Research Project II

Australian inflammatory bowel disease (IBD) patients want biopsychosocial healthcare: a content analysis.

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Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this thesis contains no materials previously published except where due reference is made. I give consent to this copy of my thesis, when deposited in the University Library, being available for loan and photocopying.

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Acknowledgements

Currently in Australia there are approximately 80,000 living with inflammatory bowel disease (IBD). This thesis is dedicated to those individuals living with IBD, and in particular thank you to the participants of this study, for their time, effort and openness in engaging with the study; and to participants of other studies being conducted to further research related to IBD.

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Finally, thank you to my fellow Master’s students and my family and friends.

Literature review

Inflammatory Bowel Disease (IBD)

IBD is a chronic illness, with two main subtypes; Crohn's disease (CD), and ulcerative colitis (UC). Predominant symptoms include pain, fatigue, frequent diarrhea, rectal bleeding, weight loss and perianal disease. Psychological symptoms including distress, anxiety and depression are also common. IBD is an organic disease characterised by physical alterations in the bowel. This is different to functional gut disorders like Irritable Bowel Syndrome (IBS) whereby patients experience symptoms without observable inflammation and damage to the gut. Individuals with IBD have significant comorbidity with IBS and are more likely to suffer from IBS than the general population (Farrokhyar et al., 2006). Study estimates range from 39% comorbidity with IBS (Halpin & Ford, 2012), up to 80% comorbidity with functional gut disorders (Mikocka-Walus et al., 2008).

Incidence and prevalence

IBD is characterised by its early onset, with some studies estimating 25% of patients with IBD are diagnosed before the age of 18 (Sawczenko et al., 2001; CCA, 2016). Epidemiological studies show that peak onset is between the age of 25-34 (Binder, 2004). Over 5 million people globally have been estimated to suffer from IBD (Burisch & Munkholm, 2015) and Australia has one of the highest incidence rates in the reported literature with an overall incidence rate of 29.6 per 100,000 (Wilson et al., 2010), alternatively stated as 1 in 250 persons aged 5-40 (PWC, 2013). Although IBD incidence is low, due to the lifelong nature of the illness, and its early onset, its prevalence is much greater. Currently there are 80,000 people with IBD in Australia, and this is predicted to increase to 100,000 by 2022 (CCA, 2019). Improving health care systems for IBD in Australia is becoming an increasing priority with its increasing prevalence.

Treatment for IBD

There is no cure for IBD, and it is managed largely through the long-term use of medications and/or surgery. IBD is a remitting-relapsing illness, meaning that individuals often experience times of remission intercepted with periods of relapse, and this IBD course varies from person to person. Medications such as immunomodulators and biologics are effective at controlling the symptoms of IBD, and in some cases can prevent the need for surgery, however they are not easily available and are expensive (GBD 2017 IBD Collaborators, 2019). Steroids are also commonly used to induce remission; however long-term use of steroids as a maintenance therapy is not recommended and continued steroid use indicates poorly controlled disease activity (Carter, Lobo & Travis, 2004). Overall, 60-75% of CD patients and 25-30% of UC patients are estimated to require surgery at some point in their lifetime (Cosnes et al., 2011). Surgery can involve removing sections of the bowel, or emergency colectomies where the entire colon is removed (Samuel et al., 2013). Individuals are therefore placed with a heavy burden of managing the unknown course of their IBD, given the chronic nature of the illness.

Aetiology

Although the precise cause of IBD is unknown, genetic, bacterial, immunological, and environmental factors are thought to be involved. Jostins and colleagues (2012) conducted a meta-analysis with over 75,0000 cases and controls which confirmed the identification of 163 IBD loci. A loci specifically indicates the location of a genetic marker. Despite this, no specific gene has been implicated to cause IBD, and the concordance amongst identical twins has been found to be as low as 20% (Halme et al, 2006). Therefore, epigenetics – an interplay between genetic susceptibilities and environmental triggers – provide a more likely aetiological pathway for the development of IBD.

In their recent review Glassner and colleagues (2020) highlighted the complexity and importance of the microbiome and gut bacteria in IBD; specifically, the microbiome may play a causal role in the pathogenesis of inflammatory responses seen in IBD, via commination with the immune system. Further, a recent case control study indicated that gastrointestinal infections which impact the microbiome drastically increase the chance of developing IBD (Axelrad et al., 2019).

Despite the evidence indicating that the microbiome plays a significant role in IBD, interventions targeted at influencing the microbiome lack sound evidence due to poor consistency in studies, study design and mixed results (Glassner et al. 2020). Such interventions may include probiotics, however, a recent systematic review and meta-analysis indicated that more evidence is needed (Derwa et al., 2017).

Environmental factors play a strong role in mediating the disease occurrence (Ananthakrishnan, 2013) to the extent that in a migrant population, IBD incidence resembles not the country of origin, but the country of residence (Williams, 2008). Environmental factors such as smoking for CD, diet, antibiotics use, pollution and sedentary lifestyle have all been implicated in IBD onset (Lawrance et al. 2013; Neuman & Nanau, 2012). It is these environmental factors which likely mediate the association between socioeconomic status and IBD (Ng et al. 2013; Neuman & Nanau, 2012).

Psychological factors such as distress have been shown to intercept disease activity with studies illustrating bidirectional links between psychological state and disease activity (Gracie et al, 2018). However, whether psychological factors play a causal role in the aetiology is difficult to discern. Therefore, further research is needed to identify precisely the complex bio-pathophysiological mechanisms of IBD, which appears to be comprised of complex biological, environmental, psychological and social factors (Boyapati et al., 2015),

The Brain-Gut Axis (BGA)

The BGA is a term which broadly encompasses the bidirectional system of communication between the brain and the gut. The BGA challenges the biomedical notion that there is a strict dichotomy between mind and body, and that physical ailments and illnesses are considered to be limited to the body alone.

The gut does not exist in isolation, and despite being known for its ability to digest food, absorb nutrients and excrete waste, the gut plays a crucial role in interacting with the brain by exchanging information along a number of neuroendocrine and neuroimmune pathways (Allen et al., 2017). A recent study found evidence that bacteria in the gut exchange signals to a part of the brain called the serotonergic system to promote the health of the intestine (Fung et al., 2019). The gut also plays a key role in immune function, hormones, and the enteric nervous system (Mater et al., 2015), alongside interacting with the central and autonomic nervous system, the body's stress response system and the rest of the gastrointestinal system (Bonaz & Bernstein, 2013).

Finally, it has been widely cited that the gut is responsible for producing up to 80% of the body's serotonin and storing up to 95% of the body's serotonin, with recent research indicated that gut microbiota influences the production of serotonin in the gut (Hata et al., 2017). Serotonin is an important neurotransmitter responsible for regulating mood, appetite and sleep, and is a key component of commonly used antidepressants, Selective Serotonin Reuptake Inhibitors (SSRI's).

Biopsychosocial links in IBD

The biopsychosocial model posits that biological, psychological and social factors all interconnect and influence the development of illness and psychological problems (Engel, 1977). This contrasts to the traditional biomedical approach which focuses on physical symptoms alone, without consideration of psychological or social contributors to illness. IBD is a biopsychosocial illness, which affects a person's physical, psychological and social wellbeing.

Physical

Patients with IBD experience pain, frequent diarrhoea and fatigue. Persistent pain has significant impacts on psychosocial functioning and QOL in individuals with IBD (Morrison et al., 2013). Pain persists in around 20% of IBD patients in remission (Bielefeldt et al., 2009). Poorly managed pain is also associated with reduced health-related quality of life (HRQOL) (Schirbel et al., 2010; Palm et al., 2005).

In addition to frequent diarrhoea, which can keep people bound to the bathroom, an estimated 24% of patients experience incontinence (Norton et al, 2013), which can occur despite patients being in remission (Keogh & Burke, 2017). A cross-sectional survey by Keogh and Burke (2017) (*n*=117) identified that 70% of respondents struggled to reach the toilet in time in the three months prior to the study and that levels of anxiety and depression were higher in those who had experienced incontinence.

A systematic review (*n*=254) by Van Langenberg & Gibson (2010) estimated the prevalence of fatigue to be up to 48% in patients in remission and up to 86% in moderate-to-severe Crohn's disease. However, this estimation was confounded by poor validation of measures, and ill-defined cut off scores.

Psychological

Patients with IBD are more likely to experience anxiety and depression. In their systematic review, Mikocka-Walus and colleagues (2016) found 19.1% of individuals with IBD experienced anxiety, and 21.2% experienced depression in comparison to the general population where 13.4% experienced depression, and 9.6% experienced anxiety. During times of acute illness upwards of 66.4% of patients with IBD experience anxiety, and 34.7% experience depression (Mikocka-Walus et al., 2016).

The literature has discussed the interconnection between psychological distress, anxiety and depression and disease onset and activity in IBD. Individuals with a history of depression are more likely to develop IBD (Frolkis et al, 2019) and depression places patients with IBD at increased risk for relapse (Kochar, 2018). A large observational cohort study (*n*=10,834) by Ananthakrishnan and colleagues (2013) found the presence of anxiety and/or depression increased a patient's chance of surgery and hospitalisation. This has been further highlighted by Wong and colleagues (2019) in their retrospective cohort analysis (n=331772) which found that depression was associated with increased costs (an average increase of $17706), and emergency department presentations. Further, depression has been found to predict prolonged length of hospital stay in paediatric IBD even when controlling for disease severity (Patel et al., 2019).

In their longitudinal study (*n*=405), Gracie et al. (2018) found support for the bidirectional nature of anxiety and IBD activity. Clinical IBD activity was significantly associated with the development of abnormal anxiety scores. Similarly, inactive IBD and abnormal anxiety scores at baseline were associated with later flares of activity, escalation of therapy and need for steroid administration.

Individuals with IBD experience consistent, long-term stress (Mittermaier et al. 2004; Levenstein et al. 2000). The remitting, relapsing and unpredictable course of IBD is a stressor in itself (Sexton & Bernstein, 2015; Keeton et al., 2015) with flare ups triggering higher levels of acute stress (Graff et al. 2009). Targownik et al. (2015) conducted a population-based study (*n*=478) which found that while perceived stress was associated with symptomatic activity, it was not associated with intestinal inflammation. Yet, Bernstein and colleagues (2016) in another publication from the same study, concluded that stress remained stable despite changes in disease activity.

Chronic long-term stress has been identified as a relapse risk factor for UC (Levenstein et al., 2000; Jaghult et al., 2013). Bitton and colleagues (2008) in their prospective cohort study found lower stress levels and less avoiding coping behaviours were associated with lower risk of relapse. A review of 11 longitudinal studies illustrated that stress and depression increased the chance of relapse, negatively influencing the course of IBD (Rampton, 2010). Further, perceived stress and distress have been found to be predictors of IBD re-occurrence (Sexton & Bernstein, 2015). Yet, a recent study by Lores and colleagues (2019) which trialled integrated psychological screening and intervention (*n*=335) and found psychological distress was not associated with disease activity. This latter finding fits with prior research which hypothesised that perceived stress as a construct is implicated in exacerbating symptoms only when the stress is symptomatic of the presence of depression and/or anxiety (Camara et al, 2011). Ultimately due to the observational nature of most of the study designs employed in the literature conclusions determining the role of stress and causality are limited.

Although the link between psychological distress and IBD disease activity is difficult to disentangle, the relationship between stress, depression and inflammation in the gut has been established biologically in mice. An experimental study by Ghia and colleagues (2009) observed that when depressive symptoms were induced in mice, it reactivated dormant colitis and gut inflammation, and that administration of tricyclic antidepressant was associated with remission. A previous review by Mawdsley and Rampton (2006) concluded that animal studies provided strong evidence for the idea that chronic and acute stress play a role in IBD onset and relapse. Therefore, despite animal studies lacking adequate transferability to humans, this research provides motivation for further research and understanding of the complex interplay between the mind and the gut and its implications for the treatment of IBD.

Social

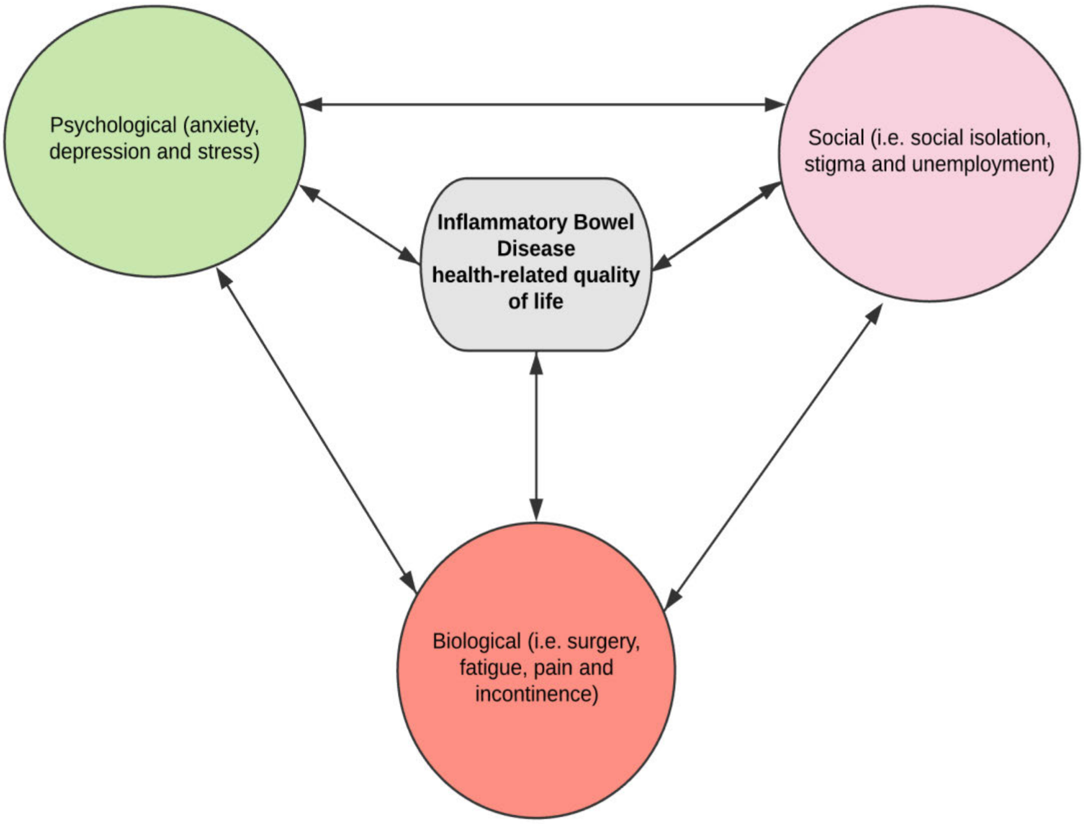
A meta-synthesis by Kemp and colleagues (2012) found people with IBD felt socially isolated due to incontinence. Jordan et al. (2018) conducted a qualitative study (*n*=25) which linked symptoms of anxiety to concerns about incontinence in social settings. A systematic review indicated that individuals with IBD may face social stigma which can impact HRQOL, however this has been identified as an area in need of further research (Taft & Keefer, 2016). In addition, perceived lack of understanding and stigma have been identified as themes associated with low mood (Jordan et al., 2018).

Further, individuals with IBD have reported higher rates of unemployment and disability compared to control groups (Sewell & Velayos, 2013). Unemployment in people with IBD has been significantly correlated with lower QOL (Bernklev et al., 2006; Moradkhani et al., 2013). Physical symptoms of IBD can influence employment opportunities for patients', with research showing that achieving remission for UC is associated with a three-fold increase in gaining employment (Reinisch et al. 2007). Patients reporting higher levels of fatigue are more likely to be unemployed (van Langenberg & Gibson, 2014.) Employment is an important factor for mental health broadly, with research showing that unemployment is associated with higher rates of mental distress (Paul & Moser, 2009). Difficulties fully engaging with work can further exacerbate the financial burden of living with IBD, and the costs associated with managing the illness.

