Patients' Perspectives on Delayed Diagnosis of Inflammatory Bowel Disease: A Qualitative Analysis

A thesis presented in partial fulfillment of requirements for the degree of

Master of Arts
in
Psychology

At Massey University, Auckland, New Zealand

Hannah Dyson

February 2024

Abstract

Aotearoa has increasingly high levels of inflammatory bowel disease (IBD) but low rates of timely diagnosis. Despite this, the impacts of a diagnostic delay (DD) for a patient with IBD are poorly understood. It is necessary to investigate the IBD patient's perspectives on the barriers and impacts of their DD. Previous quantitative research has been conducted to assess the implications of a DD, but qualitative research investigating patient's perceptions is in its infancy. This study aimed to identify what diagnosed IBD patients consider the main barriers to diagnosis and the relevant impacts of DD. Understanding how a DD can contribute to various negative psychosocial impacts is essential. Ten participants with diagnosed IBD who felt they experienced a DD were interviewed to discuss their experience. Interviews were transcribed verbatim and analysed using Braun and Clarke's (2006) reflexive thematic analysis. Four themes were identified. A lack of IBD awareness and quality of care were considered significant contributors to delay. Psychosocial impacts of 'Alive, but not living' and 'Why so stressed?' were identified as participants' perceived emotional impacts of delay, including connecting feelings of helplessness, frustration and resentment towards the health system. The findings produce an incentive to raise IBD awareness and diagnostic procedures to reduce delay time, with recommendations to introduce a holistic model of care for individuals with IBD symptoms. Further research is required to understand how subjective, retrospective recall can influence participant responses, and understanding general practitioners' perspectives of delay is warranted.

Acknowledgements

I thank the incredible ten participants who signed up to share their experiences. Discussing this extremely personal topic can be challenging for many people, and I appreciated them sharing their insights and support for this research. The participants in this research displayed extreme enthusiasm for the subject and offered additional support following the interviews, which exceeded my expectations. I hope to make you all proud of my efforts and that my contributions are valuable to the IBD literature.

To my supervisors, Dr Don Baken and Dr Sarah Malthus, thank you for your feedback, encouragement, and guidance. You both had faith in me all the way through and were thorough in your discussions of decision-making and writing. I could not have done this without you, and I appreciate your time and effort so much.

I would also like to thank the Crohn’s and Colitis New Zealand Foundation for advertising my research poster. In less than 24 hours, I had an overwhelming response of interest for this research and would not have been able to achieve that without you. Thank you very much for your support.

Lastly, I would like to thank my friends and family, who offered continuous support throughout this process. I am very proud to be the first in the family to have a degree, so I hope that the achievement of completing my thesis has made you all proud, too.

Table of Contents

Table of Figures

List of Tables

List of Abbreviations

Abbreviation	**Definition**
IBD	Inflammatory Bowel Disease
DD	Diagnostic Delay
CD	Crohn’s Disease
IBS	Irritable Bowel Syndrome
GI	Gastrointestinal

Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signature: Hannah Dyson

Date: 18th February 2024

Inflammatory bowel diseases (IBD) are chronic relapsing functional gastrointestinal disorders with substantial healthcare costs, high morbidity and increasing incidence (D'Silva et al., 2022). IBD includes Crohn's disease (CD) and ulcerative colitis (UC), which are characterised by chronic inflammation or ulceration of the digestive tract (Lee et al., 2017). What causes the abnormal response of the body's immune system is currently unknown (Kahui et al., 2017). When active, IBD presents symptoms of diarrhoea, abdominal pain, and fatigue (Rogala et al., 2008). These often remitting and unpredictable symptoms profoundly impact a patient's quality of life. People with IBD have been found to report more significant psychological distress than people without IBD (Rogala et al., 2008).

IBD is a global disease with rising incidence rates across every continent (Nguyen et al., 2017). New Zealand has one of the highest rates of IBD in the world, comparable to that of Type 1 Diabetes (Kahui et al., 2017). The prevalence of IBD is expected to grow exponentially over the next decade, with an increasing incidence of young-onset IBD and a global ageing population (Nguyen et al., 2017).

Healthcare systems must develop efficient methods to diagnose and treat IBD to ease the growing disease burden. However, IBD is challenging to diagnose due to its long prodromal period and non-specific abdominal pain complaints that can be mistaken for irritable bowel syndrome (IBS) (Nguyen et al., 2017). Timely diagnosis of IBD is essential as early health interventions have been shown to improve outcomes (Nguyen et al., 2017).

Many factors (biological, genetic, and environmental) affect IBD's incidence, prognosis, and presentation. Further, researchers recognise that IBD is a physical condition where psychological well-being, specifically stress, can drive symptoms (De Sousa et al., 2022). Stress can impact human physiology, including activation of the sympathetic nervous system and intestinal permeability, which are related to the pathophysiology of IBD (Bernstein et al., 2016). Thus, examining how perceived stress can contribute to worsening symptoms in patients with IBD, driven explicitly by diagnostic delay (DD) (including frequent doctor's visits and inadequacy of symptom management), is helpful.

Unlike many modern diseases that are treatable through medications, lifestyle changes, or medical procedures, IBD stands out as a complex chronic disease that does not currently have a cure (Kahui et al., 2017). IBD requires comprehensive treatment strategies that are currently perceived by healthcare providers as ineffective in New Zealand (Kahui et al., 2017). Patient surveys indicate a need for more comprehension of symptoms and treatment options among GPs and health advisers, leading to one in five patients reporting a DD time that surpasses two years (Kahui et al., 2017). Despite IBD's prevalence being on par with Type 1 diabetes in New Zealand, inadequate knowledge among the public and health professionals results in significant and traumatic repercussions for DD affected individuals, highlighting the need for a greater understanding of the disease (Kahui et al., 2017). These negative implications of the disease extend to the burgeoning economic and psychological burden on New Zealand society, accentuating the importance of learning how to mitigate these impacts at both the individual and societal levels (Kahui et al., 2017).

Thus, by understanding the impact IBD has on individuals physically, psychologically, and socially – interventions and treatment can provide a comprehensive approach to care, mitigating the negative ramifications currently caused by a DD and lack of psychological care for IBD patients.

This literature review will define IBD and explore the literature on its prevalence, diagnostic criteria, symptomology, and pathophysiology. It will then examine the research on late diagnosis and the various psychosocial consequences of DD. Theoretical foundations and the historical context of IBD will be included to shape the argument that adopting a holistic model of care and raising IBD awareness will reduce delay times and the impacts of a DD.

Chapter 1: Literature Review

1.1: Epidemiology

Overview

Inflammatory bowel disease (IBD) is a collective term for a group of gastrointestinal diseases that can manifest into either Crohn's disease (CD), ulcerative colitis (UC) or inflammatory bowel disease undefined (IBDU) (Bunu et al., 2019). IBD is a chronic disease that is typically diagnosed from the age of 20 years to 40 years (Black et al., 2022). The complex pathogenesis of IBD leads to a chronic, relapsing, functional gastrointestinal disorder that is currently incurable (Kahui et al., 2017; Nistor et al., 2022).

A comprehensive physical examination and a review of the patient's medical history are required to diagnose IBD. Patients are asked about their symptoms, including diarrhoea with blood or mucus in the stool, abdominal pain, vomiting, weight loss, fistulas, perianal disease (for Crohn's disease) and fever (Kahui et al., 2017). Patients are also asked whether symptoms have reoccurred to identify previous flares of the disease and the duration of complaints. Then, internal diagnostic tests such as blood tests, stool examinations, biopsies, endoscopies, and other imaging methods are conducted to rule out other causes and confirm the diagnosis (Nistor et al., 2022).

The importance of timely diagnosis is highlighted in the National Institute for Health and Care Excellence (NICE) guidelines, which determine that "A delay in assessment and diagnosis can be associated with adverse consequences, such as clinical complications and a negative effect on the persons' quality of life" (National Institute for Health and Care Excellence: Guidelines, NICE, 2003). Timely diagnosis is also essential, as research indicates that delays in diagnosis for both CD and UC are associated with an increased risk of intestinal surgery (Cross et al., 2023). However, most research agrees that DD is common, with a significant variation in both the production of symptoms and the severity of the disease in IBD patients (Kahui et al., 2017; Nistor et al., 2022). Researchers agree that diagnosing the disease is complex, with the variation of symptoms often overlapping other gastrointestinal conditions (Lee et al., 2017).

IBD presents periods of active “flare-ups, " or increased inflammation and symptoms, with remission time in between. The unpredictable nature of the disease can have a profound impact on the patient’s psychosocial and physical well-being, including chronic debilitating symptoms, reduction in the ability to work and exercise, management of bathroom access, loss of career and personal goals, and dealing with social stigma – all of them associated with reduced quality of life (QoL) (Kahui et al., 2017; Popa et al., 2022). Further, the relapsing nature of IBD brings a substantial economic burden and high healthcare costs, with no effective long-term care options currently available (Lee et al., 2017).

Research has articulated that the rising incidence of IBD poses a grave concern for an emerging epidemic with no current sustainable long-term treatment methods (Nistor et al., 2022). Paired with the complex pathogenesis of IBD, the relapsing nature of the disease, and various clusters of symptom presentation (comparable to those of cancer patients), there is a fundamental need to understand the broader impacts of having a with IBD and its psychological effects (Nistor et al., 2022).

To understand the impact and extent of DD in IBD, it is crucial to identify the barriers to diagnosis and find ways to support the health system to improve these barriers. In doing so, it is also important to understand the perceived impact of a DD from a patient’s perspective, as this phenomenon is currently poorly understood. To date, there has only been one recent study on the perspectives of DD from patients with IBD. Therefore, this study aims to explore the perceived impacts of a DD in IBD patients.

Definitions, Diagnosis, and Intervention

Although IBD is an umbrella term for Crohn’s Disease and Ulcerative Colitis, the two are distinct. Both comprise chronic, relapsing disorders that are incurable. However, Crohn’s Disease is characterised by an inflammation of any section of the gastrointestinal tract (GI tract), whereas Ulcerative Colitis affects the mucosal layer of the colon and rectum (CSSANZ Foundation, 2006). Both diseases present with periods of remission followed by periods of acute flare. CD and UC experience similar symptoms, including abdominal pain, loose stools, diarrhoea, fatigue, anaemia, cramping, or weight loss (Oligschlaeger et al., 2019). Both diseases are currently considered incurable; thus, learning how to live with the disease successfully has been the focus of recent research (Oligschlaeger et al., 2019).

Crohn’s Disease

As seen in Table 1, CD is characterised by inflammation that predominately impacts the small or large bowel. The cause of CD remains unknown. This rare condition equally impacts males and females at the rate of 5 per 100,000, primarily adults between 25 and 65 years old (Torres et al., 2017). CD causes sporadic inflammation, leading to ulceration and constriction of the bowel lining, contributing to localised and general symptoms (CSSANZ Foundation, 2006). Bleeding can lead to anaemia, and abscesses can form in the bowel, sometimes rupturing into other organs and forming fistulas. Occasionally, watery discharge may be present. Bowel ulceration causes symptoms of diarrhoea and sometimes malnutrition (Torres et al., 2017).

CD is difficult to diagnose as CD mimics many gastrointestinal disorders, including IBS. Large bowel Crohn’s disease is primarily diagnosed through endoscopy (including a colonoscopy or flexible sigmoidoscopy) (Kahui et al., 2017). Occasionally, biopsy and barium enema x-rays can be used. There is no cure for CD. Medication is used to control inflammation. However, surgical intervention to remove parts or all of the colon is highly likely (Torres et al., 2017).

Table 1. Symptoms, Diagnosis and Treatment of Crohn's Disease (Adapted from Colorectal Surgical Society of Australia and New Zealand).

Symptoms	Diagnosis	Treatment
Chronic abdominal pain, diarrhoea, malaise, fever with acute exacerbations. Blood in stool (causing iron deficiency and anaemia). Localised abdominal pain by appendix. Mouth ulcers, Weight loss & fatigue.	Endoscopy (colonoscopy or flexible sigmoidoscopy). Biopsy and barium enema x-rays. Blood tests to determine the severity of illness. Sometimes impossible to distinguish between CD/UC.	No cure. Medication containing Prednisone Salazopyrine, antidiarrhoeal, antispasmodics, iron, nutritional supplements. Occasionally Immune suppressants like azothiaprine. High likelihood of surgery.

Ulcerative Colitis

Ulcerative colitis is a rare disease, affecting roughly 5 per 100,000 in the New Zealand population. The disease equally impacts males and females and can present symptoms at any age, particularly between of 20 and 40 (Yu & Rodriguez, 2017). UC is characterised by inflammation and ulceration of the bowel lining that causes episodic or continuous diarrhoea with blood and mucus in the stool (CSSANZ Foundation, 2006). Symptoms can include an urgent need to defecate with crampy lower abdominal pains. Symptoms can be mild but also so severe that people have bowel actions up to 30 times a day (Yu & Rodriguez, 2017). UC can be mild, where people feel normal, or so severe that people have a life-threatening episode.

As seen in Table 2, UC is diagnosed by identifying mucosa in the large bowel through a colonoscopy, where biopsies are taken. Like CD, UC can be confused with other gastrointestinal conditions such as IBS. UC cannot be diagnosed through blood tests (Kahui et al., 2017; Yu & Rodriguez, 2017).

Surgical interventions are not as likely for those with UC as they are with CD. However, surgical bowel removal is required for long-standing patients who can no longer control the symptoms and they are negatively impacting their lifestyle. Medications are available for people with UC, which include salazopyrine and sometimes anti-inflammatory drugs or immune suppressants (Kahui et al., 2017).

Table 2. Symptoms, Diagnosis and Treatment of Ulcerative Colitis (Adapted from Colorectal Surgical Society of Australia and New Zealand).

Symptoms	**Diagnosis**	**Treatment**
Episodic or continuous diarrhoea with blood and mucus. Urgency to defecate, with crampy lower abdominal pains. Symptoms can be mild-severe with up to 30 bowel actions occurring a day. May run a continuous or relapsing course.	Clinical picture & appearance of the large bowel mucosa at colonoscopy. Biopsies. No diagnostic blood tests.	No cure. Medication containing Salazopyrine or related drugs such as mesalazine are very effective. Anti-inflammatory drugs such as prednisone (cortisone) are necessary for local recal preparations or tablets. Immune suppressants like azothiaprine are sometimes needed. Iron tablets, antidian-hoeals and good nutrition all help. No cure for UC other than surgical removal of the large bowel.

	Biopsies look for potential malignant change (dysplasia) are undertaken at appropriate intervals in patients with longstanding disease.

Prevalence & Incidence of IBD in New Zealand

Over the past two decades, there has been a remarkable increase in interest in the prevalence (i.e., how common a condition is) of IBD in New Zealand, although prevalence studies remain limited. Before 2005, there were only three published studies on this topic. The first was in 1962, when authors used in-patient hospitalisation and national mortality records to estimate 5 or 6 non-specific ulcerative colitis cases per 100,000 per annum in those living in the Wellington and Christchurch region (Wigley & Maclaurin., 1962). The authors acknowledge that they could not record a definitive prevalence of UC in New Zealand at that time with limited resources (Wigley & Maclaurin., 1962). Research minimally progressed in the ’80s, where incidence rates (i.e., the number of new cases each year) were 5 to 4 per 10,000 Caucasians for UC and 1 to 75 per 100,000 for CD in the Auckland Region (Eason et al., 1982).

New Zealand’s predominant ethnic groups are indigenous Māori, European and Pasifika people. All research at this time documented a minimal rate of Polynesian or Māori in their sampling, partly because many prevalence studies were based in Christchurch with a minimal Māori and Pasifika population, having only 9.1% Māori in the Christchurch region at the time (Seleq et al., 2023). Similarly, health disparities have led Māori and Pasifika people to be less likely to access healthcare than European (Eason et al., 1982; Schlup et al., 1986; Seleq et al., 2023).

More recently, studies have demonstrated a high prevalence of Crohn’s Disease in Christchurch, with 16.6 per 100,000 in 2004, an incidence rate increase of 1.6-fold more than in the preceding decade (Su et al., 2016). This incidence was one of the highest reported in the world at that time. In the Waikato region, IBD prevalence rates were 375.6 per 100,000 in December 2019, compared to 293.6 per 100,000 in 2010, marking an increase of 27.9% in 10 years (Seleq et al., 2023). December 2019 studies estimated the IBD prevalence for Māori to be 61.4/100,000, a significant increase from previous years of research (Seleq et al., 2023).

Most research consistently reports the gender distribution as equal. However, in most cases, more females are diagnosed with IBD than males in all regions. Seleq and Colleagues (2023) reported a prevalence of IBD in women at 53.4% and males at 46.7% of all cases in the Waikato region. In contrast, Su and Colleagues (2016) reported more females with CD than the UC group (53% versus 50.7%) in the Canterbury region. However, this was not statistically significant. (Su et al., 2016). Across all studies, most diagnosed are between 20 and 54 years old, where diagnosis peaked at ages 20 to 24 (Su et al., 2016; Seleq et al., 2023; Sclup et al., 1986).

The Cost of IBD

Healthcare Cost Burden

As the prevalence of IBD rises, the economic burden of IBD will continue to impact patients, their families and social networks, the healthcare system, and the New Zealand economy and health as a whole. Despite this, there are few reports on the cost of IBD to New Zealand’s economy, with the latest report being in 2017 (Kahui et al., 2017).

In a 2017 report, reported hospital admission rates for IBD increased exponentially throughout 2001-2013. At this stage, the reasons for the increase are not clearly understood. These rates saw an increase in annual medication costs, including infliximab and iron (Kahui et al., 2017). In 2016, the total estimated cost of hospital admissions was $16.9 million for people with diagnosis-related issues, including treating IBD, colonoscopies, and bowel procedures. Importantly, the report highlighted that DD resulted in delays in accessing appropriate medical intervention (such as medications), leading to the need for more invasive treatment, such as surgeries. This illustrates the cost of DD for the patient and health system (Kahui et al., 2017).

Individual Cost Burden

As IBD is a chronic condition, the ramifications of the disease are lifelong. Although little data about the indirect costs of IBD is currently available, Kahui and Colleagues (2017) report the primary economic costs caused by IBD are from loss of work attendance and productivity and lost time in education due to patients and their networks seeking diagnosis, treatment, and adjusting to lifestyle changes (Kahui et al., 2017). As the patient seeks diagnosis, these costs are accelerated by late diagnosis and the psychological effects of DD (Kahui et al., 2017). Employment-related IBD indirect costs are estimated to reduce New Zealand’s GDP by approximately $160 million, and with high loss of productivity, up to $212 million in the future (CCNZ Survey, 2017). Absences are typically due to fatigue and recovery, pain, disease symptoms, surgery, hospitalisation, or caring for dependents.

Further, IBD-related loss of employment costs are estimated to be at $16 million per year due to people downgrading their employment status to cope with disease symptoms. These people are often forced to change career trajectories after excess absences. Some patients with IBD choose to reduce their work hours to reduce stress, a risk factor for disease symptoms (Kahui et al., 2017). Although data is not available in New Zealand, overseas studies have found that up to 20% of IBD patients in Europe end up on a disability pension, with a further 25% facing unemployment or reducing their employment hours (Kahui et al., 2017). These indirect costs create a negative cascade of impacts on the patient with a delayed diagnosis of IBD. For example, reduced employment contributes to welfare costs, future lost productivity, lost tax revenue, premature death, and other costs (Kahui et al., 2017).

Many people with IBD experience delayed diagnosis with drawn-out medical pathways, making having IBD an expensive disease for the individual and health system (Kahui et al., 2017). For many patients, the disease burden imposes a substantial personal cost. As IBD is a chronic disease with unpredictable symptoms, there is a need for expensive medications, surgery, and holistic healthcare required for the rest of the patient's life (Kahui et al., 2017).

In addition to medication, surgical, and frequent GP visit costs, IBD patients and the health system are burdened by transport and other expenses. The CCNZ 2017 report estimates that IBD patients and their caregivers spend an average of $1602 and $1945 per year on costs related to IBD, with the total estimated cost of IBD patients in New Zealand being between $33.3 million and $40.4 million per year (CCNZ Survey, 2017). Other direct costs include outpatient fees, emergency department, mental health, and private medical care costs, the estimations of which are not currently known. With the extensive financial burden on an individual with undiagnosed IBD, DD not only becomes a financial cost, but it also contributes to psychological and social costs as a result.

These culminating impacts of the disease require research to fulfil two main issues. The first is decreasing DD, and the second is understanding the impacts of having a DD to improve patient experiences, which includes understanding how a delayed diagnosis impacts an undiagnosed individual's quality of life.

Quality of Life

Despite the availability of surgical interventions and medications, people with IBD still deal with symptoms that may impact their quality of life, regardless of having a formal diagnosis (Knowles et al., 2018). Previous studies have consistently found that those with

IBD (including UC and CD) have markedly reduced health-related quality of life compared to healthy individuals. (Larsson et al., 2017). This reduced quality of life reflects concerns about social isolation, lack of energy and control, and knowledge about the disease (Kahui et al., 2017; Larsson et al., 2017).

Alongside the financial and economic burden of having the IBD, these previously mentioned costs will impact a patient's quality of life. In New Zealand, 46% of patients state that IBD has impacted their earning potential and ability to participate in recreational activities and intimate relationships (Kahui et al., 2017). A patient's quality of life was also assessed concerning disease management and care. 50% of patients feel they can get to specialist appointments in adequate time, whereas 22% feel they cannot access help when needed (Kahui et al., 2017). Further, satisfaction with the New Zealand health system was assessed, where almost a third of patients felt dissatisfied. Only 1 in 3 patients felt that the time taken for diagnosis was adequate (Kahui et al., 2017).

These figures illustrate the need for a clear imperative to address the standard of care for people with IBD in New Zealand. Additionally, supporting patients with symptoms who are awaiting a diagnosis is crucial.

Current IBD Treatment Model

Most individuals in New Zealand experiencing IBD symptoms initially consult their general practitioner (GP). Of these patients, 24% present to the GP in a month or less after initial symptoms, whereas 21% take more than two years (Kahui et al., 2017). Patient surveys have also reported that frequent GP visits are costly. Unfortunately, many patients only receive a formal diagnosis after presenting to the emergency department with severe symptoms requiring higher-level care (Kahui et al., 2017).

Research has also found that among GPs, IBD is poorly understood. GPs' inadequate understanding of IBD directly contributes to delayed diagnosis, increasing testing costs and direct costs to the patient and health system (Kahui et al., 2017). Importantly, while 24% of patients present to the GP within a month of having symptoms, a significant portion – over 35%, face a delayed diagnosis of longer than a year. Shockingly, 1 in 5 respondents report their diagnosis took more than two years (Kahui et al., 2017).

Consequently, the current IBD treatment model has been deemed inadequate. Given the increasing cost burden of DD, responses to IBD need to be improved. DD qualifies as a key contributor to the cost burden on individuals with IBD and the New Zealand health system. This provokes a vital investigation into the barriers to an IBD diagnosis and understanding the impacts of a delayed diagnosis from a patient's perspective.

Further, the issue of delayed diagnosis has been partly attributed to a lack of IBD understanding among patients and GPs. New Zealand has one of the highest rates of IBD in the world, yet it is a disease that is not well understood, meaning our national level of care for those with IBD is not comparable with other countries (Kahui et al., 2017). New Zealand's IBD care model has been described as reactive rather than proactive, where patients are often waiting a long time for diagnosis and becoming greater disease burdens than they would be with a prompt diagnosis. Resultingly, individuals manifest various negative impacts, including increased stress, neglected symptom management, and reduced quality of life (Kahui et al., 2017).

Summary

Consistently, all studies detailing the prevalence of IBD in New Zealand convey a shared message: successfully treating IBD requires efficient and accurate diagnoses. To do so, understanding the impacts of delay and barriers to diagnosis are essential (Sclup et al., Seleq et al., 2023; 1986; Su et al., 2016). The burden of IBD, including morbidity on patients and families, the healthcare system and the community will continue to grow and contribute to the growing healthcare system demands in the coming years (Su et al., 2016). Despite New

Zealand having one of the highest global rates of IBD, there are few detailed reports about the prevalence, aetiology, and support of IBD in New Zealand (Kahui et al., 2016). New Zealand still needs an effective management plan for IBD and cannot currently provide equitable, patient-centred treatment to those who need it (Kahui et al., 2016).

Therefore, it is vital that research endeavours to understand IBD as a disease and learn the impacts of a DD on patients. In doing so, understanding the critical models of health that currently help healthcare professionals understand IBD are required. By understanding IBD through a psychosocial lens, treatments can be directed to decreasing patient suffering.

1.2: Understanding IBD Through a Psychological Lens

Biopsychosocial Model of Health

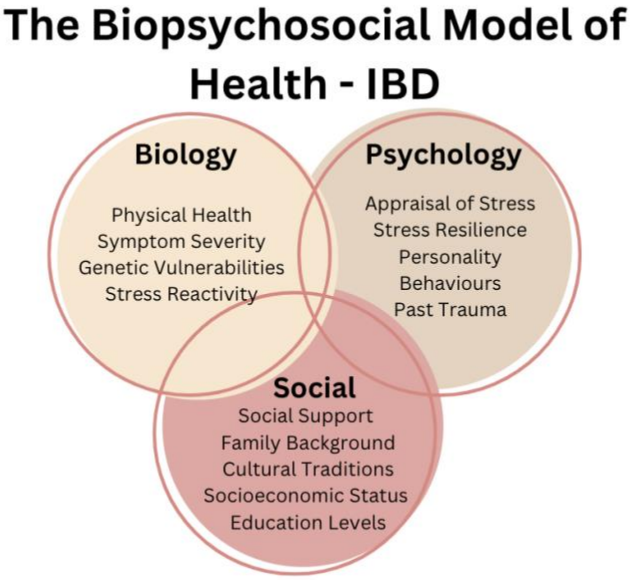
To comprehensively understand diseases and their aetiology, researchers and healthcare professionals must understand their physiological consequences. In the last decades, researchers and professionals have focused on diseases' biological elements (e.g., symptomology, pathogenesis, and treatment efficacy) using the Biomedical Model of Health (Dent et al., 2022). However, there has been a shift of orientation from the Biomedical Model, as critics argue that this is a reductionist approach to understanding disease, which neglects to explore the social and psychological aspects required for a holistic understanding of IBD (Dent et al., 2022). More recently, the importance of a diseases’ psychological and social components has been acknowledged in the literature (Dent et al., 2022). The biopsychosocial model of health has become a fundamental framework in this area of research.

Conceptualised by George Engel in 1977, the biopsychosocial model proposes that medical conditions are a product of biological, psychological, and social factors (Engel, 1977). Thus, the biopsychosocial model focuses on the biological and physiological pathology of the individual; the “psycho” variable, including thoughts, emotions, and behaviours such as psychological distress, fear and avoidance beliefs, current coping methods, and attribution. The “social” aspect focuses on the socio-economical, socio-environmental, and cultural factors (including work issues, family circumstances, benefits, economics, and support) that may contribute to the manifestation and nature of the disease (Engel, 1977). By understanding these factors, the disease can be understood through an individual’s lens. This avoids classing disease experience as universal to those who suffer from it (Dent et al., 2022; Popa et al., 2022).

Initially, IBD was considered a psychosomatic disease involving physical symptoms that lacked a medical explanation (Popa et al., 2022). People with these conditions often have excessive concerns about the disease, which hinders the individual's ability to function well. Now classed as an organic disease (or functional: referring to a physical change in an organ or body part), researchers acknowledge that psychological disturbances can increase the severity of IBD, including increased flare-ups and symptom severity (Popa et al., 2022).

Most importantly, Dent and Colleague's (2022) scoping review highlighted that although research has acknowledged the presence of psychosocial impacts on those with IBD, current robust biological treatments and interventions are based on the biomedical model (Dent et al., 2022). The existing literature implies that psychological impacts are currently considered secondary outcomes of IBD, thus commanding the need for research to view psychosocial impacts as primary outcomes considering the biopsychosocial model (Dent et al., 2022). This limitation has led to an obligation to explore the experience of IBD using the currently favoured model, the biopsychosocial model of health, to understand how patients deal with IBD through a psychosocial lens.

Figure 1. The Biopsychosocial Model of Health Relative to Inflammatory Bowel Disease (Adapted from Engel, 1977)



Psychosocial Factors in IBD

Research on gastrointestinal tract diseases such as IBD and IBS (irritable bowel syndrome) has predominantly focused on the biological impact of the disease, including symptomology and treatment efficacy (Dent et al., 2021). Comparatively, fewer studies have analysed the psychosocial impacts of having the disease, which provide insight into the lived experience and impact of GI conditions (Dent et al., 2021).

There is a body of qualitative literature that recognises that IBD can lead to many psychosocial and physical impacts that can be debilitating for the patient (Muse, Johnson & David., 2021). When IBD is active, patients are particularly impacted by the physical symptoms of IBD, which can harm their psychological and social well-being (Richard et al., 2020). Patients may also experience an increased prevalence of internalising disorders (such as depression and anxiety), social isolation, and lack of support, leading to impaired interpersonal relationships, and report a lower quality of life than the general population (Black et al., 2022; Muse et al., 2021). However, the exact nature of these relationships is yet to be determined due to the lack of prospective designs, and lack of investigation from a patient’s perspective (Black et al., 2022).

