD.
5. I think other people would be uncomfortable discussing my IBD symptoms with me.
6. I think other people would feel embarrassed if I experienced IBD symptoms on a social occasion.
7. I think other people would be revolted by my IBD symptoms.
8. I think other people would expect things from me that I cannot do because of my IBD.

Electronic Supplementary Material 2

Items used to measure Internalised Stigma:

For the following questions, please circle the number that best corresponds to your views (1 = strongly disagree; 7 = strongly agree).

1. I'm embarrassed by my IBD.
2. I feel rejected by other people because of my IBD.
3. My IBD makes me feel socially uncomfortable.

APPENDIX D

INFORMATION AND CONSENT FORM FOR CHAPTER 5

Questionnaire Coversheet



Information and Consent Form
SCHOOL OF APPLIED PSYCHOLOGY
Griffith University, Gold Coast Campus

INFORMATION & CONSENT

Community Perceptions of Health and Wellbeing (GU Ref No: 2019/046)

Who is conducting the research?

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A/Prof Megan Oaten
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Office Phone: (07) 5678 0831

Clinical Psychology

PhD researcher:

Elia-Jade Polak
School of Applied Psychology, Griffith University
Email: elia-jade.polak@griffithuni.edu.au

Why is the research being conducted?

The research is being conducted as part of the requirements of the Doctor of Philosophy in Clinical Psychology being undertaken by Elia-Jade Polak and supervised by Associate Professor Fran O'Callaghan and Associate Professor Megan Oaten. The aim of the study is to investigate perceptions of health and wellbeing in the community.

What you will be asked to do

You will be asked to complete a survey that asks about your thoughts, feelings and attitudes toward health and wellbeing. The survey is anonymous and all responses given will remain confidential. The survey will take approximately 25 minutes to complete. In return for completing the survey, you are eligible to enter a draw to **win one of three \$50 Amazon eGift Cards**. Upon completion of data collection, the winners will be randomly selected by a person not involved with the research project, and will be contacted via email.

Eligibility for participation

Participation is open to all individuals residing in Australia, between the ages of 18 to 65 years.

The expected benefits of the research

The research is expected to contribute to our knowledge and understanding of perceptions (including attitudes, thoughts and feelings) of health in Australian communities.

Risks to you

There may be minimal risks involved with participating in the survey. Firstly, the survey includes questions in relation to opinions/reactions about sexual acts/situations. *You do not need to answer every question and if you become uncomfortable when completing the survey, you can exit the survey at any time without penalty.* It is also possible that you may experience low levels of distress as a result of answering questions regarding sickness or health symptoms in the workplace. If so, you will be encouraged to contact your GP or Lifeline Australia (i.e., 13 11 14). Again you can choose to exit the survey at any time without penalty.

Your confidentiality

No identifiable information will be collected during the completion of the online questionnaires so you may be assured that the information you provide will remain completely confidential. If you wish to enter the prize draw, you will be asked to record your email address **separately** to the questionnaire responses. You will be directed to a different link where you can provide this information. This information cannot be linked to your responses. As required by Griffith University, all research data (survey responses and analysis) will be retained in a password protected electronic file at Griffith University for a period of five years before being destroyed.

Your participation is voluntary

Your participation is entirely voluntary and there will be no penalty if you decide not to complete the questionnaire. You may stop the questionnaire at any time without providing an explanation.

Mechanism for distribution and return

Questionnaires will be made available and returned online. As previously stated, all responses are confidential.

Questions / further information

If you have any further questions regarding this project please do not hesitate to contact any member of the research team on the contact details provided above.

The ethical conduct of this research

Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research* (2007). If you have any concerns or complaints about the ethical conduct of the research project please contact the Manager, Research Ethics on (07) 3735 4375 or research-ethics@griffith.edu.au.

Feedback to you

If you wish to obtain a summary of the results, please contact one of the investigators as shown above. Research results will be reported in an academic thesis, and may also be disseminated via journal articles and / or conference presentations. No personal or identifying information will be disseminated or included.

Expressing consent

You will be deemed to have understood the terms and conditions and have consented to participate in this research project by completing the questionnaire. Please print this sheet and retain it for your later reference.