Therefore, the unpredictable nature of IBD can impact social factors such as social connection, and involvement alongside relationships, and engagement in work and study, all of which can ultimately result in a reduced QOL (Jones et al, 2018).

Quality of life (QOL)

Health-related QOL (HRQOL) is an important outcome for people with IBD, as it measures an individual's perceived physical and mental health over a period of time (WHO, 2020). Individuals with IBD have lower HRQOL than healthy controls (Verma et al., 2018). Reduced QOL is associated with increased hospital admissions (Jones et al, 2018). Qualitative research has also underscored the importance of QOL which has been identified as a key concern for patients with IBD (Keeton et al., 2014). Therefore, given IBD is a biopsychosocial illness, making efforts to improve not only biological symptoms of IBD, but broader psychosocial factors which implicate HRQOL is an important goal for the treatment and management of IBD. A healthcare system which integrates multidisciplinary care in order to address the broader factors beyond biological components, as discussed in this review, and outlined in the Figure below, is better able to meet these needs.



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Evidence for psychological interventions in IBD

Disease activity

Despite psychotherapies such as gut-directed hypnotherapy and antidepressants being increasingly cited as effective at reducing physical symptoms of functional gut disorders (Ford et al., 2014), the literature is equivocal on how far psychological interventions can change the course of IBD disease activity. Qualitative research has identified that patients with IBD self-report improvements in disease course with psychotherapy (Mikocka-Walus et al., 2013). Yet, a systematic review and meta-analysis of 14 randomised controlled trials (RCT's) by Gracie and colleagues (2017) found that psychological therapies did not have any effect on disease activity, despite finding that CBT improved QOL and depression in the short term.

Cognitive-behavioural therapy (CBT)

A multicentre RCT conducted in Amsterdam and the Netherlands by Bennebroek and colleagues (2017) found that disease specific CBT was effective at improving QOL and decreasing symptoms of anxiety and/or depression, particularly in patients with poor QOL. Despite these findings, a subsequent study by Stapersma, and colleagues (2018) found that disease specific CBT for subclinical anxiety and depression was no more effective than treatment as usual (TAU) at reducing anxiety or depressive symptoms. The participants included in the study did not experience clinical levels of anxiety and/or depressive symptoms, and overall psychological and physical burden of disease was low for this patient group. This may explain why disease specific CBT failed to reduce anxiety and/or depressive symptoms more than TAU.

An American pilot study (*n*=9) by Reigada and colleagues (2013) found that integrating disease specific concerns into CBT for adolescents with comorbid IBD and anxiety was effective at reducing pain, anxiety and disease severity. However, this study was limited by the small sample size and has limited merit. A more recent pilot RCT (*n*=174) by Mikocka-Walus and colleagues (2015) found CBT did not improve disease activity but did improve QOL and reduce distress associated with IBD.

Hypnotherapy, relaxation, stress management and other interventions

An RCT (*n*=54) by Keefer and colleagues (2013) found that gut-directed hypnotherapy was effective at prolonging clinical remission in patients with inactive UC. A systematic review of 15 papers from 1987 to 2015 by Norton et al. (2017) identified a lack of research for pain as an outcome measure but drew tentative conclusions that relaxation and cognitive strategies may effective at reducing abdominal pain. Vogelaar and colleagues (2011) in their RCT (*n*=29) compared the efficacy of problem focused therapy (PFT), solution focused therapy (SFT) and treatment as usual (no psychological intervention) to reduce fatigue for patients with IBD. The SFT group saw 85.7% of patients improve on measures of fatigue, in comparison to 60% in the PST and 45.5% in the TAU group.

An RCT (*n*=45) by Garcia-Vega, and Fernandez-Rodriguez (2004) found that a stress management intervention reduced tiredness, and abdominal pain when compared to medical treatment alone, and these results were still present at 12-months. However, this study selected only participants in non-active stages of illness, and is therefore limited in its generalisability. Another RCT (n=14) investigating the effect of a Breathing, Movement and Meditation workshop found significant improvements on quality of life, physical symptoms as measured by c-reactive proteins and depressive symptoms (Gerbarg et al., 2015). However, this study was limited by its small sample size. However, Boye and colleagues (2011) (*n*=114) found that stress management (including problem solving, psychoeducation and relaxation) did not reduce the chance of relapse or disease course in their RCT.

Psychological interventions overall

In 2011 a Cochrane review identified that studies investigating psychological interventions in IBD were of low methodological quality, and although was some evidence that adolescents or those who were emotionally vulnerable may benefit from psychological interventions, the review could not recommend psychotherapy for patients with IBD due to a lack of evidence supporting its efficacy (Timmer et al., 2011). Psychological interventions used in the research have not targeted specific disease related stressors which may be one reason for the lack of effectiveness of these interventions overall in the literature (Camara et al., 2011).

Integrated multidisciplinary models of care

Despite the well-established biopsychosocial underpinnings of IBD, it has traditionally been managed as an acute illness in a biomedical model of care. This means that patients receive treatment when they are actively experiencing an IBD flare and are not engaged in treatment when they are in remission. Acute management based on a biomedical model ignores the psychosocial mechanisms in IBD and is not able to meet the needs of chronically ill patients (Wagner et al., 1996). In doing so, it leaves patients vulnerable to further damage to the gut given the chronic nature of the disease (Pariente et al., 2011).

In contrast to biomedical healthcare, an integrated model of care emphasises a coordination of services, organisations, inputs and deliveries, based on patient care, diagnosis and treatments (WHO, 2001). Since their 2001 position paper, the WHO has recommended integrated care and highlighted specifically its need for patients with chronic illness (Gröne et al., 2001).

Integrated care aims to exchange expertise so that different aspects of a patient’s treatment can work together (Shaw et al., 2011). This coordination of services is specifically suited to managing chronic illness due to the biopsychosocial impact of IBD and the biopsychosocial approach that integrated care affords. Further, multidisciplinary care involves multiple healthcare professionals collaborating together to meet the multifaceted needs of a patient (Zwarenstein et al., 2009). Australian IBD Standards recommend that an IBD patient have access a multidisciplinary team inclusive of a psychologist, dietician, and IBD nurse among others (CCA, 2016).

Mikocka-Walus and colleagues (2012) highlighted common features of integrated models of care for IBD. These include; mechanisms for active follow up for IBD patients (especially if these patients are known to be experiencing difficulties), patient education about IBD, encouragement of involvement in consumer organisations, comprehensive assessment of biopsychosocial functioning of patients at the point of entry into the healthcare system, and IBD dedicated nurses knowledgeable in IBD.

An Australian qualitative pilot study conducted with both patients and staff in a multidisciplinary primary healthcare centre (*n*=29) explored implicit descriptions of integrated care (Banfield et al, 2017). Their analysis indicated patients rely on relational aspects of outcomes and care, in contrast to existing frameworks of integrated care which have been influenced by organisational views. Their findings outlined patients' perceptions of integration, included; increased co-location of services, retaining established relationships, and ease of access to services. Continuity of care was discussed in particular in relation to completeness of records, and patients discussed person-focused care in relation to being given a choice of appointment time.

Multidisciplinary care to reduce diagnostic delay

A recent clinical update published by the Gastroenterological Society of Australia, intended for General Practitioners (GP's) in Australia highlighted that diagnostic delays for IBD frequently occurred due to GP's not suspecting IBD as a potential cause (Clinical Update for General Practitioners and Physicians: IBD, 2018). Diagnostic delays are associated with poorer patient outcomes including increases in the risk of intestinal surgery (Lee et al., 2017).

A multidisciplinary team can enable different specialists to work together to quickly ensure that mutually exclusive diagnoses and conflicting treatment plans are not prescribed, prevent delays in diagnosis or misdiagnoses especially between the different subtypes of IBD, and reduce unnecessary examinations which can cause distress (Phan et al., 2012). Early intervention has previously been shown greatly improve quality of life and reduce the cost or need for radical surgery and emergency hospitalisation (D'Haens et al., 2008).

Screening and access to psychological care

In a recent large cohort study (*n*=8222), standardised screening and early psychological intervention was highlighted as a priority, to improve paediatric IBD patient outcomes (Patel et al., 2019). Another recent study by Lores and colleagues (2019) found 90% of IBD patients in their study believed that screening for psychological distress was an important resource in ambulatory IBD care. They identified that predictors of psychological distress included; recent diagnosis, younger age, low adherence to medication and use of pain medications; these predictors may assist in identifying patients in need of psychological support. Further, engagement in psychological services is enhanced when it is delivered in an in-service integrated model of care than compared with delivery externally, with Lores and colleagues (2019) also finding a six-times increase in engagement for those treated in-services.

Despite this, a recent Australian cross-sectional study (*n*=731) by Mikocka-Walus and colleagues (2020) found that only 12% of participants had access to a psychologist, and only one-third of participants reporting access to an IBD nurse or dietician. The large majority of participants (97%) reported access to a gastroenterologist. Therefore, despite healthcare providers support for integrated multidisciplinary care and its demonstrated efficacy, these results indicate that for many participants multidisciplinary care is lacking, and a biomedical model persists whereby patients have access to a specialist one-on-one without holistic access to ancillary services.

The efficacy of integrated multidisciplinary care

The cost of IBD in Australia has been estimated in 2013 to have been $2.7 billion dollars (PricewaterhouseCoopers, 2013), with a loss in work productivity at that time approximately $361,499,232 per year. Individuals with IBD have greater health care utilisation costs compared with control groups (van Langenberg et al., 2010). A large proportion of the economic costs of IBD is due to surgery and hospitalisation (Bodger, 2002; Cohen et al., 2010). Episodic and reactive care where patients are only seen and cared for during acute flares of the disease or where there are serious complications is costlier than an integrated model of care which aims to reduce the need for emergency hospitalisation and surgery (Sack et al., 2011). Integrated care has been shown to improve patient outcomes such as reduce hospital admission rates, and other related comorbidities and complications (Mikocka-Walus et al., 2012; Schoenfeld et al., 2018). A prospective cohort study (*n*=461) before and after the implementation of an integrated care intervention was conducted by Sack and colleagues (2012). They demonstrated that integrated care significantly reduced the cost of IBD via fewer hospital admissions, optimised treatment regimes, and reduced unnecessary testing.

A recent quasi experimental study in United States found that a Total Care IBD program including the above specified specialists working in a multidisciplinary team significantly improved QOL, disease activity and reduced unplanned treatment (Regueiro et al., 2018). Research has highlighted that early management of symptomatic disease reduces admissions to hospital and surgery rates, thereby reducing costs (D'Haens, et al., 2008; van Langenberg et al., 2010). Guidelines on care for IBD have stressed the importance of rapid access to care – especially specialist care – in order to prevent IBD illness severity from escalating at which point costs through emergency surgery and individual suffering and distress increases (Carter et al., 2004).

Phan and colleagues (2012) in their Australian prospective cohort study found that within 18 months of a dedicated IBD service being implemented patient outcomes were improved as evidenced by decreased hospitalisations, steroid and opiate use. Lores and colleagues (2019), also demonstrated that when psychological intervention and screening was done in an ambulatory in-service setting in an Australian tertiary hospital, it significantly reduced emergency presentations and opiate use for those who participated in a psychological intervention. Access to psychological services is only one aspect of integrated care for IBD, yet Lores et al. (2019) demonstrated a reduced cost of $30,000 in a one-year period with integrated psychological services offered. In line with this, international guidelines for IBD recommend psychological support, to aid in improving the course of IBD (Häuser et al., 2014). Despite this, research indicates that individuals are not being asked about their mental health (Bennebroek et al., 2012).

Therefore, an integrated model of care where the individual is seen regularly during times of wellness is better able to improve quality of life and reduce complications and healthcare costs associated with the illness (Sack et al., 2012).

IBD Standards of Care

In 2016, Crohn’s and Colitis Australia published National Standards of Care for IBD (CCA, 2016). These include high quality clinical care whereby patients have access to a multidisciplinary team, quick access to specialist care and when possible access to local delivery of healthcare, alongside patient education (CCA, 2016). The latter is supported by research outlining that greater IBD specific knowledge increases patient satisfaction, medical adherence and reduces levels of distress (Waters et al., 2005). In addition, past survey estimates in the literature estimate that only 5% of healthcare providers claim to use biomedical models of care, with most believing IBD services should be integrated and involve multiple specialists (Mikocka-Walus et al, 2014).

Despite the literature outlining the efficacy of multidisciplinary care, healthcare professionals reporting their preference for multidisciplinary care, and National Standards being published, research indicates that healthcare is falling short. Specifically, Mikocka-Walus and colleagues (2020) recently conducted a cross-sectional study (*n*=731) comparing patient experiences of healthcare alongside National IBD standards and identified that National standards of IBD care were not being met. Specifically, many participants are experiencing delays in access to specialist care whist experiencing active disease, and a lack of access to multidisciplinary services. Specifically, their data indicated that up 68.2% of patients who experiences severe distress, are not engaged with a mental health clinician (Mikocka-Walus et al., 2019).

Current limitations

Recall biases and symptom-based measurement tools makes it difficult to discern or prove empirically the nature of the relationship between mental health (stress, depression and/or anxiety) and IBD symptom severity (Bernstein et al. 2010; Singh et al. 2009). Further limitations surround the methodologies used, including establishing cause and effect within cross-sectional studies (Jaghult et al., 2013). Another confounder when consuming the literature with regards to IBD and healthcare is that studies emerge from different countries, and these countries often have different healthcare systems which may confound the applicability or generalisability of results to an Australian context.

Future research

One of the core principles of integrated care is patient input and involvement in service development, to better enable provision of services, which considers patient values, preferences and culture (Mikocka-Walus et al., 2012; 2013). Therefore, an Australian study examining the patient perspectives on IBD healthcare is an area lacking in research and needing investigation (Mikocka-Walus et al., 2020).

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Research Report

Title: Australian inflammatory bowel disease (IBD) patients want biopsychosocial healthcare: a content analysis.

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Author note: This article is intended for submission to *Clinical Gastroenterology and Hepatology*. The journal guidelines specify that the manuscript should generally be no more than 4,000 words. The total length of the current manuscript is 6,500 words with the article written for the purpose of the thesis requirements of between 5,000 and 8,000 words.

Abstract

Background & Aims: Inflammatory Bowel Disease (IBD) is a biopsychosocial illness. The prevalence of IBD is increasing in Australia, which presses the need to improve healthcare for patients with IBD. To date, no study has examined the views or preferences that Australian IBD patients have for their healthcare. This article reports on Australian patient's with IBD perspectives and preferences for healthcare.

Methods: Patients with IBD (n=477) responded to an open-ended survey question 'What changes if any would you make for your IBD healthcare? And why?' within a larger, previously conducted cross-sectional survey. These previously unanalysed responses were content analysed with open coding using NVivo.

Results: Nine categories were formulated. Respondents expressed a desire to have greater access to (1) multidisciplinary services (17.70%), (2) proactive healthcare with increased follow up and long-term care planning (8.50%), and (3) treatment, services and specialist care (16.40%). Participants also requested (4) better communication (23.52%), and (5) whole of person care (10.24%). In addition, participants wanted (6) health promotion (i.e. public awareness and support groups) (10.42%). Finally, a proportion of participants were (7) happy with their healthcare (9.72%). Two minor categories – (8) administrative issues, (2.34%) and (9) improving the hospital experience also emerged (1.04%).

Conclusions: The results support existing research outlining multidisciplinary care is better suited to meet the needs of patients with IBD. Healthcare professionals should focus on facilitating patients' access to multidisciplinary services (i.e. psychologists, IBD nurses and dieticians), and increasing proactive care (i.e. follow up and long-term care planning). Asking patients about their mental health and communicating respectfully should also be priorities.