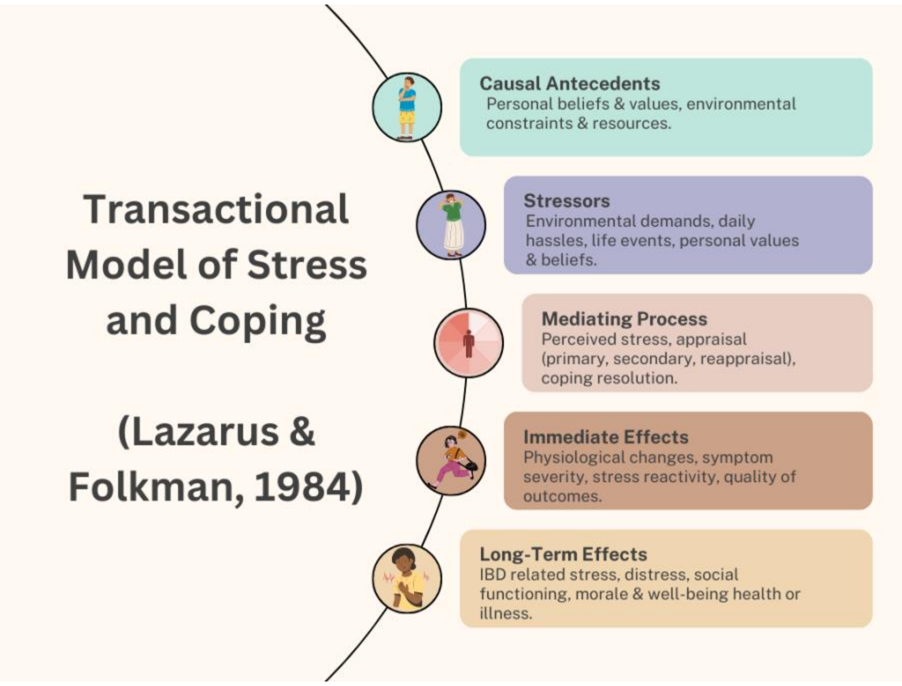
Patients often report their physical symptoms are worse when they feel anxious or depressed. This corroborates the long-standing theory that stress (experienced directly by having IBD or indirectly by the challenges IBD places on individuals) exacerbates the adversity of having the disease or having symptoms with no disease to attribute them to (Muse et al., 2021). Thus, having a comprehensive understanding of the psychological impacts of IBD is pivotal to the success of future intervention and treatment plans. In doing so, researchers must first understand the theoretical assumptions behind a disease's psychological impacts, particularly how people cope with the stress and adversity of a disease.

Transactional Model of Stress and Coping

Lazarus and Folkman (1984) define stress as “a relationship between the person and the environment that the person appraises as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, p.19). This relationship between an individual and stress is a varied interaction informed by environmental antecedents, the nature of the stressors, and the appraisal that follows this situation to predict long-term effects (Lazarus & Folkman, 1984). Thus, the *Transactional Model of Stress and Coping* by Lazarus and Folkman was created. The model denotes that a person’s ability to cope with adversity is a product of interactions between the person and the environment. The model divides stress appraisal into primary and secondary phases (Laubmeier, Zakowski & Blair., 2004). The primary appraisal stage is when one evaluates a situation to decide whether it will bring possible harm or gain. If it is considered harmful, it becomes psychologically dangerous. When this occurs, a secondary appraisal is activated, where an individual decides whether they can cope by examining the balance of situational demands (such as risk, uncertainty, etc) (Laubmeier, Zakowski & Blair., 2004).

It is possible that when an individual is diagnosed with a disease such as IBD, they can explain and, therefore, cope with any risk and uncertainty that comes with having the disease, as they have a definite cause for their symptoms. In contrast, those who have not been diagnosed with IBD and cannot identify their symptoms with a disease may experience dissonance and, consequently, an increase in stress that may outweigh rational thinking. According to the model, coping strategies become more emotionally charged and thus less negatively appraised if the individual cannot contribute their symptoms to a cause (Laubmeier, Zakowski & Blair., 2004). According to this hypothesis, increasing the likelihood of an individual being diagnosed with IBD will be beneficial to help explain their symptoms.

Figure 2. Transactional Model of Stress and Coping Relative to IBD (Lazarus & Folkman, 1984).



Stress

To capture the patient's experience with IBD, it is crucial to understand core contributors to the patient experience, such as stress. Researchers and healthcare professionals have extensively studied and discussed stress' impact on chronic diseases and daily life. The World Health Organisation (WHO) defines stress as "a state of worry or mental tension caused by a difficult situation." (World Health Organisation, 2023). Although everybody experiences stress, the way stress is dealt with is the key determinant of well-being in many people. The infamous "Yerkes-Dodson Law Bell Curve" argues that a small amount of stress (or "arousal") increases attention and interest, causing an increase in strong performance levels. A small amount of stress also collates an optimal arousal and performance level. However, excessive stress (or arousal) deteriorates overall performance (World Health Organisation, 2023). As excessive stress is frequently seen in people with

IBD, there is a crucial need to understand and reduce stress levels to reduce the negative impacts of IBD (Richard et al., 2020).

The Gut-Brain Axis

Scientists for several years have debated the role of stress in inflammation, particularly in IBD (Maunder & Levenstein, 2008). All types of stress alter the gut-brain axis and contribute to gastrointestinal diseases, including IBD (Brzozowski et al., 2016). As IBD distinctively alters gut and intestinal tract inflammation, a core reason to investigate stress in these diseases is the bidirectional influence between the gut and the brain, otherwise known as the gut/brain axis. The gut/brain axis is the direct or indirect communication via the central and enteric nervous system and host innate system, which affects the gut microbiota between the gut and the brain (Oligschlaeger et al., 2019). Stress impacts many aspects of human physiology, including activating the sympathetic nervous system and releasing proinflammatory mediators. It affects intestinal permeability, all of which are associated with the pathophysiology of IBD (Bernstein et al., 2016). Despite this, the implications of an individual's stress experience and its effect on disease activity are complex.

Stress and IBD

Stress is "a process in which environmental demands tax or exceed the adaptive capacity of an organism, resulting in psychological and biological changes that may place persons at risk for disease" (Cohen et al., 1997, p. 3). Humans experience many stressors, such as significant life events, traumatic experiences, and daily hassles. The level of stress experienced from these experiences are usually subjective and difficult to quantify (Maunder and Levenstein, 2008). However, research into stress and IBD primarily focuses on the lived experience of having symptoms, managing workload, and coping with everyday life tasks (Richard et al., 2020).

For example, a qualitative thematic analysis found that the main stressors for IBD participants included managing work-related stress, where most participants reported feeling forced to make significant life adjustments (such as changing or leaving their employment status) to decrease stress (Richard et al., 2020). Other stressors included access to specialist appointments and publicly coping with symptoms that may be deemed embarrassing or inconvenient (Richard et al., 2020). These findings corroborate recent research, which suggested that embarrassment and access to appointments contributed to delayed help-seeking behaviours and receiving appropriate treatment (Cross et al., 2023). Therefore, it is appropriate for research to further investigate what IBD patients perceive as other possible barriers to diagnosis.

Many authors have examined the association between stress and IBD symptoms, finding that psychological stress can exacerbate IBD symptoms for many diagnosed patients, contributing to a worsening quality of life and increased perceived symptom severity (De Sousa et al., 2022). Stress has been associated with relapses in patients with IBD, including those individuals who are more exposed to stressful life events, were found to have a higher rate of relapse (De Sousa et al., 2022). In a United States sample, stress was higher among women, the unemployed, young adults and those with lower education and income levels (Bernstein et al., 2016). Importantly, evidence suggests that reducing stress in patients helped their remission from IBD, which infers that reducing stress will assist with reducing symptoms in undiagnosed patients (De Sousa et al., 2022).

Importantly, some research suggests that despite the difficulty of having a chronic condition, participants adopted a positive outlook on life after adjusting to their diagnosis and gaining control of their symptoms (Richard et al., 2020; Kemp et al., 2012). Although IBD patients deal with debilitating symptoms, gaining control and acceptance was crucial to improving their quality of life. In qualitative studies, patients reported feelings of resilience and strength after accepting their disease and maintaining normality, and this finding is replicated in other studies (Kemp et al., 2012; Lenti et al., 2020). This knowledge highlights the importance of having a formal diagnosis and being taught the appropriate coping strategies to deal with the ramifications of IBD.

Perceived Stress and IBD Symptom Activity

The impact stress has on the gut-brain axis is a core reason why stress is strongly correlated with symptom severity in IBD patients. Many studies have found that stress (impacted by diet, environmental, or neuroendocrine factors) can adversely affect the gut, microbiota, and brain axis, contributing to worsened symptom severity in IBD patients (Oligschlaeger et al., 2019).

As mentioned, people experiencing the same stressors may react to stress in varying ways, highlighting that stress resilience and perception are key determinants of physical outcomes (Oligschlaeger et al., 2019). Analogous to the biopsychosocial model, research has established that those experiencing IBD symptoms are likely to experience higher perceived stress. In an IBD context, perceived stress relates to the person's beliefs about the level of controllability, manageability, and psychological impact of their symptoms. Research has indicated that perceived stress is associated with present IBD symptoms and periods of remission (Targownik et al., 2015; Popa et al., 2022).

It is hypothesised that psychological and physical symptoms are related due to a perceived negativity towards worsened states, disease awareness, and feelings of incurability (Popa et al., 2022). Long-term perceived stress may be due to unfavourable symptoms of IBD, such as fatigue, loss of bowel control or dependency on care from others. These symptoms may lead to harmful professional or familial disruptions, loss of self-esteem, and the burden of lifetime treatment and social isolation and stigma, causing an exacerbation of psychological symptoms (Popa et al., 2022). Importantly, the perceived stress that results from having IBD is subjective, as the negative appraisal of stressors can heighten an individual’s perceived stress (Popa et al., 2022).

Thus, understanding how an IBD patient forms their perception of stress before a diagnosis will provide an understanding of how a DD can impact an individual’s stress levels and its relation to other psychological and physical impacts of delay. In doing so, treatment methods can successfully aspire to reduce stress for those who are undiagnosed.

Schulman-Green Model of Self-Management

IBD, a chronic condition, demands ongoing and lifelong self-care, influencing adverse health outcomes such as symptom severity, absenteeism, and hospital admissions (Peters & Brown, 2022). The self-management of IBD includes medication adherence to alleviate symptoms (such as abdominal pain, fatigue, diarrhoea and anaemia) and treating adverse side effects of clinical treatments (Peters & Brown, 2022). Recent research has found that those living with IBD encounter a range of adverse psychological effects, including low levels of self-esteem, emotional turmoil, identity loss and difficulties fulfilling identity roles (Popa et al., 2022; Peters & Brown, 2022; Melinder et al., 2017).

Tragically, IBD's turbulent and unpredictable nature means that even when in remission, IBD will continue to impact a patient's quality of life (Knowles et al., 2018). Despite these challenges, existing self-management approaches concentrate on dietary changes, managing symptoms, and medication adherence, side-lining the crucial psychological well-being of the individual (Peters & Brown, 2022).

As the body of evidence favouring the biopsychosocial model expands, research increasingly reveals IBD's lived reality as a self-management of psychosocial factors rather than spending extensive time with a clinician (Peters & Brown, 2022). “Self-management” is defined as “the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions” (Richard & Shea., 2011, p. 261).

In response, the Schulman-Green Model of Self-Management emerged, aiming to explain the strategies individuals use to manage a chronic illness (Schulman-Green et al., 2012). By analysing a meta-synthesis of 49 chronic illnesses, using both qualitative and quantitative data, researchers identified three categories of self-management processes; (1) attending to illness needs; (2) activating resources; and (3) adapting to the challenges of living with a chronic condition (Schulman-Green et al., 2012). The first process: attending to illness needs – refers to traditional self-management strategies, including behavioural and learning strategies (Schulman-Green et al., 2012). The second process: activating resources – identifies and utilises the individual's psychological, social, and spiritual assets (Schulman-Green et al., 2012). The final process: adapting to the challenges of living with a chronic illness – involves making meaning, emotional processing, and acceptance of the ‘new self’ and illness identity (Schulman-Green et al., 2012).

The model demonstrates that self-management processes are a spectrum of unique and flexible approaches that vary among individuals (Schulman-Green et al., 2012). Recognising self-management is essential in this context as it can impact an individual’s perception of stressors. As undiagnosed individuals are not able to activate their resources and attend to illness needs as well as those who are diagnosed, introducing this model is essential when understanding the impact of delay.

By recognising that self-management approaches will differ between patients, healthcare providers should continuously communicate with patients to formulate appropriate self-management plans. Plans should identify the psychosocial consequences of DD for patients instead of focusing on medical adherence (Schulman-Green et al., 2012). However, the model needs some explanatory details. Understanding how a delayed diagnosis may impact self-management abilities and thus the perception of stressors is required.

So, What Factor of Stress is Most Important?

With an established association between stress and IBD and evidence that stress affects patients physically and emotionally, it is important to acknowledge the role of a diagnosis in how it may help people cope with stress or their management of symptoms. Few studies have investigated whether a prompt diagnosis promotes a better management of IBD symptoms, which may in turn decrease negative psychological, physical, and social impacts from a patient's perspective. Therefore, I propose four key questions that address how stress is related to IBD.

Does Stress Manifest IBD?

First, it is possible stress can contribute to the manifestation of IBD. Research has shown that psychological stress is a risk factor for increased IBD risk in adulthood, which can be reduced if detected (De Sousa et al., 2022; Melinder et al., 2017). Psychosocial stress was said to impair intestinal barrier integrity, provoking inflammation and disease (Melinder et al., 2017). Studies have ascertained that the HPA axis plays a significant role in stress and subsequent intestinal disease, accelerating the production of inflammatory cytokines in several diseases (Ge et al., 2022). However, the role of a diagnosis and managing this stress is uncertain. From this perspective, gaining an understanding of how stress is related to symptom severity is important, as those with delayed diagnoses may experience enduring stress, which could worsen the physiological symptoms of IBD. Further, understanding the role of stress may assist healthcare workers with identifying IBD in patients who have suffered significant stress, as it may be likely that those who have suffered chronic stress are more likely to have IBD.

Does a Diagnosis Cause Stress?

Conversely, individuals may feel stressed knowing they have a chronic diagnosis like IBD. In a longitudinal study, people with IBD's perception of their poor physical health was identified as a significant source of stress compared to healthy individuals. This finding is corroborated by other research (Rogala et al., 2008; Lee et al., 2017; Vavricka et al., 2012; Melinder et al., 2017). This means that to some people, acquiring an IBD diagnosis may be distressing for some people, which may lead to worsened psychosocial outcomes.

However, in studies of people's experiences with chronic diseases other than IBD, a prompt diagnosis helped individuals with psychological adjustment, have an adequate work status and increased overall satisfaction and well-being (Ridder et al., 2008). This is important, as if this is apparent in people with IBD, a prompt diagnosis would mean that people can adjust to their condition earlier, which would reduce the negative psychological, social, and physical impacts that a delayed diagnosis may otherwise exacerbate (Ridder et al., 2008). Importantly, participants in this research found that changing their perception of health, adjusting their priorities, or finding benefits in having a chronic disease reduced the disease burden (Ridder et al., 2008). In doing so, we can argue that although some people may feel overwhelmed by having a chronic disease diagnosis, gaining a prompt IBD diagnosis would give patients a better opportunity to maintain positive well-being, participation in their careers, and overall satisfaction.

Despite this, the impact of a delayed diagnosis has not yet been investigated. It is unclear whether a prompt diagnosis can reduce these psychosocial impacts. Thus further investigation is warranted.

Does a Lack of Diagnosis Cause Stress?

Research has found that having ongoing IBD symptoms that are not yet explained by a diagnosis is a potential psychosocial stressor. The extent of this stress period has not been well explained by research (Bernstein et al., 2016). Although having a chronic disease diagnosis induces a higher level of stress in some patients, a diagnosis of IBD may also provide alleviation from stress, explaining their symptoms (Rogala et al., 2008). Some research has found that those with diagnosed IBD reported a lower stress level than the community sample, which may be explained by a relief from having a diagnosis and perhaps a lower expectation for quality of life (Rogala et al., 2008). This area of research is not well-informed; therefore, researching the impact of a lack of diagnosis on patients is imperative.

Does a Diagnostic Delay Cause Stress?

Finally, many people experiencing IBD symptoms may have a poor quality of life and they cannot explain their symptoms with a diagnosis (Nguyen et al., 2017). This is known as DD, a prevalent issue in those with IBD. Although DD is well-researched in other conditions, including cancer, endometriosis, celiac, and diabetes (Nguyen et al., 2017; Goy et al., 2009), the IBD literature is in its infancy (Cross et al., 2023; Miles et al., 2017).

The literature has shown that many people with IBD symptoms experience significant limitations in their ability to perform daily activities, career tasks, and participation in social events (Cross et al., 2023). These impacts have been associated with an increased stress, decreased emotional well-being, and reduced quality of life (Cross et al., 2023). Resultingly, gaining earlier control of physical IBD symptoms should mean that people can engage in daily activities and social events without inhibition, increasing their overall well-being. However, many people require a diagnosis to gain control over their symptoms through medication and lifestyle changes (Miles et al., 2017). By this reason, a delayed diagnosis may exacerbate the negative psychosocial impacts that come with having IBD symptoms.

1.3: Diagnostic Delay and IBD

What is Diagnostic Delay?

Diagnostic delay (DD) is defined as the period between the onset of symptoms (or first likely symptoms) to a formal diagnosis by a gastroenterologist, inclusive of the time a patient took to consult healthcare services to the time of formal diagnosis (Nahon et al., 2014; Nguyen et al., 2017).

Across various research, early diagnosis has been associated with improved health outcomes (Miles et al., 2017; Khalilipour et al., 2019). Consequently, various health initiatives have been established to try and reduce DD among patients and physicians. However, there has been little research on the psychological consequences of DD in IBD (Miles et al., 2017).

Characterising Diagnostic Delay

Individuals diagnosed with IBD often have a variable duration of symptoms before diagnosis, known as DD. However, quantifying a DD is complex for researchers, and researchers tend to have various interpretations of what qualifies as a “diagnostic delay”.

For example, some research has split DD into three subtypes: patient-associated delay, parent-associated delay (for children) and healthcare-associated delay (Khalilipour et al., 2022; Vavricka et al., 2012). They argued that delay should be quantified by the time elapsed from self-reported symptom onset to the first visit to a healthcare professional (patient-associated delay). Second, a “pre-specialist delay” is related to health physicians wrongly attributing the symptoms to other illnesses, not conceiving the severity of the symptoms, or due to a lack of diagnostic resources (Vavricka et al., 2012; Khalilipour et al., 2022). In doing so, physicians such as GPs may take more time to refer patients to specialists. This self-reported time interval has been brought together to create a “healthcare-associated delay”, which refers to the time from the first physician visit to formal IBD diagnosis. They also counted the number of in-person visits to a healthcare professional with issues relating to IBD symptoms and hospital visits, phone calls and emails to healthcare services for analysis (Khalilipour et al., 2022; Vavricka et al., 2012). These researchers calculated DD as a cumulative score, totalling the average time (in months) from the first self-reported symptom onset to formal diagnosis for analysis. The shared limitations of these studies included the potentially biased participant recall of delay and possible selection bias, as participants who feel strongly about DD may be more likely to participate; thus, searching clinical records was a strength to mitigate these factors (Khalilipour et al., 2022; Vavricka et al., 2012).

In contrast, other studies have focused on the participant's perceived DD, such as Miles and Colleagues (2017), who interviewed cancer patients to assess whether perceived DD was associated with distress. Researchers asked participants, "Do you think your cancer could have been diagnosed sooner than it was?". Response options included 'yes', 'not sure' and 'no'. These answers were converted into an ordinal variable for analysis (Miles et al., 2017). They found that perceived DD remained a significant predictor for cancer-related distress and fear of cancer recurrence. The study was limited in that current stress levels and quality of life may negatively influence participants' retrospective judgements about delay; however, other research has shown that fear of cancer recurrence was not related to the tendency to infer delay based on current distress (Miles et al., 2017). This type of research models how the impacts of a DD on IBD patients may be assessed, using retrospective recall to highlight the participant's subjective experience of delay and disease-related stress.

Despite the various methods for quantifying a DD, the core caveats of creating a specific "time" to be considered a delay remain. First, asking participants about their DD requires unreliable retrospective memory recall and involves gaining access to medical data (Miles et al., 2017). Thus, investigating a perceived DD is more valuable for the present study for several reasons. DD is a subjective term that may be appraised differently between individuals, where some may perceive delay as longer than others. It is likely that even when people have varying times of DD, the psychological impact may be the same (Miles et al., 2017). Second, the researcher cannot rely on recall to create a quantifiable DD. Asking for retrospective memory recall threatens the study's reliability as there is a higher likelihood of errors (Khalilipour et al., 2022).

Third, DD is difficult to quantify as although there are ideal times for diagnosis; there is no consensus in the research that a disease should be diagnosed within a particular time frame (Khalilipour et al., 2022; Vavricka et al., 2012; Miles et al., 2017). Although early diagnosis is ideal, the present study will focus on the *perceived* DD to assess the subjective psychological impacts.

Diagnostic Delay in IBD

Research has consistently shown that with the current reactive model of care in New Zealand, the diagnostic process is commonly drawn out for those with IBD. Researchers persistently argue that the longer the diagnostic process takes, the worse outcomes the patient will experience in their psychosocial health, contributing to an economic cost burden (Kahui et al., 2017). Due to inequity in the health system, patients are commonly diagnosed after presenting to the emergency department with severe symptoms, where they are then referred and diagnosed by a gastroenterologist (Kahui et al., 2017). As the diagnosis arrives when individuals are experiencing severe symptoms, they require a higher level of care (Kahui et al., 2017). Without a change in current treatment methods, the negative impact of a DD will remain.

Despite this, diagnosing IBD is arguably a considerable challenge (Vavricka et al., 2012). In New Zealand, diagnosis of IBD is slow, and many individuals are likely suffering from IBD without being aware of their condition (Kahui et al., 2017). Many studies have found a substantial DD (both healthcare, patient, and parent-associated delay) in individuals, particularly those in geographic areas that lack substantial access to healthcare (i.e. rural areas or low socioeconomic status areas where specialists' accessibility is low) (Khalilipour et al., 2022).

Some studies have reported that the median DD period in patients with UC was four months, shorter than in patients with CD (Lee et al., 2017). Other studies found that only 26% of patients were diagnosed with Crohn's disease after experiencing gastrointestinal symptoms for over two years (Nguyen et al., 2017).

Most importantly, the variable presentation of symptoms in IBD makes the disease complex to diagnose. The aetiology of IBD is unclear but is typically characterised by persistent gastrointestinal symptoms, including haematochezia, abdominal pain, and diarrhoea (Khalilipour et al., 2022). However, many patients present with atypical symptoms such as extraintestinal manifestations and anaemia, making timely diagnosis complex (Khalilipour et al., 2022).

In New Zealand, referrals from general practitioners to gastroenterologists are limited, increasing the time interval from the first physician visit to diagnosis by a gastroenterologist (Vavricka et al., 2012). This issue is particularly prominent for those with more significant barriers to healthcare services, such as those in rural communities, areas with lower socioeconomic status, and so on (Kahui et al., 2017). As IBD symptoms are similar to IBS, this likely is one of the prominent reasons for DD. Researchers aim to reduce this delay by creating more effective health initiatives to make IBD a more manageable diagnosis, yet further research is required (Vavricka et al., 2012).

Barriers to Diagnosis

Health Literacy in New Zealand

Studies have reported that knowledge of IBD in New Zealand is low, particularly for those who have yet to attain a university degree or complete high school (Vernon-Roberts, Gearry & Day., 2020). The importance of health literacy has been outlined in various studies, whereby poor IBD awareness has been significantly associated with poorer health outcomes, increased DD, and a reduction in contact between patients and healthcare services (Colombara et al., 2001; Khalilipour et al., 2022). Health literacy is the extent to which individuals have an adequate capacity to understand basic health information required to make appropriate health decisions, such as visiting a physician (Tormey et al., 2016).

As IBD is a chronic condition that requires those with it to make complex health decisions, IBD awareness (from both patients and healthcare professionals) plays a fundamental role in patients’ success and reducing DD (Tormey et al., 2016). Patients with poor health literacy may need help understanding the importance of screening tests and reporting IBD symptoms due to the lack of understanding of the condition or urgency for care. Poor health literacy has been associated with those who experience barriers to care, such as healthcare services and communication, and thus, worse health outcomes for those with chronic disease (Tormey et al., 2016). Health services must recognise poor health literacy in their practice and strive to create an equitable level of health literacy for the population to improve health outcomes (Tormey et al., 2016). Doing so requires more training, education, and support for healthcare providers to support those with poor health literacy and thus who are unlikely to have IBD awareness (Tormey et al., 2016).

Patient Awareness of IBD

Patients with IBD symptoms should be able to identify concerns and seek appropriate healthcare, communicate concerns surrounding worsening symptoms, correctly interpret medication instructions, and understand information to prevent or improve their condition (Tormey et al., 2016). Notably, the population should be able to educate and monitor each other to help those with poor IBD awareness raise their symptoms with physicians (such as children, intellectually disabled, and so forth) to DD (Tormey et al., 2016). Therefore, having an ‘awareness’ of IBD includes the patient being able to identify their symptoms as problematic and having the means to use help-seeking behaviour to report their symptoms to a physician, which will reduce DD time.

Currently, the literature has primarily explored patient perspectives on IBD symptoms and treatment following a diagnosis, neglecting to examine the patient experience pre-diagnosis, which may help researchers and healthcare professionals understand how to reduce patient-related DD. For example, a recent systematic view analysed patient perspectives and expectations in IBD but only reviewed perspectives from the time of diagnosis (Khoury et al., 2022). As patients can be a significant contributor to DD, it is essential to raise the question: *How can patient awareness of IBD be a barrier to diagnosis?*

Comparisons can be drawn from qualitative research regarding other bowel-related conditions to create a context for the IBD literature. A study that assessed the barriers and facilitators to a colorectal cancer diagnosis measured the patient help-seeking and symptom appraisal delay interval from the patient-reported symptom onset to presentation to a GP or emergency admission. For example, colorectal cancer has patient, physician, and health system delays as key factors to DD, with similar symptoms that are subject to stigmatisation and misdiagnosis (Blackmore et al., 2020). With low disease awareness, participants normalised their symptoms and were less likely to contact a health physician or GP, which has been replicated in a recent IBD study (Blackmore et al., 2020; Cross et al., 2023).

Participants were less likely to consult a physician when symptoms could be attributed to a change of routine, stress, dietary change, haemorrhoids, and other causes (Blackmore et al., 2020). However, when participants perceived symptoms as abnormal, including excessive bleeding from the bowel, immediate help-seeking was facilitated (Blackmore et al., 2020). A recent IBD study also found that when symptoms indicated serious illnesses, participants held a reluctance to visit the GP out of fear (Cross et al., 2023).

This research is important to examine as disease awareness was a key determinant of help-seeking behaviours in colorectal cancer (Blackmore et al., 2020). In summary, the authors concluded that the nature of symptoms and disease awareness were barriers to diagnosis, prompting the requirement of further investigation of the influence of IBD awareness in this research. Although health literacy is important, the participant's appraisal of symptoms was considered an important factor in a DD (Blackmore et al., 2020; Cross et al., 2023). Therefore, further research is required to understand how patients perceive their symptoms and how this perception contributes to DD in IBD patients.

Healthcare Awareness of IBD

A report by Kahui, Snively & Ternent (2017) outlined that IBD is primarily understood by medical professionals, including GPs, national health planners, and district health boards. However, low levels of education for IBD, coupled with associated stigma and lack of public awareness, are critical contributors to DD, resulting in a substantial economic burden for healthcare ($245 million per annum in 2016) with broader social costs, including a loss in productivity (Kahui et al., 2017; Richard et al., 2011). Unsurprisingly, psychological consequences are often due to the stigmatisation of the disease, increasing the time taken to diagnose patients with IBD and, therefore, increasing healthcare costs (Kahui et al., 2017). Despite this, the healthcare awareness of IBD is poorly understood.

A recent qualitative study assessed patient views on contributors to DD in IBD. The study found that participants were further delayed when seeking healthcare advice for their symptoms as symptoms were mislabelled for other conditions such as gastroenteritis and IBS (Cross et al., 2023). These participants felt that GPs did not take their symptoms seriously and delayed referring them for further investigations. Additionally, GPs were reported to express uncertainty to patients, saying, “I don’t know what’s happening” (Cross et al., 2023). The study concluded that the misunderstanding of IBD symptoms was due to poor awareness of IBD in the healthcare community. To solve this, they suggested that education and training for health professionals for the symptoms of IBD, particularly for differentiating between IBS and IBD symptoms (Cross et al., 2023). To the author’s knowledge, this was the first exploratory study of patient perceptions of DD in IBD. Further, this study was conducted in the United Kingdom, so similar concepts of healthcare awareness must be assessed in an Aotearoa context.

By nature, IBD is an invisible disease whereby patients do not appear outwardly sick to those around them and is a stigmatised disease due to a poor level of public knowledge of IBD and its symptoms (Vernon-Roberts, Gearry & Day., 2022). Therefore, it is important to have effective methods of identifying symptoms early and ensuring the patients get adequate care and attention when they present to healthcare services. It is equally important to have a community-based awareness of IBD so that individuals can identify symptoms early and their surrounding social circles can encourage them to seek help when required.

