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

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Abstract

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.

Key words: Inflammatory Bowel Disease, illness perceptions, stigma, stigmatisation, emotional reactions, fear, disgust, quality of life in IBD, adjustment to IBD.

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 (Leventhal, Leventhal, & Contrada, 1998; 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, & Mc Evaddy, 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 the Supplemental Materials.

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 1 in the Supplemental Materials (some studies reported findings on multiple variables and if so, were only counted once in Figure 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 1a and 1b presented in the Supplemental Materials.

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 in the Supplemental Materials). 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). 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 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 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; 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 3 in the Supplemental Materials). 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; M. 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). 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). 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 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., 2016; 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., 2016; Zhang et al., 2016). 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, Fidler, 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, Fidler, 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 4 in the Supplemental Materials). 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 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 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 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, Tucac, & 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 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, 2012; 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 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 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., 2012; 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; Purcstephenson, 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 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 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 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; Purc-stephenson 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 5 in the Supplemental Materials) 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 5). Overall, quality assessment indicated that quantitative studies examining emotional reactions were of poor quality (refer to Table 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 1a for other quality criteria). On the other hand, the majority of qualitative studies satisfied assessment criteria (refer to Table 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 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 5).

Embarrassment. Embarrassment was explored in 23 studies (displayed in Table 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-stephenson 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 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, 2017; Trindade, Ferreira, & Pinto-Gouveia, 2016; refer to Table 5).

The emotion of anger was reported in nine studies (presented in Table 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 (Sammut et al., 2015) and not understanding their condition (Daniel, 2002). Factors that elicited anger in participants are presented in Table 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 5 (Dibley & Norton, 2013; Dibley et al., 2018; Jordan et al., 2018; Norton & Dibley, 2013; Piper, 2017; Purc-stephenson 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 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., 2017) 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., 2017; Trindade et al., 2016). Experiencing a higher frequency of IBD symptoms was related to feelings of inferiority and inadequacy (i.e., shame; Trindade et al., 2017; Trindade et al., 2016) 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 6 in the Supplemental Materials). 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 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 1a). Finally, Tables 1a and 1b present the quality assessment of the remaining two studies that have explored community perceptions of stigma (qualitative study, Table 1b) and emotional reactions (quantitative study, Table 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 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 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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