(Keywords: inflammatory bowel disease, biopsychosocial healthcare, models of healthcare, multidisciplinary healthcare, Australia). (259 words)

Introduction

Multidisciplinary integrated healthcare

The World Health Organisation has defined integrated care as; "the organisation and management of health services so that people get the care they need, when they need it, in ways that are user friendly, achieve the desired results and provide value for money."[1] Therefore, an integrated healthcare system coordinates different services involved in patient care. Multidisciplinary care involves promoting teamwork and collaboration amongst different healthcare professionals who are involved in the care of a patient.[2,3] The importance of integrated, multidisciplinary care has long been recognised as important in the management of a range of chronic and other illnesses,[4,5] including heart transplant,[6] cancer[7] and diabetes[8] among others. Multidisciplinary care is particularly suited to respond to the needs of patients with inflammatory bowel disease (IBD) given its chronic nature, wide extraintestinal manifestations,[9] and psychosocial factors involved.[10] A study of healthcare professionals (i.e. gastroenterologists, nurses, psychologists, and dieticians) revealed that most healthcare professionals believe that IBD care should be fully integrated, involve input from multidisciplinary services in specialist clinics, and be easily accessible.[11]

What You Need to Know

Background

IBD is a biopsychosocial illness. Studies have illustrated integrated biopsychosocial healthcare can reduce costs and improve patient outcomes. However, little is known about the patient perspective on what healthcare is wanted.

Findings

A content analysis (n=477) of IBD patients' responses to the open-ended question "What changes would you make if any for your IBD healthcare? And why?" showed 9 categories centred around biopsychosocial healthcare.

Implications for patient care

Patients with IBD want access to multidisciplinary services (including psychological care) as well as proactive care (i.e. follow up).

In line with this, Australian IBD Standards (2016)[12] outline that multidisciplinary care is the best approach for managing IBD. These guidelines outline that the multidisciplinary team should include; a gastroenterologist with IBD training, a colorectal surgeon with IBD training, a specialist IBD nurse, an accredited practising dietician, a psychologist, a stomal therapist, a radiologist, histopathologist and pharmacist with an interest in IBD, and telephone helplines. IBD care should also involve healthcare professionals knowledgeable in IBD engaging collaboratively to coordinate care in a proactive manner.[12] This collaboration is integral to an integrated multidisciplinary model of care.[13] Multidisciplinary, integrated care should also include follow-up, patient centred care, patient education about IBD, and a comprehensive assessment of a patient's biopsychosocial functioning when they enter the healthcare system.[14]

The benefits of multidisciplinary, integrated care for IBD have been demonstrated practically in numerous studies. A prospective cohort study showed that when patients received a 24/7 nurse telephone helpline, regular monitoring of blood test results, scheduled follow up, patient education and information, encouragement to join Crohn's and Colitis Australia (CCA), and other proactive changes, there was a significant reduction in healthcare cost and disease burden, and fewer inpatient admissions.[15] In addition, studies have shown that implementing IBD trained nurses, telephone helplines, information and education leaflets, newsletters, and encouragement to join CCA, increases patients' IBD knowledge, medication adherence, satisfaction with care, and quality of life.[16] Proactive changes to healthcare have been also been found to reduce symptoms of anxiety and depression, as well as hospital admissions.[16]

The implementation of telephone services alone can lead to significant improvements for patient care. An Italian prospective observational study[17] (n=1867) found that telephone helplines reduced hospitalisation, and eased communication between the patient and physicians. Further, their study estimated that one-third of calls were regarding non-medical issues, and these patients would otherwise have attended ambulatory settings.[17]

In their longitudinal study, Martinez-Vinson and colleagues (2020) observed that implementing a dedicated IBD nurse into multidisciplinary care reduced hospitalisations, overall costs and promoted outpatient care.[18] Nurses are placed in a position that enables them to identify psychological distress in IBD patients.[19] The role of IBD nurses includes communicating with patients, pain management, and assisting with managing fatigue and incontinence, as well identifying issues such as nutritional or sexual issues and referring on.[20] An Audit of IBD Care in Australia outlined that it was more common for patients to be provided with information and materials when there was an IBD nurse implemented as part of the IBD service, highlighting their important role in patient care.[21]

Further, given the high rates of anxiety and depression in patients with IBD, providing access to psychological therapy is important for improving quality of life and management of disease activity in IBD.[22] Early identification of psychological distress has been highlighted as important to patient outcomes.[23] A recent prospective study (*n*=335) showed that patients with psychological distress who engaged in psychological intervention were less likely to present to emergency, providing support for the integration of psychological care into the management of IBD to reduce costs and healthcare utilisation.[24]

Dieticians are also integral in IBD care, given the high rates of nutritional deficiencies, malnutrition and weight loss in patients with IBD,[25] and the use of enteral nutrition in the treatment of IBD.[26] Yet, quality information regarding IBD specific dietary information is variable,[27] and as will be outlined below, patients' access to dieticians is lacking.

Finally, follow up is important given the remitting/relapsing nature of IBD, in order to maintain remission or to intervene early before disease progresses and further gut damage occurs, and to improve patient experience.[28] Despite this, follow up by gastroenterologists in perioperative Crohn's is inconsistent, and coordinated multidisciplinary care is lacking.[29]

Typical model of care for IBD

Despite the evidence base for multidisciplinary care in relation to IBD, IBD is typically treated within a specialist-led biomedical model of healthcare. In this biomedical model of healthcare, the patient is seen during times of acute illness, and these interactions address biological aspects of illness. This is problematic as it does not address psychological and social factors which are important factors in a patient's quality of life. This reactive type of healthcare where acute flares and serious complications trigger patient care and intervention often results in further gut damage for patients given the chronic nature of the disease.[30]

In their systematic review (21 studies included) Prasad and colleagues (2019) found that in IBD care overall, there is an overreliance on gastroenterologists, and nurses, with little utilization of other primary healthcare providers such as general practitioners and allied health providers such as psychologists or dieticians.[31] This indicates that despite the theoretical and practical evidence for the efficacy of multidisciplinary care, specialist led care is still being heavily used in the management of IBD.

In line with this, an Australian Audit of IBD care in Australia highlighted that only 1% of patients had access to a full IBD team, 39% had access to an IBD nurse, 38-40% had nutritional screening on hospital admission, 4% had access to a psychologist, and only 28% of patients had a protocol in place for managing severe ulcerative colitis flares.[21] Therefore, despite mounting evidence for the efficacy of multidisciplinary integrated care, currently studies suggest that patients lack access to this care and are being treated in a biomedical model of healthcare.[32]

Patient-centred care and adequate communication.

Patient centred care includes patient participation and involvement, and a cohesive, genuine doctor-patient relationship where patients collaboratively decide on treatments.[33] An integral part of patient centred care also includes adequate explanation and information provision about IBD.[34] Recently Park and colleagues (2020) found that disease-related knowledge could be important to enhance patient-management and coping with disease, therefore reducing the need to escalate therapy in IBD.[35] Colombara and colleagues (2015) demonstrated that greater IBD related knowledge had the potential to reduce costs,[36] and studies have found that illness perceptions, often influenced via education and doctors communications, can influence quality of life in patients with IBD.[37]

Despite this, studies suggest that communication and patient centred care is lacking in IBD. Rubin and colleagues (2017) found that in their qualitative analysis of physician and patient interactions in Europe and the U.S., most of the consult involved quantification of symptoms with little discussion of the psychosocial impacts of illness.[38] Rarely did the physicians articulate collaborative goals with patients, and terms such as "inflammation" were used frequently with little evidence of patient understanding or physician explanation. [38] Ghosh and Mitchell (2007) (*n*=5576) identified that while nearly half of doctors in Europe did not initiate a conversation around quality of life with patients, 86% of patients would have liked to try a new type of treatment, and 56% of patients did not have any new treatments discussed with them.[9] In their qualitative study, Lai and colleagues (2019) reported that patients explained there was a delay in care, inadequate communication, and a perceived lack of control over disease management.[39] In the study, patients described feeling as though there was no long-term care plan, and they were just switching from treatment to treatment. Baars and colleagues (2010) in their survey (*n*=1,067), found that 81% of IBD patients found it very important to be actively involved in the decision-making process, and when asked about how treatment could be improved 50% stated fairer and closer collaboration with their doctor.[40] A European study (n=4670), investigating IBD patient's experiences outlined that in addition to confirming the continued biopsychosocial impact of IBD; 67% of patients had to visit the emergency department prior to diagnosis; 64% wanted their specialist to ask more questions; and 54% stated they did not get to communicate something important to their doctor.[41]

Additionally, good doctor patient-communication includes expressions of empathy. A German study by Chiapponi and colleagues (2016) (n=121) identified that women experienced greater feelings of embarrassment when discussing IBD related symptoms with their doctor.[42] Their study also posited that physician empathy is a source of support for patients given that there was a significant correlation between participants level of subjective burden and ratings of the importance of physician empathy.[42]

Preliminary studies

The current study builds on two prior publications. Firstly, Mikocka-Walus and colleagues (2019) examined the needs and access to psychological care alongside the prevalence of distress in Australian IBD patients.[43] Only 15.2% had been asked about their mental health despite hald of the participants reporting psychological distress. Access to services were also lacking with only 12.2% reporting access to a clinician, while 68.2% of participants who scored in the severe distress range on the K-10 were accessing clinician. Their study also observed a significant association between psychological distress and frequency of hospitalisation, disease activity, pain, fatigue and fistula and perianal disease. [43]

A second study by Mikocka-Walus, Massuger, Knowles, et al (2020)[44] assessed the experience of healthcare against national standards. They found that actual health service experience falls short of national standards specifically regarding access to multidisciplinary care, responsiveness, choice in care and clinical communication, and that patients are experiencing active disease, in a healthcare system that is not responsive, and where patients are not being afforded adequate patient centred care. Specifically, many participants indicated they had to wait more than two weeks to access specialist care. This goes against Australian IBD Standards, which outline that patients experiencing acute relapse should have access to specialist advice within 5 days. Only 50% had access to telephone helplines and while two-thirds had a choice in their treatment, 51% wanted to be more involved, reinforcing the need for more proactive patient centred care. Of interest, despite healthcare falling short of IBD Standards, 74.8% of participants reported being satisfied with their healthcare. This indicates that patients are unaware of the IBD Standards of Care.[12,44]

The current study

When treating IBD, integrated models of healthcare has been demonstrated theoretically and practically to improve patient outcomes and to be more cost effective.[15] Currently, standards of healthcare are falling short, and patients with high levels of psychological distress, and active disease are still facing barriers to access multidisciplinary care.[43,44] However, despite this no prior study has investigated what type of healthcare Australian patients with IBD want.

Therefore, the nature of the current project was exploratory, with the guiding purpose to investigate what Australian IBD patients want for their healthcare. A content analysis was contextually guided by this aim and used responses to an open-ended question from a previous study conducted by Mikocka-Walus and colleagues.[43,44]

Further as outlined in the Australian IBD Standards (2016), part of maintaining patient-centred services involves giving patients the opportunity to give feedback and contribute to service development (standard C2), as well as involve patients in service improvement (C5). Therefore, although it has been identified that current healthcare for IBD falls short of National

Standards of Care (2016), a study exploring what IBD patients would like to change has yet to be conducted.[12] The current study addresses this gap by capturing patients' desired healthcare.

Method

Ethics

The study was approved by the Deakin University Human Ethics Advisory Group (HEAG-H 85_2018). Participation was voluntary and anonymous.

Design

A cross-sectional survey was conducted.

Participants

Participants were recruited from Crohn's and Colitis Australia's mailing list and via social media channels. Advertisements were made in gastroenterology clinics via newsletters. A total of 731 participants completed the study, after 293 responses were removed due incomplete data. Of the 731 participants who completed the survey 477 provided either an open-ended response to the question 'What changes would you make for your healthcare?' or wrote a response in the final comment box. To be included in the study, participants needed to have a self-disclosed diagnosis of ulcerative colitis, Crohn's disease, or indeterminate colitis, be above the age of 16, be an Australian resident or citizen, and be able to complete the study in English.

Procedure

An anonymous survey was conducted via Qualtrics. Participants were invited to an online link which included a Plain Language Statement, and the survey. Initially the survey was reviewed by a small number of patients with IBD for face-validity. Finally, counselling numbers (Lifeline) were made available to participants at the conclusion of the study in the event that participation caused distress.

Analysis

Responses to the open-ended survey question: "What changes would you make to improve your healthcare for your IBD? What are your reasons?" and responses included in an additional comment box were included in the content analysis.

The computer software NVivo was used to aid in coding of the data. Open coding was carried out by one researcher. The nature of the content analysis was exploratory as no pre-existing theory-based categorisation matrix existed.[45] Categories were derived from the data in an inductive manner where the data was specifically coded and then examined and categorised more generally with interrelated codes placed together.[46]

The inductive approach included a preparation phase whereby the researcher read over and familiarised herself with the overall data set. During the preparation phase consideration was also given to the representativeness of the sample, and the amount which should be analysed. Given the research question and relatively small amount of data from the study the whole sample was analysed. The sample can be said to represent the population under investigation however there is a possibility that patients in remission, and who are not currently engaged in the healthcare system, or patients who for other reasons including a lack of access to internet were not represented in the sample.[43]

The organisation phase then included openly coding the data into smaller meaning units, and then similar codes were collapsed to form categories of similar content. During this phase, initial concepts were identified by coding the responses line by line. Only manifest content was coded, and no hidden meaning (such as grammar and phrasing) was analysed or interpreted beyond the surface meaning. Codes collapsed into categories shared a broader meaning. For example, the two codes, wait times to see GP and wait times to see specialist were collapsed to form the code ‘wait times.’ After this, categories were formed which encompassed similar codes groups.

Each open-ended response could have a number of different codes, and some data was coded in two codes. Therefore, the count of the data exceeds the number of open-ended responses.

Inter-rater reliability/trustworthiness

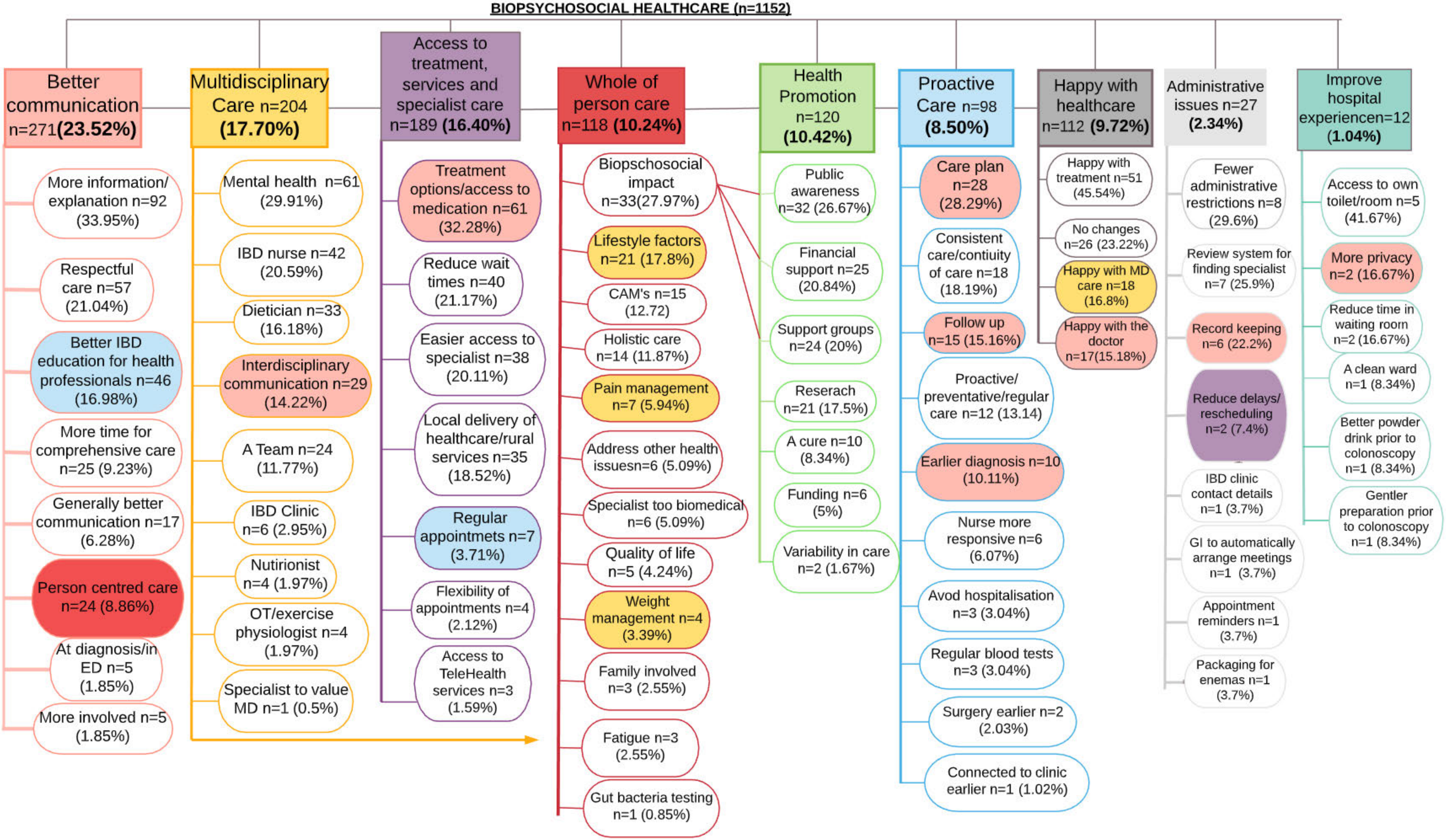
A random sample of 20% of the codes were checked by two additional researchers (ACH and AMW). The coding structure (included in Appendix A) was also checked by both additional researchers. Ambiguities arose and were either resolved at meetings between the researchers (MF, ACH and AM), or it was agreed that given the overlapping nature of the categories, that codes could fit in more than one category.