Outcomes of Perceived Diagnostic Delay

Having a diagnosis of a chronic disease like IBD is distressing for patients. However, the psychological impact of the disease may likely be worse if the patient believes the diagnosis was delayed (Miles et al., 2017). Prolonged DD contributes to the patient's ongoing disease burden, which may lead to worse disease and treatment outcomes and lasting psychological and physical damage (Khalilipour et al., 2022). Further, DD can contribute to a growing burden on the health system, contributing to an increasing number of intra-abdominal surgeries and the rate of hospitalisation (Lee et al., 2017). Early control of inflammation with immunosuppressive or biological agents improved the outcome of newly diagnosed patients with IBD, emphasising the importance of early treatment following diagnosis (Lee et al., 2017).

Lee and Colleagues (2017) retrospectively investigated the factors contributing to diagnostic delay and the outcomes of IBD. The results showed that diagnostic delay was associated with poorer outcomes than those diagnosed early, particularly an increased intestinal surgery risk in patients with CD and UC, proving the urgency for IBD patients to be diagnosed early and managed suitably (Lee et al., 2017).

Little research so far assesses stress between the onset of symptoms and diagnosis. However, it can be assumed that the DD period contributes to an exacerbation of stress in individuals, given that individuals have no distinctive explanation for their symptoms. The Transactional Model of Stress supports this.

Thematic Analysis of Diagnostic Delay in IBD

So far, few studies have used thematic analysis to investigate the impacts of DD in those with IBD. However, as with other diseases, research increasingly recognises that having a chronic disease has both biological and psychological outcomes. By shifting to a qualitative method of inquiry, researchers can understand the lived experience of participants and gain insight into the experience of having a DD, providing a more in-depth understanding of the quantitative methods alone (Richard et al., 2011).

Previous thematic analyses on IBD have primarily focused on psychosocial variables such as individuals' perceptions of their IBD experience. For example, a thematic analysis of the experience of self-conscious emotions in IBD established that analogous to the assumptions provoked by the Schulman Green model of self-management, a "lack of control" and "lack of understanding" were crucial determinants of negative emotions for participants (Robertson et al., 2022). The authors identified that a lack of control centred on the patient's desire to have a disease-free identity, reporting an increase in fear and anxiety when the disease is considered out of control or when it impacts other people in their lives (Robertson et al., 2022). Further, participants reported higher humiliation and resentment. They perceived unfair treatment due to a lack of understanding from others, supporting the idea that education and awareness are crucial in helping those with IBD (Robertston et al., 2022). These findings are consistent with previous research, which found that patients' psychological troubles stem from invisible aspects of the disease, including having a desire for control, a fear of incontinence and threats to social status (Kemp et al., 2012; de Ridder et al., 2008).

Another thematic analysis of patient experiences of DD in IBD discovered that although patients initially reported feelings of embarrassment, delaying their initial help-seeking phase, participants experienced a further delay as GPs had either not taken their symptoms seriously, misdiagnosed them, or mislabelled symptoms (Cross et al., 2023). Participants believed their DD was also due to systemic factors, including lack of access to communication and test results across primary and secondary care; many participants believed these factors believed their DDs led to poorer clinical outcomes (Cross et al., 2023). This study informs my research by providing a basis to study this topic in New Zealand participants, considering New Zealand's health system, IBD awareness, and patient experiences.

With this knowledge, further investigation is required using thematic analysis to determine the lived experience of a patient who has experienced a DD, including the pre-diagnosis and post-diagnosis period. Research has yet to establish how these emotions manifest when people cannot attribute their feelings or symptoms to a diagnosis and how a DD has impacted their emotions and symptom severity.

1.4: Rationale for the Present Study

Overview

Experiencing DD represents a global issue for IBD patients. Although DD research in New Zealand is in its infancy, the literature reports that New Zealand patients with IBD often suffer for many years before they receive a formal diagnosis (Kahui et al., 2017; Khalilipour et al., 2022). As early diagnosis is associated with better health outcomes, considering ways to reduce the clinical impact of IBD is imperative. The literature demonstrates that a proactive model of care is crucial (Kahui et al., 2017).

To develop effective proactive models of care, it is vital to understand a patient’s perspective of how a perceived DD impacts their life through a psychological lens. By understanding patient perceptions towards a delayed diagnosis, patients may identify unique barriers to diagnosis at the individual, healthcare, and societal levels, contributing to the impacts of their condition and management (Cross et al., 2023). Having these understandings may provide a context to support patients and healthcare providers in helping to reduce DD time and the psychosocial impacts of delay for IBD patients. This would assist health providers to tailor management plans to be suitable for individuals who have experienced an IBD DD and to help reduce these delays in the future.

Introducing a proactive model of care using the biopsychosocial model would include regular monitoring by health professionals to keep patients educated, supported, and motivated to comply with treatments will also help them psychologically (Kahui et al., 2017). Having sufficient context and understanding of people with IBD pre-diagnosis is essential to do this. By doing this, the psychological benefits will prevail by keeping patients and healthcare providers engaged with shaping IBD education and treatment methods. They may also help identify patients who require additional psychological support.

Rationale for Present Study

To date, only one study in the qualitative literature concerning participant perceptions of the impacts of a DD in those with IBD has been conducted. Prior research on IBD has largely been quantitative, identifying a clear association between a DD and increased stress levels and symptom severity. However, quantitative studies cannot account for the lived experience of a DD like qualitative methods can. A qualitative method can provide novel insights regarding the experience of having a DD, including the psychological and physical impacts of the delay. Analysing the lived experience of DD through conversational interviews will encourage researchers and health professionals to understand the complexities of having an IBD DD. This study may be important in shaping a holistic support model that may improve patient care for those with symptoms of IBD and those diagnosed with IBD. For example, having patient perspectives on the main barriers to diagnosis may help healthcare providers change management plans and symptom identification processes. Further, understanding how a DD impacts people with IBD psychosocially may help identify those in need of additional psychological or symptom management support—potentially influencing greater health outcomes.

The Present Investigation

The evidence suggests that a delayed diagnosis can contribute to worse health outcomes (both physically and psychologically) in individuals, culminating in a more significant disease burden on health services. Minimal qualitative research has been conducted in this area, particularly assessing New Zealand patients and their perceived experience of DD. Our questions about DD must be assessed in a New Zealand sample, given our unique cultural environment compared to other Western countries and the increasing incidence of disease. The objective is to understand the patient’s perspective of a DD and how this has impacted their life.

Research Questions

In this research, the following research questions will be posed:

1. What do people with IBD perceive as the main barriers to diagnosis?
2. What are the impacts of having a diagnostic delay on those diagnosed with IBD?

Based on previous research, I hypothesise that low levels of IBD awareness among GPs and IBD patients will be a significant barrier to diagnosis. I also hypothesise that those who have experienced a DD will experience various psychosocial impacts, including increased feelings of stress, withdrawal from social and career activities, and poor well-being due to not being able to manage their symptoms.

Research Aims and Objectives

The primary aim of this research is to examine people's experiences of a perceived DD and the relevant impacts of a DD in those with IBD. Although the literature has previously established that DD is prevalent in those with IBD, causing a worsening of symptoms severity and stress levels, little was researched from the patient's perspective. Thus, this research aimed to investigate the subjective experience of a DD instead of an objective delay and its consequential impacts.

The objectives of this research are to:

1. Understand the experience of a perceived DD in those diagnosed with IBD.
2. Determine how a DD can affect an individual's psychosocial well-being.
3. Explore potential contributing factors to a DD, given the participant's subjective experience.

Chapter 2: Assumptions, Objectives and Methodology

Before conducting this research, I must address my philosophical, ontological, and epistemological assumptions. In qualitative research, the assumptions and biases I bring into this research influence how I view and analyse my research. Making these theoretical underpinnings and assumptions explicit ensures I am critical and reflexive towards my analysis and explain the context and logic behind my choice of methodologies and analysis. My assumptions influence my epistemological position for this research, which informs my theoretical framework (Crotty, 1998).

Assumptions & Researcher Description

In traditional psychological science, understanding phenomena is derived from direct observations, argued to be unbiased and not influenced by the researcher's or participant's opinions (Chamberlain, 2015; Crotty, 1998). This objective approach to discovering information means that research should be ‘replicable’ and ‘valid’, so positivism is considered unbiased. In traditional psychology, the researcher’s assumptions are often ignored (Franklin & Ballan, 2001).

However, from a constructionist view, meaning is derived between the researcher and the participant, driven by contextual influences such as language, background, and current opinions (Conrad & Barker, 2010). To understand my position in the research, I need to address the position I hold in society: A New Zealand Pākehā woman completing her master’s degree who has IBS and experienced a DD. My interpretation of participant interactions is influenced by my societal position, shaping the meaning, while my background and assumptions impact the perceived reality in these interactions (Chamberlain, 2015).

According to Crotty (1998), the theory and methodology researchers choose and, thus, their assumptions influence our conclusions. These assumptions must be made explicit to be challenged and reflexive (Chamberlain, 2015). I am aware I cannot enter this research without bringing my own biases; I am conducting this research because I have a genuine interest in the impact of DDs and bring my own experience to this thesis.

During my late high school years, I experienced symptoms of anxiety and depression because of a toxic relationship, which coincided with the beginning of my IBS symptoms. Although unaware at the time, I was experiencing the well-established association between stress and symptom severity, a prevalent topic in health psychology research (De Sousa et al., 2022). Further, I realised I have an intrinsic desire to problem-solve. I enjoy finding solutions and consider myself an intuitive person. I wanted to understand behaviour and experiences and find solutions when interacting with others. From this experience, I was fascinated with wanting to understand human behaviour, thus prompting my interest in psychology and, therefore, studying psychology at university.

After years of assuming my symptoms were typical, I became frustrated with my reality and started visiting the doctor about my symptoms. My symptoms varied from gastrointestinal issues to skin dermatitis, chronic fatigue, and hair loss. Despite visiting the doctor multiple times a year with persistent issues, I was frustratingly told that I was ‘fine’ because my blood count was in normal range, and no further investigations were conducted. It took years of persistence and demands to be sent to a gastroenterologist, who conducted a flexible sigmoidoscopy and determined that I had IBS, not IBD – and I was subsequently sent to a dietician for review.

This delay period, coupled with my intrinsic problem-solving nature, triggered angst and frustration. I spent years having symptoms with no explanation and no means to fix them. Before my diagnosis, I was left feeling like my symptoms were inevitable, and I was helpless in solving them. My social circle was aware of my condition but always encouraged the idea that I was perhaps intolerant to food, or maybe my gut just reacted this way. These opinions are related to how gastrointestinal symptoms related to IBS and IBD are often stigmatised in society and the medical field, and those with these diseases experience not only the physical symptoms but also the negative social ramifications of having a gastrointestinal disorder (Popa et al., 2022). This led me to assume that those with IBD may resonate with this experience.

Drawing from these encounters, I inferred that individuals undergoing a diagnostic delay akin to mine would likely experience the same adverse emotions. This inference forms the basis of the assumptions in this research that those without a diagnosis may experience a heightened level of stress and symptom severity compared to those with a diagnosis or without symptoms.

During my academic career, I became fascinated with health psychology and wanted to understand how illness was perceived through a psychological lens. In a health psychology paper I took, I learned about the biomedical model of health and how, previously, illness was narrowly perceived as a biological, physical realm, and past research on chronic diseases such as IBD reflected this interpretation (Dent et al., 2022). However, the more current perspective that illness is a product of biological, psychological, and social interactions, using the biopsychosocial model, resonated with my experience (Popa et al., 2022). Having personal experience with a chronic condition, I understood that psychological and social impacts were closely related to having a physical condition and carried that belief to this research (Dent et al., 2022).

The theoretical lens for this study was further enhanced when learning about the social construction of illness by Conrad & Barker (2010). The theory denotes that the biased experience of some medical conditions results from socially constructed social and medical knowledge, reflecting inequalities of race, gender, ethnicity, and class. These constructs cover the socially constructed experience of illness, medical understanding of illness, and the cultural meaning of illness (Conrad & Barker, 2010). This theory holds great significance in the context of discussing stigmatised diseases like IBD, since gastrointestinal disorders are not as well-known as diseases like cancer and diabetes (Wright et al., 2020). My background reading and personal experience influenced the research question I formulated for this project on perceived DD rather than an objective and quantifiable measure of delay. This decision was based on my belief that the psychological impacts of delay are subjective experiences that cannot be measured in a standardised way (Melinder et al., 2017). Since I hold a social constructionism view, I decided to conduct a qualitative study to explore this topic. This way, I could gain a deeper understanding of people's experiences and perspectives on the issue.

My chosen method of Braun and Clarke’s (2006) reflexive thematic analysis acknowledges the researcher’s role in knowledge generation, utilising deductive reasoning to acknowledge my assumptions. My experience, education, skills, and opinions define who I am, and I recognise that I bring biases into the research (Braun & Clarke, 2006; Crotty, 1998). My experience has prompted my desire to research this topic and shape the methodologies.

Epistemological Position

The knowledge that I bring and subsequently draw from this research comes from the epistemological position of social constructionism. Constructionism is an epistemological view that truth or meanings exist due to our engagement with the world (Conrad & Barker, 2010). Despite experiencing the same phenomenon (in this case, having a chronic disease and a DD), individuals generate meaning differently depending on context, cultural, and social influences (Crotty, 1998). Specifically, social constructionism is the approach that different people and groups derive meaning from social phenomena by constructing their perceived reality, a dynamic process constructed by language, culture, and society – with no objective or universal validity (Conrad & Barker, 2010).

In this study, knowledge is generated from the interaction between the researcher and the participant (Crotty, 1998). Instead of meaning being objectively observed, truth occurs within the social setting (Crotty, 1998). Therefore, having a constructionism epistemology will inform my chosen theoretical perspective for this research: the social construction of illness (Conrad & Barker, 2010). The theory denotes that people's experiences with some medical conditions result from a socially constructed meaning embedded in them. The cultural meaning of illness is crucial to research due to the a lack of research based on the lived experience of the impact of a DD in IBD patients from a psychosocial lens (Cross et al., 2023; Melinder et al., 2017; Peters & Brown, 2022).

Methodology

This research involved ethical considerations, recruitment, interview questions, data collection, transcription and analysis. Semi-structured Zoom interviews were conducted to assess the participant's perspectives on the impacts of a DD for those diagnosed with IBD. The thematic analysis method was used to collate and code data, with a social constructionist approach to inquiry – generating meaning between the researcher and the participant.

Data Collection

Participants

Participants were given participant numbers to remove their identifiable features and experiences to ensure privacy. Specific places they named, including workplaces, places of living, and names mentioned, were removed to ensure identifiable features are not acknowledged.

Demographics

As seen in Table 3, ten participants were recruited for this study. Per Braun and Clarke's (2022) recommendation, approximately 15 participants are optimal for qualitative research. In this study, 10 participants were chosen given the time constraints for a one-year master's project while including enough participants for a quality study.

For this sample, the group comprised eight (80%) females and two (20%) males aged 23-56 with a mean of 38.5 years (*SD* = 12.57). Four participants (40%) were diagnosed with Crohn's disease, and six (60%) were diagnosed with Ulcerative Colitis. Diagnosis age varied from ages 18 to 53, with a mean of 31.5 years (*SD* = 13.73). Country of origin was mixed, where six (60%) participants were born in New Zealand, one (10%) born in Malaysia, one (10%) in England, one (10%) in Spain, and one (10%) in Australia. Most participants were of New Zealand European/ Pākehā ethnicity (60%), whereas one was Malaysian (10%), one Hispanic (10%) and one Australian/European (10%). Most participants (70%) come from urban living, whereas three (30%) come from rural backgrounds. The delay period (self-reported approximate time of first symptoms to diagnosis) varied between 6 months to 30 years, with a mean delay time of 8.93 years (*SD* = 9.92). Regardless of place of birth, all participants reside and receive treatment in New Zealand.

Table 3. Participant Demographics

ID	Gender	Age in years (age diagnosed)	Country of Origin	Ethnicity	Rural/Urban	Diagnosis	Delay Period (approx.)
1	F	53 (51)	Malaysia	Malaysian	Urban	UC	4 years
2	F	23 (18)	England	NZ European	Urban	UC	6 months
3	M	25 (20)	New Zealand	NZ European	Urban	CD	3 years
4	F	38 (30)	Spain	Hispanic	Urban	UC	3 years
5	M	54 (48)	New Zealand	NZ European	Urban	UC	30 years
6	F	39 (27)	New Zealand	NZ European	Urban	UC	7 years
7	F	56 (53)	New Zealand	NZ European	Rural	UC	23 years
8	F	24 (24)	New Zealand	NZ European	Rural	CD	7 years
9	F	33 (24)	New Zealand	NZ European	Urban	CD	11 years
10	F	40 (20)	Australia	Australian/European	Rural	CD	9-10 months

Researcher-Participant Relationship

As most participants were recruited through online advertisement, there were no pre-existing relationships between participants and the researcher except for one participant. One participant is a friend of the researcher who expressed interest in participating in the study when it was mentioned in conversation. To avoid coercion, the researcher ensured she knew that participation would be entirely voluntary and could find participants elsewhere if she did not want to participate. When approached about the study, the researcher did so via email instead of face-to-face to ensure that she felt comfortable declining if she wanted to do so.

The benefits of having a participant with a pre-existing relationship were that she may have felt more comfortable sharing her personal story with the researcher, providing more details that other participants may not have felt comfortable sharing with a stranger (Berger, 2015). Further, I also knew her employment area in the healthcare system, so I could ask further questions related to her knowledge that benefitted the research. However, it is also possible that knowing this participant may have hindered her confidence (Berger, 2015). To prevent this, I ensured that our conversation was entirely confidential and I would not share with mutual friends that she was a participant in my study. During the interview, she willingly shared intimate details of her story, so having this prior relationship did not impact the research negatively.

For all other participants, I shared my experience with having IBS and why I wanted to conduct this research. I articulated that I do not have IBD and, therefore, have not had the same experience as them. This was important to disclose to ensure that participants knew there were no expectations of answers.

Recruitment

Potential participants were recruited via organisations such as *Crohn's and Colitis New Zealand*, who had their own Facebook page and were willing to share my research poster, instantly giving access to those diagnosed with CD and UC. Crohn's and Colitis New Zealand are a nationally recognised organisation for IBD patients that operates in 13 regions throughout New Zealand (CCNZ, September 23). The charity offers support through education and participation in fundraising for those with IBD, so the support from this charity was invaluable in advertising the research. I provided an email address so I could be contacted directly. This advertisement was beneficial because it can reach a large target audience from various geographical areas in New Zealand. Facebook was favoured over poster placement for this reason. Many potential participants showed interest in participating within 48 hours of Crohn's and Colitis NZ advertising my poster. Participants were then chosen on a first-in, first-served basis.

The research poster (See Appendix A) included the statement "Do you have Crohn's Disease or Ulcerative Colitis?" with te reo Māori translation, "Kei a koe mate whēkau pauku/ Mate kōpiro nui?" Followed by the statement, "Do you feel you waited a long time to be diagnosed?" It was also stated that the researcher is seeking participants to "Discuss their experience and views on having either Crohn's Disease or Ulcerative Colitis, and the diagnostic process and related impacts of the disease" to ensure the participants had an idea about the study. The eligibility criteria were included.

The poster offered participants a $30 supermarket voucher as compensation for their time. $30 was chosen as a suitable compensation to ensure that it wasn't enough for participants to feel compelled to participate due to financial reasons and not too little to ensure they were adequately appreciated. The poster advertisement included te reo Māori to be inclusive of Māori participants. Participants contacted the researcher via an email address advertised on the poster. All participants who finished the interview stage were included in the final results.

Participant Selection

Participants needed a supporting device and internet connection to conduct the interview. The eligibility criteria for this study included those 18 years or older. Participants being over 18 was a criterion because previous literature found that participants under 18 were under parental care and thus were covered by paediatric medical care. For various reasons, including children in this study may have introduced biases due to autonomy and accessibility and may introduce confounding variables to the research (Khalilipour et al., 2022). The literature review, therefore, focused on adults with IBD to ensure consistency.

A second inclusion criterion was for those with a formal diagnosis of IBD, including either Crohn’s Disease or Ulcerative Colitis. It was decided to exclude other forms of IBD, inclusive of IBDU (Inflammatory Bowel Disease Unclassified), diverticulitis, indeterminate colitis, and others, to maintain consistency in the sample and ensure that participants had a definite diagnosis of IBD. A profound level of past research specifically focuses on Crohn’s Disease and Ulcerative Colitis (Cross et al., 2023). Thus, limiting the literature review and subsequent research to these two branches of IBD was appropriate.

A third criterion of the study was including those fluent in English communication and who must live in New Zealand. Fluent English communication is vital in a qualitative interview for transcription and comprehension purposes. Participants were required to understand the questions and convey their thoughts fluently, with the researcher able to comprehend and thus transcribe their words accurately to analyse the data’s themes. Participants were required to live in New Zealand to explain the DD in a New Zealand context, discussing health system factors that would not be relevant in other countries.

The final criterion of the study was including those who felt they waited a long time to be diagnosed, as in, feel they could have been diagnosed sooner. The central investigation of this research is to understand the complexities of having a diagnostic delay and how this experience may impact patients. As this study aims to understand a perceived diagnostic delay, there was no required delay time frame. Quantifying a diagnostic delay is problematic for various reasons. First, creating a threshold of diagnostic delay may exclude participants who still feel they have waited a long time (Miles et al., 2017). Second, environmental, geographical, social, and cultural factors may contribute to differing diagnostic delay times (Khalilipour et al., 2022). I assumed that even if diagnostic delay times differ between participants, the emotional impacts remain the same if people perceive they have experienced a delay. Thus, it was most important to this research to include participants who felt their diagnosis was delayed, regardless of the time frame.

Materials

The interview process was facilitated using a topic guide, seen in Appendix B, to provide structure and direction. The interviews were conducted and audio recorded via Zoom, an online conference platform that uses audio and video to communicate over the Internet. Participants needed a supporting device and internet connection to participate.

Procedure

Following the study advertisement on social media pages, participants emailed the researcher. Upon contact, participants were emailed the participant information sheet (Appendix C) and the study's aim, inclusion and exclusion criteria, and participant rights (Appendix D*)*. If participants were eligible for the study, they were asked to read and sign the consent form (Appendix E). Participants then emailed Hannah the signed consent forms. The consent forms included a section where participants could "tick" whether they wanted their transcripts returned to them after transcription, which all participants chose to do so. Once consent forms were returned, Hannah emailed participants to organise a suitable time for the Zoom interview.

The 1-hour Zoom interviews were audio recorded using the Zoom recording function with the participant's permission. Interviews commenced with the researcher introducing herself and sharing her relevance to the study, then asking the participants how they would like to open the interview. The researcher gave participants to open with a karakia, a Māori prayer often considered crucial to lifting the "heaviness" of discussions from interviews (Marques et al., 2021). Subsequently, a mihimihi was conducted, a customary Māori introduction enabling participants and the researcher to exchange personal details and establish rapport. During the mihimihi, individuals shared various aspects about themselves, including their place of origin, familial background, and the motivations driving their participation in this research. Opening the interview this way allowed participants to build rapport with the researcher, building trust before they shared their personal stories (Berger, 2015; Braun and Clarke, 2006).

The researcher saw herself as a formal interviewer who guided the interview by listening to and using participant responses to guide the interview. Interviews were semi-structured (an interview with predetermined questions but included unplanned questions using an interview guide that was guided by existing literature (Braun and Clarke, 2006; Kallio et al., 2016). The interview topic guide (Appendix B*)*, contained key questions regarding the research questions and aims. However, questions were asked based on the participant's responses to maintain the flow of the conversation.

Demographic information was first collected, including age, ethnicity, place of upbringing, where they live, and whether they were diagnosed with CD or UC. Participants were then asked to share the beginning of their story, including how their symptoms were first presented, their interpretation of their symptoms, and what happened. Participants then detailed their stories before beginning the more structured section of the interview.

The semi-structured interview was based on four main themes: how their diagnosis was reached, the key factors of diagnostic delay, the impact of diagnostic delay and stress, symptom severity, and whether a cultural worldview influenced their diagnosis. These themes were based on the findings of previous literature. Participants were then invited to share any details they deemed relevant to the study or information they felt was important for the researcher to know before closing the interview. The interview times ranged from 30 minutes to 1 hour and 30 minutes, depending on how long the participant talked.

Following the interview process, the audio recordings were transcribed and provided to the participants who opted to review their transcripts. Participants had a 3-week window following their interview to withdraw from the study if they wished. Participants could not withdraw following this period.

Transcription

All interviews were transcribed verbatim using the audio recordings on a Word document. Notations of pauses and emphasis were included to ensure the authenticity of the transcripts. Once the interviews were transcribed, the audio recordings were listened to again to check the transcript matched the audio. Once the transcript was finalised and determined to match the audio recording, the audio was discarded/ deleted.

Analysis

Given the small data set and the constructionist influence on the research, Braun and Clarke's (2006) six-step reflexive thematic analysis approach was employed to analyse themes across the data set (Braun & Clarke, 2006). A reflexive approach acknowledges the subjective nature of knowledge generation between the researcher and participants as a central component of this qualitative design (Braun & Clarke, 2006). Reflexive analysis is particularly valuable in this context, considering the subjective nature of a perceived diagnostic delay. Factors such as the length of time to diagnosis, individual perception of events, symptom severity and access to healthcare can significantly influence an individual's experience (Kahui et al., 2017). By employing reflexive analysis, I delved deeply into the dataset and explored its various dimensions by repeatedly revisiting each phase during my inquiry. This method enabled a comprehensive investigation of the impact of perceived diagnostic delay in individuals with IBD (Braun and Clarke, 2021).

With an overwhelming response following this study's Crohn's and Colitis NZ advertisement, all participant interviews and transcripts were finalised swiftly. I moved into phase one of analysis and data familiarisation (Braun and Clarke, 2021). During data familiarisation, I listened to audio recordings using electronic and hard copies of transcripts to highlight and note salient quotations to create codes. Using different media prompted me to interpret the data intuitively, and repeatedly engaging with transcripts shaped my analytic thinking as sensible yet creative. From my prior reading, constructionist study epistemology, and experience with DD having IBS – initial interpretations were made using inductive reasoning. However, I was conscious of my potential biases by regularly reviewing my notations and remaining aware that some quotations resonated with my experience. Further, I was mindful of my subjective influence in this research. I ensured to stay continually reflexive in my interpretations of responses and when giving quotations latent meanings.

Following a full immersion into the data, I noticed recurring, interesting, and relevant quotations to my research questions. I began the systematic process of coding, which is phase two of analysis (Braun & Clarke, 2021). I observed that although the barriers to diagnosis and the impacts of a delayed diagnosis were consistent across the data, there were intense emotions related to these experiences. I realised that my analysis needed to capture the semantic meaning of these observations but needed time to realise the deeper, latent discourses that my participants were conveying to me. By doing so, I categorised my data into explicit codes when considering the barriers to diagnosis and main impacts and then continued to reflect on the implicit meaning and emotion behind these experiences. This prompted me to seek ways to capture these meanings coherently. Once the data set was coded, I compiled codes onto a spreadsheet.

Upon synthesising the data, I moved into phase three of the analysis, generating initial themes (Braun & Clarke, 2021). I compiled comprehensive clusters of quotations with shared meanings using colour coding to answer the research questions. As some quotations related to several themes, I continued to refine codes into candidate themes with a continuous review of the literature, using inductive reasoning and reflection on where they fit best (Braun & Clarke, 2021). During my review, themes with shared meanings were collated with deep consideration of the underlying assumptions and emotions implied. I ensured that while developing a critical exploration of the meanings, giving the participants their “voice” was prioritised (Braun & Clarke, 2021).

This process naturally led to phase four, developing and reviewing themes (Braun & Clarke, 2021). I regularly reviewed this research's scope while focusing on the research questions. In doing so, refining themes that had relevant implications for the diagnostic process and impacts of delay were prioritised while eliminating themes that were insignificant to the research inquiry. Revising was essential to this process to let things go and ensure each theme held a purpose in answering the research questions. Ensuring themes were distinguished and relevant to the overall story of my research led to phase five, fine-tuning (Braun & Clarke, 2021). In this process, I split my core themes into main headings and subthemes, maintaining cohesiveness with each other and the data. Themes were then given concise, informative names that explained the explicit meaning of each theme while conveying their emotive meaning (Braun & Clarke, 2021).

Finally, I began writing up my analysis. While synthesising the codes to create a vivid and compelling narrative about the barriers to diagnosis and the impacts of delay, regular revisits to previous phases promoted a comprehensive inquiry. This final phase six is reflected in Chapter 3.

Ethical Considerations

This research project was conducted per the Code of Ethical Conduct for research, teaching and evaluations involving human participants. The Massey University Human Ethics Ohu Mataika 1, application OMI 23/24 reviewed and approved this project.

The project was submitted to Ohu Mataika 1 for approval. Participants were given an information sheet and consent form to ensure they understood the purpose of the research and their participant rights. Participants were told their rights to withdraw from the study and were given information on well-being services if they found the interviews unsettling.

Confidentiality issues were considered as this project dealt with sensitive and confidential information. Each participant was given a participant number, whereby no one except the sole researcher would be able to identify participants. The data from this study was kept on a password-protected laptop and a confidential Massey One Drive. Only the researcher had access to transcripts. The audio recordings were destroyed after transcription. Once the analysis was completed, Massey University would retain the data for five years.

