HOW DO PEOPLE WITH INFLAMMATORY BOWEL DISEASE UNDERSTAND THEIR PAIN?

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Work that has been derived from other sources has been indicated and referenced within the thesis.

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Overview

Volume one of this thesis comprises three parts.

Part I presents a conceptual introduction which aims to give a broader overview to the empirical study presented in part II. A review of the literature is used to present the key ideas, concepts and theories that are pertinent to this research and its objectives. The discussion outlines Inflammatory Bowel Disease (IBD), chronic pain and specifically, visceral pain. Experience and understanding of IBD pain are discussed and placed in a broader context. Qualitative research on making sense of pain is presented and synthesised.

Part II presents an empirical study exploring individuals' understanding of their IBD pain. IBD pain is a neglected area of research, despite being one of the most common and debilitating symptoms in IBD. The study interviewed 20 people adults with IBD utilising the Grid Elaboration Method (GEM). Thematic analysis was used to analyse the data and produce three, overlapping themes: *making sense of my pain, navigating my care and support* and *it takes its toll*. The findings showed that making sense of one's pain is experiential, inextricably linked with navigating support and managing the impact of pain. The findings indicate that IBD pain warrants more attention and should be proactively integrated into assessments and management approaches.

Part III of this thesis presents a critical appraisal of the research process, including both its learning opportunities and challenges, as experienced by the researcher. This section encompasses ideas gathered from a bracketing interview and reflective research journal which was kept throughout the research process to aid reflexivity.

Impact statement

The findings from this thesis have numerous areas of potential impact, ranging from research to clinical settings, as summarised below.

Research/academic settings

The findings emphasise the importance of pain in IBD, its multi-faceted nature and impact on individuals. This study is therefore important in influencing future research. In sum, this study suggests that further research is necessary and should endeavour to explore IBD pain from several angles: its nuances, fluctuations, its assessment (including how it can be most helpfully measured or captured in clinical practice) and its management (including ongoing research into evidence-based interventions that are person-centred). This appears integral to ensuring that individuals with IBD can access effective support for pain and increase their quality of life.

This study is also one of the first to apply the Grid Elaboration Method (GEM) to a clinical health setting. Whilst formal feedback was not collected, this novel methodology appeared to be well received, engagement was high and participants' spontaneous positive comments included being able to talk about the subject of IBD pain without restriction. Consequently, this study speaks to the potential that the GEM has in its application to clinical health settings, providing rich data and allowing participants to be heard. This is particularly helpful when considering the potential impact of power dynamics, in both clinical and research settings. Therefore, the GEM carries potential to provide a helpful methodology that begins to address, albeit without limitations, the inherent biases and power structures embedded in many research studies.

Clinical settings

This study also impacts clinical practice. First, discussions around IBD pain and comorbid symptoms should be integrated into assessments and routine IBD appointments. Second, and relatedly, IBD services can address IBD pain more proactively, or develop pathways for appropriate and reliable signposting, when NHS services are under-resourced. In the study, it was evident that many individuals were unsure why they experience pain. IBD services would benefit from trialling person-centred pain education and closely examining how information is consolidated and applied. A holistic approach to managing IBD and pain is likely to provide the best outcomes. The study's interviews suggested vast heterogeneity amongst those affected and that managing IBD pain is often multi-faceted and dependent on individuals' preferences. IBD teams can present management ideas, ranging from exploring different medications, through to systematically monitoring their pain and trying other approaches, such as diet changes, pacing of valued activity or alternative therapies. The study has also emphasised the significant emotional and psychological component in IBD pain and IBD teams would be well advised to work towards an integrative mind-body outlook on pain and its management. Clinicians should be aware of the burgeoning brain-gut axis research in this area and the interrelatedness of psychological wellbeing and IBD symptom experience. This study gives further weight to previous research summarised in the literature review and encourages IBD teams to always consider mental health, its impact and refer to onward support as appropriate.

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PART I:

LITERATURE REVIEW

Abstract

This conceptual introduction reviews literature relevant to the empirical research study presented in part two of this thesis.

The discussion synthesises a range of research that attempts to begin to explore some of the nuances in pain and Inflammatory Bowel Disease (IBD). To aid coherence, the narrative is structured around two key sections: pain and IBD. The review builds a foundation for the research study by firstly discussing pain more broadly, including chronic and visceral pain, before examining the nature of IBD and IBD pain specifically.

In summary, the conceptual introduction has demonstrated the importance of a holistic, biopsychosocial approach in pain, which includes research developments in neurophysiology and neuroimaging. Pain in IBD continues to be neglected yet has a significant impact on individuals with IBD and their quality of life. There is a lack of research in which participants discuss their understanding of their IBD pain. Implications of this are discussed in the context of the empirical study presented in part two of this thesis and its aims.

Introduction

The research study presented in part two of this thesis explored individuals' understanding of their IBD pain. IBD is known to be a complex, multifaceted disease, which can have a significant impact on quality of life. Amongst the vast spectrum of symptoms that IBD is associated with, pain is frequently reported as one of the most burdensome difficulties (Sweeney et al., 2019). However, understanding and subsequent effective management of IBD pain continues to be challenging and adequate research is still lacking in this area (Norton et al., 2017).

As a result, the current project aimed to help narrow this research gap by inviting people with IBD to openly discuss their IBD pain and, specifically, aimed to explore how they make sense of their IBD pain. A novel approach in this research, the Grid Elaboration Method (GEM; Joffe & Elsey, 2014), aimed to address the power dynamics inherent in many research interviews and, instead, allowed participants to free associate on the topic and then elaborate on their associations. By using this paradigm, the interviews allowed participants to discuss what felt pertinent to them, as opposed to being automatically focused on the researcher's agenda and innate biases.

By adopting this novel approach, it was hoped that this research would delve deeper into people's understanding of their IBD pain and further our understanding of people's experiences and sense-making. The benefits of this exploratory approach are far-reaching and can not only help to deepen our knowledge of IBD pain, but also stimulate further research in this area.

This conceptual review will explore essential background, relevant research and the wider context of IBD pain, in order to help situate the empirical study presented in part two of this volume.