Results

Demographic statistics are provided in Appendix A. The data was initially examined to see if there was a difference between participants who chose to provide an open-ended response, and participants who chose to leave the box blank. A chi-squared test of independence indicated that there was no significant difference between type of IBD (CD, UC or IC) and whether or not participants provided an open-ended response or comment, $\chi 2$ (2, N=731) = 1.965, *p* =.374. A Fisher’s exact test also revealed that there was no significant association between participants experiencing distress vs. no distress and choice to provide an open-ended response, F=1.965, *p* =.374, or between men, women and other gendered participants (F=1.811, p=.368).

Categories

Open coding resulted in the emergence of the following main categories; ‘better communication’, ‘multidisciplinary care’, ‘proactive care’, ‘access to treatment, services and specialist care’, ‘health promotion’, ‘whole of person care’, ‘happy with healthcare’, ‘improve hospital experience,’ and ‘administrative issues.’ All categories and subcategories with sample codes and extracts can be found in a table Appendix B. In total, the count of total codes was 1,152. This is due to participants responses containing multiple codes, and some segments being coded twice, and therefore the number of codes exceeds the number of participants. A diagram of the categories and the codes contained is represented in Figure 1. Where the sub-codes have been filled with colour, this indicates where a code could be considered to link or overlap with another category. The category percentages show what proportion of the total count of codes were attributed to that category; the percentages shown under the categories show what proportion of the category each sub code contained.



BIOPSYCHOSOCIAL HEALTHCARE (n=1152)

- Better communication n=271**(23.52%)**
  - More information/ explanation n=92 (33.95%)
  - Respectful care n=57 (21.04%)
  - Better IBD education for health professionals n=46 (16.98%)
  - More time for comprehensive care n=25 (9.23%)
  - Generally better communication n=17 (6.28%)
  - Person centred care n=24 (8.86%)
  - At diagnosis/in ED n=5 (1.85%)
  - More involved n=5 (1.85%)
- Multidisciplinary Care n=204 **(17.70%)**
  - Mental health n=61 (29.91%)
  - IBD nurse n=42 (20.59%)
  - Dietician n=33 (16.18%)
  - Interdisciplinary communication n=29 (14.22%)
  - A Team n=24 (11.77%)
  - IBD Clinic n=6 (2.95%)
  - Nutirionist n=4 (1.97%)
  - OT/exercise physiologist n=4 (1.97%)
  - Specialist to value MD n=1 (0.5%)
- Access to treatment, services and specialist care n=189 **(16.40%)**
  - Treatment options/access to medication n=61 (32.28%)
  - Reduce wait times n=40 (21.17%)
  - Easier access to specialist n=38 (20.11%)
  - Local delivery of healthcare/rural services n=35 (18.52%)
  - Regular appointments n=7 (3.71%)
  - Flexibility of appointments n=4 (2.12%)
  - Access to TeleHealth services n=3 (1.59%)
- Whole of person care n=118 **(10.24%)**
  - Biopschosocial impact n=33(27.97%)
  - Lifestyle factors n=21 (17.8%)
  - CAM's n=15 (12.72)
  - Holistic care n=14 (11.87%)
  - Pain management n=7 (5.94%)
  - Address other health issuesn=6 (5.09%)
  - Specialist too biomedical n=6 (5.09%)
  - Quality of life n=5 (4.24%)
  - Weight management n=4 (3.39%)
  - Family involved n=3 (2.55%)
  - Fatigue n=3 (2.55%)
  - Gut bacteria testing n=1 (0.85%)
- Health Promotion n=120 **(10.42%)**
  - Public awareness n=32 (26.67%)
  - Financial support n=25 (20.84%)
  - Support groups n=24 (20%)
  - Reserach n=21 (17.5%)
  - A cure n=10 (8.34%)
  - Funding n=6 (5%)
  - Variability in care n=2 (1.67%)
- Proactive Care n=98 **(8.50%)**
  - Care plan n=28 (28.29%)
  - Consistent care/contiuity of care n=18 (18.19%)
  - Follow up n=15 (15.16%)
  - Proactive/ preventative/regular care n=12 (13.14)
  - Earlier diagnosis n=10 (10.11%)
  - Nurse more responsive n=6 (6.07%)
  - Avod hospitalisation n=3 (3.04%)
  - Regular blood tests n=3 (3.04%)
  - Surgery earlier n=2 (2.03%)
  - Connected to clinic earlier n=1 (1.02%)
- Happy with healthcare n=112 **(9.72%)**
  - Happy with treatment n=51 (45.54%)
  - No changes n=26 (23.22%)
  - Happy with MD care n=18 (16.8%)
  - Happy with the doctor n=17(15.18%)
- Administrative issues n=27 **(2.34%)**
  - Fewer administrative restrictions n=8 (29.6%)
  - Review system for finding specialist n=7 (25.9%)
  - Record keeping n=6 (22.2%)
  - Reduce delays/ rescheduling n=2 (7.4%)
  - IBD clinic contact details n=1 (3.7%)
  - GI to automatically arrange meetings n=1 (3.7%)
  - Appointment reminders n=1 (3.7%)
  - Packaging for enemas n=1 (3.7%)
- Improve hospital experiencen=12 **(1.04%)**
  - Access to own toilet/room n=5 (41.67%)
  - More privacy n=2 (16.67%)
  - Reduce time in waiting room n=2 (16.67%)
  - A clean ward n=1 (8.34%)
  - Better powder drink prior to colonoscopy n=1 (8.34%)
  - Gentler preparation prior to colonoscopy n=1 (8.34%)

[redacted]

‘Multidisciplinary care’

The category of multidisciplinary care was defined as access, or increased access, to a range of healthcare professionals in addition to specialist care, and/or a desire for increased interdisciplinary communication between any or all of the health professionals. Multidisciplinary care accounted for 17.7% of the total codes. Participants expressed a desire to have access to a multidisciplinary team or IBD clinic, which included access to mental health treatment, IBD nurses, dieticians and nutritionists, an occupational therapist or exercise physiologist and for healthcare professionals in their team to communicate with one another. Extracts which encapsulate what the overarching meaning of what participants intended in the category of multidisciplinary care include;

“A team that communicate with each other on a regular basis” (Participant 450, Female with Crohn’s, 56 years old)

“I think incorporating other specialists such as dieticians, physiologists and GPs would lead to much better outcomes.” (Participant 444, Male with Ulcerative Colitis, 36 years old)

The largest subcategory in multidisciplinary care was access to mental health support or treatment, accounting for just over 33% of all codes in multidisciplinary care. This sub code included respondents wanting to be asked about their mental health, for example;

“In my treatment so far, little mention or advice on the impact on mental health aspects of this socially isolating disease has been made…” (Participant 468, Male with Ulcerative Colitis 59 years old)

The sub-code also included participants wanting to have access to mental health treatment (psychologists, psychiatrists, counsellors and some unspecified); and wanting increased access (more sessions). Participants expressed that they would particularly have liked to have access to mental health support after diagnosis, or during flare ups;

“…Have some mental health services offered for support and accepting diagnosis…” (Participant 17, Female with Crohn’s, 48 years old)

"Seek assistance with my mental health as the last few months during my flare up I have felt helpless and un worthy but I never really thought about it to be honest and it is starting to hit home." (Participant 53, Female with Crohn's, 28 years old)

In this, participants described how the biological and social impacts of IBD had impacted negatively on their mental health;

"I have a lot of fatigue and anxiety since being diagnosed and often feel that I can't live my life to the fullest for my age. I think mental health needs to be considered", (Participant 9, Female with Crohn's, 31 years old)

"Psych support in adjusting to my new lifestyle with IBD (i.e. dietary changes and the social impacts of this; inability to travel easily impacting former life goals etc.)" (Participant 461, Female with Ulcerative Colitis, 33 years old)

Another large proportion of codes in multidisciplinary care, came from participants wanting access to an IBD nurse. This links to the proactive care category, as some participants elaborated that the IBD nurse would give them someone to talk to prior to, or instead of seeing the specialist;

"I never met an IBD nurse, I think this will be a really good thing before seeing the specialist. Sometimes their time is taken by less important cases while the bad cases are kept waiting. The IBD nurse will be a really good addition to work with when you don't really need to get to specialist but need to talk to someone." (Participant 271, Female with Crohn's, 43 years old)

Participants wanted access to dieticians with knowledge in IBD; "*…Access to Dietician educated in IBD",* (Participant 346, Female with Ulcerative Colitis, 65 years old) and a small number of participants mentioned wanting access to occupational therapy or exercise physiology; *"I think occupational therapy directly related to IBD should be available, and offered to all IBD patients on diagnosis."*(Participant 262, Female with Indeterminate Colitis, 49 years old)

Finally, participants expressed a wish to have different healthcare professionals communicate with one another, whether by interdisciplinary meetings or otherwise; "*Better communication between GP and specialists.*" (Participant 13, Female with Crohn's, 53 years old)

Several participants also described problematic conflicting treatment advice from different professionals as a result of a lack of communication;

"...It's an awkward position to be in when you have 2 gastroenterologists with different approaches and/or competing treatment plans/viewpoints..." (Participant 31, Female with Crohn's, 43 years old)

'Whole of person care'

Whole of person care accounted for 10.24% of the total codes. The title of the category reflects the general sentiment that participants wanted to be treated as a whole person, with psychosocial issues, a life outside of their IBD, and access to 'holistic' treatment for IBD (including references to complementary and alternative medicine).

In response to the question 'What changes would you make for your healthcare?' participants described the biopsychosocial impact of their IBD;

"...I kept saying I am in pain and experiencing persistent ongoing diahorrea [biological]. *I was passing blood and became encontinent. My work suffered and I became a recluse...*[social] *I lived on Lomotil. I have never felt so alone I was prescribed anti-depressants.* [psychological]*..."* (Participant 259, Female with Indeterminate Colitis, 58 years old)

The strong expressions of the biopsychosocial burden indicate that participants did not feel their biopsychosocial experience had been understood, recognised or considered in their healthcare experience. In addition to stressing the biopsychosocial impact of IBD, participants expressed a desire for their healthcare professionals to consider them as a whole person, with ancillary issues outside of their gut inflammation. This included wanting to have their pain, fatigue, and weight addressed. Further, participants felt that due to their IBD, healthcare professionals made assumptions that all issues were related to IBD;

"I am a long-term patient. Acknowledgement at times that not all is related to crohns would be good as many blame it. Being open to other issues that could be impacting my life." (Participant 322, Female with Crohn's, 39 years old)

Participants expressed that their healthcare was currently too 'specialised' meaning that specialists failed to see other issues, and were only concerned with test results, or pathology in the gut;

"…My feeling has been that the specialist doctors have blinkers on when treating their patients – that is, so long as the IBD is under control, they are happy …" (Participant 458, Female with Crohn's, 60 years old)

Moreover, participants wrote that specialists failed to consider the 'big picture,'; *"Specialists concentrate on their own field and don't appear to consider the big picture."* (Participant 113, Female with Indeterminate Colitis, 75 years old)

In this way, some participants expressed that their current healthcare failed to consider their quality of life, and focused too much on the biomedical aspects of IBD;

"The emphasis was on treating my flare up rather than taking a long term view of my overall health and exploring all options I could undertake to improve my overall quality of life." (Participant 444, Male with Ulcerative Colitis, 36 years old)

Participants explained that they wanted their healthcare to consider lifestyle factors (i.e. stress, diet and exercise) as a part of their IBD management; *"Specialists often say what you eat will not affect the condition, but I believe diet should be explored more,"* (Participant 457, Female with Crohn's, 46 years old), while a portion of participants described the positive impact changes in diet had made; *"...I empower myself by managing symptoms by dietary* *means. Unfortunately this is not a dominant paradigm in treatment options…"* (Participant 2, Female with Crohn's, 69 years old)

Lastly, participants expressed wanting increased access to complementary and alternative treatments including marijuana. Common phrases included 'alternative' 'complementary' 'natural' 'dietary management' 'naturopath' 'alternative' or providing a comparison to traditional medicine. Participants expressed they wanted their healthcare professionals to be more open to complementary treatments, and some participants described how complementary and alternative treatment assisted them to manage their IBD;

"…I have been treating myself with complementary medicines, food and other methods and am doing very well…" (Participant 381, Male with Crohn's, 58 years old)

Whole of person care heavily overlaps with multidisciplinary care. This can be seen where participants describe the biopsychosocial impact, and where in multidisciplinary care they request access to services which can address the broader psychosocial elements of their illness. It can also be seen in the way participants describe wanting lifestyle factors such as diet, exercise and stress to be addressed, and in multidisciplinary care, participants expressed wanting access to dieticians, occupational therapists, and mental health treatment.

The key distinction between 'multidisciplinary care' and 'whole of person care' was the specificity between the two categories. Multidisciplinary care referred to participants clearly expressing a desire for a multidisciplinary model of healthcare inclusive of specific healthcare professionals, whereas whole of person care captured participants expressing a sentiment that their current healthcare fails to take account of either their personalised experience, or broader psychosocial factors with a focus on their individual quality of life. The results contained in the categories of whole of person care together with multidisciplinary care, show that participants want the individual biopsychosocial impact of their IBD to be considered in their healthcare experience.

‘Proactive care’

Nearly 9% of the total codes came from participants expressing a desire for a more proactive rather than reactive healthcare. Phrases in this category included; ‘proactive care’, more ‘routine’ and less ‘ad hoc’ care.