Another key ethical consideration was the potential harms of this research. It was recognised that although there was no obvious threat of harm to the participants, some participants may experience emotional discomfort related to disclosing their experiences of diagnostic delay. To mitigate this, participants had the right to pause or stop the interview indefinitely at any time, and well-being service contacts were included in the information sheet.

There were many potential benefits of this study that balanced out the potential harm. First, participants may have benefitted from self-reflection, helping others, and relieving isolation.

Two workplaces will be sent a summary of findings after the study, including the Gastroenterology Department at Palmerston North Hospital. The Gastroenterology Department shared a contract with Massey University to acknowledge new research in their practice. They will benefit from direct knowledge of the experience of a diagnostic delay and how to understand patient experiences better. Crohn’s and Colitis New Zealand will also receive a summary of findings as a koha (Māori custom of offering) for advertising this study.

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 23/24. If you have any concerns about the conduct of this research, please contact the Chairperson, Massey University Human Ethics Ohu Ma'tatika 1, email humanethics1@massey.ac.nz.

Chapter 3: Analysis and Discussion

The main research questions were to identify what people with IBD perceive as the main barriers to diagnosis and to investigate what the impacts are of having a DD on those diagnosed with IBD. Overall, four main themes were identified in the data analysis. To answer the first research question, the two themes were: 1) 'Lack of IBD awareness' and 2) 'Quality or quantity of care?' as seen in Table 4. The two themes identified to answer the second research question were: 3) 'I was truly alive, but I wasn't really living for a long time'. and 4) 'Why so stressed?' as seen in Table 5.

The first theme explores how participants believed a lack of IBD awareness has contributed to their DD. This theme includes three subthemes: 'Limitations of the GP', 'Lack of patient awareness', and 'Does anyone know what IBD is?' This theme encapsulates how initial unawareness of IBD led to misdiagnosis, dismissal of symptoms, and a DD.

The second theme, 'Quality or Quantity of Care?' depicts the dissonance between patients and healthcare providers regarding symptom severity, diagnostic procedures and management care. The subthemes of this impact included the 'Mistrust in health providers' and a 'Frustration and Anger from Delayed Diagnosis'.

Further, participants implied a shared feeling of helplessness concerning their symptoms and DD. Thus, the theme 'I was truly alive, but I wasn't really living for a long time' was created. The two subthemes: 'Losing autonomy' and 'Incontinence and shame', explored participant vulnerabilities due to their delay.

Finally, although stress was a prevalent finding, it manifested in several ways. The theme, 'Why so stressed?' was created, which explored the main subthemes participants identified as stressors, including 'Psychological burden', 'Burden to family', 'Physical burden', 'Career sacrifice', and 'Subjective stress and symptom severity'. The feeling of helplessness was also seen throughout this theme, as participants and others around them didn't understand their condition, symptom severity, or help-seeking needs.

Table 4. Barriers to Diagnosis and Their Impacts Themes

Theme	Subtheme	Example Quote	Characteristics
Lack of IBD awareness	Lack of GP awareness	"Because she's a general practitioner, she wouldn't think beyond haemorrhoids." (Participant 1) "The main problem lies with general practice in my view, there's a lot of ignorance." (Participant 5)	Initial unawareness leads to misdiagnosis, dismissal in symptoms, and delayed diagnosis.
	Lack of patient awareness	"I'd never heard of IBD." (Participant 7) "I thought I had a virus." (Participant 4)	
	Does anyone know what IBD is?	"It's probably your period!" (Participant 6) "If you say to someone, 'I've got IBD', and they said, 'Oh! I had diarrhoea the other day and I was sick.' It's like no no no!" (Participant 10) "They thought I was making up stories to stay at home." (Participant 9)	
Quality or quantity of care?	Lack of further investigation	"They just decided that it was haemorrhoids again so gave me the cream or whatever it was again." (Participant 2) "I went to the doctor and, nothing again." (Participant 8) "They don't investigate further." (Participant 10)	Feelings of dissonance – the disagreement between patients and healthcare providers about symptom severity, diagnostic procedures, and management care.
	Mistrust in healthcare providers	"I've got no confidence in him treating me, and I've been getting very very sick." (Participant 1)	

		“I certainly have a distrust of medical professionals.” (Participant 9)	
	Frustration and anger from delayed diagnosis	“I was kind of left with a lot of anger for quite a long time too because I think it should have been looked at, and had I been looked at, it would not have progressed to that point and they actually could have treated it earlier. I had to change careers, I had to do all sorts of things.” (Participant 5) “Perhaps they could have saved me from crashing and burning and getting diagnosed at that point.” (Participant 10)	Frustration and resentment: retrospective negative reflection on the diagnostic procedure, misdiagnoses, and undermining of symptom severity.

Table 5. The Psychosocial Impacts of a Diagnostic Delay

Theme	Subtheme	Example Quote	Characteristics
‘I was truly alive, but I wasn’t really living for a long time’	Losing autonomy	“I was like bed, or toilet, bed, or toilet. There it was basically my existence.” (Participant 6) “Crohn’s did take a lot of that autonomy away from me for a long time It was really hard to live with that.” (Participant 3) “I had to go home and live with my Mum… I was housebound.” (Participant 10)	Helplessness: the vulnerability of participants when themselves or others didn’t understand their condition, symptom severity, or help-seeking needs.
	Incontinence and shame	“It was also a dignity stripper, because, I mean besides the fact that you know, your sort of soiling in your pants without a moment’s notice sort of thing, which is probably the most humiliating experience I’ve ever had, dehumanising.” (Participant 5) “So it's like it's also embarrassing like I don't want people like having to run to a public toilet because I can't control my bowels at 23 years old.” (Participant 8)	

Why so stressed?	Psychological burden	“It was like I was living a life where the rules were changing constantly, and I had to keep up with them.” (Participant 3) “Psychologically I felt like I didn’t have a future.” (Participant 10) “I definitely was like on the edge of fight or flight for a really long time. Really long time.” (Participant 7)
	Burden to family	“My wife and I had both independently, although we hadn’t communicated it to each other at that time. We thought this is probably colorectal cancer, I’m probably dying. I started making preparations to basically wrap up all my fares and make sure that everything was right for my wife when I died because I assumed, ‘This is it, I am doing to die.’ She did as well.” (Participant 5) “For my daughter's first two years I couldn't really get off the couch most of the time.” (Participant 8)
	Physical burden	“I was not sleeping, I was so tired. I was now what I know to be anaemic and had lost 10 kilos, and there was nothing more I could do… I was pale, very obvious signs of muscle wasting, I wasn’t eating anything, I couldn’t keep anything down, and had started vomiting as well.” (Participant 2)
	Subjective stress and symptom severity	“Yeah I think stress is related to them [symptom severity], especially before I got diagnosed I think a lot of that, like into that my body was stressed because I couldn’t do anything. I couldn’t digest anything. I think a lot of stress does carry through into how I felt.” (Participant 2) “By that stage, it was already getting quite bad. The stress was not helping, and the external stress was making me sicker, and me being sicker was

	making me more stressed." (Participant 3)

Theme 1: Lack of IBD Awareness

Upon investigating the main barriers to diagnosis, participants articulated a shared message: limited IBD awareness led to delay. The theme, 'Lack of IBD awareness', was identified following the recognising of various codes with this shared meaning. Codes frequently suggested that the limited symptom knowledge and identification at an individual, healthcare, and societal level contributed to their diagnostic delay and their negative experience of pre-diagnosis symptoms.. Having 'Awareness' related to the familiarity of IBD, symptom recognition, the seriousness of IBD, understanding the impact on daily life, and understanding the public perception of IBD. IBD is a regularly misunderstood disease and is often confused with other gastrointestinal disorders such as IBS. In past research, low-level awareness has been identified as a core contributor to diagnostic delay (Popa et al., 2022; Melinder et al., 2017). Thus, a lack of awareness is a fundamental concept when considering the impact of diagnostic delay.

The final part of this section describes how participants felt that their diagnosis could have been made more promptly with more awareness. Lacking IBD awareness is critical to research understanding as it impacts various other research themes. For example, the lack of IBD awareness was central to contributing to the negative psychosocial impacts of DD and losing faith in the health system (Kahui et al., 2017).

Lack of GP Awareness

Perceived Main Barrier to Diagnosis

During interviews, participants described what they perceived as the main barriers to an IBD diagnosis. The most common response was a lack of IBD awareness among GPs. For medical professionals, having an awareness of IBD means they are familiar with the symptoms, diagnostic procedures, and treatment of IBD (Richard et al., 2020; Kahui et al., 2017).

Participant 5 (54 years, 30-year delay) attributed their delay to "Just lack of awareness from the GP." Several other participants agreed, as Participant 1 (53 years, 4-year delay) says, "It took a long time for them to even recognise it was IBD I was suffering from." Echoing previous research, IBD is poorly understood among GPs (CCNZ Survey, 2017). Recognising the lack of GP awareness of IBD in this research is crucial to understanding the initial disconnect between patients and healthcare professionals. A lack of GP awareness has likely been the catalyst for the later described diagnostic delay and its related impacts.

Poor Symptom Recognition and Misdiagnosis

When understanding why participants believed there was a lack of IBD awareness, they articulated that IBD symptoms were misdiagnosed and often mistaken for other illnesses, including food poisoning, IBS, or haemorrhoids. Participant 6 (39 years, 7-year delay) mentioned difficulties with misdiagnosis, saying, "They put it down to a stomach bug, something bad I'd eaten." This is endorsed by Participant 4's (38 years, 3-year delay) statement, who said her symptoms were attributed to "Stress. Stress and IBS."

Widespread unawareness among numerous doctors was evident, as participants reported encountering this issue despite seeking medical attention from various health professionals, such as Participant 8 (25 years, 7-year delay), who said: "I saw maybe 7 to 10 doctors in those five years, and every single doctor just goes straight to IBS."

These findings produce several implications. First, distinguishing between haemorrhoids, IBS, and IBD appears to be problematic. In some cases, the GP may be correctly diagnosing haemorrhoids or IBS, given the participant has those symptoms. However, GPs remain uncertain that the patient's condition is, in fact, IBD, which has been seen in previous research (Vavricka et al., 2017). Perhaps these patients did not present with unique symptoms related to IBD, such as rectal bleeding. Otherwise, an absence of a colonoscopy means that obvious symptoms are misdiagnosed (Kahui et al., 2017). Despite this, participant perceptions remain certain that a low level of IBD symptom recognition among GPs was regarded as a significant barrier to an IBD diagnosis, prolonging the diagnostic time by attributing symptoms to other causes. Consequently, this generated a negative experience for participants.

Perceptions of the Scope of a GP

It was evident that due to the misdiagnosis of symptoms, participants questioned the scope of a GP in their ability to diagnose IBD correctly. As Participant 1 (53 years, 4-year delay) outlines, "Because she's a general practitioner, she wouldn't think beyond haemorrhoids." As participants frequently judged the limited scope of GPs' knowledge of IBD, there is an implied message that participants do not trust GPs to identify their disease, supporting a mistrust of healthcare professionals from the beginning of their symptomatic journey. These results are similar to previous research, where a lack of IBD awareness in GPs led to one in five patients reporting a diagnostic delay that surpasses two years (Kahui et al., 2017).

While some attribute their misdiagnosis to the scope of the GP, others recognise that given the complexity of the disease to diagnose, this may be difficult for a GP to achieve. As Participant 10 (40 years, 9-10 month delay) states, "Even medical professionals really struggle to understand the impact of IBD because it's invisible. You can't see someone's colon." These statements suggest two factors: first, diagnosing may be difficult for GPs, given their limited scope in practice. Second, there is a barrier to identifying IBD, which may be attributed to the hidden nature of the disease. As these perceptions lead to a negative perception of a GP, understanding why this is apparent is essential.

Confusion In The Medical Field

The issues of misdiagnosis and the scope of the GP discussed by participants so far highlight that there is potential confusion in the medical literature between the symptoms of IBD and IBS. It is possible that GPs are uneducated about the unique symptoms of IBD and are uncertain of when it is appropriate to send a patient for referral. Consider this extract below:

> Not enough people think about the impact of diagnostic delay, and I think there is a lot of confusion, even in the medical field and the IBD literature, between IBS and IBD. Doctors use them interchangeably, not realising they're different (Participant 10, 40 years, 9-10 month delay).

This statement implies several ideas. First, it is possible that a lack of GP awareness is centred on identifying the unique symptoms of IBD to differentiate between IBS and haemorrhoids. If this were true, education surrounding differentiating the two would be required. Second, the participant also implies that by neglecting to think about the impact of delay, there is a lack of incentive to differentiate the conditions. Previous studies have shown that a lack of healthcare awareness could result in health professionals failing to comprehend the seriousness of IBD fully, increasing diagnostic delay time (Vavricka et al., 2012; Khalilipour et al., 2022). This finding was consistent with the present study. Suppose GPs were to understand the importance of obtaining a prompt IBD diagnosis despite the presentation of symptoms looking like haemorrhoids or IBS. In that case, there may be more incentive to refer a patient for a colonoscopy to rule out the possibility of IBD, which would reduce delay.

The need for GPs to have clarification between IBS and IBD is articulated by Participant 8 (24 years, 7-year delay), who says, "I just think having an actual bowel disease is so much more [than IBS], and they need to be more aware of it." This statement highlights the patient's desire to be treated properly due to the negative ramifications of IBD, implying that the consequences of IBD symptoms are worse than IBS. As previous findings have shown, the impacts of DD on IBD are poorly understood among GPs (Popov et al., 2022; Lee et al., 2017). This statement shares the conveyed message with others: the implications of IBD are negative with DD; thus, being educated about the impacts of DD in IBD may encourage comprehensively treating gastrointestinal symptoms with urgency, which is crucial to reducing impacts.

Diagnosing IBD

Finally, when discussing how GP awareness is considered a barrier to diagnosis, participants believed that GPs were partially unaware of the diagnostic process for IBD. Consider this statement:

> But also upset that there are health professionals out there, and a disease that is so prevalent, especially in New Zealand – who just didn't prioritise that and didn't have a clue about the steps to go through to refer someone more quickly than sort of, three months down the line (Participant 2, 23 years, 6-month delay)

There are two components of this statement, the first is about priority. As previously discussed, perhaps a lack of IBD awareness among GPs, including the differentiation between IBS and IBD symptoms and recognition of the negative impacts of delay, means that referral is not considered a priority. Second, this participant perceived their GP as unaware of how to refer a patient promptly. When retrospectively reflecting on the diagnostic process, this participant shared their frustration at these issues. They continue below:

> Now, I know what it took to be diagnosed. I think there needs to be more public discussion about this. New Zealand has a really high prevalence of this, and it just flies under the radar. I think that the lack of awareness, and I'm not saying all healthcare professionals, but the ones I dealt with initially were really unaware (Participant 2, 23 years, 6-month delay)

These statements are consistent with the literature, as the current care model of GPs diagnosing IBD in New Zealand is considered inefficient (Kahui et al., 2017). It appears that when a GP is perceived as unaware of the diagnostic procedure, frustrations are heightened when reflecting on how prompt the diagnosis could have been. This shows that a GP's lack of awareness extends from symptom recognition to diagnostic processes. Participants perceive GPs as uneducated in this area, which has increased feelings of frustration.

This perception of unawareness is seen in Participant 6 (39 years, 30-year delay), who describes, "If you come in with something slightly different, and they don't know, so they don't look at it? I think they just go, same old, same old." The unawareness of symptoms not only leads to misdiagnoses but also appears to hinder further investigation of symptoms. As a resolution to this issue, one participant offered a unique insight into solving the lack of GP awareness by saying:

> So I think GPs look at a patient and go, 'I don't know what to do with this person.' I remember that same GP opening a textbook when I went to see him, looking at me and going, 'Maybe it is this.' But a good GP, I've discovered, is somebody who says, 'I don't know,' and picks up the phone and calls a registrar at the hospital.
>
> (Participant 10, 40 years, 9-10 month delay)

The solution provided by Participant 10 explains that from a patient's perspective if a GP cannot recognise symptoms of IBD, there should be an incentive to seek advice elsewhere. Resultingly, this participant perceived their GP as more competent and caring for their situation. Research on how a GP's actions may impact a patient's perception and trust has not been explored in the literature. Therefore, further investigation of how trust can be impacted by a GP's willingness to refer would be a valuable contribution to reducing the impacts of DD, as a GP's unawareness appears to influence patient perceptions.

This solution has yet to be discussed in previous research and, therefore, is important to note for healthcare professionals. Investigating the availability of specialists in a GP's area to contact if needed would be beneficial. If a GP is aware of the diagnostic process or that they can seek advice elsewhere, patients may perceive GPs as giving adequate care while decreasing diagnostic time.

Summary

We can conclude that in this sample, participants perceived GPs to have inadequate awareness of IBD symptoms and judged their scope to identify IBD promptly. When the GPs awareness was perceived as inadequate, participant frustration increased. Future research should investigate how GPs can be perceived as more competent to patients to increase the trust between the patient and healthcare provider.

Lack of Patient Awareness

Lack of IBD Education

Upon the initiation of symptoms, the majority of participants reported being unaware of IBD. For example, Participant 1 (53 years, 4-year delay) explained, "Previously, I didn't even know what IBD was about." This was a common response with other participants, where Participant 7 (56 years, 23-year delay) explained that when they had initial symptoms, "I kind of just dealt with it because I didn't really know, I'd never heard of IBD." Low-level patient awareness is seen in previous IBD research, which determined that a lack of IBD education contributed to a patient-centred diagnostic delay (Cross et al., 2023; Richard et al., 2020).

Having low awareness of IBD is a contributing factor to diagnostic delay for various reasons. First, as one participant stated, they 'just dealt with it' because they were unsure their symptoms were the result of a serious disease. This means they would be unaware that seeking medical help was needed. Because of this, help-seeking and thus a diagnosis would be delayed. As increasing awareness of disease symptoms has been successful in previous research regarding similar conditions, such as colorectal cancer – we can assume that increasing awareness of IBD may promote help-seeking behaviour and reduce delay (Blackmore et al., 2020).

Self-misdiagnosis

As a result of low IBD awareness, participants, similarly to GPs, attributed their symptoms to an alternative illness, as Participant 2 (23 years, 6-month delay) mentions, "I just put it down to a stomach bug", which was similar to Participant 4 (38 years, 3-year delay)'s response, "I thought I had a virus" (Participant 4).

Self-misdiagnosis is a threat to achieving a prompt diagnosis, as an IBD study has shown that low disease symptom awareness meant patients were more likely to normalise their symptoms or attribute them to other causes. Resultingly, they were less likely to activate help-seeking behaviours, which delayed diagnosis (Cross et al., 2023). This finding was also found in colorectal cancer research (Blackmore et al., 2020). Therefore, understanding why people self-misdiagnose, for reasons in addition to low disease awareness, is crucial.

Unpredictability of IBD Symptoms. One of the reasons for self-misdiagnosis in IBD patients is due to the unpredictability of IBD symptoms. Given IBD has a turbulent, relapsing nature of flare-ups, many people experience periods of remission (Popa et al., 2022; Targownik et al., 2015). When participants experienced flare-ups, they perceived themselves as cured or attributed their symptoms to temporary stomach issues like a virus. Participant 7 (56 years, 23-year delay) described this experience, saying: "I had some mucus and blood in my stool, and then it went away, so I was like, 'Oh, it must have been a tummy bug then.'" Having flare-ups highlights the complex pathogenesis of the disease and its variability of symptoms (Nistor et al., 2022). It is likely that those who don't experience persistent symptoms are less likely to consult a health physician, compared to those with persistent symptoms or experiencing a rapid condition change.

A Fear of More Serious Illness. Another reason participants in this sample tended to self-misdiagnose themselves was out of fear that their symptoms might indicate severe illness as a temporary coping mechanism. This reason for delay has also been seen in previous research (Cross et al., 2023; Richard et al., 2020; Popov et al., 2021). There were several reasons why participants were afraid of their symptoms. Consider the quotation below:

> When you're really unwell, and you don't understand – and I was only 20, I was not old. And it's scary for a young person…So I think, probably, I just tried to deal with it for a little bit more than I should've, I suppose (Participant 7, 56 years, 23-year delay)

For a young person, having symptoms that indicate a serious illness may be intimidating for several reasons. First, serious illness may be perceived as only occurring in older generations. Second, young participants may feel less comfortable consulting a GP with their symptoms. Finally, young people may be less aware of IBD than adults However, further investigation into the impacts of age on help-seeking behaviours is required.

Another participant seen excusing their symptoms out of fear can be seen in the quotation below:

> I knew it was rectal blood. So I think if you can kind of find a comforting excuse, then you want to believe that's the case. Even though you might know deep down that something is wrong. And I think I allowed myself to do that" (Participant 10, 40 years, 9-10 month delay)

Having a lack of awareness may mean that people downplay their symptoms to a minor illness without understanding the possible implications of ignoring symptoms. As low-level awareness means individuals are unaware of the seriousness of their symptoms or that IBD is a potential cause, delaying help-seeking could be detrimental to an individual's health.

At other times, using a comforting excuse, as described by Participant 10, means they may be afraid of what a diagnosis could mean. For example, changing their lifestyle or relationships with their family and friends. Delaying facing their fears head-on would then delay this stress.

These findings imply that delayed help-seeking out of fear of a more serious illness is a threat to a prompt diagnosis. Further, a lack of IBD awareness can exacerbate these emotions. Those who are aware of IBD symptoms may be more likely to seek help. However, additional factors may influence help-seeking, such as age. Future research is required to investigate the fear of illness and its influence on DD.

How Misdiagnosis Influences Patient Actions

As explained, a lack of IBD awareness meant that GPs were likely to misdiagnose IBD symptoms. However, seeing an interaction between the GP and patient unawareness intersect was interesting. For example, many participants reported immediately consulting a GP when symptoms presented. During the first GP visit, participants were often told their symptoms were predominantly due to haemorrhoids, IBS, and stress. Participants accepted this diagnosis and changed their appraisal of symptoms to less severe conditions, as the GP described. Participant 4 (38 years, 3-year delay) described this, saying, “I was very relaxed about it. They said I was having IBS, so I thought, ‘Okay, I’ve got IBS, nothing else can be done. I didn’t do any research, anything.”

On other occasions, some participants were told multiple times that despite persistent symptoms, there was no serious cause of their symptoms. Consider this experience of Participant 6 (39 years, 7-year delay), “I got really bad diarrhoea. I didn’t do anything about it because I was sick of being told the same old thing. So I just didn’t do anything, and I didn’t go to the doctor.”

These two quotations show two reasons why misdiagnosis is dangerous. First, Participant 4's statement shows that when patients trust their GP, they are likely to accept the diagnosis, even if it is incorrect. For this participant, there was no obvious reason to investigate their symptoms further. Becoming accepting of an IBS diagnosis means this participant is less likely to advocate for further investigation, which would delay diagnosis significantly. As she had a 3-year delay, accepting the incorrect diagnosis would have been a key barrier to diagnosis.

Additionally, Participant 6's response conveys a different message. Their response shows that a repeated misdiagnosis meant help-seeking behaviour was no longer considered useful. For them, approaching their GP was seen as pointless. Having this view is a threat to DD as the patient was likely to avoid medical attention until their symptoms were extremely severe. This may be one of the contributing reasons why IBD patients are often diagnosed following hospitalisation from severe symptoms (Kahui et al., 2017).

In other cases, some participants identified with having symptoms, even if they were unable to attribute them to IBD. Consider Participant 6 's (39 years, 7-year delay) experience, "I just accepted that as probably what it was, so I lived all through my 20's, 30's and 40's… it was sort of like, 'Oh, that's just who you are! So I brushed it off." These feelings of dismissal undoubtedly contributed to DD as participants saw no reason to investigate further.

These findings highlight the importance of thoroughly investigating a prompt diagnosis if symptoms of IBD present. A prompt diagnosis means that people are diagnosed before their symptoms are severe. Although there is limited IBD awareness among patients, there should not be an expectation for the layperson to identify IBD symptoms, therefore addressing GP awareness is essential in achieving positive outcomes for patients. These findings also signify the trust that patients have in their GP to diagnose them correctly, and an incorrect diagnosis may erode their trust.

Despite this, understanding the extent of IBD awareness is also important for people surrounding a person with IBD symptoms, as families can also be influential in help-seeking behaviours.

Summary

In summary, a lack of patient awareness is a significant barrier to diagnosis. As participants were unaware what IBD was, they were not able to understand the severity of dismissing symptoms. Due to this, they were less likely to advocate for a comprehensive investigation. Patient unawareness also led to accepting the GP's diagnosis, even when it was incorrect. This finding shows how patient and GP awareness interact together. With improved awareness, patients are likely to play a role in decreasing DD.

Does Anyone Know What IBD is?

The final aspect of 'lack of awareness' includes the community and societal level, determining the extent of knowledge and understanding of IBD. Having a high level of community awareness is crucial for reducing diagnostic delay, as poor health literacy has been associated with poorer health outcomes, including diagnostic delay and reduced contact between healthcare systems and patients in the IBD literature (Colombara et al., 2001; Khalilipour et al., 2022). The general population critically influences others in educating about disease symptoms and responding appropriately when people share symptoms. As most participants confided in someone close to them about their symptoms, wrongful attribution of symptoms would have worsened the diagnostic delay (Colombara et al., 2001). The community participants primarily described in this study were their close family, friends, and work colleagues., so highlighting community knowledge is essential.

It was clear that, consistent with patient and GP awareness, people in the participants' communities were unsure of what IBD was and attributed the participant's symptoms to other conditions. Participant 6 (39 years, 7-year delay) explained, "Everybody always put it down to, ‘Oh you’ve got like, maybe you’ve got giardia, or maybe you’ve got food poisoning, or maybe you’ve eaten some chicken that wasn’t right.’ Anything like that was always what it was put down to.”

As patient perspectives of an IBD diagnosis have only recently been researched, addressing community awareness of IBD has not been investigated in the literature (Cross et al., 2023). However, the impacts of low-level awareness would be similar to those seen in patients with low awareness. For example, when families or people surrounding people with IBD symptoms suggest their symptoms are not indicative of a serious illness like IBD, symptoms may be dismissed or ignored. Attributing symptoms to food poisoning would be a common response from others, yet can be dangerous as it may delay help-seeking. Although families and communities may endeavour to relieve anxiety in those with IBD symptoms, they may be inadvertently unhelpful.

Wrongful attribution of symptoms is also seen in the quotation below:

> I remember telling my Mum one day, calling her in a paddock being like, ‘Oh my God, there’s blood!’ and she said, ‘It’s probably your period!’ And the next day, I got my period so I thought, ‘Okay! That’s what it was.’ But I knew it wasn’t, I knew it was rectal blood. (Participant 10, 40 years, 9-10 month delay)

This quotation shows that despite a family member wrongfully attributing IBD symptoms to a period, the individual was still aware that there was rectal blood present. However, this family member was unaware that bleeding could be from other causes, reflecting the little public knowledge of IBD, and resultingly, the inability to understand the severity of symptoms such as bleeding (Popov et al., 2021).

There was one participant who experienced a significant level of IBD unawareness, where her family did not believe in IBD as a disease. This unawareness was combined with GP unawareness of IBD, as despite persistent issues, IBD was not considered a possibility.

This quotation shows how low-level IBD awareness interacts between the GP, the patient, and the patient’s family:

> I think it was always like that constant fight, and it got to the point that I was sick of going to the doctors and my parents were getting sick of taking me as well! To the point where once my parents asked the doctors if it was a psychological thing if I didn’t even like school, because they started to take the side of the doctors more than me telling them I’m actually not well… they thought I was just kind of making up stories to stay home because there was never an answer as to why I was constantly sick. It was always like I felt I was competing between doctors and parents as to not being well really! (Participant 9, 33 years, 11-year delay)

This participant’s symptoms initiated at a very young age. It is possible that the GP did not consider IBD as a diagnosis due to her age. Similarly, the family of this participant may have struggled to accept that a chronic diagnosis is possible for a child. However, this lack of awareness meant that symptoms were attributed as excuses or a psychological issue. Having this perspective, therefore, would have greatly delayed diagnosis, as shown in her 11-year delay.

Summary

In summary, analogous to GP and patient awareness of IBD, community awareness is essential. Communities, particularly family members, play an integral role in encouraging help-seeking behaviour and advocating for a diagnosis. It was found that when symptoms were attributed to other conditions, patients were less likely to seek further investigation. This finding is important as although GP awareness should be prioritised, recognising the influence of the community in reducing delay is essential. Further, if family members develop IBD symptoms themselves, it is essential that they are aware of IBD so they can rule it out as a diagnosis with a GP.

Theme 2: Quality or Quantity of Care?

The theme, ‘Quality or Quantity of Care?’ explores the common reality of many people with IBD symptoms who continuously present to the doctor only to be misdiagnosed with no further investigation by healthcare specialists. This theme covers what the participants and researcher examined as a main barrier to diagnosis. A lack of investigation explores the lack of referrals or exploration of other explanations of IBD symptoms as a result of a lack of awareness. The quality of care was considered a product of awareness levels, particularly among GPs.

A key frustration for participants was when they articulated their desire for earlier intervention, explaining that receiving comprehensive healthcare in initial presentations to the GP will reduce diagnostic time, thus reducing the negative impacts of delay. This theme is essential to explore as a main barrier to diagnosis because of its related impacts of distrusting health providers and negatively reflecting on the diagnostic process. This theme explores novel barriers to diagnosis that the literature has not explored in depth.