Inclusion of research

To ensure that the review covered key information and research, a number of electronic databases were used to identify relevant publications, including PsycINFO and Web of Science. Search terms included ‘Inflammatory Bowel Disease’, ‘Crohn’s disease’, ‘ulcerative colitis’ and ‘pain’. Further articles and relevant sources of information were also found through scanning of reference lists, searching Google Scholar and the UCL library catalogue. The search focused on literature available in English and paediatric literature was not used for the discussion, as this is a vast area in its own right. The type of information used to inform and structure this review ranged from books to papers from peer-reviewed journals. Throughout the discussion, the term ‘individuals with IBD’ is used in preference to ‘patients’ or ‘service-users’, to emphasise individuality and not identify individuals with IBD primarily in a help-seeking role. However, cited research often uses different terminology, most commonly ‘patients’, so this can also be found in this discussion.

The review has been structured into two overarching, yet inevitably overlapping, sections: pain and IBD. The former outlines the relevant ideas in pain research, ranging from pain models to pain classification. The latter provides an overview of IBD, IBD pain and its management. Given the interrelatedness of IBD pain with other symptoms, a summary of other common IBD symptoms is also presented. The discussion also adds further nuance and contextual depth, for example, reference is made to wider systemic factors, such as the healthcare system.

Altogether, the presented review provides a summary of key ideas, theories and research that sets the foundation for the empirical study in part two of this volume.

Pain

"Of pain you could wish only one thing: that it should stop. Nothing in the world was so bad as physical pain. In the face of pain there are no heroes."

George Orwell, 1984

Pain has been defined in a myriad of ways. A widely used definition by the International Association for the Study of Pain (IASP), states that pain is "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (Raja et al., 2020). It can also be helpful to conceptualise pain as an archetypal, survival system serving multiple functions, such as drawing attention to threats or promoting recovery (Wall, 1994). Nevertheless, all definitions of pain agree that it is a universal human experience, that is highly subjective: "pain is whatever the experiencing person says it is, existing whenever he [sic] says it does" (Pasero et al., 1999, p.17). Pain continues to pose challenges in both clinical and research settings. Given its subjectivity, there are no universally standardised pain tests, self-report measures or diagnostic procedures. Pain assessments rely on individuals to describe or quantify their pain, whilst identifying which pathology, if any, the experienced pain may be associated with (Ebert & Kerns, 2010).

Models of Pain

Numerous models of pain exist. Historically, single factor models, such as the biomedical model of pain, dominated the field and assumed a linear relationship between tissue damage and the experience of pain (Turk & Burwinkle, 2007). As a result, treatment was focused on relieving pain by addressing the perceived root of the pain. As the field developed, it became apparent that such models are incomplete, as pain is considerably more complex and intrinsically psychological as well as physical. Many pains do not arise from actual damage and therefore, cannot be explained by simplistic models (Williams, 2007). In Western medicine, stigmatising labels, such as ‘psychogenic’ or ‘psychosomatic’, have been used to suggest that an individual’s pain was ‘not real’ or disproportionate to observable pathology (Sullivan & Ferrell, 2005). This problematic and invalidating approach to conceptualising pain is inconsistent with evidence and unrelated to pain mechanisms and research developments in this area (Sharpe & Williams, 2002; Wall, 2000).

The Gate Control model of pain was crucial in beginning to integrate psychological and biological factors in pain (Melzack & Wall, 1965). The model explains that as pain messages travel towards the brain, they are modulated by both peripheral and central nervous system processes. In brief, the brain can modify, either decreasing or increasing, the original pain signal received from the point of impact. The nerve ‘gates’ refer to spinal cord synapses that moderate pain messages, using other peripheral information and excitatory or inhibitory brain activity. As a result, the Gate Control model highlights the importance of psychological factors and therefore the potential of psychological treatments in influencing the neurophysiological processing of pain and individuals’ pain experience.

The biopsychosocial model (Engel, 1977) expanded the neurophysiological focus of the Gate Control model, to include broader psychological and social factors (Sellinger et al., 2010; Turk et al., 2011). The model views pain experience as a dynamic, multi-directional interaction between biological, cognitive, affective and sociocultural factors (Turk & Monarch, 2002). It posits that individuals’ unique contexts, with different beliefs, behaviours and emotional responses to pain, interact with their environments, including other people. This biopsychosocial approach to pain has informed cognitive-behavioural models and treatments for pain and chronic pain in particular (Turk & Monarch, 2002). Such models are built on cognitive therapy principles which state that how individuals interpret situations, and their subsequent behaviours, affect how they feel, both physically and emotionally (Beck, 1987). Treatment aims to alleviate emotional distress and physical discomfort by changing unhelpful cognitions, such as catastrophising, and pain-related behaviours, such as inactivity, which decondition muscles and can lead to further disability in chronic pain. Collectively, this approach intends to alleviate emotional distress, physical disability and increase quality of life. How individuals adapt to their pain is seen as heavily determined by the meaning they give to their pain, how threatening it is perceived to be and the resulting coping strategies they adopt (Eccleston & Crombez, 2007). Experimental studies have given weight to this idea, by demonstrating that an increased sense of threat results in increases in pain (e.g., Wiech et al., 2010).

Pain mechanisms & classifications

Acute versus chronic pain

One important distinction is ‘acute’ versus ‘chronic’ pain (Zeller et al., 2008). Broadly speaking, acute pain is associated with injuries, surgeries, procedures and traumas, and is typically seen as being temporary, while healing occurs. A good response to treatment is expected. In contrast, chronic pain, or persistent pain, is usually classified as pain lasting more than three to six months and can be continuous or intermittent in nature (Ebert & Kerns, 2010; Ickowicz et al., 2002). Its cause may be less clear or have no identifiable pathology, and response to treatment is often poorer than for acute pain. While any type of pain can have a significant impact on the person, chronic pain is one of the leading causes of disability worldwide (Vos et al., 2012). The World Health Organisation (WHO) and its International Classification of Functioning, Disability, and Health (ICF) utilise a social model of disability and define individuals with disabilities as including ‘‘those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'' (Cieza & Stucki, 2008). Chronic pain often has far-reaching effects on individuals, reducing quality of life (Hadi et al., 2017), increasing healthcare use (Blyth et al., 2004), and affecting mental health (Banks & Kerns, 1996). Whilst acute pain is often seen as helpful, as it represents a warning of potential or actual tissue damage that will heal with time, chronic pain remains challenging for both individuals and healthcare providers (Sengupta, 2009) and continues to have a significant economic cost to society (Breivik et al., 2013). In chronic conditions, such as IBD, the picture can be even less clear, as chronic pain associated with diagnosed conditions can be accompanied by acute pain flares that can signal deterioration in condition or acute medical crisis (Zeitz et al., 2016).