“My relationships with my Drs and IBD nurse are fine but it is a reactive relationship rather than a proactive one…” (Participant 265, Male with Crohn’s, 63 years old)

In some responses, participants expressed a feeling that their healthcare professionals did not care unless something was seriously wrong, indicating negative perceptions of acute and reactive healthcare experiences;

“*After severe anaemia from toxic azothioprine month long stay in hospital I realised that you must monitor your own health and follow up because doctors just don’t care unless something is wrong.”* (Participant 126, Male with Crohn’s, 28 years old)

A large proportion of codes in proactive care arose from participants articulating that they would like a care plan for the future, or expressing a sense of frustration at receiving assistance only in an acute setting without a plan for long-term management;

“…I feel there is never a clear plan and I get stuck in hospital for days waiting for my symptoms to improve. I feel most things get done when I present to emergency, then when I’m admitted I am left with no clear plan.” (Participant 418, Female with Crohn’s 42 years old)

This often included a desire to have a plan in place for what the next step would be in the event of a flare up (including treatment options, and who to contact), as well as knowledge on how to monitor their own health in order to determine if hospital was necessary. In this way, a care plan for the future can be seen to overlap with ‘better communication’ as well as ‘multidisciplinary care’ given that participants wanted various healthcare professional to be involved in developing the care plan;

“I think all patients with IBD should have a firm written plan of Action that they & GP, Specialist, & Pharmacist (and maybe Dietician) all agree to and can put into action when needed – The plan should have 3 major components to it 1: Normal – The day to day treatment – Drugs,

Dosage, & Diet 2: Flare Up (including an individualised description of what their signs of a flare up are) – immediate steps, medications and action 3 Emergency – When to seek emergency care and symptoms and instructions of what emergency symptoms are for the individual 4: All contact information for everyone in the Care team." (Participant 266, Male with Crohn's, 60 years old)

In addition, participants expressed a desire to have more follow up, including more responsiveness from their IBD nurse;

"...Follow up from doctors or nurses on discussed requirements is lacking. I have to constantly chase things, so improvement in that regard is needed." (Participant 249, Male with Ulcerative Colitis, 47 years old)

Consistent care and/or continuity of care contained responses which included 'consistent' 'regular' 'continuity of care' or describing that they wanted to see a regular gastroenterologist at each visit. Some participants also described the negative impact of losing the long-term consistent care which they had with one doctor (i.e. due to retirement), highlighting the feelings of support that consistent care provided for participants;

"…I am feeling as though my whole support network has come crashing down and I know the care I had in the past is just that – in the past." (Participant 19, Female with Crohn's, 63 years old)

Proactive care supports the overarching results, that is participants are requesting increased integrated biopsychosocial healthcare. If patients are assisted to manage, adjust and understand their illness, through a range of multidisciplinary services, it will enable proactive management of IBD as ancillary issues arise, rather than reactive healthcare whereby patients only interact with the healthcare system during acute periods of gut inflammation.

'Access to treatment, services and specialist care'

Participants wanted increased access to treatment, services and specialist care, which accounted for just over 16% of the total data. This also connects with proactive care, as participants described barriers to treatment, services and specialist care, impacting on their healthcare and impeding proactive management of IBD.

Regarding access to treatment, many participants expressed frustration at the barriers faced when accessing biologics;

"The amount of time and how hard it is to access stronger medication eg: I was hospitalised numerous times, lost 15kg (down to 45kg and am 5'11) within 9 months due to 30 trips to the bathroom per day but had to fail all drugs first (which most takes months to kick in and find out still aren't working) to be able to be approved for infliximab." (Participant 40, Female with Ulcerative Colitis, 28 years old)

Participants also described lengthy weight times and a desire to have quicker access to support, which commonly included phrases such as "easier access to the specialist";

"Even with a referral I had to wait 2 months to see my Gastroenterologist after my surgery" (Participant 373, Female with Crohn's, 34 years old)

"Access to medical support 24/7 rather than having to wait months to see specialist as symptoms can change quickly…" (Participant 443, Female with Crohn's 36 years old)

In addition, participants wanted local delivery of healthcare. This included participants using words like 'closer to home', 'local', and those describing having to travel to receive healthcare from more rural or remote areas;

"I live rurally and have to fly to my specialist in […]. Given my symptoms this brings on anxiety with having to find a toilet and being stuck on a plane with the seat belt sign turned on…." (Participant 272, Female, Ulcerative colitis, 32 years old)

Participants also requested more regular appointments, and this was linked in with a sense that infrequent and ad hoc appointments resulted in feeling unsupported;

"Be able to see gastroenterologist more frequently…" (Participant 425, Male with Ulcerative colitis, 78 years old)

"My private gastroenterologist only sees me every 3 years. I only see him the day of the colonoscopy, there is no consultation appointment to talk about anything else. I feel like I'm just a

money maker to him. I wish he was more interested in my care…" (Participant 108, Female with Ulcerative Colitis, 55 years old)

Finally, participants wanted more flexible appointment days, and access to TeleHealth services to reduce barriers to accessing specialist care.

'Better communication'

Better communication accounted for 23.5% of the total codes. Better communication encapsulated communications between health professionals and patients, both explicit and implicit, and verbal, written and non-verbal. The data indicated participants perceived information provision and explanation as being important to feeling cared for, and supported;

"More information at the beginning when I was initially diagnosed would have been good. I had no idea about CD and was initially given no information, so assumed it would be fixed in a few weeks once the medication fixed it, I did not know it was life long. I also did not know the level of illness I had, whether it was mild or severe. More information at all levels of care is important to physical and mental health. More information so patients are aware of what having IBD entails would be terrific. After 4 ½ years I am still learning and feel that I don't know much about the disease or treatments available. I am lucky in that mine is mild so far, which may be why I was not given much information, but knowledge or where to get knowledge would have been a help emotionally so that I felt supported and so that I was not left floundering in no mans land wondering what was going on." (Participant 320, Female with Crohn's, 52 years old)

In addition to information and explanation about IBD, medications, and treatment options, participants wanted to be made aware of services available to them, be given the opportunity to ask questions, and be provided with information that they could understand. Some participants described a process of information seeking, and how information and education had assisted them to manage their IBD;

"I tend to manage my IBD myself through researching information such as that found on the Crohn's and Colitis website" (Participant 169, Female with Ulcerative Colitis, 61 years old)

Participants also described a lack of empathy and understanding where their experiences and complaints had been dismissed, and where they had not been believed or listened to;

"…I was fobbed off for several months, GP kept telling me I had anxiety and haemorrhoids. In fact I had a severely ulcerated colon and was diagnosed with Crohn's disease…"; (Participant 447, Female with Crohn's, 42 years old)

Their responses communicated a sense that healthcare professionally failed to understand their experience;

"…Reminding my specialist that it is really tough living with IBD…" (Participant 419, Female with Crohn's, 44 years old)

Participants also described negative interactions where they felt they had been prescribed medication and sent on their way without proper care;

"... I think specialists should have more care and follow up processes to help properly manage their patients, rather than to prescribe medication and send me on my way." (Participant 377, Female with Crohn's, 30 years old)

Many participants perceived that healthcare professionals did not provide person centred care, and had failed to see them, and communicate with them, as individuals with varying circumstances and experiences. They described wanting more patient choice. Frequent phrasing centred around doctors generalising patients, or participants emphasising the individual differences in IBD. As can be seen on Figure 1, this is related with 'Whole of Person Care'.

"doctors tend to look at blood tests then generalize patients, everyone is different and reacts differently …." (Participant 122, Male with Ulcerative Colitis, 49 years old)

"Realise we are humans not just a disease [….]*"* (Participant 59, Female with Ulcerative Colitis, 50 years old)

Better communication also included 'improved education and understanding of IBD for health care professionals' including General Practitioners, Emergency Department staff and even specialists. Participants expressed a frustration that the healthcare professionals they had been in contact with did not have an adequate understanding of IBD. This was coded better communication due to participants perceiving a lack of education and understanding undermined communication, understanding, diagnosis in their healthcare;

"Some GP's do not seem to know much about IBD. I have a j-pouch and always seem to have to explain what it is. Also they cannot understand why I would still need Imodium, Prednisolone enemas and Panadeine Forte." (Participant 48, Female with Ulcerative Colitis, 57 years old)

Notably, better IBD education for healthcare professionals corresponds with 'respectful care' in the category 'better communication.' The following extract highlights how lack of IBD education was linked to participants feeling dismissed, and/or perceptions of a lack of care;

"…I would like to see GP's better informed about Colitis. Mine kept telling me it's just a gastro bug… or perhaps it was just in my head and to focus on something else. Hard to do when it's so life consuming." (Participant 110, Female with Ulcerative Colitis, 44 years old)

Better IBD education for healthcare professionals also links to proactive care and access to specialist care. Many participants expressed that if their doctors had adequate knowledge of IBD, they might have referred them to a specialist or diagnosed them sooner instead of dismissing their complaints;

"*…it took 5 years of active Crohns with recurring anal fissures, significant weight loss and repeated GP visits and numerous doses of antibiotics before I was finally referred to a gastroenterologist. More awareness by GPs and earlier diagnosis would have really been beneficial for me as I might have avoided surgery and psychological problems if treatment had started sooner."* (Participant 27, Female with Crohn's, 66 years old)

'Health promotion'

Just over 10% of participants expressed a desire to have increase public awareness, funding, financial support, access to support groups as well as more research into new treatments and to find a cure. A small number of participants also expressed concerns or a desire to address the variability in healthcare services. Extracts to illustrate these categories can be found in Appendix A. The participants expressed they were misunderstood by the public, with some participants expressing few understood the seriousness of IBD, or the difference between IBD and IBS.

"*…I'd like there to be more heightened awareness of IBD and what it means for those with living with it. Too often it's confused with IBS…*" (Participant 223, Female with Ulcerative colitis, 64 years old)

Given that a large proportion of participants described their biopsychosocial experience of IBD (in the category 'Whole of person care'), including the social impacts of IBD; it is unsurprising that they also expressed a desire to have increased public awareness, financial support, funding and access to support groups given these are all social supports. This indicates that currently healthcare for IBD could do more to support patients social experience of IBD.

'Happy with healthcare'

The results indicate that just under 10% of codes of the total dataset reported being happy with their current healthcare. Notably, approximately 16% of codes under 'happy with healthcare' category was attributed to participants being happy with multidisciplinary care;

"I love my team! They look after me extremely well, I'm very happy." (Participant 475, Female with Ulcerative Colitis, 45 years old)

Other responses included participant stating 'no changes', or 'happy with treatment' or describing that they had a good relationship and were happy with a particular doctor.

Other categories

Improved hospital experience and administrative issues emerged as minor categories only accounting for 2.34% and 1% of the total data coded respectively. As can be seen in the diagram displayed above in Figure 1, improved hospital experience encapsulated participants wanting more privacy, access to their own toilet and/or room, to reduce the wait time in hospital. Administrative issues contained ancillary concerns which were considered to be separate to 'better communication' as defined above including; a review system for finding a specialist, better record keeping, appointment reminders, reduce delays/rescheduling, to be given IBD clinic contact details, appointment reminders, and improved packaging for enemas.

Discussion

Overview and findings

This was the first study which explored Australian IBD patient perspectives of healthcare. Despite there being a large body of qualitative research on the patient experience of living with IBD,[47,48,49,50] qualitative studies on patients perspective of healthcare in IBD are rare.[51] Previous qualitative studies have focused on healthcare professionals' attitudes and perspectives.[11] Other studies which have investigated patient perspectives of quality of care have done so using largely quantitative methods[43,52] or have assessed patients from other countries.[51] In an integrated model of healthcare, patient perspective and feedback on healthcare are an important tenant towards developing and maintaining optimal care.[12,53] Therefore, the current study fills an important gap in the literature; the patient perspective on healthcare.

The current study found patients with IBD want multidisciplinary, proactive healthcare, easier access to treatment, services and specialist care and better communication with their healthcare professionals along with other categories. Of note, these requests directly relate to Australian IBD Standards of Care.[12] The findings support the current standards[12] as being relevant, but also reinforce that not only is the current healthcare falling short on objective quality of care measures,[44] but it is also failing patients' expectations.

The biopsychosocial experience

Although it is well established in the literature that IBD is a biopsychosocial illness, with chronic physical symptoms,[54]high rates of psychological distress,[43,55] and negative impacts on social functioning,[56,57,58] the current results wherein participants have stressed the biopsychosocial impact of IBD indicate that patients perceive healthcare for IBD is failing to adequately address these biopsychosocial elements.

Participants referenced widespread physical manifestations of IBD (i.e. fatigue, pain and weight), which is congruent with past literature outlining the prevalence and negative impact that fatigue and pain have on quality of life.[59,60,61] The results also triangulate recent research which has highlighted high rates of psychological distress in patients with IBD[43] and the benefits of addressing psychological factors in routine IBD care.[24] These results go further to conclude that patients perceive their mental health to be important in their IBD healthcare and want access to mental health treatment in the routine care of IBD. Finally, qualitative research on the experience of living with IBD has outlined social factors including social isolation and stigma; the current study adds to this by indicating how patients would like these factors to be addressed in their healthcare, through increasing health promotion (i.e. public awareness, access to support groups and financial support).

The multidisciplinary model of care

In addition to describing unmet biopsychosocial needs, this study outlines that patients want these elements addressed by a proactive multidisciplinary model of healthcare. Previous research has stressed the need for multidisciplinary healthcare over biomedical healthcare in IBD, where the patient is only seen in times of acute illness often by a specialist doctor; highlighting multidisciplinary care as being more cost effective, and yielding better patient outcomes.[15,24,16] However, this is the first study to identify that patients' themselves perceive greater emphasis on addressing the biopsychosocial elements through multidisciplinary care is needed.

Although this study confirms prior research which identified patients want increased access, communication, public awareness, GP involvement, a cure and more research,[51] the current study extends on this. Mikocka-Walus and colleagues (2018)[51] were limited by a small sample size (n=64) and their study was conducted with participants from the United Kingdom. The current study focuses on Australian patients' who exist in a different healthcare system and also adds to the findings, by highlighting changes in the model of healthcare delivery wanted. Therefore, the current results triangulate the importance of multidisciplinary care in Australia; not only is it more effective on objective measures and wanted by most healthcare professionals in Australia,[11] but patients with IBD also want multidisciplinary care.

Access to psychologists, IBD nurses and dieticians

Distress in patients with IBD can be predicted partly by poor adjustment.[62] Participants in the current study reflected this by highlighting that being asked about mental health or being provided with mental health treatment was especially wanted when diagnosed or during times of acute illness. In their study, Mikocka-Walus and colleagues (2019)[43] (n=731) found despite 50% of respondents experiencing distress, only 16.1% were asked about their mental health and only 12.2% had access to a mental health practitioner as part of their IBD care. This study extends these findings by outlining that participants are asking for mental health treatment as part of their IBD care.

Participants also requested access to IBD trained nurses, which further cements the importance of IBD nurses in the IBD team as being able to provide quick advice and support,[18, 19, 20] as well as provide a point of contact between the specialist and patient.[63] This study also extends on this by highlighting the perceived value that patients have for IBD nurses in their care, with IBD nurses being the second highest sub-category in multidisciplinary care.

Qualitative research has underscored the need for trained dieticians to be involved in IBD care, with results indicating participants use diet as a means to self-manage IBD, but many were unassisted in this by their primary healthcare professionals, and used alternative, and sometimes unreliable sources of information.[64] The current study confirmed that while some participants perceived changes in diet to have helped manage IBD, others wanted access to dieticians. This is important given that recent study estimates that only 30% of patients with IBD have access to a dietician.[44] Together with past research, the current results indicate that dieticians are needed to mitigate the risks of patients seeking unreliable dietary information to self-manage their IBD.

Proactive care and access to treatment, services and specialist care

Acute reactive management of IBD can lead to further gut damage. In addition to this, the current study can now conclude that Australian patients want increased, ongoing and regular care, follow up, and care planning for the future as part of their ongoing IBD care, not only during acute flares. In addition, the current study is consistent with and reinforces that despite IBD Standards citing patients should have specialist care within 5 days of an acute flare,[12] not only are one-third of patients left waiting more than two weeks,[44] patients are wanting quicker access to the specialist and reduced wait. The current study can further outline that patient perceptions of healthcare appear to link access to treatment, services and specialist care and proactive care; barriers in access are barriers to proactive care, and increased access to services and specialist care aid in proactive perceptions of IBD care.

Better communication

The current study reinforces findings from a survey conducted in the United Kingdom, that patients with IBD want improved communication.[51] The importance of adequate doctor patient communication to facilitate information and explanation about a patients' illness has been highlighted in the literature across a range of chronic illnesses including IBD.[34.36]Information provision and explanation is integral to a patient being able to adjust and self-manage their illness.[35] A hospital-based cohort study showed when participants perceived a lack of control over decisions regarding their treatment, they were likely to experience anxiety and a sense of alienation.[16] Therefore, the current results add further weight to the importance of adequate doctor-patient communication and how it can affect the biopsychosocial elements of IBD; by influencing psychological elements (alienation, anxiety) and biological elements (self-management). In the current study this was confirmed by patients wanting increased patient centred care.