Lack of Further Investigation

Misdiagnosis

Many participants' stories began with trusting health providers to care for their health needs adequately. However, many were misdiagnosed with IBS, haemorrhoids, diverticulitis, stress, or other gastro-related illnesses before being diagnosed with IBD. Often, GPs prescribe treatments and medications for these diseases, unknowingly delaying the correct treatment for participants. When seeking a diagnosis, doctors did not further investigate their symptoms; thus, a ‘lack of investigation’ is an important barrier to diagnosis.

For example, Participant 10 (40 years, 9-10 month delay) explains that upon visits to the doctor with symptoms, “A doctor says, ‘It’s exam time, you’re stressed, you’re running to the bathroom with diarrhoea, you must have IBS.’ And they don’t investigate further.”

Although the association between stress and IBS has been well established in the literature, this quotation provides an example of how IBD gets overlooked. Often, GPs with minimal time to investigate a patient (roughly 15 minutes) will try to explain the symptoms by attributing them to situational stressors and IBS (De Sousa et al., 2022). Despite these triggers being common for gastrointestinal symptoms, this practice method leaves patients inadequately investigated for further explanations of their symptoms. This explanation reflects previous findings, showing that many patients who present with IBD symptoms are often diagnosed with IBS or told their symptoms are due to stress or lifestyle factors (Cross et al., 2023; De Sousa et al., 2022).

Further investigation was overlooked upon a misdiagnosis as the incorrect diagnosis was unknowingly accepted as the correct answer. Participant 1 explains how a misdiagnosis influenced further interactions with their GP:

> I think the focus was like, because of my diagnosis [of haemorrhoids] and because I would start explaining what’s happening to me, they were always thinking it was haemorrhoids. They never thought about, you know, the symptoms could be this or IBD (Participant 1, 53 years, 4-year delay)

Further, participants cited that GPs often found a simple explanation for their symptoms, such as haemorrhoids, and did not further investigate why the patient had haemorrhoids or if there were further explanations. Interestingly, a previous study found that when participants’ symptoms could be explained by haemorrhoids, stress, dietary change, or other lifestyle reasons, they were less likely to consult a physician, thus delaying help-seeking behaviour such as a further investigation (Blackmore et al., 2020). This effect appears not only for patients contributing to delay but also for GPs.

Constraints of a GP

In many cases, participants did indeed have haemorrhoids, but GPs did not prompt a further investigation of the cause of the haemorrhoids. There could be various reasons for this lack of further investigation. First, a lack of further investigation could be due to the minimal time GPs have with their patients, leading to them needing an immediate answer (Kahui et al., 2017). Second, the lack of further investigation could be a reflection of the low IBD awareness, meaning that other, more well well-known gastrointestinal conditions such as IBS are investigated instead. Third, and most likely, is because the symptoms of IBD mimic many other, sometimes less serious conditions; thus, investigating other options first is a more accessible avenue for GPs to explore, given low IBD awareness, the time limits for a GP, and accessibility to testing (Dent et al., 2021; Brzozowski et al., 2016). This finding also reflects among this sample, there may be a lack of awareness of participants on the constraints of the health system. It is possible that participant perceptions described in this research are not well informed of these constraints and may influence responses in this research.

Lack of Awareness

Although some participants believe that the lack of further investigation was due to the GP not taking their symptoms seriously enough, as Participant 9 (33 years, 11-year delay) explains: “It was never, I suppose, at the time for them to take it seriously, and it was always putting it down to other possibilities.” A lack of IBD awareness is likely a contributing factor. This statement returns to the argument that there may be no incentive to investigate further when other conditions can explain symptoms. From this, we can assume that with better IBD education, there may be a greater incentive to explore IBD as a possible diagnosis sooner (Cross et al., 2023). However, these assumptions cannot be made without further investigation. Future research should assess the GP's reasoning as to why no further investigation is conducted.

Testing Incentive

Another example of a lack of further investigation was that when diagnostic tests were run and nothing was found, some participants reported that GPs did not conduct further tests. For example, Participant 7 (56 years, 23-year delay) explains that “The first one [visit] they just said I was fine, it was just a blip. The second one was a parasite, which it wasn’t because the tests showed that. But then they didn’t have a next step for me.”

It is possible that the GP does not know what the next step should be, thus telling the patient they are fine. However, the absence of a referral to a specialist is problematic as the patient does not have the opportunity to find out what is wrong with them, and their diagnosis is further delayed. It appears that among this sample, there seems to be a reluctance to investigate further, as explained by Participant 9:

> I was admitted twice. I think back to when I first kind of started getting symptoms, and that’s when they thought it was an appendix. They did an ultrasound, but that was the only form of scanning back then that they did as well, and again it showed nothing wrong with the appendix, so I was out again the next day even if I still had symptoms (Participant 9 (33 years, 11-year delay)

Despite this, the reason behind a lack of further investigation cannot be ascertained without further research. Although this participant partially attributed their delay to access to diagnostic resources such as scanning, DD is still being reported today. People only appear to get tested when a GP identifies the testing as warranted. Therefore, based on participant responses in this sample, there is a perceived lack of testing incentive. However, understanding testing protocols through a GPs perspective will provide a comprehensive understanding of why this is. There may be many contributing factors to why GPs are not testing further, but research on this is required. Regardless, participants hold the perception that there is a reluctance to test further, which has resulted in frustrated and negative views of the GP.

Summary

In summary, there are many possible reasons why GPs do not investigate IBD symptoms further. This may be due to a lack of resources, limited time with a patient, or a lack of IBD symptom awareness. Future research should investigate GPs' perspectives on IBD symptoms, referrals, and the diagnostic process for IBD. These results may contribute to a complete picture as to why this lack of investigation is occurring, as participants in this sample believe a lack of further investigation is a barrier to diagnosis, analogous to previous research (Cross et al., 2023; Blackmore et al., 2020; Khoury et al., 2022). Gaining a complete understanding of the reasons behind limited investigation could reflect areas in the health system that need changing, and that may otherwise not be addressed without further research.

Mistrust in Healthcare Providers

An important subtheme of 'Quality or Quantity of Care?' is the mistrust in healthcare providers. In participant interviews, the primary reason for losing faith in the healthcare system was because of repeated visits to healthcare providers, only to be misdiagnosed or due to the lack of further investigation. Participants expressed wanting an investigation until the correct diagnosis was made. Having a mistrust in healthcare providers is, therefore, a direct impact of misdiagnosis and a lack of further investigation. Thus, it is an essential subtheme to explore when investigating the barriers to diagnosis and the related impacts of experiencing a diagnostic delay.

The most common pattern seen during interviews was that participants initially believed in GPs and health workers to provide adequate care for their symptoms. This is seen in participant accounts like Participant 10 (40 years, 9-10 months delay), who said, "I remember me not being concerned because they haven't looked further." However, many participants explained that their symptoms did not subside and instead got increasingly severe. Despite many attempts to get help from a GP, no diagnosis was made.

This pattern meant that emotionally, participants reported feeling increasingly frustrated and stressed by the lack of attention they were receiving for their symptoms. Resultingly, many reported having to self-advocate for their condition to convince healthcare workers that their symptoms were more serious than they were being told. In these cases, frustration appeared directed at the GP or specialist they were seeing at an individual level, which is consistent with previous findings (Popov et al., 2022). This pattern of losing trust is seen in the extract below:

> My wife especially would say that I was kind of more trusting at that stage of general practitioners; I kind of generally accepted whatever they told me up until that point. My wife was a bit more sceptical, and she actually, at one stage, was almost shouting at the guy. You know, 'There is something seriously wrong here, this is not haemorrhoids! He's in agony, it's this!' I was losing weight, I was dreadfully pale. And he said, 'No, no, no.' (Participant 5, 54 years, 30-year delay)

Many participants explained that their lack of trust in the health system to treat them started with particular specialists or doctors, such as Participant 1 (53 years, 4-year delay) who explains, "So I spoke to my GP and I said, 'I really need to change my specialist because I've got no confidence in him treating me, and I've been getting very, very sick." This Participant explained that her lack of trust was because of dissonance between herself and the GP, as described below:

> These are the people you really rely on and think, 'Oh my God these are the people that will help me get better', and it's the same person who's just turned around and shut me off, saying 'You have to listen to me, you are not the specialist, I am the specialist.' That sort of stuff. I think personally, that's not good (Participant 1 53 years, 4-year delay)

In this context, Participant 1 was trying to advocate for her symptoms as something more serious than she was being told but was accused of overreacting and thinking she had more knowledge of her symptoms than the specialist. The impact was that she initially believed that she would be receiving help but then felt shut out by the specialist following repeated visits for help. Similarly seen in previous studies, the lack of investigation and disagreements with healthcare providers appear to be significant contributors to mistrusting health professionals (Cross et al., 2023; Popov et al., 2022). Although Participant 1 had an isolated experience with one particular specialist, similar incidents of dissonance between the patient and doctor were mentioned during interviews, as seen with Participant 9:

> He then actually brought the psych team in to talk to me, to make sure I wasn't psychologically in my head, to which the psych team walked out and said I was one of the happiest, easy-going people that they had actually ever come across. I ended up getting a formal complaint from my doctor then, because I had to go and get a colonoscopy without any form of sedation or whatever else they used because I was pregnant and I couldn't actually take any of it, I just wanted to prove a point at that stage (Participant 9, 33 years, 11-year delay)

Being accused of attention-seeking behaviour has been addressed in previous research, where participants in other research similarly experienced poor acknowledgement from their healthcare providers during the initial stage of seeing a GP with symptoms (Popov et al., 2022). Analogous to this sample, patient frustration resulted (Popov et al., 2022).

As a result, disagreements between doctors and participants in this sample appeared to impede the level of trust in the specialist. Participant 5 (54 years, 30-year delay) explains, "It kind of shattered my faith in general practitioners, it really did."

These findings show that although participants held an initial trust in healthcare providers, their faith was destroyed following the lack of further investigation of symptoms, misdiagnosis, and also the dissonance experienced between the GP and patient. These findings imply that the delivery of information by a GP may negatively impact a patient's perception. Investigation into how maintaining rapport and empathy towards a patient can influence the level of trust in a healthcare provider would be valuable. These findings also reflect the broader issue of low IBD awareness, as the misdiagnoses and disagreements regarding symptoms appear to stem from a lack of knowledge. Despite this, GPs are being negatively perceived as ignorant.

The Health System

In some cases, DD was blamed on the health system's process of obtaining a diagnosis, and thus, participants explained losing their trust in the GP and the health system. As Participant 3 describes:

> Because of the way the health system is run and structured, there's no incentive for doctors/ GPs whatever sort of thing, to try and sort this thing. They are more like the ambulance at the bottom of the cliff. It's about triage, and managing caseload because the demand is too intense, and there isn't the resources to deal with it. I've had to experience those frustrations of the health system very graphically over the last few years (Participant 3, 25 years, 3-year delay)

Participant 3 describes the frustration that results from experiencing a diagnostic delay. This participant refers to the 'ambulance at the bottom of the cliff', which implies that the resources are available when it is too late to save people. The DD could be attributed to a lack of further investigation or lack of IBD awareness that was previously examined. The mistrust in the health system reflects various barriers to diagnosis. Therefore, to reduce this mistrust, several barriers need to be changed.

Additionally, Participant 6 described that because of her DD, she lost faith in the health system. Her frustrations are articulated below:

> Probably annoyed? Yeah. I think that’s probably why I ended up going away from conventional modern medicine and I looked at more holistic… I think that the way that I was not taken seriously at the beginning and while I was younger probably made me do what I did and go away from them… I think I’d lost faith in them. Because they would just keep not really looking at it, and I kept getting the same, same, repeat reasoning, which wasn’t the reason at all (Participant 6, 39 years, 7-year delay)

The experience of moving away from modern medicine due to DD is not likely a common finding. However, it is important to acknowledge that losing faith in healthcare providers is possible following a DD, and it can burden the health system with untreated, more severe symptoms (Kahui et al., 2017). This participant perceives medicine as unable to fix her IBD and thus has chosen to steer away. Investigating the prevalence of people who hold this opinion following a DD would be an interesting study to conduct, as an increase in people with this mindset would reflect a devastating impact of delay on the health system.

Summary

In summary, the findings in this sample are consistent with previous studies that have found that following a DD, participants lack trust in healthcare providers to treat their condition (Popov et al., 2022; Cross et al., 2023). These patient perspectives can be useful to inform future patient-clinician conversations and to ensure that their IBD concerns are taken seriously. A continuation of dismissal may lead to patient frustration and a potential avoidance of the health system.

Frustration and Anger from Delayed Diagnosis

Although some participants articulated a sense of relief once they have been diagnosed, many participants felt resentful towards their DD. Many people who are yet to receive an IBD diagnosis experience physical and emotional turmoil or a worsening of their condition that is irreversible (Melinder et al., 2017; Popa et al., 2022). As a result, frustration and anger from DD were identified. This subtheme is essential to investigate as the prevalence of frustration in this sample meant that this subtheme offers a novel perspective to the literature (Cross et al., 2023).

Consistent with previous literature, participants in this sample recognised that they were particularly impacted by the physical symptoms of IBD, which harmed their psychological and social well-being (Richard et al., 2020; Black et al., 2022; Muse et al., 2021). Importantly, participants felt they would be more psychologically and physically successful if their symptoms were diagnosed and treated earlier. As Participant 3 (25 years, 3-year delay) explained, “If I had been diagnosed sooner, it would have at least meant that I had a better chance of getting the medications I needed, sooner.” For many, the belief that their diagnosis should have happened sooner elicited emotional stress and upset, as the subjective worsening of their untreated symptoms impacts other areas of their lives, including their careers. Participant 5 explains this belief:

> The whole thing just I don’t know, it devastated me. I was kind of left with a lot of anger for quite a long time too, because I think it should have been looked at, and had I been looked at, it would not have progressed to that point and they actually could have treated it earlier. I had to change careers, I had to do all sorts of things (Participant 5, 30-year delay)

These emotional impacts described by participants in this study of having a diagnostic delay and, thus, a desire for earlier intervention are analogous to previous findings (Kahui et al., 2017; Muse et al., 2021). Participant 5 discussed his change of career as a result of his diagnostic delay, primarily because he had persistent, untreated symptoms. This resulted in lessening his workload, which is a well-established financial burden for IBD patients (Kahui et al., 2017). Additionally, untreated IBD symptoms are not only a financial threat to the patient but also to those who are caretaking for the patient. This financial threat for individuals also poses an economic threat to the economy as a whole (Kahui et al., 2017). The loss in productivity, therefore, is essential to avoid by making a prompt IBD diagnosis and striving to treat symptoms as soon as possible so they are well managed. Many participants reflect on their condition and wonder whether their condition may be more manageable with an earlier diagnosis. This is seen in Participant 9’s statement:

> When I got diagnosed, it took me 15 months before I was back at work. Still, to this day, working full-time is too much for my body. I would love the idea of working full-time, but just physically, I think that the fact my body got so shattered back then, I just can’t get the energy to do it now. So, part of me always wondered if they had gotten the right treatment while I was still young and my body could fight it a bit better, how my body would be responding to everything today. Yeah, I think in my mind, I think if I had, I would hope that it would be a huge improvement to what it is now (Participant 9, 33 years, 11-year delay)

However, having to change careers is only one negative psychosocial impact that someone may experience with untreated IBD symptoms. It is important to acknowledge that the cascade of negative impacts untreated IBD symptoms can have is devastating. For example, changing an integral part of someone’s livelihood not only impacts them financially, but also affects their mental and emotional well-being. For many, having control, a purpose, and a sense of achievement in their lives contributes to positive mental well-being, giving people the ability to appraise their symptoms and events rationally and positively (Laubmeier, Zakowski & Blair., 2004). Participant 10 (40 years, 9-10 months) articulates this, “Perhaps they could have saved me from crashing and burning and getting diagnosed at that point.” It would be valuable for researchers to investigate whether those diagnosed with IBD promptly have the same feelings of resentment, loss or change in lifestyles to evaluate the extent of how a diagnostic delay can influence a person's life and well-being and the extent of IBD's impact on these factors alone.

Another important factor in the frustration at DD is due to a lack of social participation. Undiagnosed symptoms can influence stress exacerbation, which carries into the patient's social life and interactions with others (Muse et al., 2021). One participant provides an example of this, saying:

> I guess if I had been diagnosed earlier, it would've made my life a little bit, made more sense in my life. I would've understood why. As a young person, you go out for dinner with your mates, and you can't do anything! It was, just, yeah. Now I look back and think, 'Damn, I wish I'd known earlier what it was.' (Participant 6, 39 years, 7-year delay)

When this participant discusses making 'sense' in her life, she is referring to having an explanation for her symptoms. Based on the Transactional Model of Stress and Coping, it can be theorised that a diagnosis can provide an explanation for the symptoms patients experience, thus reducing the feeling of risk and uncertainty that contributes to psychologically harmful thought patterns (Laubmeier, Zakowski & Blair., 2004). If this is true, the appraisal of symptoms would less likely be considered harmful, reducing negative impacts.

Social Connectedness

One participant uniquely expressed that a key desire for earlier intervention was due to connectivity and networking with other people with IBD. Although most participants in this study and previous findings have primarily focused on their symptom severity and treatment options as a desire to be diagnosed sooner, other studies have expressed that having a social connectedness for people with IBD is essential to positive well-being (Kahui et al., 2017; Muse et al., 2021). As Participant 9 describes:

> I think if I had got diagnosed sooner, I probably would have… there's like the camps you can go to for teenagers and all that sort of stuff, like Camp Purple where people with like Crohn's and colitis go and hang out…getting diagnosed sooner whether or not I would have had the opportunities to go and meet like-minded teenagers with the same/similar things going on. As with now as an adult, it's harder to find and connect with people who's going through the same similarities. (Participant 9, 33 years, 11-year delay)

Participant 9 exemplifies that reducing diagnostic time can decrease the psychological and social harm that is caused by active symptoms of IBD (Richard et al., 2020). As those who are diagnosed have treatment plans and medications to control their symptoms, patients can proactively participate in social events like Participant 9 described that can help them cope with their condition.

Allowing this participant's voice to be heard in this research is essential to raise questions about future research utilising participant perceptions– these being: are there differences in coping strategies between adolescents and adults with IBD? How much does age impact the social connectedness of individuals with IBD? These questions would help researchers understand the perceived experience of a diagnostic delay between age groups and potentially inform future policies about working with different age groups, as these questions are yet to be raised in the literature. Using these perspectives also highlighted the value of using the Biopsychosocial model when considering the impact of DD, as social connectedness was considered a cherished factor in reducing the impacts of DD.

Summary

In summary, the frustration and anger of a DD were directed towards the negative psychosocial impacts that come with having IBD. The perceived impacts of delay were that participants were unable to access medications to control their symptoms, had to change their careers, and were limited in connecting with others with IBD. This theme supports the theory that a prompt diagnosis would reduce these psychosocial impacts and produce better outcomes for IBD patients.

Theme 3: 'I was truly alive, but I wasn't really living for a long time.'

The theme, 'I was truly alive, but I wasn't really living for a long time' captivates the reality that undiagnosed people with IBD go through. The contrasting phrases, "I was truly alive" and "but I wasn't really living" suggest a duality in the participant's perception of existence. "I was truly alive" implies a state of physiological existence, but "I wasn't really living for a long time" suggests a lack of purpose, fulfilment, or meaningful engagement with life. This statement brilliantly depicts the lived reality described by participants with undiagnosed IBD, experiencing symptoms which control their lives and limit autonomy, causing psychological and physical burdens as an individual and their families, resentment, incontinence and shame, and social isolation. Many participants also cite the need for emotional support.

Losing Autonomy

Losing autonomy can have profound negative impacts on an individual's life. Autonomy is the ability to control your life and make independent decisions (Van Wilder et al., 2021). When autonomy is lost, people often experience adverse impacts such as loss of personal freedom, emotional distress, strain on relationships, reduced sense of empowerment, dissatisfaction with life and various other consequences (Van Wilder et al., 2021).

When discussing autonomy when people had symptoms before an IBD diagnosis, participants related to two main ideas: losing physical autonomy and social autonomy.

Physical Autonomy

Participants described losing 'physical autonomy' as being bound to the bathroom due to extreme incontinence, which most participants described as taking up most of their lives at that time. Participant 6 (39 years, 7-year delay) describes her loss of autonomy as “I was like bed, or toilet, bed, or toilet. There it was basically my existence.” Several other participants agreed, including Participant 5 (54 years, 30-year delay), who explained, “I was going to the toilet 30 times a day.” This incapacitation level can significantly negatively impact a person’s well-being (Richard et al., 2020). These impacts include limited physical activity and mobility, leading to a decline in health. The loss of autonomy from these persistent symptoms can mean patients depend on others for daily tasks and activities, impacting self-esteem and confidence (Richard et al., 2020; Black et al., 2022).

Many participants reported that despite multiple visits to their GP, they had not received adequate treatment for their symptoms until their symptoms were severe and debilitating, as Participant 5 described:

> The third time I went to him [the doctor], by this stage I’d lost a lot of weight, I was skinny as, I was in agony most of the day. I was running to the toilet upwards of 25 times a day (Particiapnt 5, 54 years, 30-year delay)

These ongoing challenges may lead to a sense of helplessness, negatively impacting overall well-being. This frequent bowel movement is described in previous research as a debilitating symptom of having IBD (Muse et al., 2021) and has been associated with negative psychological impacts (Targownik et al., 2015; Popa et al., 2022).

In many cases, participants such as Participant 3 found that before diagnosis, gaining control and predicting their symptoms was difficult, despite attempts to control diet.

> I just started waking up in the morning and would vomit immediately. I couldn’t eat, couldn’t eat food without getting sick. I could eat the right food and still get sick. There was no difference no matter what I did (Participant 3, 25 years, 3-year delay)

When people experience this level of incapacitation, they are likely to feel vulnerable and helpless. Despite attempts to gain control by eating the right food, Participant 3 still explains they were sick. This shows that when people are undiagnosed with severe symptoms, their quality of life significantly declines (Rogala et al., 2008).

Social Autonomy

Having little knowledge about gaining control of their symptoms impacted participants' attendance to social events, making participants feel socially withdrawn, fearing embarrassment or discomfort associated with their symptoms. This shows the relationship between physical and social loss of autonomy. Participant 4 (38 years, 3-year delay) says, "I always think twice before going to someone's house. For dinner, for lunch, whatever. I am quite delicate and cannot have certain types of food that would make me sick or bloated." These statements articulate the difficulty of participating in social activities that may lead to isolation. They describe how the participant may feel controlled by their symptoms and thus have to reconsider attending social gatherings in fear of rapidly increasing symptoms.

This loss of autonomy also disrupts family roles, as Participant 8 describes her experience as a new mother:

> For my daughter's first two years, I couldn't really get off the couch most of the time… I felt like a pretty bad Mum because I was just in pain all the time. She'd be crying in her cot, and I couldn't even get off the couch because I was that sore (Participant 8, 24 years, 7-year delay)

Participant 8 explains that having extreme symptoms impaired her independence and ability to look after her daughter. Her statement explained how losing her physical autonomy impacted her socially, as she couldn't carry out parental tasks, which disrupted the bonding between mother and child. She then described how this experience impacted her, "You know how babies love to climb on you and play with you, and they couldn't even touch my tummy without it being sore, and then you're frustrated and you get angry, and it's pretty horrible" – highlighting the loss of personal freedom and emotional strain that is caused by losing autonomy, which has also been found in previous studies (Van Wilder et al., 2021). This participant is an example of how a holistic model of health is essential in treating IBD, as physical symptoms have a debilitating impact on an individual's psychosocial well-being (Oligschlaeger et al., 2019).

Young Participants

A few participants felt their untreated symptoms limited their ability to engage in various aspects of their lives, including social events. This was particularly seen in participants that IBD symptoms from a young age, such as Participant 3:

> Crohn's did take a lot of that autonomy away from me for a long time. It was really hard to live with that. When everyone else was, you know, at my age drinking, partying… or whatever. I was just curled up inside a lot of the time. I took that for granted, I took a lot of things for granted (Participant 3, 25 years, 3-year delay)

By saying, "I took a lot of things for granted", Participant 3 reflected on their life before symptoms and articulated how much of an impact their symptoms had on their day-to-day life. As IBD diagnosis peaks in those aged 20-24 years old (Su et al., 2016; Seleq et al., 2023; Sclup et al., 1986), having an understanding of how a diagnostic delay can impact a young person's life is particularly important to this research as people in their youth are the most likely to have IBD, and therefore may be those most impacted by a DD. Losing social autonomy as a young adult was regularly reported in this study, with most participants describing this isolation as frustrating. Consider this statement:

> Definitely a lot pissed off because I did lose a lot of my childhood and teenage years" because "I'd be too scared to go to [parties] because I didn't want to be the one that was stinking up the bathroom, or didn't know what my body was actually going to do at the time (Participant 9, 33 years, 11-year delay)

This period of increased symptoms was regularly described as ‘lost time’, leading to feelings of resentment and psychological burden, consistent with previous research (Robertson et al., 2022).

The Importance of Intuition With Your Body

Participant 9 (33 years, 11-year delay) highlights the need to understand your body, the triggers for symptoms, and treatment methods to alleviate symptoms in social situations, as she found this difficult to achieve before diagnosis, “It was just the fear of going, and this is before getting diagnosed by like going out in a competition and not knowing what your body was going to do or being too sick to play as well.” By having a diagnosis, IBD patients can have some form of control, which research has established can alleviate negative psychosocial impacts (Larsson et al., 2017).

The importance of control is consistent with theoretical underpinnings such as the biopsychosocial model, which depicts that the level of controllability an individual may have regarding their symptoms directly impacts psychosocial impacts, including their perceived stress levels (Cohen et al., 1997). By having control and, therefore, regaining autonomy – the patient can achieve stable perceived stress and positive psychosocial impacts consistent with patients in remission (Targownik et al., 2015; Popa et al., 2022). These findings imply that by reducing the delay period to diagnosis, patients with IBD can promptly establish successful treatment methods to regain control and thus reduce the lack of autonomy IBD symptoms can impose.

Summary

Consistent with previous findings, losing autonomy due to losing physical and social independence was detrimental to participants (Khalilipour et al., 2022; Oligschlaeger et al., 2019). Losing autonomy negatively impacts an individual’s social life, independence, and family participation. These findings highlight the need for a holistic treatment model to engage with all aspects of the Biopsychosocial model to promote positive well-being (Cohen et al., 1997). In doing so, these findings support the premise that a prompt diagnosis would help individuals gain control over their IBD symptoms, thus reducing the negative psychosocial impacts of IBD.

Incontinence and Shame

In this sample, the subtheme ‘Incontinence and Shame’ was generated as participants believed incontinence significantly impacted their well-being, social participation, and self-identity. Faecal incontinence (the accidental loss of stool) has been identified in past research as a prevalent issue for people living with IBD, primarily concerning the lack of bowel control (Dibley et al., 2013). It may involve urgency, where the person cannot get to the toilet in time, or passive incontinence, where the person is unaware of the faecal loss while passing it (Dibley et al., 2013). Faecal incontinence can have a devastating social, personal, and emotional impact on an individual, which causes extreme emotional distress (Dibley et al., 2013; Kemp et al., 2012). Incontinence is a core reason why people with IBD lose autonomy over their physical, social, and emotional well-being. However, these subthemes have been generated separately as incontinence alone was a prevalent aggravator of feelings of shame and embarrassment, thus holding a significant impact on a person’s psychosocial life.

Participant 1 (53 years, 4-year delay) describes the impact of being incontinent, “Everywhere I go, I started having this panic about, you know, ‘What if something happened to me? Where’s the toilet?’ You know, that sort of feeling?” Participant 1’s statement describes the psychological distress that is exacerbated due to a loss of control of her body and how this has impacted her everyday movements. For many participants, incontinence and shame were also related to losing autonomy in their social life, which has been addressed in previous findings (Dibley et al., 2013).

In this sample, being incontinent caused participants to feel withdrawn from their social life, experiencing a loss of autonomy and a lack of control. For many participants, having this experience at a young age was particularly embarrassing, perhaps due to the stigmatisation of IBD symptoms (Wright et al., 2020). As Participant 8 (24 years, 7-year delay) articulates, “It’s also embarrassing, like I don’t want people having to run to a public toilet because I can’t control my bowels at 23 years old.” Participant 8’s statement also allows the reader to understand that although being incontinent is embarrassing on a personal level, it can also cause distress due to the patient worrying about others’ perceptions of their symptoms (Robertston et al., 2021).

> That kind of burden is – I’m a 27-year-old woman, and I’m incontinent. Like you can imagine the feelings that come with that, with not being able to live your life, and the shame and embarrassment of doing that constantly. And yearning for the life you had only a few years earlier (Participant 10, 40-years, 9-10 month delay)

As Participant 10 describes their experience, age appeared to be an aggravating factor in the impact of incontinence and shame, which can adversely affect self-identity (Robertston et al., 2021). A young individual experiencing incontinence may be subject to more critical peers with less understanding or more of a desire to be thought well of by their peers. Societal norms may let people believe that incontinent people are often elderly or have more obvious physical conditions that aren’t subject to the same stigma as IBD. Further, it is less likely that younger generations understand IBD symptoms (Popa et al., 2022). Despite this, highlighting how being incontinent at a young age can exacerbate shame is essential to address, as most people affected by IBD are typically diagnosed in their youth (Black et al., 2022). These findings can guide future research in exploring how having an understanding of IBD symptoms can prevent negative impacts of shame and raise questions as to what support systems are most effective for young people who are incontinent.