There are numerous pain mechanisms linked to different types of pain and the mechanisms involved in acute and chronic pain differ. Many pain conceptualisations exist, but the pain distinctions put forward by Woolf (2010) are particularly useful in the context of IBD, given that they include inflammatory pain. Woolf (2010) has differentiated between *nociceptive*, *inflammatory* and *pathological* pain, and summarised their function and mechanisms. First, nociceptive pain refers to an adaptive and early-warning system that involves sensory receptors, nociceptors, responding to noxious stimuli, such as extreme changes in temperature or sharpness. Nociception, the process of noxious stimulus information being relayed from receptors to the brain, is protective and demands immediate attention and action. Second, inflammatory pain refers to pain associated with hypersensitivity and tenderness following tissue damage, inflammation or specific peripheral pathology via the activation of the immune system. Heightened sensory sensitivity helps to promote recovery and avoid further damage. Inflammatory pain can have an adaptive and protective role and typically stops after a period of time; however, it can also continue beyond the presence of noxious stimuli and threat.

Third, pathological pain has been described by Woolf as a “disease of the nervous system” (pp 3742, Woolf, 2010) and can refer to either *neuropathic* pain, stemming from damage to the nervous system, or *dysfunctional* pain, now commonly referred to as *central sensitisation* (De Ridder et al., 2021). This refers to a dysfunction in the nervous system, typically in conditions that do not have noxious damage or inflammation. As outlined in the Gate Control model of pain (Melzack & Wall, 1965), pain is not a linear pathway of signals travelling from the periphery to the cortex, where conscious pain experience occurs. Pain undergoes a process of modulation from the first synapse, regulated by excitatory and inhibitory central nervous system circuits, that have the ability to increase or diminish pain based on cognition, mood, attention and other psychological factors (Ossipov et al,. 2010). Pain modulatory circuits can become disturbed as pain becomes chronic, with amplification increased and inhibition decreased (Costigan et al., 2009; Woolf, 2010). Increased peripheral nociceptor sensitisation alongside increased central sensitisation at spinal and supraspinal levels reflect complex changes and plasticity in both the peripheral and central nervous systems. Moreover, these changes in neural processing mean that noxious stimuli no longer need to be present for the experience of pain to occur (Woolf, 2010).

Developments in technology and functional imaging have demonstrated the range of brain areas involved in pain experience, also called the ‘pain matrix’, and the increased involvement of emotional brain circuits, specifically the prefrontal and limbic systems, as pain becomes chronic (Apkarian et al., 2011; Ossipov et al,. 2010; Schweinhardt & Bushnell, 2010). This demonstrates a shift from encoding sensory-discriminative aspects of pain experience to encoding affective-motivational information via associative learning systems (Reddan & Wager, 2019). This can increase pain, as the experience of pain becomes connected to various contexts. Cumulatively, this research has not only shown the complexity of pain, neuroplasticity and the potential for manipulation of pain experience via factors such as expectations and learning, but also highlighted structural brain changes in individuals with chronic pain (Baliki et al., 2012). This gives further support to the formulation of chronic pain nervous system dysfunction.

In summary, acute pain mechanisms are typically time-limited and alert an individual to tissue damage or threat. Nociception functions to prevent further harm, promote recovery and recedes as healing occurs. In contrast, for some people pain becomes repeated and chronic, resulting from central and peripheral nervous system changes and sensitisation that prolongs the experience of pain beyond any tissue damage or threat. Some individuals may be more susceptible to developing chronic pain and hypersensitivity; the evidence has thus far shown a small heritable component (Williams et al., 2010; Hartvigsen et al., 2009; Costigan et al.,2010). These findings give hope to future preventative interventions for at-risk individuals (Woolf, 2010). Equally, understanding different types of pain and their associated mechanisms may, with time, lead to the development of tailored, effective management strategies.

Somatic versus visceral pain

Another important distinction in pain is somatic versus visceral pain. The former refers to pain stemming from tissue such as skeletal muscle, skin or bone, while the latter refers to pain arising in or around the visceral organs (Chang, 2015; Ebert & Kerns, 2010). Somatic pain is typically well localised and may be accompanied by evidence of structural damage or abnormality. In contrast, visceral pain is usually poorly localised and may be referred to other areas, for example, other organs or dermatological sites (Sengupta, 2009), making identification of its origin more difficult. Visceral pain can be acute or chronic and can stem from various difficulties: inflammation of a visceral organ (e.g., IBD or appendicitis), obstruction of urine flow or bile (e.g., kidney stones), changes in gastrointestinal function (e.g., Inflammatory Bowel Syndrome) or other issues, such as bladder problems or endometriosis (Robinson & Gebhart, 2008). Sometimes visceral pain can be attributed to specific pathology, but often it is not possible to ascertain an underlying cause of the pain (Grundy et al., 2019).

Given that clinical pain research has largely focused on somatic pain, visceral pain remains less understood and less well managed (Bakshi et al., 2021). Pain management strategies which have stemmed from somatic pain research often do not apply well to visceral pain and visceral nociceptors may differ from those in somatic pain (Robinson & Gebhart, 2008). Visceral pain tends to be poorly localised, the result of both sparse innervation of the viscera and spinal neurons receiving information from various visceral areas as well as nearby somatic locations, resulting in referred pain (Brierley et al., 2018). Different information is encoded by visceral and somatic afferents: visceral nociception encodes, for example, stretch and torsion, rather than touch or temperature extremes. As a result, visceral hypersensitivity may lead to normal movement or stretch of visceral organs becoming painful. Whilst the function of somatic nociceptors in the experience of pain seems more clearly defined, visceral afferents are autonomic, with typically low activation thresholds, and the function they have in both nociception and the experience of pain remains less clear (Grundy et al., 2019).