Strengths

The current study design and content analysis, allowed for both a large sample size which had the capacity to reflect a wider range of the views/experiences of patients with IBD in Australia, but also to obtain detailed and individual responses which a quantitative analysis would not have been able to capture.

Limitations

The data was obtained at the end of a larger study; therefore, participants may have been fatigued while they completed the responses to the open-ended question. Completion of the survey prior to the open-ended question (including completion of the K-10, and measures of disease activity) may have also primed participants to discuss biopsychosocial aspects of their illness. Further, participants responses could not be clarified for meaning or to resolve ambiguity as the researchers were not present. The current analysis had fewer participants from remote areas, and therefore their experiences and desires for healthcare may not be accurately reflected.[44] Finally, the overlapping nature of the codes, means that they are not entirely distinct, and the nature of content analysis means the count of codes may be biased by some participants repeating certain codes multiple times.[46] However, the overlapping nature reflects multidisciplinary models of care and the interactive biopsychosocial elements of IBD.

Implications for future research

Despite IBD standards, and research advocating for proactive multidisciplinary healthcare, it is lacking and wanted from patients. Given that research suggests most healthcare professionals in Australia have endorsed multidisciplinary care for IBD[11] future research could investigate what current barriers remain in the implementations of biopsychosocial healthcare in Australia. In line with this, the current results did not elucidate the higher-level organisation and management of the healthcare system. Future research could examine what organisational changes are needed to facilitate patients access to integrated multidisciplinary healthcare services, to aid in reducing wait times, and facilitating access to a broader range of treatment options. Finally, future research could explore if there are key differences between IBD patients experiencing acute flares, in remission or other variables that influence desired healthcare.

Concluding remarks and implications for healthcare

Healthcare professionals should focus on improving communication, and increasing information provision and explanation, as well as increasing interdisciplinary communication. Communicating in patient-centred terms so that patients are heard understood and have a choice in their treatment should also be a priority. Patient’s should be asked about their mental health, particularly during acute illness, or during diagnosis. Facilitating patients’ access to multidisciplinary services (i.e. psychologists, dieticians and IBD nurses) should also be a priority alongside increased follow up and developing collaborative care plans with patients.

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Appendix A – Demographics

Table 1

Demographics

Age	17-84 (Average 48)
Gender	73% female, 26.8% male, 0.2% other
IBD type	UC: 41.1%, CD 55.8%, Indeterminate colitis: 3.1%
Remoteness	Inner Regional: 22.2%, Major Cities: 70.6%, Outer regional: 5.9%, Remote:1%, Very remote: 0
Education	12.5% less than year 12, 36.5% Bachelor's degree. 17.0% vocational education (TAFE), 15.3% year 12, 10.3% Master's degree, 2.5% PhD, 5.9% other
Marital status	66% married/de facto 21.4% single (never married) 6.7% divorced 27% separated .6% other
Employment status	Employed full-time 30.4% Unemployed/looking for work 23.3%, unemployed/not looking for work 1.9% Student 6.7% Unable to work 8.2% Retired: 16.6% Self-employed: 5.5% Homemaker: 4.2%

Appendix B – Table with content analysis coding structure (categories, sub-codes and extracts)

Table 1

Category: Multidisciplinary care

Codes	Sub-codes	Extracts
Access to mental health treatment n=61	To be asked about mental health	*"More conversation around mental health – 9/10 you'll say I'm fine even if you're not…"*
	More access to mental health	*"Longer access to mental health plans"*
	Access to mental health	*"Access to therapist to discuss the disease…"*
Access to IBD nurse n=42	Access to IBD nurse	*"I never met an IBD nurse, I think this will be a really good thing before seeing the specialist…"*
	IBD nurse helped	*"…the nurses on the other hand have been caring and extremely* involving in *everything we do."*
Access to dietician n=33	N/A	*"Access to a Dietician educated in IBD"*

	Interdisciplinary communication n=29	Better interdisciplinary communication	*“Better communication between the GP and the specialists”*
		Reduce conflicting treatment advice	*“It’s an awkward position to be in when you have 2 gastroenterologists with different approaches…”*
		Interdisciplinary meetings have improved care	*“I found I have had better care…where they meet regularly with other gastroenterologists and colorectal surgeons to discuss different cases…”*
	A team n=24	N/A	*“Dedicated team comprising of dietician, nurses and physiologist”*
	IBD clinic n=6	N/A	*“I would like access to an IBD specialist unit of some kind, I have never been offered anything other than my consultations…”*
	Nutritionist n=4	Want access to nutritionist	*“…Nutritionist would be good as well”*
		Nutritionist helped	*“…a nutritionist…has improved my IBD a lot….”*
	OT/exercise physiologist n=4	N/A	*“I think occupational therapy directly related to IBD should be available, and offered to all IBD patients on diagnosis”*
	Specialist to value MD services n=1	N/A	*“Encourage gastro’s to recognize the value of complementary treatments from dieticians and psychologists”*

Table 2

Category: Better communication			
	Codes	**Sub-codes**	**Extracts**
	More information/explanation n=92	More information about IBD or explanation	*“Early information and education. When I was diagnosed, no one spoke to me about the seriousness of UC, what can happen I ended up nearly dying and waking with an ileostomy during my second flare EVER”*
		More information provided about medication side effects (including having long term effect of medications discussed)	*“more information on drugs and side effects”*
		More written information	*“Having some written information would be great too” “*
		Information/education helped manage	*“The internet has thrown me a lifeline with many forums on the topic”*
		To be made aware of services available	*“Told about options and what I have access to. I don’t feel I have any support at all”*
		Easy to understand information	*“Easy to understand answers”*
		To be able to ask questions	*“Feel it’s difficult at times to ask questions.”*

		Information about treatment options	*"more information about IBD, treatment options, other health care professionals etc."*
		Pregnancy information	*"I think more studies and information for people pregnant living with IBD"*
	Respectful care n=57	To be believed	*"At one stage the GP said it was all in my head?"*
		To be heard and understood	*"Listening to the patient more rather basing treatment off tests alone"*
		More understanding/empathy	*I don't feel important or valued. Just a number. When I show concerns about my multiple meds and the possibility of reducing them now that I'm in remission I feel like its all too hard. Possibly just easier for the specialist to continue the same"*
		To be informed about own treatment	*"As surgeons haven't told me what the outcome of either of my bowel ops would be I was worried when I still had diarrhea etc. Liaison between the gastro and surgeon AND patient. I was told nothing about what to expect after my first bowel op."*
		Don't want to be told 'take these meds' and sent away	*"I think specialists should have more care and a follow up process to help properly manage their patients, rather then to prescribe medication and send me on my way"*

		For doctor to ask more questions	*though he does leave it up to me to ask the questions and ask for the referral to my Gastroenterologist”*
		Not to be dismissed	*I hate being dismissed as I don’t know anything and they the doctors are superior and not to be questioned”*
		To be treated with respect	*“Often I have been dismissed and treated with disrespect in the emergency department. I feel they do not resonate with us”*
		Not to be kicked out of ED	*“…they’re so eager to kick you out as quickly as possible afterwards”*
	Better IBD education for healthcare professionals n=46	GP’s	*“GP’s need to research IBD and realise the effect it has on your life”*
		ED staff	*“The emergency department healthcare system. They need to be educated about IBD….”*
		Better education for healthcare professionals generally	*“more IBD education generally and hopefully this will lead to more empathy for patients who present with this disease …”*
	More time for comprehensive care n=25	More time	*“I prefer my IBD doctor to give more time to explain to me and help find a solution for my active crohn’s. She is usually in a hurry.”*

		IBD clinic too busy	*“Infusion centre staff need better support. They are always short staffed and this is grossly unfair to them and patients” “*
		Specialist forgetful	*“…He forgot I’d had the IBD check before starting Humira and suggested again I did the test. When I told him I already had, he admitted the application forms for Humira must be sitting in his desk & had been there for a while, all the while I had been on pred for months and struggling along. Humira failed and now I’m on remicade but he keeps forgetting and reapplying for a new script of Humira instead of the remicade which is frustrating.”*
	Generally better communication n=17	*N/A*	*“Face to face contact could be improved. Particularly with specialists”* *OR specific example* *“Unfortunately, I had very negative experiences with my original Gastro who would tell me I was ‘very lucky, many people are worse than me!’ When you are 18 and having to continually rush the toilet, have constant stabbing pains and feeling nauseous, I didn’t really feel very lucky!”*

	Person centred care n=24	N/A	*“better one on one care more personal attention”*
	At diagnosis/in ED n=5	N/A	*“I would change the way my initial diagnosis was made. After a colonoscopy without a suspected Crohn’s, I was told quite abruptly that I had crohn’s disease straight after the colonoscopy. I was told I needed to immediately take budenofalt (steroid) and immunosuppressants and I’d be on medication for the rest of my life. This was too much to take in, straight after a colonoscopy and without any forewarning. Because of this I changed gastroenterologists and saw a private specialist form the same clinic”*
	Doctor to be more involved n=5	N/A	*“More interest from GP”*

Table 3

Category: Access to treatment, services and specialist care

	Codes	**Sub-codes**	**Extracts**
	Treatment options or access to medications n=61	Access new treatments or drugs (more treatment options, drug trials and alternative to steroids)	*"I would like access to trials for new treatments…"*
		Reduce regulatory restrictions on biologics	*"I hate that there is such a time delay when changing drugs. When you are really sick and you have to wait for approcal of new drugs (ie biologica) it cuses more stress and pain…"*
		Medication management (i.e. new meds, improved management of scripts)	*"More support when ringing up for scripts or help.."*
		Reduce immunosuppressant use	*"Find a way to reduce dependency on Meseal"*
		Treatment for perianal disease	*"Would like more help with perianal disease…"*
	Reduce wait times n=40	Wait times	*"Waiting times for the specialist…"*
		Quick access to support	*"Access to medical support 24/7"*
		Telephone advice	*"A phone help line…"*
	Easier access to specialist care n=38	Easier access generally	*"Easier access to specialists"*
		Easier way to contact specialist	*"To make contacting Gastroenterologist easier…"*
		GP to provide specialist referral sooner	*"…It took me 1 month of seeing 5 doctors in the ACT before I was sent to a specialist.."* *"…It would be better to have easier access to private Gastro's…"*

		Access to private GI More specialist colonoscopies Access to fistula repair surgery Fecal transplant Frequent colonoscopy Ileal pouch surgery	*“I want to get Fistula Repair surgery done…”* *“sincerely wish that Fecal transplants were more easily accessible in hospital environment…”* *“Maybe have a colonoscopy once every 12 months rather than the current 24 months”* *“Ileal pouch surgery – colorectal surgeons don’t do the procedure often enough…”*
	Local delivery of healthcare (rural and remote access) n=35	N/A	*“…more locally available specialists to shorten consultation/access delays…”*
	More regular appointments n=7	N/A	*“More regular specialist visits every 6 months is way too long a lot can happen in 6 months”*
	Flexibility of appointment days, IBD clinic open more days n=4	N/A	*“…I would like choice of our patient clinics. The one I was attending was evening only, and very difficult to attend..”*
	Access to TeleHealth services n=3	N/A	*“…even be able to have follow up appointments with my ibd team over Skype or phone”*

Table 4

Category: Whole of person care

	Codes	**Sub-codes**	**Extracts**
	Biopsychosocial impact n=33	Biopsychosocial impact	*“…The cost both financial and emotional adds to the stress of managing complex and chronic disease”*
		Burden of ongoing healthcare	*“…It becomes so hard to manage and juggle all of these appts and tests.”*
		Psychosocial changes helped	*…without the stress of being at work…I have been able to manage my bowel symptoms much better..”*
		Want psychosocial changes	*“Changing my employment so have less stress”*
	Lifestyle factors	Lifestyle changes (diet, stress and exercise) Diet helped	*“…I can manage the symptoms through diet and stress reduction however, they do not see this as a legitimate alternative to medication even though I experience it and know that it works for me”* *“…My diet and avoiding some food has increased my quality of life…”*
	CAM’s	CAM’s (alternative) Marijuana CAM’s helped Doctors to be more open to CAM’s	*“…I think using alternative meds should be suggested…”* *“Access to medicinal marijuana products”* *“…Since seeing a naturopath ….I am finally managing my disease”*

			"…there is a lack of respect between traditional health care and alternative…"
	Holistic care	N/A	*"A holistic approach…"*
	Pain management	N/A	*"…That my Gastroenterologist acknowledged and treated my pain, and that my concerns about pain weren't dismissed…"*
	Address other health issues	Including muscle dysfunction and rectoceale	*"…I would like to be seen as a whole person with other possible issues (eg I have fibromyalgia/connective tissue disease and a DVT history. Medical personnel only appear to treat 1 ailment at a time…"*
	Specialist too biomedical	N/A	*"…One observation I have is all gastroenterologists focus almost exclusively on prescription drugs…"*
	Quality of life	N/A	*"…not looking at the whole person or quality of life"*
	Weight management	N/A	*"…I just feel I may need a little more assistance with weight gain issues"*
	Family involvement	N/A	*"…Sharing info with people in my life so they understand"*
	Fatigue	N/A	*"…However I am discharged from surgical and my gastroenterologists do not ask about fatigue and when I mention it I am dismissed as my illness essentially is no longer…"*
	Gut bacteria testing n=1	N/A	*"maybe even gut bacteria testing incase we don't have the right ones or too much of some,…."*

Table 5

Category: Health promotion

	Codes	**Sub-codes**	**Extracts**
	Public awareness n=32	Public awareness	*"More public awareness and understanding…"*
		Access to public toilets	*"It can be difficult to find bathrooms quickly. If more people were aware of how embarrassing ibd can be then there would be more public facilities available…"*
		More workplace support	*"…Workplaces to be more understanding of IBD, and other related symptoms such as fatigue"*
	Financial support n=25	Decreased cost of medication	*"More access to reduced price medication and services…"*
		Access to healthcare card/Centrelink	*"…more support from Centrelink and access to disability"*
	Support groups n=24	Support groups	*"…more support groups to talk to other people to see what others are going through…"*
		Access to ACCA helped	*"Make sure all new patients are encouraged to access ACCA"*
		Support groups helped	*"…I'm very grateful to be part of such a wonderful group."*
	Research n=21	Research	*"…I hope more research can be done to figure out this baffling disease*
		Dissemination of research	*"Be kept informed of the latest research…"*
	A cure n=10	N/A	*"…I don't want to manage IBD, I want a cure"*

	Funding n=6	N/A	*"Funding for care and medications -very expensive…"*
	Variability in care n=2	N/A	*"…However, I have friends with Crohn's/colitis for whom this isn't the case"*

Table 6

Category: Proactive care			
	Codes	**Sub-codes**	**Extracts**
	Care plan n=28	Care plan Participant expressing concern for future	*"A care plan and strategies for flare ups"* *"I have a mild case of Colitis and am concerned that this may get worse as I get older and I don't really know what to do to help with this"*
	Consistent care/continuity of care n=18	N/A	*"try and have a regular team of people to support you, familiar faces are important…"*
	Follow up n=15	N/A	*"…In all cases of seeing a specialist – I have never had any support or follow up and think this is something that is very important…"*
	Proactive/preventative care/regular care n=12	N/A	*"…Currently if the patient is well specialists provide 5-10 mins with no or little feedback"*
	Earlier diagnosis n=10	N/A	*"To get that early diagnosis is key! You know your own body better than anyone else. Get that second or even third medical opinion if you think you're not being listened to.."*

	Nurse more responsive n=6	N/A	*"…often the IBD nurse never gets back to me when I call, and rarely answers my calls"*
	Avoid hospitalization n=3	N/A	*"….to avoid the emergency department"*
	Regular blood tests n=3	N/A	*"I have irregular blood tests which concerns me greatly as I'd like to be confident that any negative impact from Infliximab would be identified promptly…"*
	Surgery discussed earlier n=2	N/A	*"I would like to see surgery discussed earlier on in treatment of IBD…"*
	Connected to the clinic sooner n-1	N/A	*"…Would have liked to be connected to them* [IBD clinic*] sooner, not over 2 years after my diagnosis"*