Losing control over bowel movements was a clear source of distress for participants, as being incontinent makes them feel humiliated and out of control.

> It was also a dignity stripper because, I mean, besides the fact that you know, your sort of soiling in your pants without a moment's notice sort of thing, which is probably the most humiliating experience I've ever had, dehumanising (Participant 5, 54 years, 30-year delay)

During interviews, many participants regarded their diagnostic delay experience as 'dehumanising'. This shows that the psychological impact of extended periods of waiting for a diagnosis means that individuals who suffer symptoms for a prolonged period may feel denied of their worth, dignity, or human qualities. Incontinence may intensify feelings of humiliation. Due to this, although experiencing shame is an individual impact of a diagnostic delay, it is vital to address how impacts work cumulatively to create a negative experience. In this instance, being incontinent is shameful, embarrassing, and distressing to many people, but addressing other factors of stigma, discrimination, and a lack of IBD awareness also plays into this impact as participants were often concerned about other people's opinions.

These findings are analogous to Kemp et al.'s (2012) meta-synthesis, which found that nearly all studies reported a patient's fear of incontinence. Similarly, patients in previous studies did not report frequent incontinence but rather felt an overwhelming level of shame from a previous experience of incontinence and constantly remained fearful of another episode. This, in turn, impacted patients' behaviour by causing them to withdraw from social events and isolate themselves (Kemp et al., 2012). Having avoidant behaviours by being socially withdrawn and isolated then impacts a person's psychological well-being, which is described by Kemp et al. (2012) as being 'detained by the disease.'

Interestingly, one participant suggested that having support while patients await a diagnosis may be beneficial. Seeing as incontinence can cause patients to be socially withdrawn, or physically housebound, support before a diagnosis was needed.

> Even when I was waiting to be diagnosed, I think you know I was spending, like I said before, 20 hours a day in my bed, not able to move. I didn't have a social life, I could barely eat dinner with my flat because I just couldn't eat. So I think there needs to be some sort of support while you're waiting (Participant 2, 23 years, 6-month delay)

Summary

This impact highlights that although incontinence may be an inevitable symptom of IBD for some individuals, ensuring patients regain control over their symptoms as early as possible is crucial. In doing so, diagnostic times need to be reduced to decrease the impact of symptoms. As participants cite having a loss of control, fear, and thus becoming avoidant – taking control over IBD is essential. To reduce the fear of being judged or stigmatised, campaigns to reduce the stigma associated with IBD symptoms would help reduce this impact. As age hasn't been discussed as a factor in previous studies, it is worth future research investigating how different age groups may be impacted differently by incontinence.

Theme 4: Why So Stressed?

The theme, 'Why so stressed?' addresses how stress as a result of having DD in IBD can manifest in various ways. These include a psychological and family burden, the need for a holistic approach to treatment, and how stress impacts individuals' subjective symptom severity. As stress has been a predominant impact in the previous literature, it is vital to comprehend what particular stressors individuals experience from a patient's point of view.

Psychological Burden

A significant impact that a diagnostic delay has on those with IBD is a psychological burden. Psychological burden refers to the emotional stress that people carry, usually caused by trauma or adverse events. Having a significant psychological burden can deeply affect their well-being and overall health (Engel et al., 2021).

During the Diagnostic Process

In this sample, participants described a psychological burden as a result of dealing with the health system. When participants were asked how the diagnostic delay had impacted them, there was a collective sense of frustration, upset, and loss of control during the diagnostic process. Many responses were consistent with Participant 2 (23 years, 6-month delay), who describes her journey to diagnosis as a “Very, very, very lengthy journey.” She stated, “It really *** me off. I had a lot of anger at the time, like waiting constantly, just sort of being passed onto the next person the whole time.” Other participants similarly described their experiences like Participant 3 (25 years, 6-month delay), who felt that healthcare workers didn’t prioritise his case by saying, “It was always about, ‘Look, we can bring your case to a panel, but unless you’re basically like truly down and out, unless you’re pretty emaciated, we’re not going to give it to you.” Participant 3 felt being treated like this was, “Pretty dehumanising… going through a system that needs to be basically calculated by dollar value.”

During the diagnostic process, having this experience has inevitably caused IBD patients to feel unvalued in the healthcare system. This impact is an extension to experiencing traumatic symptoms such as incontinence, whereby patients experience a culmination of persistent, adverse symptoms – only to feel dismissed by the health system when they attempt help-seeking behaviours. As a result of not feeling listened to by healthcare workers, participants believed they did not feel valued or listened to, which caused an increase in psychological stress. These negative psychological impacts can lead to worsened mental health states that could be avoided with a prompt diagnosis.

Interestingly, participants appeared to be psychologically impacted by the delay regardless of their diagnostic delay time. Participant 10 (40 years, 9-10 month delay) describes, “The whole process was about 9-10 months for that, so possibly shorter for a lot of people, for me that was really long.” Participant 10’s account highlights that although people experience varying lengths of diagnostic delay, the subjective appraisal of the delay is the most important determiner of how impacted a person may be.

This is consistent with previous research, which says that people with undiagnosed symptoms are subject to a psychological burden (Bernstein et al., 2016). This study focused on the subjective perspectives of participants, as the impact of a delay was assumed to be more about the psychological impact, rather than the length of the diagnostic delay. However, the research about whether a diagnosis can relieve psychological stress is in its infancy, and further investigation is required.

To investigate the role of a diagnosis further, participants were questioned about their delay experience. During interviews, participants articulated growing concerns and fears associated with not having a diagnosis. For example, Participant 10 (40 years, 9-10 months) says, “I had an increasing sense of ‘something is wrong’, and I didn’t know what it was.” Participant 3 (25 years, 3-year delay) cleverly describes this feeling, saying, “It was like I was living a life where the rules were changing constantly, and I had to keep up with them.” Acknowledging that the world is changing around him and that he was responsible for keeping up with everything else suggests that he felt socially isolated and overwhelmed during this experience, which has had a prevalent impact in other studies (Kemp et al., 2012).

The psychological burden that participants carried before receiving a diagnosis also relates to their stress and anxiety. This experience, for many participants, appeared to introduce paranoia, where they were concerned that any changes to their bodies would lead to something rather sinister. For example, Participant 3 (25 years, 6-month delay) described his experience as, "I would feel any sort of like sensation in my body, and my mind would instantly jump to something bad. I'd dismissed something like that before, and it had failed me pretty miserably." Similar to anxiety about incontinence, stress about symptoms would often be based on past experiences, but the impact of those is lasting.

Participant 3 describes a hyper-awareness of his symptoms due to previous experience. His experience can be applied to the Transactional Model of Stress and Coping, which explains that an earlier negative experience forms his appraisal of sensations in his body. Due to a previously negative experience, he then attributes his symptoms to a potentially harmful state, increasing stress and worry. As Participant 3, at this time, could not attribute his symptoms to IBD, his coping strategies would more likely be emotionally charged and negatively appraised (Laubmeier, Zakowski & Blair., 2004).

This perspective is important because the physical impacts of undiagnosed IBD can easily lead to negative psychological impacts, as this example illustrates. Future research should investigate how to assist people in this position to support those vulnerable to this increased stress, which may simultaneously worsen their physical condition.

Coping Mechanisms

An important way to reduce the psychological burden of a diagnostic delay is by understanding the coping mechanisms an individual may have pre-diagnosis. For example, Participant 10 (40-year, 9-10 months) described their diagnostic delay experience as feeling out of control. However, she articulated that "I didn't feel any relief by having a diagnosis. I wasn't stressed because I didn't know what was wrong. I was stressed because I was unwell." In saying this, it can be argued that although a diagnosis is important for some IBD patients to experience relief or an explanation of their disease (Berstein et al., 2016), perhaps having control over symptoms is a more important factor in reducing psychological burden.

This is important to address because even once participants received a diagnosis, some argued, like Participant 9, said, “I don’t think you ever stop stress, there’s always some sort of cloud hovering, but you have to kind of brush it aside if you want to try and get through life.”

Summary

As previous research has noted, following a diagnosis, patients with other chronic diseases were required to find new coping mechanisms to adjust to their condition, including psychological adjustment, work status, and well-being (Ridder et al., 2008). Despite a diagnosis not providing relief for some, it may at least help IBD patients gain control over their symptoms with a treatment plan and give them more time to adjust to new expectations of their lifestyle. Further research in this area is required to guide support methods and treatments for people in this situation.

Burden To Family

Another psychosocial impact identified from this sample was feeling like a burden to their families. Many people suffering a chronic disease require support groups, including family, to successfully guide and assist the individual through the adverse consequences of a chronic health condition (Richard & Shea., 2011; Shulman-Green et al., 2012). However, many participants felt that because of their DD, they were a burden to their family. Consequently, feeling like a burden added to their psychological stress, and thus the ‘Burden to Family’ is an essential psychosocial impact to analyse.

For many participants waiting for a diagnosis, the persistent, unexplained symptoms led to emotional turmoil for not only the individuals experiencing them but also their families. Having an unwell family member with no definitive explanation can be distressing.

Participant 2 (23 years, 6-month delay) described the stress of her unknown condition, saying, “I think during that time I was very stressed, my parents were stressed (as they should be), my flatmates were stressed about me. I think I carried a lot of that stress as well.” This psychological burden related to an individual’s family may impact their well-being (De Sousa et al., 2022). Seeing other people’s stress related to a personal condition may induce guilt in the individual, increasing feelings of embarrassment and shame (Robertson et al., 2022).

Additionally, it can be hypothesised that when IBD patients are experiencing symptoms without a diagnosis – a lack of IBD awareness may play a crucial role in how families appraise the stressful situation and overcome it.

> None of us knew what Crohn’s was at the time, we were just a bit shocked but relieved that I’d finally been diagnosed, but a bit pissed that it took 10 years to finally get the answers as well. Here we are! (Participant 9, 33 years, 11-year delay)

Having an increased familial awareness of IBD and its symptoms may drive help-seeking behaviours, but it may also help families become more sympathetic towards an individual’s situation. As Participant 9 described, none of her family knew what Crohn’s was, meaning that they are less likely to have understanding and strategies to manage Participant 9’s symptoms. In doing so, individuals may feel more isolated and like a burden to their families which increases stress (Robertston et al., 2022). Although the literature has not examined this subject in depth, it would be worth investigating how a lack of awareness contributes to feelings of burden to an IBD patient’s family.

Family Independence

During interviews, participants described that the burden on their family was related to losing or adjusting their role in the household, such as Participant 5 (54 years, 30-year delay), who said, “For a long time, I’ve not been able to work. That also strips your dignity, it strips your self-worth. I felt like I was a parasite living off my wife kind of thing, and she would be horrified to hear me say that because I did kind of say that once and she, you know, gave me what for saying something like that. And she was right, but I did feel like that." In this situation, although Participant 5's family may not perceive him as a burden, the self-conscious emotions of feeling like a burden still exist.

> Before I was contributing equally to the household and all this kind of thing to have her carry us financially, have to tend to me, all of those things it's, well, I know these are acts of love and everything else, and when you marry it's you know in sickness and health and all of those things, and she lives that. But, you don't really expect that to happen and you do feel like you're sponging almost. It does a lot, especially to someone who is normally very independent, very much aware of my responsibilities and duties, and various other things. It was dehumanising (Participant 5, 54 years, 30-year delay)

This example provides an explanation of how a diagnostic delay can impact the 'social' aspect of the biopsychosocial model. When family circumstances are compromised, such as not being able to functionally contribute to a household, it shows that the impacts of the disease are more than physical. Instead, having physical symptoms can lead to changes in family dynamics and participation, which in turn, negatively impacts people's well-being (Engel, 1977; Dent et al., 2022). Importantly, this statement provides context for how detrimental a diagnostic delay can be. If individuals are unable to control their symptoms, the impacts go further than affecting the individual alone. Introducing support plans for families who are caring for someone who is chronically ill would be helpful.

Finally, the impact of a diagnostic delay can go as extreme as people fearing the worst of their situation, such as preparing for death. One participant articulated that his symptoms were severe enough for him and his wife to independently plan for his death.

> My wife and I had both independently, although we hadn't communicated it to each other at that time. We thought this is probably colorectal cancer, I'm probably dying. I started making preparations to basically wrap up all my fares and make sure that everything was right for my wife when I died because I assumed, 'This is it, I am doing to die.' She did as well, I found that out only afterwards because I didn't want to say anything to her for fear of upsetting her, but she was doing the same thing. She thought, 'This is it, he's on his way out (Participant 5, 54 years, 30-year delay)

This participant statement was crucial to include as the psychological impact of preparing for your own, or your partner's death is extreme. This partnership likely suffered anticipatory grief, which can lead to extreme emotional distress. The emotional strain this couple endured while they prepared for an impending death would have significantly impacted their well-being and the dynamic of their relationship. If Participant 5 had received a prompt diagnosis, the concerning burden on this couple would have ceased to exist.

Summary

In summary, addressing the burden to the family an individual with DD can feel highlights how reducing diagnostic delay in IBD patients should be an urgent discussion. Losing independence in family roles and seeing grief in others introduce psychological impacts of this experience which could be severe.

Need for A Holistic Approach

Psychological Support

While waiting for a diagnosis, participants found that there was no emotional or psychological support to help them navigate their symptoms. Additionally, they found that techniques for managing stress were not recommended when presenting to the GP. Because of this, many participants argued that there was a dire need for a holistic approach to treating IBD symptoms. Thus, the subtheme of 'Need For a Holistic Approach' was generated. This theme is crucial to assess as IBD is gradually being treated as a holistic chronic disease, with more focus on the psychological and social well-being of individuals, as well as the physical symptoms (Kahui et al., 2017). Analogous to the biopsychosocial model, all three aspects have an impact on each other, and treatment methods should reflect this to reduce the psychological impacts of a diagnostic delay in IBD patients.

> The thing was, a lot of the advice I was being given, both in the run up to my prognosis, and diagnosis was pretty lacklustre. There wasn't any referral to counselling or anything for the psychological damage that it can inflict. Participant 3 (25 years, 3-year delay)

Without psychological support, people who are awaiting an IBD diagnosis may not have successful coping mechanisms to deal with their symptoms. Additionally, the lack of psychological support for IBD patients' social networks may mean worsened psychological outcomes for families and friends also. Participant 2 (23 years, 6-month delay) also relayed the need for psychological help.

> I think having someone there would have been really beneficial. For the stress levels too, like you're just waiting to know what's going on, and just having someone you can talk to from an external point of view would have been very beneficial (Participant 2, 23 years, 6-month delay)

It seems apparent that there is a gap in the treatment of people with IBD. A lack of psychological support can negatively impact a person's physical symptom severity, worsening their condition (Popa et al., 2022). By reducing stress levels and aiding those who suffer from a diagnostic delay, the impacts may be reduced (Kahui et al., 2017) At this stage, the New Zealand health system does not offer psychological help for those suffering IBD symptoms, even after a diagnosis (Kahui et al., 2017).

> They don’t really look at the wider picture. They don’t look at the role of stress, they don’t look at the impacts on people. And frankly, they tend to side their advice on the dietary side of things too, when these things should be addressed altogether. Crohn’s disease isn’t curable, but it is much more manageable when you take the psychological and nutritional into account (Participant 3, 25 years, 3-year delay)

There are various methods of preparing an individual for a chronic disease diagnosis. First, healthcare specialists can provide the patient with educational materials. Second, increasing IBD awareness will help patients and their families be aware of the symptoms, and have knowledge of what the nature of the condition is. And third, preparing patients for the nature of IBD may reduce the shock factor of receiving a diagnosis, and help them employ better coping mechanisms when dealing with the disease (Laubmeier et al., 2004).

Networking

Additionally, when participants suggested the need for emotional support, the majority suggested that the most effective method would be via networking and support groups. Many participants believed that although receiving support from a psychologist may be useful, having support groups with people who have had a similar experience of a diagnostic delay will be the most impactful. As Participant 5 (54 years, 30-year delay) says, “I think support groups more than formal counselling.” Support groups would be a cost effective and efficacious method of helping people with IBD.

Adopting other methods of support

Finally, one of the key reasons to acquire a holistic view when helping people who have experienced DD is also due to trust levels between the patient and specialist. As previously discussed, having a DD and lack of awareness from a GP has contributed to mistrust in healthcare providers. However, healthcare specialists using a narrow approach to treatment has increased feelings of frustration and mistrust from patients. Participant 7 illustrates this context well:

> A very very high rated Melbourne gastroenterologist, they were still telling people, or me, that diet has nothing to do with it. It will help the symptoms, but it won't cure the disease. Which I still believe is true, but for example, I could have, after a few years I was on a liquid only diet because I was really unwell, but there was no nutritional support, no dietician support, no nothing. It was 'just have liquid food', and that was the end of it. There was no discussion of Ensure, no discussion of dietician or curing foods, and I lost 12 kilos. You know? So it's really bad (Participant 7, 56 years, 23-year delay)

Following her explanation of her experience, she remarks, "I think there's a real, even from a top specialist, there can be a real disconnect between the patients and the holistic view of what it actually means to have a chronic illness and how it affects you."

Summary

This perspective shows that patients feel strongly about having a holistic approach to treating IBD symptoms, which should be considered in future treatment plans. Helping patients take control of their symptoms through holistic methods will likely increase their psychological well-being, participation in social activities, and quality of life.

Subjective Symptom Severity and Stress

The final impact of 'Why so stressed?' identified in this sample was the subjective symptom severity of participants and its relation to their perceived stress. Stress is a prevalent discussion in the literature, but findings are often critiqued due to the lack of accuracy of participant recall (Khalilipour et al., 2022; Vavricka et al., 2012). However, this study focused on participant perceptions of symptom severity and stress, as having a negative appraisal of these two factors will, regardless, contribute to negative psychological consequences (Cross et al., 2023; Popa et al., 2022; Melinder et al., 2017). Discussing symptom severity and stress is a core aspect of the impacts of diagnostic delay, as its impacts on individuals are well-established. Still, previous researchers have prompted a further investigation into participant perspectives, which this study aims to achieve (Cross et al., 2023).

Lifestyle Stress

One participant found that experiencing an influx of lifestyle-related stress may have initiated her symptoms.

> It was when I had just moved to England. I didn't speak a word of English. So my symptoms after I had quite a big stress episode. And then I started going to the toilet continuously. But definitely, I think England killed me! (Participant 4, 38 years, 3-year delay)

This participant suggests that following a stress episode, her symptoms began. It is possible that the experience of stress could have manifested her IBD symptoms, as stress is often linked to gastrointestinal issues (Melinder et al., 2017). However, it is possible that other factors such as diet could have influenced this initiation of symptoms.

The Role of a Diagnosis

During interviews, participants were asked whether they felt there was any difference in their stress levels before and after their diagnosis. Many participants, like Participant 10 (40 years, 9-10 month delay) felt relief with a diagnosis because there was a reason behind their symptoms, and how they were feeling. "Definitely. Yeah [stress relieved with a diagnosis]. Because there was a reason for how I was feeling." Similarly, Participant 2 (23 years, 6-month delay) "I wouldn't say it [stress] was alleviated. I think it was a relief in a sense, 'Okay, I've got an answer.'" Participant 9 also felt that although a diagnosis came as a shock, having a reason behind their symptoms helped them feel relieved.

> I think at the time when I got diagnosed, I was relieved, definitely shocked, but I think just a sense of having a reason and a purpose as to why I was sick, without feeling like no one understood me or believed me, or all that kind of stuff behind it (Participant 9, 33 years, 11-year delay)

Having this relief from a diagnosis meant that their stress levels were reduced, as there was an explanation for their symptoms. Thus, for these participants, a diagnosis provided a relief of stress, as opposed to causing stress. However, I assumed that most participants were relieved by a diagnosis, and this wasn't always the case. Some participants felt upon receiving a diagnosis, their stress levels increased as a diagnosis should have come much earlier:

> I know when I was diagnosed and I heard the words, 'Oh yeah you do have Crohn's', it was like a mix of relief, like yay, I finally have an answer to being angry. 'You should have known this five years ago (Participant 8, 24 years, 7-year delay)

So perhaps, in this situation, although having a diagnosis may provide relief for some, having a delayed diagnosis may further encourage higher stress levels, but further research is required in this area.

Interestingly, many participants found that once they had received a diagnosis, the stress was not completely alleviated. I had assumed that with a causal explanation for their symptoms, stress would be alleviated. However, participants pointed out that receiving a chronic diagnosis certainly introduces a different type of stress, where persistent symptoms may be better managed but not completely subsided. A great example of this was Participant 10 (40 years, 9-10 month delay) articulates this well, saying: "I didn't feel any relief by having a diagnosis. I wasn't stressed because I didn't know what was wrong, I was stressed because I was unwell." The implications are that although a diagnosis can somewhat alleviate stress, it does not necessarily remove it; the stressor changes. Regardless, a prompt diagnosis will benefit patients, but helping patients learn to manage stress is still essential to control symptom severity.

Stress & Symptom Severity

In this sample, most participants agreed that their stress was related to their symptom severity:

> Yeah, I think stress is related to them [symptoms], especially before I got diagnosed. I think a lot of that, like that my body was stressed because I couldn't do anything. I couldn't digest anything. I think a lot of stress does carry through into how I felt (Participant 2, 23 years, 6-month delay)

Participant 2's perspective that stress and symptom severity are related is also corroborated by Participant 3's (25 years, 3-year delay) account, who says: "By that stage, it was already getting quite bad. The stress was not helping, and the external stress was making me sicker, and me being sicker was making me more stressed." Participant 3 particularly highlights the bidirectional link between stress and symptom severity. Previous findings have discussed this association, which depicts that stress influences gut-brain communications, which affects symptom severity (Ge et al., 2022). Although this association has been primarily assessed quantitatively, having this insight shows that in this sample, participant perspectives align with the objective measure of stress and symptoms (Ge et al., 2022).

These findings imply that, consistent with past research, when individuals experience stressful events, they are likely to perceive their symptom severity as worsened compared to when they are not stressed. Because of this, managing external stress should be a priority for those experiencing IBD symptoms, whether they are formally diagnosed or not. As DD can cause stress, and stress is related to changes in symptom severity in other gastrointestinal conditions, it would benefit healthcare workers to apply stress management techniques to anyone experiencing symptoms similar to IBD (Nguyen et al., 2017). Although timely diagnosis of IBD is essential, this also supports the argument that treatment of IBD should have a holistic approach to reduce the negative impacts of a diagnostic delay, as previously discussed.

As discussed, the various impacts of a diagnostic delay can include affecting an individual's psychological, social, and physical well-being. Often, participants noted that when their symptoms were heightened, there was additional stress due to symptoms impacting their daily lives. This stress was often relieved once they had control of their symptoms. Nearly all participants perceived their stress as less severe once in remission, as their symptoms weren't impacting their daily lives. Participant 2 (23 years, 6-month delay) further described this: "I am much more in control [than before being diagnosed] of my stress now because I don't really have any issues day to day with my IBD. I'm in remission, so I don't have any day-to-day stresses."

Summary

In summary, stress can exert itself in many forms, the solution to alleviating stress in those with IBD, or undiagnosed symptoms is complex. Although a diagnosis may be helpful to many, receiving a chronic diagnosis is also a cause of stress, and many experience symptoms post-diagnosis that may contribute to stress. Having control over stress is, therefore, the most important factor to assess in those with IBD, and further research is required to ascertain this.

Chapter Four: Discussion

This study aimed to examine people's experiences of a perceived DD and the relevant impacts of a DD in those with IBD. Two research questions guided this study: What do people with IBD perceive as the main barriers to diagnosis? What are the main impacts of having a DD on those diagnosed with IBD? This was achieved through interpreting the perspectives of adults diagnosed with IBD. To interpret the findings, I used my experience of DD alongside existing broader IBD research, which is paramount for reflexive thematic analysis (Braun & Clarke., 2006). The motivation for this study was that previous research has not investigated the subjective experience of what IBD patients perceive as contributing factors to and the relevant impacts of a diagnostic delay.

To the author's knowledge, at the initiation of the study, this was the first study to explore the patient's perceptions of diagnostic delay in those diagnosed with IBD. However, recently, there was a published study of a similar nature, and its results have been included in the literature review and discussion of analysis.

Reflections

Before this investigation, researchers have established that low health literacy and IBD awareness are significant contributors to diagnostic delay (Colombara et al., 2001; Khalilipour et al., 2022; Kahui et al., 2017). Further, a diagnostic delay can remarkably contribute to worsened health outcomes in many forms, including increased rates of surgeries, hospitalisation rates, and lasting psychological, physical, and social damage that IBD symptoms can inflict (Khalilipour et al., 2022; Lee et al., 2017; Miles et al., 2017). Consistent with past research, low IBD awareness was found to be a prevalent barrier to diagnosis. Based on these findings and from personal experience, at the initiation of this research, I held the assumption that IBD patients desire a diagnosis as an explanation for their symptoms and that with a prompt diagnosis, stress and negative psychosocial impacts would be alleviated.

However, I was surprised to find that in addition to the negative psychosocial impacts symptoms may cause for some IBD patients, frustration and resentment towards the health system from DD and mistrust in healthcare providers were a more prevailing cause of emotional adversity, which is a novel finding to the literature. Many participants articulated to me that even with a diagnosis, stress is persistent. However, having a prompt diagnosis would mean that IBD patients may have earlier control of their condition through medications and lifestyle. This prompted me to return to my literature review chapter and realise that the level of resentment in IBD patients who have experienced DD is not well-researched. Delay outcomes have been mainly quantitatively measured, primarily focusing on symptomatic rather than emotional outcomes.

By exploring this idea, I developed my understanding of a DD's unique and subjective influence on an individual. As this thesis is about the perceived impact of a DD, it was important to explore the impacts of a delay in various areas, such as the journey to diagnosis, participants’ emotions towards the healthcare system, and the psychosocial impacts related to the delay from a subjective perspective. It was interesting to hear that many people retrospectively reflected on their diagnosis experience negatively due to various reasons. This change in perspective offers new insights into future research, where investigating the notion of resentment when reflecting on a DD may produce valuable findings.

Findings and Implications

The findings presented a nuanced intersection of factors that impacted the participants in this sample. A delayed diagnosis in this sample meant that many participants experienced a significant portion of their lives undiagnosed and, therefore, unable to access effective treatment. Being undiagnosed, for many, led to feelings of dissonance and helplessness.

Being undiagnosed also meant that participants felt misunderstood by healthcare providers, family, and friends – which led to feelings of resentment and frustration, which have been earlier described in these findings and the diagnostic delay literature (Cross et al., 2023; Vavricka et al., 2012; Khalilipour et al., 2022). These impacts have been established as connections between themes of this research, summarised in Table 6.

This research found that, across all themes, a lack of IBD awareness served as the foundation for all themes of the impact of DD. Every subtheme alluded to how a lack of awareness has contributed to their diagnostic delay, as well as the relevant psychological and social impacts of a delayed diagnosis. Addressing the current approach to IBD intervention and care is essential to reduce the impacts of diagnostic delay.

Table 6. Connections Between Themes

Theme	**Characteristics**
Lack of Awareness	Initial unawareness leads to misdiagnosis, dismissal of symptoms and a delay in diagnosis.
Dissonance	The disagreement between patients and healthcare providers about symptom severity, diagnostic procedures, and management care.
Helplessness	The vulnerability of participants when themselves or others didn’t understand their condition, symptom severity, or help-seeking needs.
Frustration and Resentment	Retrospective negative reflection on the diagnostic procedure, misdiagnoses, and undermining of symptom severity.

Barriers to Diagnosis

One of the key questions in this research was addressing what participants perceived as the main barriers to diagnosis. With dramatically increasing rates of IBD, it is essential to understand the barriers to diagnosis to guide policymakers and researchers in reducing DD.

Previous research has established that low health literacy and a lack of IBD awareness are primary barriers to diagnosis. Still, research hasn’t investigated the perception of an IBD patient (Melinder et al., 2017; Popa et al., 2022). Interestingly, although a lack of IBD awareness was cited as a core contributor to the delay, there were also other prevailing factors, such as a lack of incentive from GPs to investigate the IBD symptoms that were mentioned.

Aotearoa’s Current Approach to Care

In New Zealand, gastroenterologists can formally diagnose people with IBD through a colonoscopy and the hospital emergency departments that treat people with severe IBD (Kahui et al., 2017). Many participants were not diagnosed until several years after repeated GP visits, with a worsened symptom severity and high levels of stress and emotional burden, where they presented to the emergency department and were finally diagnosed.

As a result of this DD, participants discussed absences from work or school, career changes, or withdrawal from social interactions. The loss of productivity caused by these absences is predicted to cost around $16 million per year (Kahui et al., 2017). Further, these absences were found to exacerbate negative psychosocial impacts in participants, such as feeling psychologically burdened. These impacts of a DD are consistent with previous research and are recognised threats to an individual’s quality of life in the literature (Kahui et al., 2017; Popa et al., 2022).

Having a DD means that IBD patients are at risk of financial loss due to repeat visits to their GP. These repeat visits with no diagnosis made, alongside repeated payments for these appointments, can heighten emotional stress. This emotional stress caused by financial loss poses an economic cost for the New Zealand health system as repeat visits mean GP resources are being wasted, and increases in stress means that people are more likely to seek psychological support or services (Kahui et al., 2017; Lee et al., 2017).