Chronic, visceral pain is estimated to affect at least 20% of the global population and has significant negative consequences for impacted individuals and in terms of costs to society (Grundy et al., 2019). Numerous, interlinking factors contribute to chronic, visceral pain, ranging from the gut microbiome through to complex brain processes. It is evident that a dysregulated system contributes to maintaining chronic, visceral pain (Bakshi et al., 2021). Specifically, following a period of visceral inflammation, prolonged sensitisation of visceral afferents (Bielefeldt et al., 2002) and changes in the central nervous system sensitisation amplify ascending spinal signalling (Gampierakis et al., 2020). Structural and functional changes in the prefrontal and limbic areas of the brain further demonstrate the brain changes in individuals with chronic, visceral pain (Bao et al., 2016; Thomann et al., 2017) and could begin to explain the increased risks of psychological difficulties in individuals with chronic, visceral pain, such as IBD (Graff et al., 2009; Sweeney et al., 2018). Research on the brain-gut axis, the bidirectional communication system between the brain and the gastrointestinal tract, further emphasises brain modulation of afferent input from the gut (Weltens et al., 2018). The brain-gut axis works to regulate visceral homeostasis, but can also influence higher cognitive functions, emotions and affective behaviours. Abnormalities in the brain-gut signalling have been shown in many chronic conditions, including IBD (Mayer, 2011).

Understanding pain

Research has emphasised the importance of individuals accessing accurate knowledge about their condition as a crucial first step in pain management (Butler & Moseley, 2013). Understanding and learning about pain is a heterogenous, multi-layered process. Information that is received and processed about pain can influence the development of pain-related beliefs and influence how pain is interpreted and managed, for better or worse (Goubert et al., 2011). How people conceptualise their chronic pain can help to predict its severity and chronicity (Turner et al., 2000; Walsh & Radcliffe, 2002). This has been examined in various conditions. For example, a research study in Myotonic Muscular Dystrophy has shown that changes in pain-related beliefs can affect pain intensity and pain interference (Nieto et al., 2012). In musculoskeletal pain, misconceptions about pain have been shown to be common and contribute to worsening distress and disability (Crombez et al., 2012). Moreover, the process of individuals learning and receiving accurate information about their pain can be challenging in itself, given the mixed information available online and from services, as well some healthcare professionals not being aware of the most up-to-date pain research and recommendations (Moseley, 2002).

In chronic pain, education is theoretically very important in challenging lay assumptions that all pain reflects damage and requires caution about activity, which tends to be the most-widely held view for musculoskeletal pain (Newton-John, 2002). Focusing on physical aetiology can disempower individuals and hinder their pain management by prioritising pharmacological approaches over potentially helpful strategies to manage flare-ups (Baird & Sheffield, 2016; Salmon, 2000). How pain-related avoidance can perpetuate pain is summarised in the Fear Avoidance model of pain (Vlaeyen et al., 2016), which draws on cognitive-behavioural principles, to show how pain can be maintained when it is interpreted as threatening and avoidance of activity ensues, leading to worsened disability and pain.

Instead, the foundation of many chronic pain treatments is teaching individuals that their pain may reflect a dysfunction in the pain system and inactivity could worsen chronic pain disability (Baird & Sheffield, 2016; Vlaeyen & Linton, 2000). Pain education hopes to enhance knowledge, reduce individuals' anxieties and help to move them towards valued activities that may have understandably been previously avoided, but where underactivity contributes to pain severity (Arnstein, 2004). Accumulating evidence has shown that pain education can be helpful, compared to no intervention, in reducing pain disability and may be equally as effective as other non-educational interventions (Barbari et al., 2020; Engers et al., 2011; Haines et al., 2009). Specific components of pain education appear to be key, specifically, allowing individuals to tell their story, which can enhance pain re-conceptualisation and facilitate coping with one's condition (Watson et al., 2019).

Pain neurophysiology education is a well-known approach in this area that moves away from a biomedical account of pain and instead, focuses on desensitising neural systems by teaching neuropsychological explanations of pain (Moseley & Butler, 2003). The evidence for the efficacy of this approach has thus far been mixed. Whilst some studies have reported significant successes and proposed pain neurophysiology education as superior to other pain education approaches (Moseley & Butler, 2015), systematic reviews have shown that pain neurophysiology education leads to only clinically small improvements (Clarke et al., 2011; Geneen et al., 2015). Moreover, research showing greatest benefits have been carried out directly by the creators of the approach, so may carry a level of bias (King et al., 2018). This shows that further research is needed to explore the potential benefits of pain neurophysiology education and how individuals process and apply information about their pain.

Few studies have focused on exploring how individuals understand their pain and the implicit or explicit models of pain that they may hold. However, sense-making and striving for understanding is central to living with chronic pain (Smith & Osborn, 2007; Toye et al., 2017). Setchell et al. (2017) used an online survey to explore how people with chronic, low back pain understand their pain and why it is recurring. Discourse analysis of 130 qualitative responses showed four predominant discourses: body as a machine, low back pain as permanent/immutable, low back pain is complex, low back pain is very negative. The narratives were at times dissonant, but largely viewed pain as being static and unfixable, aligning with a traditional, biomedical view of the body. The study also showed that most participants acquired their knowledge about pain mainly from healthcare professionals and the internet, which further highlights the importance of accurate information provision. In sum, the research emphasised that contemporary biopsychosocial approaches to pain were rare, and this could have considerable impact upon avoidance, chronicity of pain and disability, and quality of life.

A qualitative study by Keen et al. (2021) also aimed to investigate sense-making in chronic pain and explored how people understand their chronic pain and engage with pain neurophysiology education. Twelve individuals with varied chronic pains were interviewed about their chronic pain using the Grid Elaboration Method (GEM; Joffe & Elsey, 2014) and then asked about a pain neurophysiology education article. The study highlighted both conceptual and experiential pain representations, structured around three themes; communicating pain, explaining pain and living with pain. The authors emphasised the diverse and often dissonant views and models held by participants. Participants showed some agreement with the presented pain neurophysiology education but felt that it did not translate into practical guidance that they could use.

Exploring how individuals with pain make sense of their pain could allow a deeper understanding of the complexities of pain and pain-related beliefs. It could also give an insight into potential implicit or explicit models that individuals may hold about their pain. This could be valuable for both research and clinical purposes, for example, the development of relevant education and management interventions.

Inflammatory Bowel Disease

IBD is a term used for chronic, gastrointestinal conditions that involve a dysregulated immune response to intestinal microflora in the gastrointestinal tract, leading to inflammation (Baumgart & Carding, 2007). IBD typically refers to two types of diseases; Crohn's disease (CD) and ulcerative colitis (UC). The former can affect the gastrointestinal tract at any point between the mouth and the anus, whereas the latter affects only the colon. When a case cannot be easily classified as either condition, IBD unclassified (IBD-U) may be used as a diagnosis (Zhou et al., 2011). IBD has no known aetiology and there is currently no cure for the disease. For many, IBD starts in childhood or adolescence and progresses with often fluctuating and unpredictable periods of inflammation, with accompanying pain and diarrhoea (Ng et al., 2017). In terms of prevalence, in high income countries the burden of IBD remains high, with prevalence rates around 0.3 to 0.5% (Kaplan & Ng, 2017). Low and middle-income countries, whilst showing a lower prevalence rate, are following the same trajectory as high-income countries and rates of the disease are rising (Kamm, 2017).