Table 7

Category: Happy with healthcare

	Codes	**Sub-codes**	**Extracts**
	Happy with treatmen n=51t	N/A	"I wouldn't change anything everything has been really well"
	No changes/nil n=26	N/A	"None"
	Happy with MD care n=18	N/A	*"At present I have a good team looking after me"*
	Happy with doctor n=17	N/A	*"Thank goodness I have a wonderful GP who cares"*

Table 8

Category: Administrative issues

	Codes	**Sub-codes**	**Extracts**
	Fewer regulatory restrictions n=8	Fewer regulatory restructions hould not need continuing referrals Want recurring colonoscopy without administration Not having to visit GP for blood test forms	"*More understanding from regulators that out diseases do not always fit into neat boxes…"* *"…I think with a long term chronic illness referrals should not be necessary"* *"Having scheduled colonoscopy on an annual basis without having to go through the gp/specialist…"* *"Not having to visit the GP to get blood test forms…"*
	Review system or assistance finding specialist n=7	N/A	"We need a forum/review system for Gastroenterologist and other specialists so we can find a good one"
	Record keeping n=6	N/A	*"Better note taking systems so I'm not repeating myself over and over"*
	Reduce delays or rescheduling n=2	N/A	*"…finding out that they have exams and need to be rescheduled two weeks before is really awful…"*
	Confirmed contact details for IBD clinic n=2	N/A	*"Having confirmed contact details for the ibd clinic…"*

	GI to automatically arrange meeitngs n=1	N/A	*"…gastroenterologist to automatically arrange meetings for me like the hospital does…"*
	Message to remind for appointments n=1	N/A	*"A message to remind you of upcoming appointments, I have found my memory is significantly worse than it was…"*
	Packaging for enemas n=1	N/A	*"Well it's a simple thing, but the packaging used for steroid enemas in Australia are horrendous! …."*

Table 9

Category: Improve hospital experience and patient comfort			
	Codes	**Sub-codes**	**Extracts**
	Access to own toilet and room in hospital n=5	N/A	*"…I felt there wasn't adequate access to toilet facilities. I was having to open up my bowels up to 15 times a day and in almost all cases with urgency…"*
	More privacy n=2	N/A	*"More consideration when going to public hospital for Flexi sig. they administer an enema with just the curtain (very little privacy)…"*
	Reduce time in waiting room n=2	N/A	*"I was left in the waiting room for 4 hours…"*
	A clean ward to sit in n=1	N/A	*"A clean ward to sit in"*

	Better powder drink prior to colonoscopy n=1	N/A	*"…Invent a new Bowell prep tablet for prior to colonoscopy, the existing powder drink is dreadful and difficult to drink…"*
	Gentler preparation for colonoscopy n=1	N/A	*"Each reaction to the colonoscopy preparation gets worse to the extent that I never want to have one again – even at the risk of cancer. Surely a gentler preparation could be used…*

Appendix B – Clinical Gastroenterology and Hepatology Guidelines

Author Information

Clinical Gastroenterology and Hepatology (*CGH*) publishes clinical articles on all aspects of the digestive system, including the liver and pancreas. The types of articles *CGH* publishes include original papers, review articles, and special category manuscripts. Manuscripts must be prepared in accordance with the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals" developed by the International Committee of Medical Journal Editors (http://www.icmje.org). *CGH* is a member of the Committee on Publication Ethics (COPE) (http://publicationethics.org/).

CGH has a total circulation of approximately 19,000—about 16,000 in the United States and 3,000 in other countries. 70% of subscribers are AGA members.

CGH is indexed in Current Contents, Excerpta Medica, MEDLINE®, Science Citation Index, and Scopus.

CGH strongly encourages the submission of papers on a breadth of clinical topics in gastroenterology and hepatology, especially randomized controlled trials, high-quality observational including epidemiological and outcomes studies, and novel case series. *CGH* is interested in several aspects of clinical and translational studies including treatment, prevention, screening, and diagnosis. High-quality systematic and meta-analyses are also welcome and will be highlighted in a special section. Publication priority will be determined by factors such as novelty, impact upon clinical practice, strength of the experimental design, and mechanistic insight.

Ethical Standards
Conflict of interest Policy
Plagiarism, Duplicate Submission/Publication Policy
Image Manipulation Policy
Open Access Policies
Information about Article Types
Submission Checklist
Graphical Abstract
Preprint Server Policy
Reporting Clinical Trials
Manuscript Processing and Review
Publication
Editorial Office

ETHICAL STANDARDS

CGH strongly discourages the submission of more than one article dealing with related aspects of the same study. In almost all cases, a single study is best reported in a single paper.

The Journal editors consider research/publication misconduct to be a serious breach of ethics and will take action as necessary to address such misconduct, which includes submission or publication of information that:

- Is intentionally erroneous,
- Has been published elsewhere by a different author without acknowledgment (plagiarism),
- Has been published elsewhere by the same author without acknowledgment (duplicate publication), or
- Is subsequently published elsewhere by the same author without acknowledgment, attribution, or permission from the AGA Institute, as holder of the copyright, to reprint or adapt the material.

Each author who submits a manuscript to *CGH* must attest to several author statements in the manuscript management system, thereby assigning copyright of the manuscript to the AGA Institute and affirming authorship responsibility, manuscript originality, payment of color reproduction fees, IRB/Animal Care Committee approval, role of study sponsor, financial disclosures, and funding sources.

Breaches of *CGH*'s ethical standards may result in proscribed submission for all authors of the concerned manuscript and, when appropriate, notification of the authors' institutions. All authors are fully responsible for the content of the manuscript.

The publication of abstracts is not considered duplicate publication but should be disclosed in the cover letter accompanying the manuscript submission.

CONFLICT OF INTEREST POLICY

A. Potential Conflicts of Interest

The following are examples of COI that may occur with editors, authors (including invited authors), and reviewers. Interactions considered pertinent are from the start of the research activity in a specific program until such time that a submission is anticipated to be published or one year from submission date, whichever is longer.

a. Editors: Editors who make final decisions about manuscripts must have no personal, professional, or financial involvement in any of the issues they might judge. Examples of personal involvement with an author include former student, fellow, mentor, or relative. Examples of professional involvement include academic rivalry, being from the same institution or research group as the author, evaluating a manuscript for which they are listed as an author, or collaborating (e.g., co-authoring research article or grant) with an author. Examples of financial involvement include employment, consultancies, honoraria, stock ownership or options, expert testimony, grants/patents received, and royalties with an entity (or competing entity) discussed in the manuscript.

It is a COI for editors of the AGA Institute journals to hold a position of editorial responsibility for a competing publication. The Ethics Committee reviews disclosure statements submitted by editors and notifies either/both the Secretary/Treasurer and editor of any potential conflicts. The procedures contained in Section C of the "AGA/AGA Institute Policy on Disclosure of Potential Conflict of Interest" apply if a conflict is found to exist.

b. Authors: COI for an author may arise if there exists a financial arrangement (e.g., employment, consultancies, honoraria, stock ownership or options, expert testimony, grants/patents received, and royalties) with a company whose product figures prominently in the submitted manuscript or with a company that makes a competing product.

c. Reviewers: COI for reviewers exist when they have had an ongoing collaboration, original publications, or grants with the authors within the previous two years, except when part of a multicenter group from a different site; are from the same institution as the authors; or have any financial arrangements (e.g., employment, consultancies, honoraria, stock ownership or options, expert testimony, grants/patents received, and royalties) with a company whose product figures prominently in the submitted manuscript or with a company that makes a competing product.

B. Process

Potential COI are to be disclosed at the beginning of the peer-review process.
a. *Editors:* An associate editor having COI with a submitted manuscript must recuse himself from handling the manuscript and request that the manuscript be reassigned. The editor-in-chief having COI with a submitted manuscript must assign review to an associate or guest editor for handling. A manuscript submitted by the editor-in-chief or one of the associate editors must be assigned to another member of the board. The editor/author must recuse themselves from all decisions and discussions relating to their submitted manuscript. Editorial staff will ensure that editors submitting manuscripts to their own journal are blinded in the system to the details of their manuscript's review.

b. *Authors:* The senior or corresponding author assumes full responsibility for supplying the following information on the title page at manuscript submission:
i. For each author, disclosure of any financial arrangement with any company whose product figures prominently in the submitted manuscript or that makes a competing product; or a statement for each author that there is no conflict to disclose.
ii. A disclosure of all funding sources supporting the work and all institutional or corporate affiliations.
iii. A list of individuals who provided writing assistance for the manuscript and the source of funds that supported this assistance.

In addition, at manuscript submission, each author must attest to several author statements in the manuscript management system, thereby assigning copyright of the manuscript to the AGA Institute and affirming authorship responsibility, manuscript originality, payment of color reproduction fees, IRB/Animal Care Committee approval, role of study sponsor, financial disclosures, and funding sources.

Based on the information provided, the editors will determine whether COI exists and decide to either a) reject the manuscript or b) publish the manuscript with the COI disclosed.

c. *Reviewers:* When invited, reviewers must decline to review a manuscript if a potential COI exists. After review, all reviewers must agree to and initial one of the following statements, which appear in the journals' manuscript tracking system:

i. I, the undersigned Reviewer, certify that I have not had an ongoing collaboration, original publication, or grant with the authors within the previous two years, except in the case of being a part of a multicenter group from a different site, nor am I from the same institution as the authors. I also certify that I do not have any financial arrangements (e.g., employment, consultancies, honoraria, stock ownership or options, expert testimony, grants/patents received, and royalties) with a company whose product figures prominently in the submitted manuscript or with a company that makes a competing product.

ii. I have listed any potential conflicts on interest in the Comments to Editors field.

If the reviewer discloses a potential COI after the review, the handling associate editor decides if the review should still be used to judge the manuscript.

C. Sanctions

Should an editor, author, or reviewer fail to disclose a potential COI and this is discovered after publication, the following sanctions may be applied according to the severity of the infraction.

a. *Editors:*

i. A letter of reprimand and warning as to future conduct from the editor, in the case of an associate editor, or from the Chair of the Publications Committee, in the case of the editor.

ii. Dismissal from the position.

b. *Authors:*

i. A letter from the editor of explanation and education where there appears to be a genuine misunderstanding of principles.

ii. A letter from the editor of reprimand and warning as to future conduct.

iii. A letter from the editor to the author's institution or funding body.

iv. Publication of a notice detailing the author's failure to disclose the COI.

v. Publication of an editorial detailing the full details of the misconduct.

vi. Refusal to accept future submissions from the author on a sliding scale of one-to-five years.

vii. Formal retraction or withdrawal of the paper from the scientific literature. viii. Reporting the case to the Office of Research Integrity (ORI).

c. *Reviewers:*

i. A letter from the editor of explanation and education where there appears to be a genuine misunderstanding of principles.

ii. A letter from the editor of reprimand and warning as to future conduct.
iii. A letter from the editor to the reviewer's institution.
iv. Refusal to allow the individual to review for the journal on a sliding scale of one-to-five years.

This policy was developed in accordance with the guidelines set forth by COPE and ICMJE.

PLAGIARISM, DUPLICATE SUBMISSION/PUBLICATION POLICY

A. Definitions

a. Plagiarism: Unreferenced use of published and unpublished ideas. It may occur at any stage of planning, research, writing, or publication and applies to print and electronic versions.

b. Duplicate Submission/Publication: Occurs when two or more papers, without full cross-reference, share the same hypothesis, data, discussion points, or conclusions.

B. Sanctions

Should plagiarism or duplicate submission/publication be identified, the journal editors will apply the following sanctions according to the severity of the infraction. They will apply sanctions to individual authors depending on their type of involvement with the article, as provided at the time of submission on the title page.

a. A letter of explanation from the journal editors to the authors where there appears to be a genuine misunderstanding of principles.

b. A letter of reprimand from the journal editors as to future conduct.

c. A formal letter from the journal editors to the author's institution, employer, or funding body.

d. Publication of a notice or editorial in journal.

e. Refusal to accept submissions from the author for a range of one-to-five years.

f. Formal withdrawal or retraction of paper from the scientific literature.

g. Journal editors report the case to Office of Research Integrity, which promotes integrity in biomedical and behavioral research supported by the U.S. Public Health Service; monitors institutional investigations of research misconduct; and facilitates the responsible conduct of research through educational, preventive, and regulatory activities.

This policy was developed in accordance with the guidelines set forth by COPE and ICMJE.

IMAGE MANIPULATION POLICY

A. Definition*

Image manipulation is the misrepresentation of data by selectively altering portions of an image. The expectations for how images should be ethically handled are:

a. No specific feature within an image may be enhanced, obscured, moved, removed or introduced.
b. The grouping of images from different parts of the same gel, or from different gels, fields or exposures must be made explicit by the arrangement of the figure (e.g., using dividing lines) and in the text of the figure legend.
c. Adjustments of brightness, contrast or color balance are acceptable if they are applied to every pixel in the image and as long as they do not obscure, eliminate or misrepresent any information present in the original, including backgrounds. Non-linear adjustments (e.g., changes to gamma settings) must be disclosed in the figure legend.
*Language used with permission from The Journal of Cell Biology.

B. Process

The journals' graphics staff will screen images at random during the submission process and will review images that editors, reviewers or readers suspect have been manipulated. If manipulation is suspected, the staff and editors will initiate an investigation with the authors and possibly their institutions.

C. Sanctions

Should image manipulation be verified before or after publication of an article, one of the below sanctions will be applied, based on the severity of the infraction. The journal editor-in-chief and board of editors will determine, on a case-by-case basis, the severity of the infraction and corresponding sanction. Sanctions will be applied to individual authors depending on their type of involvement with the article, as provided at the time of submission on the title page.

a. A letter of explanation from the journal editors to the authors where there appears to be a genuine misunderstanding of principles.
b. A letter of reprimand from the journal editors as to future conduct.
c. A formal letter from the journal editors to the author's institution or employer.
d. Rejection or withdrawal of manuscript acceptance.
e. Publication of a correction or editorial.
f. Retraction of the published article.
g. Refusal to accept submissions from the author for a range of one-to-five years. For particularly egregious cases or series of cases, a life-time ban may be considered.

The AGA reserves the right, on a case-by-case basis, to report particularly egregious cases to the relevant funding bodies.

This policy was developed in accordance with the guidelines set forth by COPE.

OPEN ACCESS POLICIES

Compliance With Funders' Open Access Policies

CGH's publishing partner, Elsevier, has established agreements and developed policies to allow authors who publish in Elsevier journals to comply with manuscript archiving requirements of various funding bodies (for example, the National Institutes of Health), as specified as conditions of researcher grant awards. For a full list of funding bodies with which Elsevier has agreements, go to https://www.elsevier.com/about/publishing-guidelines/policies/funding-body-agreements. These agreements and policies enable authors to comply with their funding body's archiving policy without having to violate their publishing agreements with *CGH*. The agreements and policies are intended to support the needs of the Journal's authors, editors, and society publishing partners, and to protect the quality and integrity of the peer-review process.

Author-Sponsored Articles

CGH offers authors the option to sponsor immediate open access to their articles online at www.cghjournal.org and www.sciencedirect.com. Authors can elect to sponsor their article only after receiving notification that their article has been accepted for publication in *CGH*. The charge for article sponsorship is $3000, which is used to offset publishing costs of typesetting, tagging, and indexing of articles, hosting articles on dedicated servers, supporting sales and marketing costs to ensure global dissemination via www.cghjournal.org and www.sciencedirect.com, and permanently preserving the published journal article. The fee excludes taxes and other potential author fees such as submission, page fee, and color charges, which are additional. Authors who have had their article accepted and who wish to sponsor their article to make it immediately freely available should complete and submit the sponsored article order form. You will need your Elsevier Production Article Number to complete the form. You will receive this number via email once your accepted manuscript has been received and processed by the Elsevier team.