As participants have described, they were often diagnosed once they were gravely ill. Therefore, a prompt diagnosis would reduce avoidable, more invasive interventions, which would help reduce the burden of delay. With the growing prevalence of IBD in Aotearoa, we do not have the resources to cope with the various impacts of DD and need to consider a proactive method of IBD diagnosis.

Removing the Barriers to Diagnosis

According to a 2017 national report, the current IBD care model is reactive, inadequate and inconsistent (Kahui et al., 2017). Thus, to determine how to make care models proactive, we must understand IBD patients' perceptions of the barriers to diagnosis, as these perspectives are novel to the literature. A lack of symptom identification, misdiagnosis, dismissal of symptoms, and a lack of further investigation were consistently reported in this sample. Participants frequently did not feel listened to by their GP, which compromised their trust in health providers. Feeling disconnected from a GP or mistrusting them will make patients less likely to seek help. So how can we help them?

Raising Awareness. Among this sample, the lack of IBD awareness was seen as the original issue that prevented further investigation and encouraged misdiagnosis of symptoms. Given previous research, a lack of IBD awareness as a barrier to diagnosis was not a surprising finding in this sample (Robertson et al., 2022; Kemp et al., 2012; de Ridder et al., 2008; Vernon-Roberts, Gearry & Day., 2022; Cross et al., 2023; Kahui et al., 2017; Richard et al., 2020). However, limited studies have assessed the impact a lack of awareness has from a patient's perspective (Cross et al., 2023).

Participants perceived GPs or specialists as unaware of IBD symptom identification or the severity of IBD, so they were less likely to investigate further. Additionally, analogous to other IBD research, the lack of IBD awareness among participants and their families meant that symptoms were disregarded or misattributed to other conditions, and misdiagnoses made by GPs were generally accepted by participants, which hindered advocacy for further exploration (Blackmore et al., 2020; Cross et al., 2023).

Interestingly, once a GP made an initial misdiagnosis, participants were consequently more likely to disregard their subsequent flare-ups, which hindered help-seeking behaviour. As explained in the Schulman-Green Model of Self-Management, disease knowledge plays a fundamental role in a person's ability to self-manage. If people did not know how and why to manage their condition, self-management efforts were inhibited (Schulman-Green et al., 2017). A lack of awareness was also related to mistrust in healthcare providers, as GPs who were perceived to have inadequate knowledge about IBD symptoms were considered less trustworthy. Consequently, participants were left with delayed diagnoses and lost trust in the healthcare system. Suggestions can be made to assist with raising awareness.

Suggestions to Raise Awareness. First, raising awareness in communities of IBD symptoms and the differences between conditions such as IBS and haemorrhoids and when patients should consult a health physician with symptoms through public messaging and campaigns could encourage earlier help-seeking. As many people with IBD symptoms are in their youth, increasing public awareness of IBD symptoms, the seriousness of symptoms, and where to access help through social media platforms would be particularly effective. In studies of bowel-related cancers, raising public awareness was an effective method of improving help-seeking behaviour (Durkin et al., 2019).

Further, implementing IBD training and education in GP practices may assist with earlier identification. Methods are available, such as the Royal College of General Practitioners' collaboration with Crohn's and Colitis UK, who have created an IBD toolkit to educate GPs about identifying and managing IBD (Royal College of General Practitioners, 2015). One of the key features noted in this toolkit is that IBD can be diagnosed mainly in teens or people in their twenties and that it can occur at any age. Bringing awareness to the prevalence of IBD in young people may help a GP identify patients whose symptoms are dismissed because of their young age, and may encourage an investigation of IBD (Royal College of General Practitioners, 2015). The tool kit could also be tailored to the New Zealand health system by including and managing IBD in Māori and Pasifika communities and ensuring culturally appropriate diagnosis and management.

Using a tool kit like this may reduce delay times, assisting patients in reducing flare-ups with medications and treatment. This would mean that flare-ups are more manageable, reducing hospitalisation rates and symptom severity and decreasing the psychosocial impact of flares (Nistor et al., 2022). Having IBD recognition from a GP will not only mean earlier intervention and diagnosis, it could also mean that IBD is less commonly mistaken for conditions such as haemorrhoids, stress or IBS. Finally, if GPs and patients know the severity of IBD symptoms and the importance of a prompt diagnosis, there may be an incentive to investigate gastrointestinal symptoms further (Kahui et al., 2017).

Reducing Dissonance. Dissonance in this research refers to disagreements between patients and healthcare providers about symptom severity, diagnostic procedures, and management care. Many participants felt that their GP was not listening to their symptoms being as severe as they were saying, which created disagreement. The impact of this was that participants felt unheard and not cared for by their GP or specialist. Similar perceptions have been shared in the IBD literature, as participant perceptions towards GP management of symptoms have primarily been negative (Cross et al., 2023). However, the overarching emotion of dissonance is a novel finding.

Dissonance was seen when GPs dismissed a participant’s symptoms and told them it was psychological or when the diagnosis was delayed to what participants viewed as an unreasonable extent. Further, dissonance was seen when participants believed they could manage their symptoms through diet and lifestyle. However, they were told by healthcare workers their efforts would be futile. Participants consequently perceived their GP as ignorant and uneducated, encouraging some participants to avoid medical treatment. At the same time, many were fastidious in their choice of GP in later years, which was seen in the theme of mistrust in healthcare providers. The implications of this impact are possibly dire, as an increasing desire for pseudoscience as a result of mistrust in health professionals can potentially damage people’s health and pose an economic threat (Kahui et al., 2017). Although raising IBD awareness will help avoid this issue, establishing better rapport between the GP and patient is also essential to resolve dissonance issues.

Suggestions to Reduce Dissonance. GPs should feel incentivised to create a trusting relationship with their patient and show empathy towards their concerns. Particularly when a diagnosis is not reached, showing the patient that they are pursuing a solution or providing other recommendations for diet change, reducing stress, and other holistic approaches to well-being may be effective. This would mean that IBD patients are less likely to feel dismissed by their GP and, thus, are willing to approach them when symptoms persist. This issue highlights the pivotal role of the biopsychosocial model. Not only is a patient directly impacted by their condition, but the management and treatment of a condition should also be treated considering their physical, psychological, and social health. It appears that in this sample, recognition of lifestyle in the role of IBD is poor.

As a result of dissonance between GPs and patients, many participants described a feeling of helplessness when they could not control their condition in other ways. As the literature in this area is in its early stages, further research is required to investigate how dissonance between a patient and doctor can influence delay time and how dissonance can contribute to the negative impacts of delay. It would be interesting to conduct a study to investigate people who believe they have a serious disease, where it ended up being something less sinister, like haemorrhoids. It may be likely that some people perceived their symptoms as sinister, although IBD may not have physically manifested until much later in life. This means their diagnostic delay may be shorter than they believe, but further investigation is required to assess this phenomenon. As this was a frequently reported interaction between the GP and patient, it is worth investigating the prevalence of cases where symptoms are caused by a minor illness, even when they're perceived to be part of a more grave diagnosis.

Moreover, the feeling of helplessness was identified as a product of dissonance between a GP and a patient. Similar suggestions can be made to improve helplessness as these connections between themes are related.

Reducing Helplessness. In this study, helplessness is described as the participant's perceived inability to help their symptom severity or help-seeking needs. Compellingly, feelings of helplessness primarily arose due to the dissonance between participants and their GP, as they felt they could not help to improve their condition. Helplessness was related to many psychosocial themes in this research, including the psychological burden participants carry, incontinence and shame, and losing autonomy. For many, helplessness manifests as loss of control and autonomy, which are detrimental to maintaining positive well-being and low-stress (Cohen et al., 1997; Oligschlaeger et al., 2019).

While seeking a diagnosis was not the objective for many participants, most participants sought psychological and nutritional advice to help manage their symptoms, and many were told that diet was not related to their symptoms. Being unable to adjust their lifestyle habits meant that participants felt more out of control, increasing the psychological burden and shame, particularly when incontinent. Additionally, the feeling of helplessness for many participants extended to when they felt withdrawn from careers, social experiences, and food-related activities without psychosocial and nutritional support. The lack of psychological support also compromised participants’ well-being in other areas of this research, including participants’ ability to cope with stress.

Suggestions to Reduce Helplessness. It appears that, akin to addressing awareness and dissonance, feelings of helplessness can be solved through increasing IBD awareness. GPs will have a better understanding of diagnosis and treatment, meaning they will be able to tell patients what they can do to manage their condition better. Second, addressing helplessness is related to the GP's approach, ensuring they convey empathy towards the patient’s situation by assuring them they can help regain control over their symptoms. As helplessness and dissonance appear to have a reciprocal influence on each other, several suggestions can be made to help reduce both feelings simultaneously.

Addressing Psychosocial Support. According to a 2017 national report, most IBD patients cannot access psychological support as IBD is categorised as a Non-Communicable Disease rather than a Long-Term Condition, meaning IBD patients do not qualify for psychological support (Kahui et al., 2017). Many participants found having a diagnostic delay incredibly distressing when their GP wasn’t perceived to be on their side. Neglecting to provide psychological and nutritional health support means that people may feel more helpless as they cannot cope with their symptoms. This issue also represents the current lack of acknowledgement of IBD as a biological condition with psychosocial consequences.

Analogous to the Shulman-Green Model of Self-Management, maintaining control of one’s chronic condition through attending to illness needs, activating resources, and adapting to the challenges of having a chronic disease is crucial (Shulman-Green et al., 2012). Without dietary and well-being support, patients resort to self-investigation of methods that might help them feel in control. In contrast, those who don’t feel they have the resources to control their condition feel helpless, which negatively impacts their psychological health. This shows that by using a holistic model of health, gaining control of a patient’s physical symptoms will significantly help their psychosocial well-being. Gaining control is particularly important, as many participants reported feeling more in control following a diagnosis as they had the resources to cope with their symptoms.

This prompts a critical need to introduce psychological support. Analogous to the biopsychosocial model and numerous IBD studies, practices such as cognitive behavioural therapy can improve the quality of life of IBD patients (Kahui et al., 2017). Additionally, it has been recommended to provide free counselling or emotional and well-being support for those who have suffered DD. These services should be available to those waiting for a diagnosis and feeling distress, but also to diagnosed patients coping with their DD experience (Kahui et al., 2017). These services would promote positive mental well-being, and having a GP provide holistic support options for those with undiagnosed symptoms may increase trust and rapport between them and the patient.

Reducing Frustration and Resentment. Finally, this study revealed an interesting pattern not articulated in the IBD literature. Participants discussed the barriers to diagnosis and the impacts of DD separately, but these factors should be congruent. The concluding impact of a DD described by participants was feeling frustrated and resentful towards the health system and their DD journey, as they did not perceive a delayed diagnosis as reasonable. This research describes frustration and resentment as the retrospective negative reflection on the diagnostic procedure, misdiagnoses, and undermining of symptom severity.

It was apparent that participants who perceived GPs to lack IBD awareness knowledge tended to mistrust healthcare providers. Consequently, when a delayed diagnosis caused significant disruption to their lives, including an absence from social events, career changes, and poor mental health – emotional frustration and resentment became directed towards healthcare providers. Although they initially placed trust in their GP to have IBD awareness and provide appropriate care for their symptoms, participants ultimately felt betrayed by the health system as their delayed diagnosis worsened their physical symptoms, leaving them in emotional turmoil. A key frustration for participants stemmed from the realisation that a timely IBD diagnosis is feasible, given the availability of diagnostic procedures and medical resources.

During interviews, the complexity of diagnosing IBD when symptom recognition is poor was discussed with participants. Although many participants lacked IBD awareness themselves, they revealed an implicit expectation for GPs and specialists to identify IBD as part of their duty of care.

Suggestions to Reduce Frustration and Resentment. To reduce frustration and resentment, adopting a holistic model of care alongside the biopsychosocial model would mean that the psychosocial and nutritional aspects of having IBD symptoms would be cared for. In doing so, healthcare workers can acknowledge the impact physical symptoms of IBD have on a patient's psychosocial well-being, thus reducing the feelings of dissonance and helplessness that have been described in this research. Further, increasing awareness of IBD recognition and intervention would encourage more prompt diagnoses, reducing diagnostic delays. If these factors are addressed, frustration and resentment towards the health system should diminish.

Summary

In summary, various recommendations can be made to ease the burden of IBD. These issues raised by participants are summarised in Table 7. Although this research cannot contribute to primary prevention and addressing social determinants of health and equity, these recommendations may ease the growing burden of IBD from a patient's perspective.

Table 7. Summary of Systemic Issues and Recommendations

Issues	Recommendations
Lack of public awareness about symptoms of IBD.	Increase public campaigning of IBD symptoms, the difference between IBD and IBS, and when to consult a health physician.
Lack of GP awareness of IBD.	General Practitioners toolkit – identifying and managing IBD. Tailored to the Aotearoa population.
Lack of further investigation/ incentive for referrals.	Increase awareness of the severity of IBD and the diagnostic process.
Patients feel unheard or not cared for by GPs and specialists that they reduce help-seeking behaviours or avoid medical practices.	Further training for GPs to build rapport, listening skills, and being open to further investigation when a solution is not reached. Emphasising empathy towards symptoms.
Patients become so unwell with diagnostic delays that they need a higher level of care.	Using toolkits, raising awareness, and creating incentives to refer for a prompt diagnosis.
Neglected psychosocial and nutritional health support.	Free counselling or emotional and well-being support for those suffering a flare should be made available (recommended by Kahui et al., 2017).

Limitations

Appraisal and Perception

The results of this study should be interpreted with several limitations in consideration. This study focused on subjective participant experiences of those impacted by a DD. This means the purposefully biased sample of people who feel impacted by a DD may skew the findings towards the passionate perspective that the healthcare system has led to severe outcomes for IBD patients. This is a problem as, for example, participants who have experienced stress as a result of DD may be prone to interpreting their diagnostic journey with a negativity bias, where they focus on negative aspects of their DD experience while overlooking the positive experiences. As stress can heighten emotional reactions, people may appraise events as more overwhelming than they objectively were.

Further, this negative appraisal of events may mean that participants may not have considered other perspectives or alternative explanations. For example, they may not have considered the accessibility for a GP to refer them for an IBD test. This is particularly important to consider when participants discuss their perceptions of the GP, as the GP or specialists may have been considering the most thorough investigation they believe they can, even when the participant doesn't realise this.

As this study did not investigate the participants' ability to cope with adversity and stressful events, future research is warranted to conclude the extent to which different levels of coping mechanisms may influence a patient's appraisal of diagnostic delay. Particularly, researching people with a positive diagnostic experience and their appraisal of events would be interesting to corroborate this perspective that negative experiences of stress may negatively influence perception.

An Absence of Perspectives

Further, the conclusions made in this study's findings need to be cautioned, as it was chosen not to include healthcare workers' perspectives in diagnosing IBD, which limits the generalisation of these findings. Without diagnostic, treatment, and IBD care knowledge from a GP's perspective, we cannot ascertain the ease or difficulty of obtaining an IBD diagnosis. Additionally, we cannot decipher whether a lack of further investigation was due to factors such as accessibility or a lack of IBD awareness that participants discussed. Despite this, considering the research centred on participant perspectives, further investigation should investigate the perspective of a GP in obtaining a diagnosis. Having the GP's perspective would create a more versatile argument about what recommendations should be made to improve the diagnostic process.

Additionally, it is essential to acknowledge that this study purposefully recruited participants who felt impacted by a diagnostic delay. Accordingly, we must appreciate that there will be some IBD patients who experienced a delay and did not feel negatively impacted by it. Further, there may be people with IBD awareness who seek a diagnosis promptly. These people with delay may have had mild symptoms, meaning the delay was not as detrimental to their overall health and well-being. Further inquiry is therefore warranted to hear from these people's perspectives about whether a diagnostic delay impacted them or not and whether this impact is a positive, negative, or neutral experience.

Subjectivity

When analysing the overall impact of the subthemes, subjectivity appeared to be a prevailing factor of influence and, therefore, must be addressed. A reflexive thematic analysis was chosen to be coherent with the theoretical assumptions of this study as it recognises the researcher's subjective influence on the findings. From a social constructionist view, knowledge is generated by the interactions between the researcher and participant, where different people derive meaning based on their perceived reality, with no objective or universal validity (Conrad & Barker, 2010). Despite this, subjectivity remains a factor when assessing this study's findings.

Before recruiting participants, I considered whether relying on the subjective, retrospective recall of IBD patients impacted by a diagnostic delay would ensure a valid study. However, participants were recruited because they felt impacted by a DD, and this was done because they were the most appropriate group to answer the research questions. Further, having a sample of ten people may mean they are not a representative group of all people who have experienced DD in IBD, in that other people who have experienced a DD may disagree with participant statements. However, there were several consistencies in the findings that present an impactful argument as to what some people who have experienced DD in IBD perceive as the main barriers to diagnosis and the impacts of diagnosis. Further, I ensured that interpretations of participant interviews highlighted the subjectivity of responses while giving participants their voice. Further, avoiding strong language and making generalisable conclusions was essential to mitigate this limitation. The results and interpretations, therefore, acknowledge the potential emotional influence and memory decay that may lead to inaccurate recall of past events for participants.

Further, as the sole researcher, I acknowledge that the formulation and analysis of this research are subject to my personal experiences, backgrounds, and opinions, which may have influenced the interpretations of the results. For example, subjective diagnostic delay limits the findings as this research only gathered information about a perceived diagnostic delay, and not a specific delay period. This means that studies that require a specific period of delay may produce different results.

However, it was important to acknowledge that the definition of DD may have differed between participants based on their subjective perceptions. I chose to do this as quantifying a DD has introduced problems such as exclusion in previous research limitations, and I believed the perceived impact of a delay would remain, regardless of how long the delay was (Vavricka et al., 2012; Nguyen et al., 2017; Nahon et al., 2014; Miles et al., 2017). Relying on a perceived diagnostic delay has been seen in previous findings and is compatible with my epistemology and methodology (Cross et al., 2023). I ensured that the results reflected a perceived diagnostic delay and that conclusions were not generalised to everybody who has experienced a DD for this reason.

Sample

Finally, one of the motivations behind this study was the lack of IBD research in New Zealand. New Zealand has a unique, diverse population with minority groups such as Māori and Pasifika peoples. Unfortunately, people from these ethnic groups did not participate in this research. This may be due to an insufficient Utu or reciprocity of this research or the researcher's Pākehā background. Further, no recruitment from this population may reflect the low diagnosed incidence of IBD in these groups (Seleq et al., 2023; Wigley & Maclaurin., 1962). This is a limitation as the sample of this research may not reflect the general population of people with IBD in New Zealand. These minority groups require further research on the prevalence of IBD and whether they are impacted by a DD.

Strengths

Despite these limitations, the current study's use of a reflexive thematic analysis through a social constructionist perspective offers a novel and meaningful contribution to the diagnostic delay in IBD literature and its impact from a patient perspective. Utilising participant perspectives as the primary analysis element produced an understanding of diagnostic delay that complements and supplements the existing literature. Overall, the findings present a nuanced intersection of how a diagnostic delay impacts IBD patients. Investigating other perspectives of the diagnostic process may be useful in further research on IBD diagnostic delay (e.g., the GP's perspective, people who are not impacted by a delay, or those who did not experience a delay) as well as investigating the influence of appraisal in retrospective recalls of events. Further, having an IBD patient's perspective may be useful in informing treatment methods that recognise the biopsychosocial model designed to help reduce a diagnostic delay and the impact of delay in IBD.

Reflection of the Social Constructionist Influence on This Research

During every stage of this research, I was conscious of my social constructionist view, which allowed context, time, and culture to explain how people construct and make meaning of their diagnostic delay experience. This meant I was continually reflexive in my planning, structuring, and analysis of each research stage. Throughout this period, I aimed to communicate participant perceptions as their truth and actively resisted analysing findings using a biased manner, which would have impaired the integrity of my research. Maintaining this approach throughout the research meant I was conscious of the language I used to develop ideas and ensured participant voices were empowered throughout the findings.

By implementing a social constructionist view to this research, my findings were driven by the analytical interpretations created by the participants and myself as the researcher. Thematic analysis recognises the human impact on research. Therefore, I also acknowledge that with a different sample of people, and if another individual conducted this research – different knowledge, experience, assumptions and understandings would likely result in different analytical conclusions (Braun & Clarke, 2006). From this, I understand that the findings of this research do not constitute a single truth. Instead, the findings reflect what was found in the context of this study, ensuring I was continually reflexive in the process to ensure quality.

Conclusion & Further Research

Throughout this thesis, I have captured participant perspectives on the impact of a diagnostic delay, which provides a novel and fundamental perspective to the literature. This research found that issues of limited awareness and quality of care provided a barrier to diagnosis but also contributed to various psychosocial impacts of having IBD. There were significant emotional impacts on participants, including feeling helpless, frustrated and resentful. These impacts pose a threat to the IBD burden by demanding more resources for physical, psychological, and social support that the New Zealand health system cannot cope with. Improvements to reducing DD in IBD can be made by increasing IBD awareness and reducing feelings of dissonance between a patient and healthcare worker while acknowledging the severity of IBD symptoms using empathy, which would encourage healthcare trust.

All participants acknowledged their limited opportunities to share their experiences and enthusiasm for change. With future research, policy and treatment methods can be modified to provide a more holistic model of health using the biopsychosocial model. However, support is required to understand the perspectives from people who have not been negatively impacted by a diagnostic delay and from healthcare workers’ perspectives on achieving a prompt diagnosis to create a well-rounded argument towards inducing policy change.

Final Reflections

From my experience of having a diagnostic delay with IBS and with a passion for psychology, I have wanted to research this area. In acquiring my degree, a Bachelor of Arts with Honours in Psychology, I have developed my knowledge and understanding of the role of human behaviour in disease, which has deepened my interest in mental health in the healthcare realm. Now that I have had the opportunity to research an area of great interest to me, I hope I have positively contributed to the IBD literature and that my research may help those suffering from IBD. I have found the process of conducting my research and writing this thesis to confirm my desire to be a clinical psychologist, as I am passionate about helping others and researching to find possible solutions.

References

Al Khoury, A., Balram, B., Bessissow, T., Afif, W., Gonczi, L., Abreu, M., & Lakatos, P. L.. (2022). Patient Perspectives and Expectations in Inflammatory Bowel Disease: A Systematic Review. *Digestive Diseases and Sciences*, *67*(6), 1956–1974. https://doi.org/10.1007/s10620-021-07025-y

Berger, R. (2015). Now I See it, Now I Don’t: Researcher’s Position and Reflexivity in Qualitative Research. *Qualitative research*, *15*(2), 219-234. https://doi.org/10.1177/1468794112468475

Bernstein, M. T., Targownik, L. E., Sexton, K. A., Graff, L. A., Miller, N., & Walker, J. R. (2016). Assessing the Relationship between Sources of Stress and Symptom Changes among Persons with IBD over Time: A Prospective Study. *Canadian Journal of Gastroenterology and Hepatology, 2016,* 1–8. https://doi.org/10.1155/2016/1681507

Black, J., Sweeney, L., Yuan, Y., Singh, H., Norton, C., & Czuber-Dochan, W. (2022). Systematic Review: The Role of Psychological Stress in Inflammatory Bowel Disease. *Alimentary Pharmacology & Therapeutics*, *56*(8), 1235-1249. https://doi.org/10.1111/apt.17202

Blackmore, T., Norman, K., Kidd, J., Cassim, S., Chepulis, L., Keenan, R., Firth, M., Jackson, C., Stokes, T., Weller, D., Emery, J., & Lawrenson, R.. (2020). Barriers and Facilitators to Colorectal Cancer Diagnosis in New Zealand: A Qualitative Study. *BMC Family Practice*, *21*(1). https://doi.org/10.1186/s12875-020-01276-w

Braun, V., & Clarke, V. (2021). Thematic Analysis: A Practical Guide. London: Sage

Braun, V., Clarke, V. (2006) Using Thematic Analysis in Psychology, Qualitative Research in Psychology, 3:2, 77-101, DOI: 10.1191/1478088706qp063oa

Brzozowski, B., Mazur-Bialy, A., Pajdo, R., Kwiecien, S., Bilski, J., Zwolinska-Wcislo, M., Mach, T., & Brzozowski, T. (2016). Mechanisms by which Stress Affects the Experimental and Clinical Inflammatory Bowel Disease (IBD): Role of Brain-Gut Axis. *Curr Neuropharmacol*, *14*(8), 892-900. https://doi.org/10.2174/1570159x14666160404124127

Bunu, D.-M., Timofte, C.-E., Ciocoiu, M., Floria, M., Tarniceriu, C.-C., Barboi, O.-B., & Tanase, D.-M. (2019). Cardiovascular Manifestations of Inflammatory Bowel Disease: Pathogenesis, Diagnosis, and Preventive Strategies. *Gastroenterology Research and Practice*, *2019*, 3012509. https://doi.org/10.1155/2019/3012509

Cantoro, L., Di Sabatino, A., Papi, C., Margagnoni, G., Ardizzone, S., Giuffrida, P., ... & Kohn, A. (2017). The Time Course of Diagnostic Delay in Inflammatory Bowel Disease over the Last Sixty Years: an Italian Multicentre Study. *Journal of Crohn's and Colitis*, *11*(8), 975-980. https://doi.org/10.1093/ecco-jcc/jjx041

Casati, J., & Toner, B. B. (2000). Psychosocial Aspects of Inflammatory Bowel Disease [Article]. *Biomedicine & Pharmacotherapy*, *54*(7), 388-393. https://doi.org/10.1016/S0753-3322(01)80006-8

Chamberlain, K. (2015). Epistemology and Qualitative research. *Qualitative research in clinical and health psychology*, 9-28. https://www.researchgate.net/publication/311716158_Qualitative_research_in_health_psychology

Crohn’s and Colitis New Zealand. (2023, September). About Us. https://crohnsandcolitis.org.nz/

Colorectal Surgical Society of Australia & New Zealand (2006) Crohn’s Disease, https://colorectal.co.nz/wp-content/uploads/2014/09/Crohns-Disease-more-information.pdf

Colorectal Surgical Society of Australia & New Zealand (2006) Ulcerative Colitis, https://colorectal.co.nz/wp-content/uploads/2014/09/Ulcerative-Colitis-more-information-CSSANZ.pdf

Cohen, S., Kessler, R. C., & Gordon, L. U. (1997). *Measuring Stress: A Guide for Health and Social Scientists*. Oxford University Press on Demand.

Colombara, F., Martinato, M., Girardin, G., & Gregori, D. (2015). Higher Levels of Knowledge Reduce Health Care Costs in Patients with Inflammatory Bowel Disease. *Inflammatory Bowel Diseases*, *21*(3), 615–622. https://doi.org/10.1097/mib.0000000000000304

Conrad, P., & Barker, K. K.. (2010). The Social Construction of Illness: Key Insights and Policy Implications. *Journal of Health and Social Behavior*, *51*(1_suppl), S67–S79. https://doi.org/10.1177/0022146510383495

Cross, E., Prior, J. A., Farmer, A. D., & Saunders, B.. (2023). Patients' Views and Experiences of Delayed Diagnosis of Inflammatory Bowel Disease: A Qualitative Study. *BJGP Open*, *7*(4), BJGPO.2023.0070. https://doi.org/10.3399/bjgpo.2023.0070

Dent, E., Davinson, N., & Wilkie, S.. (2022). The Impact of Gastrointestinal Conditions on Psychosocial Factors Associated with the Biopsychosocial Model of Health: A scoping review. *Applied Psychology: Health and Well-being*, *14*(2), 626–644. https://doi.org/10.1111/aphw.12323

De Sousa, J. F. M., Paghdar, S., Khan, T. M., Patel, N. P., Chandrasekaran, S., & Tsouklidis, N. (2022). Stress and Inflammatory Bowel Disease: Clear Mind, Happy Colon. *Cureus*. https://doi.org/10.7759/cureus.25006

Dibley, L., & Norton, C.. (2013). Experiences of Fecal Incontinence in People with Inflammatory Bowel Disease. *Inflammatory Bowel Diseases*, *19*(7), 1450–1462. https://doi.org/10.1097/mib.0b013e318281327f

Durkin, S. J., Broun, K., Spittal, M. J., & Wakefield, M. A. (2019). Impact of a mass media campaign on participation rates in a National Bowel Cancer Screening Program: a field experiment. *BMJ Open*, *9*(1), e024267. https://doi.org/10.1136/bmjopen-2018-024267

Eason, R. J., Lee, S. P., & Tasman-Jones, C. (1982). Inflammatory Bowel Disease in Auckland, New Zealand. *Australian and New Zealand journal of medicine*, *12*(2), 125-131. https://doi.org/10.1111/j.1445-5994.1982.tb02443.x

Engel, F., Berens, S., Gauss, A., Schaefert, R., Eich, W., & Tesarz, J. (2021). Higher Levels of Psychological Burden and Alterations in Personality Functioning in Crohn's Disease and Ulcerative Colitis. *Frontiers in psychology*, *12*, 671493. https://doi.org/10.3389/fpsyg.2021.671493

Engel, G. L. (1977). The Need for a New Medical Model: A Challenge for Biomedicine. *Science*, *196*(4286), 129-136. https://www.science.org/doi/abs/10.1126/science.847460

Franklin, C., & Ballan, M. (2001). Reliability and Validity in Qualitative Research. *The handbook of social work research methods*, *4*(273-292).