IBD encompasses a range of symptoms, such as diarrhoea, rectal bleeding and abdominal pain, and is typically characterised by periods of inflammation, flares, and remission (Farrell et al., 2014). Many have argued that given the severe nature of IBD and its far-reaching effects on the whole person, a gastrointestinal-centric view of the condition does not fully account for individuals' experiences and difficulties (Andrews et al., 2009). As with other conditions, the biopsychosocial model (Engel, 1977; Turk et al., 2011) is helpful in beginning to understand the many interconnected factors that contribute to the experience of IBD beyond the physical. Specifically, early life factors, both biological and experiential in nature, affect longer term physiological functioning and susceptibility to pathology (Drossman, 1998). The medical condition can in turn be influenced by environment and psychosocial functioning, thus resulting in idiosyncratic experiences of the condition, symptoms, behaviour and outcomes, which can all in turn feed back and influence the other factors (Drossman, 1998). For inflammatory conditions, such as IBD, it is hypothesised that influences are mediated through the hypothalamic-pituitary-adrenal (HPA) immune axis (Shanahan & Anton, 1988; Sternberg et al., 1992). A biopsychosocial understanding of IBD is therefore helpful as a framework when considering IBD and experience of the condition. Given the challenges that IBD presents, it is unsurprising that individuals with IBD have been shown to have a worse quality of life than healthy controls (Knowles et al., 2018a). Moreover, active disease results in a further decrease of quality of life and is also poorer, on average, in Crohn's disease than in colitis (Knowles et al., 2018b).

Inflammatory Bowel Disease Pain

IBD pain is commonly reported during disease onset and relapses (Wagtmans et al., 1998). It is estimated that around 70 to 80% of individuals experience pain during active disease (Bielefeldt et al., 2009), typically linked to inflammation which results in the activation of gut afferent nerve endings (Beyak & Vanner, 2005). Abdominal pain can also stem from strictures with subsequent bowel distension, abscesses, fistulae, small bacterial overgrowth or postsurgical pain (Bakshi et al., 2021; Jelsness-Jorgen et al., 2017). However, pain often persists beyond periods of inflammation and has been shown to refer from the gut to other areas, for example, other visceral regions (Minderhoud et al., 2004). Around 50% individuals continue to experience pain when clinical markers suggest that the condition is controlled (Bielefeldt et al., 2009). Based on knowledge of pain processing and circuitry, it is hypothesised that referred and chronic pain in IBD may be rooted in central nervous system dysregulation and visceral hypersensitivity (Bielefeldt et al., 2009), although the details and mechanisms of chronic pain development and maintenance are still poorly understood (Farrell et al., 2014).

While abdominal or gastrointestinal pain are often most discussed, individuals often report other types of pain; both musculoskeletal pain (Falling et al., 2019) and inflammatory rheumatic disease manifestations are common (Gran & Husby, 1992). Non-inflammatory joint pain has been shown to be widespread in IBD, especially Crohn's disease, with significant impact on individuals' quality of life (Palm et al., 2005). However, research around the presence of other pain conditions, such as fibromyalgia and chronic widespread pain (CWP), has thus far been inconclusive. For example, some have argued that fibromyalgia and CWP are as common in IBD as in the wider population (Palm et al., 2000), whilst other studies with prospective designs suggest that conditions such as IBD predispose individuals to develop fibromyalgia and CWP later in life as a result of central sensitisation (Larrosa et al., 2019).

IBD pain can have a significant negative impact on day-to-day functioning, work and social life (Bajorek et al., 2015). The impact of IBD and pain is extensive, affecting an individual physically, socially and emotionally (Wolfe & Sirois, 2008). The condition also affects individuals' relationships and sexual wellbeing (Nightingale, 2006). Understandably, all of these factors can carry an emotional burden and IBD patients have often reported a sense of embarrassment and helplessness (Casati et al., 2000). Mental wellbeing and IBD pain have been linked with a range of psychological difficulties, such as depression and anxiety (Sweeney et al., 2018). A review exploring the controversies and intricacies of psychological comorbidity in IBD has emphasised that anxiety and depression frequently interact with IBD (Mikocka-Walus et al., 2007), but methodological weaknesses of research studies prevent clarification of the nature of this relationship.

Research continues to explore possible explanations for the high rates of pain and symptom burden in IBD, independent of disease activity. Proposed hypotheses range from the presence of sub-clinical inflammation (Farrokhyar et al., 2006), through to psychosocial difficulties that undermine coping mechanisms and increase hypervigilance, as identified in Irritable Bowel Syndrome (IBS; Collins et al., 1999). Research in IBS, a functional gastrointestinal pain disorder that can symptomatically overlap with IBD, can offer some ideas about the intricacies of IBD pain (Bakshi et al.,2021). The overlap between IBS and IBD remains controversial (Barbara et al., 2014), however, the application of a biopsychosocial framework and brain-gut axis research in IBS may also be valuable in IBD. Given the brain-gut axis encompasses the bi-directional interactions between the central and autonomic nervous systems, the stress system (hypothalamic-pituitary-adrenal axis) and the gastrointestinal tract, it is crucial to consider in the context of gastrointestinal difficulties. Research into brain-gut axis interactions in IBS continues to accumulate (Mayer & Tillisch, 2011) and the relevance of the brain-gut axis in IBD is now also being considered. For example, research has shown the relationship between psychological factors and disease activity; symptom experience in IBD has been shown to be associated with severity of psychological symptoms, such as anxiety and depression (Bonaz & Bernstein, 2013; Gracie et al., 2019).

Pain management

Given its impact, research continues to explore pain management in IBD, but without consensus on how pain should be managed and a lack of effective interventions for IBD (Norton et al., 2017). Pharmacological interventions are typically offered as first-line treatments and can be helpful for many, specifically for targeting mucosal inflammation (Torres et al., 2017). However, pain in IBD often persists beyond resolution of disease markers. Analgesic medication may provide some relief, but its use long-term is problematic, often causing gastrointestinal complications (Zeitz et al., 2016). For example, opioid use can carry adverse effects and risks addiction, and nonsteroidal anti-inflammatory drugs can exacerbate IBD (Bakshi et al., 2021). Alternatives, such as tricyclic depressants, could have the potential to reduce IBD abdominal pain while avoiding typical risks associated with analgesics, but such treatments have only been examined in other, related conditions, such as IBS, and could have side effects or long-term dependency (Rahimi et al., 2009).