Terms and Conditions of Entry into the Draw

1. The prize draw is being run by Associate Professor Frances O'Callaghan, Associate Professor Megan Oaten and Elia-Jade Polak of Griffith University to encourage participation in our study exploring community perceptions of health and wellbeing.
2. By electing to participate, you accept these terms and conditions as governing the prize draw. Instructions on how to enter the prize draw and details advertising the survey form part of the conditions. Any personal information you provide to us in the course of entering the prize draw will be dealt with by us in accordance with our privacy policy (published at: <http://www.griffith.edu.au/about-griffith/governance/plans-publications/griffith-university-privacy-plan>).
3. Three (3) prizes will be awarded in prize draw, each prize being an Amazon eGift Card and being worth \$50. Should the advertised prize become unavailable as a result of circumstances beyond our control, we are free (at our sole discretion) to substitute a cash prize equivalent to the value of the prize advertised.
4. Entry is free (other than the cost of accessing the website which is your responsibility). Entry is open between February 2019 and May 2019. Entries received after the closing date will not be accepted.
5. To enter the prize draw, you must:
 - (a) be aged between 18 to 65 years;
 - (b) be a resident living in Australia, and
 - (c) provide a valid email address.
6. You may not enter the prize draw if you are: i) a member of the research team, ii) employed by the research team; iii) an immediate family member (i.e. a spouse-partner, child or sibling) of someone identified at 1 or 2 above.
7. You may only submit one entry in the prize draw.
8. All survey and other materials provided by you become our property. No responsibility is taken for late, lost or misdirected surveys or entries.
9. Following the closing date, the prize winners will be selected randomly from valid entries received. Each entry can only be drawn once.
10. Subject to system malfunction, the draw will occur on May 31st, 2019. If the systems supporting the draw are not functioning as they should when the draw is due, the draw will be held as soon as possible once the systems become functional again. Prize winners do not need to be present at the time of the draw.
11. Prize winner names will not be published.
12. The relevant prize will be sent to each prize winner at the email address captured within the survey instrument. If an address has not been supplied, the entry will be treated in accordance with clause 14. The majority of prizes will be emailed within two weeks of the draw.
13. The right to a prize is not transferable or assignable to another person.
14. If any prize winner cannot be contacted within three (3) months of the draw, then that person's right to the prize is forfeited and the prize will be treated as an unclaimed prize.
15. Only one redraw of unclaimed prizes will take place, and other existing prizes are not affected. The redraw prize winner(s) will be randomly selected from remaining valid entries and notified within two (2) weeks of the redraw. If the redraw prize winner(s) cannot be contacted within three (3) months of the redraw, then we may determine that the relevant prize(s) will not be awarded.
16. Prizes cannot be substituted for another prize at the election of the prize-winner.
17. We are not liable for any loss, expense, damage or injury sustained by any entrant in connection with this prize draw, the prize or redemption of the prize, except for any liability which cannot be excluded by law (in which case, that liability is limited to the minimum allowable by law).
18. We may suspend the promotion if we determine that the integrity or administration of the promotion has been adversely affected due to circumstances beyond its control. We may disqualify any individual who tampers with the entry process.

Your assistance with this research is greatly appreciated

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APPENDIX E

SUPPLEMENTARY MATERIALS FOR CHAPTER 5

Copy of Vignettes:

Disclosure Condition	Non-Disclosure Condition
<p><i>Bathroom Frequency:</i> It is a Wednesday afternoon and you are attending the weekly staff meeting at work. A person that you work with, Alex, discloses that they have inflammatory bowel disease. Due to this, Alex uses the bathroom three times during the hour-long staff meeting. The bathroom is next to the meeting room and due to the loud noises, it is clear that Alex is passing a bowel movement.</p>	<p><i>Bathroom Frequency:</i> It is a Wednesday afternoon and you are attending the weekly staff meeting at work. A person that you work with, Alex, uses the bathroom three times during the hour-long staff meeting. The bathroom is next to the meeting room and due to the loud noises, it is clear that Alex is passing a bowel movement.</p>
<p><i>Flatulence:</i> It is a Wednesday afternoon and you are at work. You need to use the toilet and walk into the work bathroom. While in the toilet, you can hear noises and can smell faeces from the cubicle next to you. Afterwards, you wash your hands at the basin and notice that your colleague, Alex, walks out from the toilet cubicle where the smells and noises were coming from. Alex discloses that this is a result of having inflammatory bowel disease.</p>	<p><i>Flatulence:</i> It is a Wednesday afternoon and you are at work. You need to use the toilet and walk into the work bathroom. While in the toilet, you can hear noises and can smell faeces coming from the cubicle next to you. Afterwards you wash your hands at the basin and notice that your colleague, Alex, walks out from the toilet cubicle where the smells and noises were coming from.</p>
<p><i>Incontinence:</i> It is a Wednesday afternoon and you are attending the weekly staff meeting at work. You are sitting in the staff meeting room waiting for the meeting to start. You notice that your colleague, Alex, suddenly gets up and walks quickly out of the room. As Alex does this, you notice that Alex has soiled their trousers. After the staff meeting, Alex discloses to you that this is because they have inflammatory bowel disease.</p>	<p><i>Incontinence:</i> It is a Wednesday afternoon and you are attending the weekly staff meeting at work. You are sitting in the staff meeting room waiting for the meeting to start. You notice that your colleague, Alex, suddenly gets up and walks quickly out of the room. As Alex does this, you notice that Alex has soiled their trousers.</p>

Willingness for contact:

In this situation presented in the scenario above, how likely is it that most people would be <i>comfortable</i> to:	1 Not at all likely	2	3	4	5	6	7 Extremely Likely
1. Work on a small team project with Alex?							
2. Share an office with Alex?							
3. Shake hands with Alex?							
4. Sit beside Alex in a twenty minute staff meeting?							
5. Have lunch with Alex?							
6. Talk to Alex while lining up to order a coffee at a café?							
7. Walk with Alex from the office building to the work car park?							
8. Share a car ride with Alex to a work conference?							
9. Share an umbrella with Alex while walking to a meeting across the road from your office building?							
10. Socialise with Alex outside of work?							
11. Share hotel accommodation with Alex for a work trip?							
In the Disclosure condition only: ask Alex questions to find out more about the symptoms of inflammatory bowel disease?							

Emotional Reactions:

In response to this situation presented in the scenario above, which emotion(s) would most people likely feel?	1 Not at all likely	2	3	4	5	6	7 Extremely
1. Embarrassment							
2. Fear							
3. Sympathy							
4. Disgust							
5. Happiness							
6. Anger							
7. Sadness							