Ge, L., Liu, S., Li, S., Yang, J., Hu, G., Xu, C., & Song, W. (2022). Psychological Stress in Inflammatory Bowel Disease: Psychoneuroimmunological insights into bidirectional gut-brain communications. *Frontiers in immunology*, *13*, 1016578. https://doi.org/10.3389/fimmu.2022.1016578

Goy, J., Hall, S. F., Feldman-Stewart, D., & Groome, P. A. (2009). Diagnostic Delay and Disease Stage in Head and Neck Cancer: A systematic review. *The Laryngoscope*, *119*(5), 889-898. https://doi.org/10.1002/lary.20185

Kallio, H., Pietilä, A.-M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, *72*(12), 2954-2965. https://doi.org/10.1111/jan.13031

Kemp, K., Griffiths, J., & Lovell, K. (2012). Understanding the Health and Social Care Needs of People Living with IBD: A meta-synthesis of the evidence. *World Journal* *of Gastroenterology : WJG*, *18*(43), 6240-6249. https://doi.org/10.3748/wjg.v18.i43.6240

Khalilipour, B. S., Day, A. S., Kenrick, K., Schultz, M., & Aluzaite, K. (2022). Diagnostic Delay in Paediatric Inflammatory Bowel Disease—A Systematic Investigation. *Journal of Clinical Medicine*, *11*(14), 4161. https://doi.org/10.3390/jcm11144161

Knowles, S. R., Keefer, L., Wilding, H., Hewitt, C., Graff, L. A., & Mikocka-Walus, A. (2018). Quality of Life in Inflammatory Bowel Disease: A systematic review and meta-analyses—Part II. Inflammatory Bowel Diseases, 24, 966–976. https://doi.org/10.1093/ibd/izy015

Larsson, K., Lööf, L., & Nordin, K. (2017). Stress, Coping and Support Needs of Patients with Ulcerative Colitis or Crohn's Disease: A Qualitative Descriptive Study. *Journal of Clinical Nursing*, *26*(5-6), 648-657. https://doi.org/10.1111/jocn.13581

Laubmeier, K. K., Zakowski, S. G., & Bair, J. P. (2004). The Role of Spirituality in the Psychological Adjustment to Cancer: A Test of the Transactional Model of Stress and Coping. *International Journal of Behavioural Medicine*, *11*(1), 48–55. https://doi.org/10.1207/s15327558ijbm1101_6

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer publishing company.

Lee, D. W., Koo, J. S., Choe, J. W., Suh, S. J., Kim, S. Y., Hyun, J. J., Jung, S. W., Jung, Y. K., Yim, H. J., & Lee, S. W. (2017). Diagnostic Delay in Inflammatory Bowel Disease Increases the Risk of Intestinal Surgery. *World Journal of Gastroenterology*, *23*(35), 6474–6481. https://doi.org/10.3748/wjg.v23.i35.6474

Lenti, M. V., Cococcia, S., Ghorayeb, J., Di Sabatino, A., & Selinger, C. P. (2020). Stigmatisation and Resilience in Inflammatory Bowel Disease. *Internal and Emergency Medicine, 15*(2), 211-223. https://doi.org/10.1007/s11739-019-02268-0

Marques, B., Freeman, C., Carter, L., & Pedersen Zari, M. (2021). Conceptualising Therapeutic Environments through Culture, Indigenous Knowledge and Landscape for Health and Well-Being. *Sustainability*, *13*(16), 9125. https://www.mdpi.com/2071-1050/13/16/9125

Melinder C, Hiyoshi A, Fall K, et al. (2017). Stress Resilience and the Risk of Inflammatory Bowel Disease: A Cohort Study of Men Living in Sweden. *BMJ Open* 2017;7:e014315. doi:10.1136/bmjopen-2016- 014315

Miles, A., McClements, P. L., Steele, R. J. C., Redeker, C., Sevdalis, N., & Wardle, J. (2017). Perceived Diagnostic Delay and Cancer-related Distress: A Cross-sectional Study of Patients with Colorectal Cancer. *Psycho-Oncology*, *26*(1), 29-36. https://doi.org/10.1002/pon.4093

Muse, K., Johnson, E., & David, A. L.. (2021). A Feeling of Otherness: A Qualitative Research Synthesis Exploring the Lived Experiences of Stigma in Individuals with Inflammatory Bowel Disease. *International Journal of Environmental Research and Public Health*, *18*(15), 8038. https://doi.org/10.3390/ijerph18158038

Nahon, S., Lahmek, P., Lesgourgues, B., Poupardin, C., Chaussade, S., Peyrin-Biroulet, L., & Abitbol, V. (2014). Diagnostic Delay in a French Cohort of Crohn's Disease Patients. *Journal of Crohn's and Colitis*, *8*(9), 964-969. https://doi.org/10.1016/j.crohns.2014.01.023

National Institute for Health and Care Excellence: Guidelines [Internet]. London: National Institute for Health and Care Excellence (NICE); 2003-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK11822/

Nguyen, V. Q., Jiang, D., Hoffman, S. N., Guntaka, S., Mays, J. L., Wang, A., Gomes, J., & Sorrentino, D. (2017). Impact of Diagnostic Delay and Associated Factors on Clinical Outcomes in a U.S. Inflammatory Bowel Disease Cohort. *Inflammatory Bowel Diseases*, *23*(10), 1825–1831. https://doi.org/10.1097/mib.0000000000001257

Nistor, O. I., Godfrey, C., Ross-White, A., & Wilson, R. (2021). Systematic Review and Meta-analysis on the Incidence, Prevalence and Determinants of Discomfort in Inflammatory Bowel Disease. *Journal of the Canadian Association of Gastroenterology*, *5*(2), 96–97. https://doi.org/10.1093/jcag/gwab043

Oligschlaeger, Y., Yadati, T., Houben, T., Condello Olivan, C. M., & Shiri-Sverdlov, R. (2019). Inflammatory Bowel Disease: A Stressed "Gut/Feeling". *Cells*, *8*(7). https://doi.org/10.3390/cells8070659

Popa, D., Pîrlog, M., Alexandru, D. O., & Gheonea, D. I. (2022). The Influence of the Inflammatory Bowel Diseases on the Perceived Stress and Quality of Life in a Sample of the South-Western Romanian Population. *Current Health Sciences Journal*, *48*(1), 5–17. https://doi.org/10.12865/chsj.48.01.01

Rogala, L., Miller, N., Graff, L. A., Rawsthorne, P., Clara, I., Walker, J. R., Lix, L., Ediger, J. P., McPhail, C., & Bernstein, C. N. (2008). Population-based Controlled Study of Social Support, Self-perceived Stress, Activity and Work Issues, and Access to Healthcare in Inflammatory Bowel Disease. *Inflammatory bowel diseases*, *14*(4), 526-535. https://doi.org/10.1002/ibd.20353

Richard, A. A., & Shea, K. (2011). Delineation of Self-care and Associated Concepts. *Journal of nursing scholarship*, *43*(3), 255-264. https://doi.org/10.1111/j.1547-5069.2011.01404.x

Richard, L., Noller, G., Derrett, S., Sullivan, T., Doolan-Noble, F., Mccombie, A., Schultz, M., Ho, C., & Stokes, T.. (2020). Patients’ Accounts of Living With and Managing Inflammatory Bowel Disease in Rural Southern New Zealand: a qualitative study. *BMJ Open*, *10*(11), e041789. https://doi.org/10.1136/bmjopen-2020-041789

Robertson, N., Gunn, S., & Piper, R. (2022). The Experience of Self-conscious Emotions in Inflammatory Bowel Disease: A Thematic Analysis. *Journal of Clinical Psychology in Medical Settings*, *29*(2), 344-356. https://doi.org/10.1007/s10880-021-09778-0

Royal College of General Practitioners. Inflammatory Bowel Disease Toolkit https://elearning.rcgp.org.uk/course/view.php?id=702

Seid, M., Sobo, E. J., Gelhard, L. R., & Varni, J. W. (2004). Parents' Reports of Barriers to Care for Children With Special Health Care Needs: Development and Validation of the Barriers to Care Questionnaire. *Ambulatory Pediatrics*, *4*(4), 323–331. https://doi.org/10.1367/a03-198r.1

Seleq, S., Weilert, F., & Fulforth, J. (2023). Inflammatory Bowel Disease in Waikato, New Zealand: Incidence and Prevalence. *Internal Medicine Journal*. https://doi.org/10.1111/imj.16072

Sewitch, M. J., Abrahamowicz, M., Bitton, A., Daly, D. S., Wild, G., Cohen, A., Katz, S., Szego, P., & Dobkin, P. L. (2001b). Psychological Distress, Social Support, and Disease Activity in Patients With Inflammatory Bowel Disease. *The American Journal of Gastroenterology*, *96*(5), 1470–1479. https://doi.org/10.1111/j.1572-0241.2001.03800.x

Schlup, M., Maclaurin, B., Barbezat, G., & De Lambert, B. (1986). Crohn's Disease: A Ten Year Retrospective Review at Dunedin hospitals. *The New Zealand Medical Journal*, *99*(797), 141-144. https://pubmed.ncbi.nlm.nih.gov/3457289/

Su, H. Y., Gupta, V., Day, A. S., & Gearry, R. B. (2016). Rising Incidence of Inflammatory Bowel Disease in Canterbury, New Zealand. *Inflammatory Bowel Diseases*, *22*(9), 2238–2244. https://doi.org/10.1097/mib.0000000000000829

Tormey, L. K., Farraye, F. A., & Paasche-Orlow, M. K. (2016). Understanding Health Literacy and its Impact on Delivering Care to Patients with Inflammatory Bowel Disease. *Inflammatory Bowel Diseases*, *22*(3), 745–751. https://doi.org/10.1097/mib.0000000000000622

Torres, J., Mehandru, S., Colombel, J.-F., & Peyrin-Biroulet, L. (2017). Crohn's Disease. *The Lancet*, *389*(10080), 1741-1755. https://doi.org/10.1016/S0140-6736(16)31711-1

Van Wilder, L., Pype, P., Mertens, F., Rammant, E., Clays, E., Devleesschauwer, B., Boeckxstaens, P., & De Smedt, D.. (2021). Living with a Chronic Disease: Insights from Patients with a Low Socioeconomic Status. *BMC Family Practice*, *22*(1). https://doi.org/10.1186/s12875-021-01578-7

Vavricka, S. R., Spigaglia, S. M., Rogler, G., Pittet, V., Michetti, P., Felley, C., Mottet, C., Braegger, C. P., Rogler, D., Straumann, A., Bauerfeind, P., Fried, M., & Schoepfer, A. M. (2012). Systematic Evaluation of Risk Factors for Diagnostic Delay in Inflammatory Bowel Disease. *Inflammatory Bowel Diseases*, *18*(3), 496–505. https://doi.org/10.1002/ibd.21719

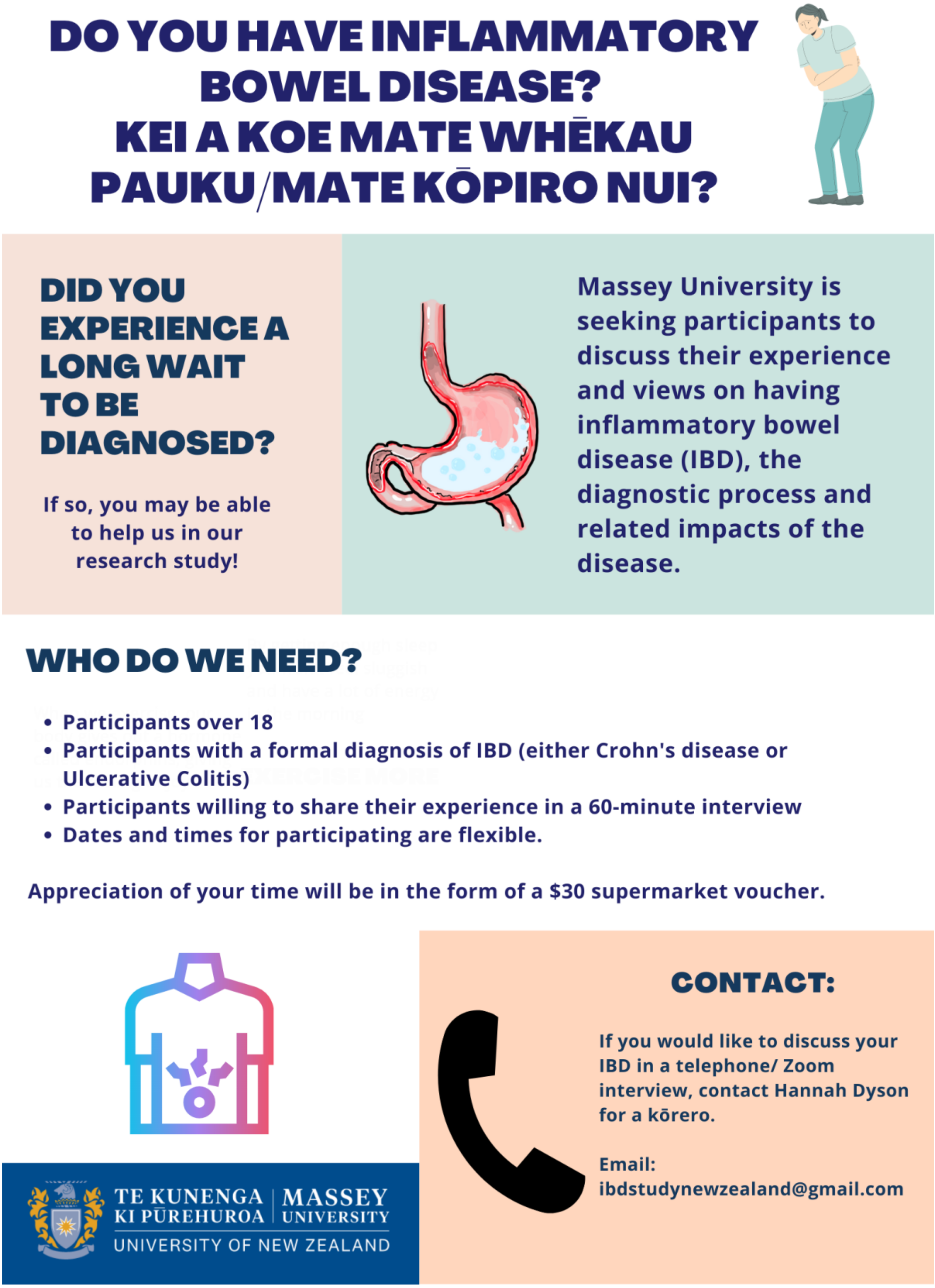
Vernon-Roberts, A., Gearry, R. B., & Day, A. (2020). The Level of Public Knowledge about Inflammatory Bowel Disease in Christchurch, New Zealand. *Inflammatory Intestinal Diseases*, *5*(4), 205–211. https://doi.org/10.1159/000510071

Yu, Y. R., & Rodriguez, J. R. (2017). Clinical presentation of Crohn's, Ulcerative Colitis, and Indeterminate Colitis: Symptoms, Extraintestinal Manifestations, and Disease Phenotypes. *Seminars in pediatric surgery*, *26*(6), 349–355. https://doi.org/10.1053/j.sempedsurg.2017.10.003

World Health Organisation. (2023). What is Stress? https://www.who.int/news-room/questions-and-answers/item/stress

Wigley, R. D., & Maclaurin, B. P. (1962). A Study of Ulcerative Colitis in New Zealand, Showing a Low Incidence in Māori’s. *British medical journal*, *2*(5299), 228–231. https://doi.org/10.1136/bmj.2.5299.228

Appendix A: Research Poster



DO YOU HAVE INFLAMMATORY BOWEL DISEASE?

KEI A KOE MATE WHĒKAU PAUKU/MATE KŌPIRO NUI?

DID YOU EXPERIENCE A LONG WAIT TO BE DIAGNOSED?

If so, you may be able to help us in our research study!

Massey University is seeking participants to discuss their experience and views on having inflammatory bowel disease (IBD), the diagnostic process and related impacts of the disease.

WHO DO WE NEED?

- Participants over 18
- Participants with a formal diagnosis of IBD (either Crohn's disease or Ulcerative Colitis)
- Participants willing to share their experience in a 60-minute interview
- Dates and times for participating are flexible.

Appreciation of your time will be in the form of a $30 supermarket voucher.

TE KUNENGA KI PŪREHUROA | MASSEY UNIVERSITY
UNIVERSITY OF NEW ZEALAND

CONTACT:

If you would like to discuss your IBD in a telephone/ Zoom interview, contact Hannah Dyson for a kōrero.

Email:
ibdstudynewzealand@gmail.com

Appendix B: Topic Guide

Topic Guide: Patients

The Impacts of Diagnostic Delay in IBD Interview Topic Guide

-

All information will be self-reported and no clinical records will be accessed. In doing this, the study acknowledges possible bias and misinformation. Consequently, the study is focussing on the participant's *perceived* diagnostic delay. The study is focusing on the subjective experience of DD.

-

Pre Interview

Establish rapport by having a mihimihi/ casual conversation with the participant. I will ask them about themselves, where they are from, and what they do for work, for example.

This is to make them feel comfortable talking to me and feel settled.

-

Introduction

-

a. Check participants have read and understood the information sheet.
b. Explain arrangements for: recording, anonymity.
c. Check patient's recollection for how they were diagnosed with IBD
d. Ensure participant is aware of withdrawal procedures.

Demographics

a. How old are you?
b. What is your ethnicity?
c. Where in New Zealand did you grow up? (e.g., rural)
d. Where do you live now?
e. Crohn's/ Colitis?

-

Experience of symptom onset and diagnosis

-

e. How did initial symptoms present?
f. How did you interpret these symptoms?
g. Age at symptom onset (calculate disease period).
h. How long after the initial symptom presentation did you contact a health clinician?

i. At first consultation, how were symptoms interpreted by the health clinician?
j. At first consultation, what management plans/ diagnoses were made?
k. How long after original consultation did diagnosis take?

-

How was final diagnosis reached

-

l. Diagnosed from original/ first consultation/ referral?
m. Diagnosed after worsening/ change of symptoms?
n. What happened at the referral appointments?
o. What investigations occurred?
p. What management was tried (right/wrong diagnosis made)?
q. Age of diagnosis
r. How many months do you think diagnosis took, from first symptom presentation to diagnosis?

-

Key factors of DD

-

1. What do you perceive as the main barriers to diagnosis? (consider your own actions as barriers, and then barriers experienced from healthcare specialists and the system[HD1] [HD2] [HD3]).
2. What was your personal impact of diagnostic delay?
3. Do you feel your symptoms/ management may have been different if you were diagnosed sooner?
4. Did the diagnostic delay have an impact on your quality of life? How so?
5. Further details regarding complications/ narrative of diagnosis and disease course.
6. Do you feel that any other factors contributed to your diagnostic delay?

-

Impact of DD – Stress

-

a. Did you feel that your symptoms were taken seriously? If so, why? If not, how so?
b. How did this affect your stress levels?
c. Did you feel that health clinicians were listening to your concerns?
d. How did this affect your stress levels?
e. How did you feel before and after being diagnosed?
f. Before diagnosis, did you feel in control of your stress?

-

Impact of DD – symptom severity

-

a. General overview of symptoms: before/ after diagnosis
b. Before diagnosis, did you feel in control of your symptoms?

c. Do you think your stress levels are related to your symptom severity? How so?
d. Do you feel that your symptoms changed once you received a diagnosis?
e. Do you feel that your symptoms were affected by the diagnostic delay?
f. How have your symptoms influenced your quality of life?
g. Once diagnosed, Did you receive symptom management plans? (If so), How did you feel about them?

-

Impact of DD – Cultural Worldview

-

a. Do you feel that health clinicians understood your health concerns within your cultural perspective?
b. Did you feel that cultural differences impacted your diagnostic delay?
c. How has your culture influenced your experience of IBD?
d. Are there any other factors we haven’t discussed that you believe are important to DD?

Close of Discussion

-

a. Summary of discussion: any closing remarks?
b. Check consent is still valid.
c. Give participants the option about a transcript to read and check they are happy with what they have said.
d. Emotional support information.

Appendix C: Information Sheet

PARTICIPANT INFORMATION SHEET

Diagnostic Delay in Inflammatory Bowel Disease Study
Lead researcher: Hannah Dyson
Supervised by: Don Baken and Sarah Malthus
Cultural consultation: John Pahina & Julia Ioane
Department: Psychology
Contact email: ibdstudynewzealand@gmail.com

Tēnā koe, thank you for expressing interest in our study. Before you decide whether to participate, it is important that you understand why the research is being done and what it will involve. Please take your time to read the following information.

About myself

Hello! My name is Hannah Dyson; I am in my fifth year of study, working towards my Master's degree in psychology. I am 23 years old and was born and raised in Tamaki Mākaurau.

In my late high school years, I began to experience gut-related issues that have impacted my health, work, and social life. Over this time, I still haven't concluded what is causing them! My experience has prompted a great interest in diagnostic delay and the impacts of a diagnostic delay in gut-related conditions, which drew me to conduct this study. I hope my research is a valuable contribution to the IBD literature, and I look forward to hearing your stories.

The purpose of the study

Those with IBD can experience a considerable delay before diagnosis, referred to as "diagnostic delay" (DD). In this study, your diagnostic delay is defined as whether you feel you waited a long period to be diagnosed and could have been diagnosed sooner. DD may be associated with various physical, social, cultural, and psychological impacts.

We want to hear about your experience of diagnostic delay and how it has impacted you. Only a few studies on IBD have been conducted in Aotearoa, New Zealand, so we want to understand the impacts of a diagnostic delay in IBD on the Aotearoa population.

Recruitment

We are looking to recruit ten people for this study.

What happens if I decide to take part?

When an appropriate date and time are organised between you and Hannah, you will be asked to take part in an interview via Zoom. The interview will take approximately 60 minutes.

The interview is asking about *your* experience, so there are no right or wrong answers. You do not need to prepare for the interview.

The interview will be sound-recorded. Following the interview, the recordings will be transcribed to make a written copy of the interview. Recordings and transcripts will be stored on a secure, confidential Massey cloud system and destroyed after 5 years.

What are the possible benefits of the study?

The findings of this study will contribute to knowledge about diagnostic delay and its impacts in New Zealand. Some participants find it beneficial to express their stories in qualitative research, which may relieve isolation and increase the feeling of helping others.

What are the possible risks of the study?

As the study involves participating in a Zoom interview regarding your experience, we do not anticipate any immediate risks for you. However, some questions regarding IBD, stress, and symptom severity may provoke distressing memories. If this is the case, the interview can be paused or stopped indefinitely if you wish.

We do not think this will be needed, but if this were the case, you might find some of the support services on the attached form helpful. Please refer to the counselling and well-being support services sheet at the end of this document.

Will my information be kept confidential?

Yes, your information will be treated with the **strictest confidence.** Information will be kept on a secure, password-protected server. Each person interviewed will be given a participant number, so your information on transcripts has no identifiable features.

What happens if I no longer want to participate?

You can withdraw from the study at any time before the interview. After the interview, if you do not want to view a transcript of the interview you can withdraw up to 2 weeks after the interview. If you choose to view a copy of the transcript, you can withdraw up until 3 weeks after the transcript is sent to you. The consent form has a tick box for you to specify which option you select.

You can withdraw from this study by emailing Hannah Dyson, the researcher: at ibdstudynewzealand@gmail.com.

Withdrawing means we will no longer contact you directly and remove your information from the study.

How will the results be presented?

The data will be used to discover key themes and patterns through a qualitative method called Thematic Analysis (Braun & Clarke, 2021).

The main findings from the study may be published in a psychology journal. They are used to improve the understanding of the impacts of diagnostic delay in IBD. These findings may have future implications for clinical care and policy in New Zealand.

Your participant rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Decline to answer any particular question;
- Ask any questions about the study at any time during participation;
- Ask for the recorder to be turned off at any time during the interview.
- Withdraw from the study (up to 2 weeks after your interview or following your transcript being returned);
- Be given access to a summary of the project findings when it is

concluded

Who is funding and organising the research?

The research is funded and organised by the School of Psychology at Massey

University. **Who should I contact for more information?**

If you have any questions or would like further information about this study, please contact:

Hannah Dyson
ibdstudynewzealand@gmail.com

Don Baken
d.m.baken@massey.ac.nz

Sarah Malthus
s.malthus@massey.ac.nz

What should I do now if I want to participate?

If you would like to participate, please print and sign the consent form accompanying this information sheet and return it to Hannah via e-mail at: ibdstudynewzealand@gmail.com

Upon receiving your consent form, Hannah will contact you to arrange a convenient time and date for your Zoom interview.

> *This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 23/24. If you have any concerns about the conduct of this research, please contact the Chairperson, Massey University Human Ethics Ohu Matatika 1, email humanethics1@massey.ac.nz.*

Thank you for reading this information sheet. If you wish to participate, I look forward to hearing from you.

Counselling and Wellbeing Support Services

If you feel you would like some counselling or extra support with your wellbeing we encourage you visit your doctor or health clinic to check in with where you're at, and make some plans for longer term support. If you are eligible, your GP may be able to help you access low-cost counselling services, or access WINZ for funding for counselling. Your employer may be able to connect you with Employee Assistance Programme, through which you can access free or low-cost counselling.

If you are a University Student, you may be eligible for free or subsidised counselling through Student Health. We encourage you to phone your student health clinic to chat with a GP or Nurse, and see what other help is out there for you.

The below services are free, and available to you now:

Puawaitanga

- Individual counselling over the phone for support with anxiety, low mood, relationships, grief, stress and general wellbeing. They offer free, phone-based counselling for 12 months. Available 9am-9pm every day.
- Call at 0800 782 999, email support@puawaitanga.nz to set up your first session.

Need to Talk?

- Free call or text 1737 at any time for support from a trained counsellor

Gumboot Friday Free Counselling (Under 25s)

- You can find a counsellor through gumboot Friday at the below link, for face-to-face or digital counselling, for free for persons 25 or younger.
- https://www.gumbootfriday.org.nz/get-a-counsellor

Lifeline Aotearoa

- 0800 543 354
- Free telephone counselling, available any day, any time.

Youthline

- 0800 376 633, or free txt 234, or email talk@youthline.co.nz

The Lowdown

- Text 5626, for support to help young people understand depression or anxiety

The Depression Helpline

- 0800 111 757, or free text 4202, to talk to a counsellor about how you're feeling

Samaritans

- You can call at any time of day 0800 72 66 66
- People on the phone will talk to you and help with feelings of loneliness, depression, despair, distress, suicidal feelings.

Anxiety Trust

- 0800 269 4389
- Phone support for people experiencing anxiety. Can connect people with support groups (free), counselling (may cost).

St John Caring Caller Programme

- 0800 780 780
- A free telephone friendship service, for people who are feeling lonely, and live alone. Volunteers phone regularly to check that things are ok, and have a chat.

Rural Support Trust

- 0800 787 254
- A free 24/7 support line for people living rurally, needing to talk about health and wellbeing, and the pressures of living rurally

A more comprehensive list of services in your area, specific to your individual needs can be found below, though not all services provide counselling, and not all counselling provided is free:
https://blog.opencounseling.com/hotlines-nz/

Appendix D: Participant Interest Email

Dear ___,

Thank you for expressing interest in this study. Before reading further information, please ensure you are eligible for the study by reading the inclusion and exclusion criteria below. If you are not eligible for the study, please do not read any further information and let me know if you are not eligible. This study is for New Zealand participants only and you will need a supporting device and internet connection to participate.

This study aims to investigate people's experiences of a perceived diagnostic delay in those with inflammatory bowel disease (IBD) and the relevant impacts of a diagnostic delay experience.

Inclusion Criteria:

- 18 years and over
- Diagnosis of IBD (specifically Crohn's Disease or Ulcerative Colitis)
- Fluent English communication
- If you feel you have waited a long time to be diagnosed (where you believe you could have been diagnosed sooner) with either Crohn's Disease or Ulcerative Colitis.

Exclusion Criteria

- Younger than 18 years old
- No formal diagnosis of IBD
- Participants who cannot communicate in English will be excluded.

If you are eligible for this study and wish to participate, please read the participant information sheet and sign the consent form by printing, signing, and returning the signed document attached to me via email.

Please return the signed consent form to: ibdstudynewzealand@gmail.com with the preferred contact details. You will need to be able to access Zoom (via the mobile app or desktop) to participate.

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 23/24. If you have any concerns about the conduct of this research, please contact the Chairperson, Massey University Human Ethics Ohu Matatika 1, email humanethics1@massey.ac.nz.

Ngā mihi,

Hannah Dyson

Appendix E: Consent Form

Massey University School of Psychology

Impacts of Diagnostic Delay in Inflammatory Bowel Disease

PARTICIPANT CONSENT FORM

I have read, and I understand the Information Sheet. Any questions of the study I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study. I understand participation is voluntary.

Please tick to indicate your consent to the following:

- I agree to the interview being sound recorded.
- I understand my participation is confidential, and no material that can identify me will be used.
- I agree to participate in this study under the conditions set out in the Information Sheet.
- I wish to receive a summary of the study findings via email.
- I do not wish to review my transcript and am aware I can withdraw within two weeks of the interview; or,
- I wish to have my transcripts returned to me and am aware I can withdraw within two weeks of my transcripts being returned to me.

Declaration by Participant:

I ___________ [print full name]__________ hereby consent to take part in this study

Signature: ________________________ Date: _______________