Psychological approaches to IBD management have typically focused on stress management and other factors, such as medication adherence (Bakshi et al., 2021). A Cochrane meta-analysis of 21 randomised controlled trials concluded that psychological interventions did not lead to improvements in emotional states, quality of life or reductions in disease activity in IBD (Timmer et al., 2011). A narrative review reported similar findings, but emphasised that therapies such as CBT may be more helpful for individuals with IBD who present with comorbid psychological difficulties (Balloo & Keefer, 2017). Nonetheless, as previously discussed, given that stress and psychological difficulties can lead to worsening inflammation and pain, via the dysregulation of the brain-gut axis, this area of research warrants further attention (Reguiero et al., 2017). For individuals not interested in therapy, self-management therapy offers a practical approach to effective coping based on behavioural strategies, but the effectiveness of this approach in IBD is yet to be established (Balloo & Keefer, 2017; Chao et al., 2019). Self-management focuses on increasing patient independence and sense of control (Holman & Lorig, 2004), which could be beneficial, as certain psychosocial factors such as pain catastrophising and symptoms of depression can worsen IBD pain and pain-related disability (Fretz et al., 2020). This further emphasises the role of psychological variables in individuals' pain and disability and future research should focus on psychologically-based, tailored support in IBD (Bakshi et al., 2021; Sweeney et al., 2021). A review of pain management interventions for abdominal pain in IBD also concluded that relaxation and cognitive work may be effective, but intervention development is needed (Norton et al., 2017). Recent research in the area is showing promising outcomes, for example, a recent study by Sweeney et al. (2021) showed that an online therapist-supported

CBT-based self-management intervention was acceptable to individuals with IBD and showed positive effects for improving quality of life and reducing psychological distress.

Understanding pain in IBD

To date, qualitative studies in IBD pain have been limited. Two qualitative studies have explored the experience of IBD pain and one has explored beliefs about pain and the utility of an ‘IBS’ label in quiescent IBD.

In a recent study by Sweeney et al. (2019), 14 individuals with IBD were interviewed about their pain and authors reported three key themes; ‘vicious cycles’, ‘finding solutions’ and ‘attitudes’. First, ‘vicious cycles’ explored the cyclical nature of IBD symptoms, as well as other patterns, such as cycles of anxiety which emphasised the emotional impact of pain. The authors explained ‘finding solutions’ as participants’ ongoing desire for effective pain management and their various long-term and short-term strategies, learned over time through trial and error. Finally, ‘attitudes’ summarised how participants approached their pain, ranging from tolerance to defeat or acceptance. In summary, the authors emphasised that the findings demonstrated the burden of IBD pain and the lack of clear treatment approaches. The interviews highlighted participants’ continued struggle when trying different ways of managing their pain, and its emotional toll. In addition to adequate pain management, the findings also highlighted the need for better IBD pain assessment and psychological support. Due to the heterogeneity of experiences and symptoms, approaches should always endeavour to be holistic and individual.

In another study exploring pain experiences in IBD, 16 hospitalised IBD patients were interviewed (Bernhofer et al., 2017), resulting in five key themes: ‘feeling discredited and misunderstood’, ‘desire to dispel the stigma’, ‘frustration with constant pain’, ‘need for caregiver knowledge and understanding’, and ‘nurse as connector between patient and physician'. Given its hospital setting, discussions centred on the medical environment, with interactions with healthcare staff and medication often at the fore of participants' accounts. However, as in the study by Sweeney et al. (2019), authors emphasised the emotional impact of IBD pain and the desire to find appropriate and tailored IBD pain treatments. Collectively, these studies emphasise the need for further research into IBD pain, its assessment and management of its physical and emotional components.

Given the persistence of pain beyond remission for many individuals with IBD, a recent study by Huisman et al. (2022) explored how individuals with pain during remittent IBD make sense of and cope with pain. The study was also particularly interested on individuals' views about the utility of an IBS label as a way to understand pain in remittent IBD. A thematic analysis of 23 semi-structured interviews showed that, whilst sometimes IBS labels aid coping, they do not bring clarity and understanding. The authors concluded that IBD needs to be considered within its context and individuals would benefit from receiving explanations about their pain, which reflect the multifactorial nature of the condition.

Inflammatory Bowel Disease – other symptoms

IBD encompasses a variety of symptoms that typically co-exist alongside pain. The type, frequency and severity of symptoms experienced varies between individuals and fluctuate given the often-unpredictable nature of the condition (Dibley et al., 2021). For brevity, the discussion here has chosen to focus on fatigue and bowel urgency, given that they are very common, but other symptoms such as bloody stools/rectal bleeding, diarrhoea and weight loss are also experienced by many (Fawson et al., 2021). Research has consistently emphasised pain, fatigue and bowel urgency as key priorities for individuals and these symptoms have become the focus of a key research program, IBD-BOOST, which aims to better understand these symptoms and explore their management (Norton et al., 2021).

First, fatigue is a very common symptom in IBD, but its prevalence has been difficult to gauge, due to varying definitions of fatigue (Jelsness-Jorgensen, 2017). A helpful definition outlines fatigue as “an overwhelming, debilitating, and sustained sense of exhaustion that decreases one’s ability to carry out daily activities, including the ability to work effectively and to function at one’s usual level in family and social roles” (Dantzer et al., 2014). A review by Czuber-Dochan et al. (2013) emphasised that fatigue is experienced by at least 40% of individuals with IBD. Whilst fatigue may be expected during active disease periods, affecting around 86% of individuals, it is also common during remission, affecting around 41 to 48% (Van Langenberg & Gibson, 2010). It is worth noting that these prevalence levels are comparable to rates of fatigue in other chronic conditions, such as cancer (Stone & Minton, 2008) or multiple sclerosis (Johansson et al., 2008). Fatigue can have a negative impact on quality of life (Minderhoud et al., 2003) and patients have concerns about their energy levels and coping (De Rooy et al., 2001). Anxiety, stress and depression have frequently been associated with fatigue in IBD (Czuber-Dochan et al., 2013), but it has been difficult to clarify the direction and nature of associations (Mikocka-Walus et al., 2007). It has been noted that the experience of fatigue, from a patient perspective, has historically been neglected in research (Czuber-Dochan et al., 2013). The studies that do exist have shown that individuals often report that fatigue is overlooked in healthcare appointments and little support or advice is given on the subject (Czuber-Dochan et al., 2014). Further, there is no consensus on fatigue assessment tools and no specific guidelines on suitable fatigue assessment in IBD (Czuber-Dochan et al., 2013). Research has highlighted the multidimensional nature of fatigue, encompassing physical, mental, cognitive and emotional components, with various durations and severity (Whitehead, 2009). This further emphasises the difficulties in terms of measurement and treatment. Overall, it is evident that further research is needed to consider the experience of fatigue in IBD, its assessment and management.