Open Issue Highlights and Archives

AGA supports free access to *CGH* on the broadest possible basis while adhering to a publishing model that is economically sustainable over a long horizon. To that end, for each issue of the Journal, several original research articles are identified by the Journal's editor as critical content for readers and thus are made immediately open access. Additionally, all content older than 12 months is free to all online. Also, many special sections of each new issue are immediately free to all online.

Manuscript Posting

Authors of articles published in *CGH* may voluntarily post their accepted manuscripts to personal websites or institutional repositories immediately upon acceptance.

INFORMATION ABOUT ARTICLE TYPES

Original Articles

Original Articles are full-length reports of original research and will be considered for either the Alimentary Tract or

Pancreas, Biliary Tract, and Liver sections of the Journal. Articles cover topics relevant to clinical studies in these areas of interest. They may discuss nutrition, morphology, physiology, pathophysiology, epidemiology, imaging, or therapy. Both adult and pediatric problems are included. To be published, the work presented in the manuscript must be original; on occasion, confirmatory studies of timely and important observations will also be acceptable. In addition, other considerations for evaluating the acceptability of a submitted manuscript include its importance, the soundness of the experimental design, the validity of the methods, the appropriateness of the conclusions, and the quality of presentation.

Original articles submitted to *CGH* cannot exceed 4,000 words including the figure and table legends, and references. No more than six figures and/or tables are permitted, though more may be included online as supplemental material. Each figure may have up to six panels (labeled A-F). The editor reserves the right to publish excessively long tables as online-only material. Your manuscript will be returned to you if it does not meet these criteria.

- **Manuscript:** only **Microsoft Word** documents will be accepted.
- **Title page**: title; authors' names; authors' institutions; corresponding author contact information; conflict of interest statement **(for all authors)**.
- **Word count:** **4,000 words** (inclusive of main text; references; table/figure legends).
- **Abstract:** 260 words, structured as follows: background and aims; methods; results; conclusion; 4-5 keywords.
- **Tables/Figures: 6 tables (no panels) and/or figures (up to 6 panels) total**.
- Please submit figures as **separate attachments** in **JPEG, TIFF, EPS,** or **PDF** formats (**300 PPI** resolution).
- **Randomized Controlled Trials:** Provide **CONSORT checklist** and **patient flowchart** as supplemental attachments.
- **Clinical Trials:**
- Provide the **clinical trial registry website and trial number** at the **end** of the "conclusions" section of the **abstract**.
- Include a statement in the **"methods" section** of the manuscript **affirming** that **"all authors had access to the study data and reviewed and approved the final manuscript**.
- Include the **clinical trial protocol in English** as a supplemental attachment.
- **Revised manuscripts:**
- **References:** please **list names of authors who share first authorship in bold** text. In addition, **include the phrase "Author names in bold designate shared co-first authorship" at the end of the references section**.
- **What You Need to Know:** This note will appear as a box on the second page of the published version of each article, containing summarizations about your study under the following 3 headings: **BACKGROUND, FINDINGS, IMPLICATIONS FOR PATIENT CARE**. Please provide **25-30 words** under each of these 3 headings that very briefly summarize your study in relation to each category.

Narrative Reviews Invited Only)

Narrative Reviews are invited reviews from experts in the field on a particular topic of interest to the CGH readership. These reviews are typically 6,000 words (references are included in this word count) in length and include a maximum combination of six tables and/or figures.

Systematic Reviews and Meta-analyses

Systematic Reviews and Meta-analyses are solicited and unsolicited manuscripts that feature an organized and detailed review of the scientific literature about a particular topic. This section is peer-reviewed and acceptance for publication is not guaranteed. The length must not exceed 6,000 words (references are included in this word count) and a maximum combination of six tables and/or figures can be included. For meta-analyses of randomized, controlled trials, authors must provide a CONSORT checklist at manuscript submission and follow the PRISMA reporting guidelines found here: http://prisma-statement.org/. For meta-analyses of observational studies, authors must follow the MOOSE reporting guidelines found here: http://www.editorialmanager.com/jognn/account/MOOSE.pdf. Your manuscript will be returned to you if it does not meet these criteria.

- **Manuscript:** only **Microsoft Word** documents will be accepted.
- **Title page:** title; authors' names; authors' institutions; corresponding author contact information; conflict of interest statement **(for all authors)**.
- **Word count: 6,000** words (inclusive of main text, references, and table/figure legends).
- **Abstract: 260** words, structured as follows: background and aims; methods; results; conclusion; 4-5 keywords.
- **Tables/Figures: 6 tables (no panels) and/or figures (up to 6 panels) total**.
- Please submit figures as **separate attachments** in **JPEG, TIFF, EPS,** or **PDF** formats (**300 PPI** resolution).
- **Randomized Controlled Trials:** Provide **CONSORT checklist** as a supplemental attachment.
- **Revised manuscripts:**
- **References:** please **list names of authors who share first authorship in bold** text. In addition, **include the phrase "Author names in bold designate shared co-first authorship" at the end of the references section**.
- **What You Need to Know:** This note will appear as a box on the second page of the published version of each article, containing summarizations about your study under the following 3 headings: **BACKGROUND, FINDINGS, IMPLICATIONS FOR PATIENT CARE**. Please provide **25-30 words** under each of these 3 headings that very briefly summarize your study in relation to each category.

Image of the Month

Image of the Month presents a striking clinical image(s) that is meant to challenge and inform the reader. Although priority will be given to exceptionally unique submissions, and those that are not similar to recently published cases; authors should be encouraged to present quality images of more commonly encountered diseases and conditions.

All submissions will be considered for both print and online-only publication. Any Image of the Month submissions that contains video alone will be limited to electronic publication only. Authors of Image of the Month submissions are not required to pay for color image reproduction. All submissions should contain no more than four (4) color or black and white images of 300 DPI resolution. Images should be accompanied by a Word document containing a brief description of no more than 200 words with no abstract, figure legends, or references. Submissions should not have more than 3 authors. The text should succinctly present relevant clinical information, including a short description of the patient's history, relevant findings, clinical course, response to treatment, and condition at last follow-up. Endoscopy images should be free of lettering, words, or numbering and associated pathology images should be included when appropriate. Image of the Month articles are indexed on PubMed. Your manuscript will be returned to you if it does not meet these criteria.

- **Manuscript:** only **Microsoft Word** documents will be accepted.
- **Title page:** title; **authors' names (limit of 3);** authors' institutions; corresponding author contact information; conflict of interest statement **(for all authors)**.
- Title should be declarative and succinct. Editors may modify the title according to journal style.
- **Word count: 200** words.
- **Abstract:** No abstract.
- **References:** No references.
- **Figures: 4 figures (no panels) total. No figure legends/image captions,** all pertinent information must be included in main text.
- Please submit figures as **separate attachments** in **JPEG, TIFF, EPS,** or **PDF** formats (**300 PPI** resolution).

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Letters to the Editor

Letters to the Editor offer opinions on papers published in *CGH*. Such correspondence is evaluated only for articles published within one month of submission of the letter (eg, for the January 2020 issue, letters submitted after February 29, 2020 will not be considered). Those letters deemed of interest to the Journal (typically less than 25% of those submitted) are sent to the authors of the original article for a response; the authors are given 2 weeks to reply. A decision will then be made whether to publish the letter with or without its reply.

Letter to the Editor submissions must not exceed 750 words, with no more than 8 references (not included in the word count). Original or unpublished data will not be considered. For the references, use the following format: Jones RS, et al. Clin Gastroenterol and Hepatol 2011; 2: 373 -380 (only first author is listed and article title is not included). The correspondence and the reply cannot include more than 3 authors each. All letters become the property of *CGH* and are subject to editing by the Journal. Letters are selected based on their relevance and originality. *CGH* will not publish letters commenting on manuscripts for which letters have already been published. Your manuscript will be returned to you if it does not meet these criteria.

- **Manuscript:** Only **Microsoft Word** documents will be accepted.
- **Title Page:** title; authors' names (**limit of 3**); authors' institutions; corresponding author contact information; conflict of interest statement (**for all authors**).
- **Word Count: 750** (includes main text only).
- **Abstract:** No abstract.
- **Tables/Figures: Not permitted**.
- **References:** Limited to **8**.
- Format: Jones RS, et al. Gastroenterology 2011;2:373-380 (only the first author is listed, unless manuscripts with joint first authors are cited, and article title is not included).
- **Must reference an article in press or an article appearing in the current issue at time of submission**. (e.g., a response to a January article must be submitted by the end of February).

Research Correspondence

Research Correspondence are concise and smaller scientific reports of original research studies. The format is as follows: no abstract, article text must not exceed 750 words (not including table, figure, or references) and 8 references and may include up to 1 table or figure. If needed, these may include 1-2 additional figures or tables as supplementary material, for describing results, and up to an additional 500 words of text for describing methods. The text cannot be used to provide additional results or discussion. These reports are not the same as a Letter to the Editor and must not duplicate other material published or submitted for publication. Research correspondence must be divided into the following sections: Introduction, Methods, Results, and Discussion, and all article titles should be declarative. Your manuscript will be returned to you if it does not meet these criteria.

- **Manuscript:** Only **Microsoft Word** documents will be accepted.
- Must be divided into following sections: **Introduction, Methods, Results,** and **Discussion**.
- **Title Page:** title; authors' names; authors' institutions; corresponding author contact information; conflict of interest statement (**for all authors**).
- **Word Count: 750** words (includes main text only).
- 500 additional words of text for describing methods may be included as supplementary material.
- **Abstract:** No abstract.
- **Tables/Figures/Videos: May include up to 1 table (no panels), figure (up to 6 panels), or video**.
- **1-2 additional figures or tables** for describing results may be included **as supplemental material**.
- Please submit figures as **separate attachments** in **JPEG, TIFF, EPS,** or **PDF** formats (**300 PPI** resolution).
- **References:** Limited to **8**.
- Format: Jones RS, et al. Gastroenterology 2011; 2: 373-380 (only the first author is listed, unless manuscripts with joint first authors are cited, and article title is not included).
- These reports are not the same as a Letter to the Editor and must not duplicate other material published or submitted for publication.

Continuing Medical Education (CME)

Selected issues of *CGH* will contain continuing medical education exams associated with articles that appear in the issue. AGA members can take the exams online free of charge. Non-AGA members are required to pay a $15 processing fee. Readers can claim 1.0 *AMA PRA Category 1 Credit*™ and 1 Maintenance of Certification (MOC) credit. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Successful completion of this CME activity, which includes participation in the evaluation component, enables the participant to earn up to 1 MOC point in the American Board of Internal Medicine's (ABIM) MOC program. Participants will earn MOC points equivalent to the amount of CME credits claimed for the activity. It is the AGA's responsibility to submit participant completion information to ACCME for the purpose of granting ABIM MOC credit.

SUBMISSION CHECKLIST

All manuscripts should be typed in 12-point font size and double-spaced and should contain the following sections in the order given below. All manuscripts submitted to *CGH* are made available for online review. Authors should submit their manuscripts, with figures and tables, electronically via our website, http://www.editorialmanager.com/cgh . Complete instructions for online submission are located on the website.

Cover Letter

CGH strongly encourages authors to suggest three to four referees (include their e-mail address, phone, and fax numbers) and the Associate Editor they believe best qualified to review their paper. Authors may also list a non-preferred Associate Editor and non-preferred referees, but the ultimate selection of an Associate Editor and referees is at the sole discretion of the Editor and Associate Editor, respectively. A list of our current Associate Editors can be found at http://www.cghjournal.org/content/board-of-editors.

State reasons for deviations, if any, from standard format and clarify any potential conflicts related to the exclusive nature of the publication. The cover letter must also categorize the manuscript into one of two groups: Alimentary Tract or Pancreas, Biliary Tract, and Liver.

Title Page

Title--Use no abbreviations. Limit: 120 characters including spaces. Must state the main finding of the study.

Short Title--Limit: 45 characters with spaces.

Authors--Include first names of all authors and name and full location of department and institution where work was performed.

Grant Support--List grant support and other assistance.

Abbreviations--List abbreviations alphabetically. (Note: In general, the use of abbreviations is discouraged.)

Correspondence--Provide name, complete address, e-mail address, and telephone number of corresponding author.

Disclosures--All authors must disclose any potential conflicts (financial, professional, or personal) that are relevant to the manuscript. If the author(s) has nothing to disclose, this must be stated.

Preprint server--If your manuscript is posted to a preprint server, you must indicate as such on the title page and include the DOI of the preprint.

Writing Assistance--The names and funding source for individuals who provided writing assistance must be listed.

Author Contributions--This information no longer needs to be included on the Title Page. Instead, the Corresponding Author will select from a list of roles for each co-author from CRediT Taxonomy. Detailed instructions can be found at https://www.editorialmanager.com/cgh when submitting a manuscript.

Corresponding Author Duties:

When submitting a manuscript, the Corresponding Author needs to contribute the following:

- Have an active account on editorialmanager.com/cgh with a current email address.

- Submit the manuscript with all of the steps.
- List a current email address for all co-authors, so they can confirm their roles and co-authorship for the paper.
- Respond promptly to all editorial correspondence.

Abstract

Abbreviations must be spelled out at least once. Do not use footnotes or references. Structured abstracts should be 260 words or less and include the following sections:

Background & Aims: Provide one-to-two sentences of background information to indicate why the study is interesting and important. Provide one sentence to state the main question addressed by the article.

Methods: Methods should include information on the following aspects of study design, when applicable.

- Design--describe the basic study design, e.g., randomized controlled trial, cross sectional study, cohort study, case series, survey, etc.
- Setting--specify whether the study was conducted in a primary or tertiary care setting, in an ambulatory care clinic or hospital, in the general community, etc.
- Participants--indicate the number of study subjects, how they were selected, what key features were included. What data were collected?
- Intervention--report the method of administration and duration of the intervention. Describe control groups and what methods were used to analyze the data.
- Describe main outcome measures.

For studies that are quality improvement (QI) related, authors must include a statement about IRB review. Authors must include one of the two statements: 1) This study received IRB approval, and include protocol number; or 2) This study was exempt from IRB review after institutional IRB review.

Results: Describe the main findings of the study, including confidence intervals or P values. Report the absolute values and risk differences so that readers can determine the absolute, as well as the relative, impact of the results. Please be consistent in reporting either number or percentage values.

Conclusions: State conclusions that are directly supported by the evidence and the implications of the findings. For clinical trials, state the clinical trial registration web site and number (e.g., ClinicalTrials.gov, Number NCT002209456).

Keywords

Include three-to-four keywords associated with your manuscript, separated by semicolons (e.g., active vitamin D; parathyroid hormone-related peptide; hypercalcemia; bone resorption).

The keywords should be terms not already included in the title or abstract. Should your manuscript be accepted, the keywords will appear with the published manuscript, making it easier to find in literature search engines such as PubMed.

What You Need to Know

All revised original research submissions (including Alimentary Tract articles; Pancreas, Biliary Tract, and Liver articles; and Systematic Reviews and Meta-analyses) must include text for a "What You Need to Know" box to appear on the second page of the published article. The text should include and relate to the following three headings:

- Background
- Findings
- Implications for patient care

Please provide 1-2 sentences (25-30 words) under each of these three headings that succinctly summarize your study in relation to each category. This text should not include nonstandard abbreviations. Please upload this content in a single Word document file, separate from other manuscript materials.

Body of paper

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13. Meltzer SJ, Ahnen DJ, Battifour H, et al. Protooncogene abnormalities in colon cancers and adenomatous polyps. Gastroenterology 1987;92:1174-1180.

Book:

18. Day RA. How to write and publish a scientific paper. Philadelphia: Institute for Scientific Information, 1979.

Article in Book:

22. Costa M, Furness JB, Llewellyn-Smith IF. Histochemistry of the enteric nervous system. In: Johnson LR, ed. Physiology of the gastrointestinal tract. Volume 1. 2nd ed. New York: Raven, 1987:1-40.

Dataset:

5. Oguro M, Imahiro S, Saito S, et al. Mortality data for Japanese oak wilt disease and surrounding forest compositions, Mendeley Data, v1; 2015. http://dx.doi.org/10.17632/xwj98nb39r.1.

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