Secondly, bowel urgency, or faecal incontinence (FI), defined as “the involuntary loss of liquid or solid stool that is a social or hygienic problem” (Norton & Whitehead, 2009), is very common in IBD: a large study by Norton et al. (2013) of nearly 5,000 questionnaire responses showed that around three quarters of people with IBD experience FI, even when in remission. The study also showed that quality of life was seriously diminished by FI, which can cause considerable fear and anxiety, given the emotional distress and social embarrassment it can cause (De Rooy et al., 2001). Affected individuals often avoid going out of the home and many specific situations (Rockwood et al., 2000), exacerbating social isolation and affecting employment, social lives and self-esteem (Wilson, 2007). Research by Norton et al. (2013) also showed that individuals rarely sought help for FI, consistent with earlier research (Leigh & Turnberg, 1982), and potentially indicating social embarrassment. In broader FI literature, the prevalence of FI is typically similar across both genders (Perry et al., 2002), but Norton et al. (2013) showed that in IBD specifically, FI appears to be more common in females. In terms of age, broader FI literature suggests that FI is more common with increasing age (Delvaux, 2003), but in IBD this pattern was less clear, even though FI was evidently less common in younger participants (Norton et al., 2013). The authors suggested that this might be due to the increased likelihood of surgery at a later age in IBD, among other factors. In summary, FI has historically been a seriously neglected area in IBD, but more attention is now being paid to its prevalence and impact, as well as raising clinicians’ awareness of this difficulty and proactively asking patients about it. Future research urgently needs to explore appropriate and effective interventions to address FI in IBD to help improve individuals’ quality of life.

It may be useful to consider IBD symptoms collectively. A recent study exploring patients' self-management of pain, fatigue and FI found they are interconnected, so that when one symptom cluster improves or deteriorates, the others are similarly affected (Dibley et al., 2021). Studies such as this emphasise the need to investigate individuals more comprehensively, and in clinical practice, the potential of targeting symptoms simultaneously via one symptom cluster. The Common-Sense Model of Illness Representations (Leventhal et al., 2016) can be a useful model to guide clinicians in understanding and exploring patients' illness experiences and symptoms. Specifically, it allows clinicians to gain a better sense of how symptoms and illness perceptions interact with their coping strategies.

Context & Healthcare

When considering the context of IBD pain and its management, navigating healthcare can have its challenges. It is not uncommon for pain patients, and in particular chronic pain patients, to have negative experiences with healthcare and feel that they are met with lack of empathy or interest (Hadi et al., 2017). In IBD specifically, the priority of medical appointments is typically symptom assessment using disease activity indices and examining inflammatory markers, such as faecal calprotectin. As a result, individuals with IBD often feel that other symptoms and illness experiences are not explored (Czuber-Dochan et al., 2014; Dibley & Norton, 2013), unsurprising where healthcare services are over-stretched and the frequency and duration of appointments is less than needed (Fawson et al., 2021). Another difficulty in IBD is that individuals often experience symptoms despite their objective disease markers appearing well managed, so clinicians may not ask about pain or symptoms (Norton et al., 2017). Some individuals have time to explore this with their IBD clinical nurse specialists, but given the lack of available and evidence-based interventions for self-management, IBD clinical nurse specialists are often unable to suggest specific strategies that could be helpful (Fawson et al., 2021). The importance of exploring IBD symptoms in appointments is evident and gradually, patient-reported outcomes that highlight symptom burden are becoming more routinely used as part of assessment and intervention planning and monitoring (Van Denn et al., 2020).

In summary, this section has provided an overview of IBD, IBD pain and other common IBD symptoms that often interact and co-exist with pain. The discussion has shown that IBD is a multidimensional condition which can be highly debilitating. Pain management strategies for IBD pain, as well as other IBD symptoms, are lacking and further research is needed.

Conclusions

Pain is a multifaceted, highly complex area, especially chronic, visceral pain. The experience of pain is influenced and modulated by a wide range of factors, which vary from person to person. In the context of IBD, a chronic condition with acute episodes and flare-ups, distinguishing acute pain that signals an urgent medical problem may overlap with chronic pain that does not signal a medical emergency and is not related to active inflammation or tissue damage. Navigating this, alongside many other symptoms and, often, comorbid difficulties, can be highly challenging and confusing. The uncertain trajectory of the condition and variability of flares can make understanding the condition particularly difficult, confusing and stressful. Furthermore, accumulating research around the brain-gut axis and its role within IBD is demonstrating the multitude of factors that can influence IBD pain and the impact of stress and psychological difficulties.

The review found no qualitative research that directly examined individuals' understanding of IBD pain. However, understanding pain underpins self-management and is often a priority for individuals with chronic pain. As a result, the current research study aimed to address a research gap and explore how individuals make sense of their IBD pain.

By using a novel qualitative design, the study aimed to reduce rigid structure or limits on what individuals say about their understanding of their pain. The methods specifically avoided giving instructions to consider a particular area of pain, for example, abdominal pain, and did not differentiate or mention acute/chronic or active/quiescent pain. In sum, it aimed to elicit individuals' spontaneous responses to the term 'pain', without restrictions. In conclusion, this novel design is intended to deepen our knowledge of individuals' perceptions and understandings of their IBD pain, which is fundamental in improving person-focused treatment.

Takeaway messages:

- Pain is a complex, multifaceted phenomenon, which typically functions as a protective mechanism. A biopsychosocial approach is helpful in conceptualising the various components that may contribute to pain experience.
- Neurophysiological research has shown that in chronic pain, there are significant changes in the nervous system, and this can amplify pain experience over time. Evidence of neuroplasticity shows that these changes are malleable.
- IBD is a debilitating, multi-symptom condition, which typically has an uncertain prognosis and fluctuating severity. Pain is a significant challenge for many individuals, often lasting beyond periods of observable inflammation, yet it is generally poorly understood and managed.
- No studies have explored how individuals with IBD understand their pain, yet how people make sense of their pain could have considerable implications. Understanding how people conceptualise their pain can give insight into what models they hold about their condition and how they subsequently manage it.

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PART II:

EMPIRICAL PAPER

Abstract

Background and aims: Inflammatory Bowel Disease (IBD) is a chronic, gastrointestinal tract condition. Pain is one of the most widespread and debilitating symptoms in IBD, yet research about how individuals make sense of their IBD pain is lacking. As a result, the current study aimed to explore how individuals with IBD understand their pain.

Methods: The study interviewed 20 participants, recruited via the Crohn's & Colitis UK charity. The Grid Elaboration Method (GEM, Joffe & Elsey, 2014) was used to elicit free associations that participants had about their understanding of their IBD pain, which were elaborated and transcribed. Patterns from the data set were analysed using thematic analysis (Braun & Clarke, 2006).

Results: The study found three overlapping themes; *making sense of my pain, navigating my care and support* and *it takes its toll*, comprising seven sub-themes. These showed that participants made sense of pain experientially, multi-dimensionally and in the broader context of IBD and its symptoms. The psychological impact of pain was evident in all interviews.

Conclusions: The findings reflect other research in IBD pain, demonstrating the importance of paying attention to pain, both in clinical and research settings. IBD assessments and management approaches should routinely integrate pain, and a holistic, whole-body view of IBD is recommended.

Introduction

IBD is classified as a chronic, inflammatory, gastrointestinal disease, comprising two main conditions: Crohn’s disease and ulcerative colitis. The disease encompasses a range of debilitating symptoms, ranging from pain, cramps, swelling, extreme fatigue, diarrhoea and weight loss (Norton et al., 2021). IBD has no known aetiology and there is currently no cure for the disease. Symptoms tend to fluctuate, and individuals with IBD often cycle between flare-ups and remission, experiencing a sense of uncertainty and unpredictability around their condition. This can have a significant impact on quality of life (Knowles et al., 2018) and mental wellbeing (Mikocka-Walus et al., 2007). Given the burdensome nature of the disease, effective and innovative management approaches, as well as research into preventive interventions are crucial, yet lacking (Norton et al., 2017).

Pain has been highlighted as one of the most widespread and debilitating symptoms in IBD. Studies show that around 70% of people with IBD experience pain during active disease periods and at least one fifth of individuals continue to experience pain during disease remission (Bielefeldt et al., 2009). Studies have shown the significant impact of IBD pain, including increased disability, healthcare use, lost work hours and overall poorer quality of life (Coates et al., 2019). Pain has historically been attributed to inflammation, but it is now apparent that IBD pain is not linear and can arise from a multitude of factors (Srinath et al., 2014). In chronic diseases, such as IBD, it can be difficult to gain a comprehensive understanding of pain, as the condition is associated with ongoing pain, but fluctuating, acute pain flares could be a sign of disease deterioration (Zeitz et al., 2016). Furthermore, visceral pain continues to be more elusive and under-researched than musculoskeletal pain (Sengupta, 2019). Hypotheses around central nervous system dysregulation and visceral hypersensitivity in chronic IBD pain have been proposed, but further research is needed in this area to better understand the possible mechanisms (Bielefeldt et al., 2009; Norton et al., 2017). Growing research into the brain-gut axis, the complex, bi-directional relationship between the gut and the brain, is continuing to demonstrate the potential impact of psychological factors in gastrointestinal conditions such as Irritable Bowel Syndrome (IBS), a functional gastrointestinal condition that can present symptomatically similarly to IBD, but has no distinct biomarkers or known pathology (Drossman, 2016). Importantly, the value of brain-gut axis research within the field of IBD is now also becoming apparent (Barbara et al., 2014; Bonaz & Bernstein, 2012). This further emphasises the need for a biopsychosocial approach, placing IBD pain in context, with interlinking psychosocial factors (Drossman, 1998; Turk et al., 2011).

Given the often confusing and fluctuating nature of IBD pain, it is useful to explore how individuals with IBD make sense of their pain. Research in other chronic pain presentations has suggested that accessing accurate knowledge about pain can be important in subsequent pain management (Butler & Moseley, 2013). How pain is conceptualised can underpin pain-related beliefs, which in turn can influence how pain is experienced, for example, its intensity, accompanying distress and disability, as well as how people manage their pain (e.g., Crombez et al., 2012). In summary, in order to support pain management, it is helpful to understand how individuals make sense of their pain. Qualitative research on IBD pain is limited, with only two studies exploring the experience of IBD pain (Bernhofer et al., 2017; Sweeney et al., 2019) and only one exploring beliefs about pain and 'IBS' labels in remittent IBD pain (Huisman et al., 2022). The latter emphasised the need for more understanding about remittent IBD pain and the lack of practical utility in using IBS labels. The authors highlighted the need to examine IBD pain within its context, acknowledging the heterogeneity of IBD presentations. Furthermore, web-based survey research exploring conceptualisations of 'flares' and 'remission' in IBD found that many individuals with IBD seemed to hold limited knowledge about important factors in IBD, such as inflammation, tissue damage and the role of psychosocial factors, such as stress (Trivedi et al., 2019).

Due to the lack of research in this area, the current study aimed to explore how individuals understand their IBD-related pain. The study aimed to cast light on how individuals make sense of their visceral discomfort and pain, what meanings they assign to it and what they may have learned about their pain from varied sources, for example, from interactions with healthcare professionals to online forums.

This study used a novel method to address some of the inherent biases, goals and power dynamics within typical qualitative methodologies (such as semi-structured interviews), to allow participants to lead with their own agenda, instead of following an interview schedule designed and prioritised by the researcher. The Grid Elaboration Method (GEM; Joffe & Elsey, 2014) is a novel approach developed to elicit how people think and feel about a specific topic, whilst minimising researchers' framing of the topic. The method is built on past approaches, such as the Free Association Narrative Interview method (Hollway & Jefferson, 2012), but the GEM aims to reduce the bias from using prepared interview questions. Whilst this methodology has been developed in the field of social psychology, its use is being extended to other settings, such as educational psychology (Park & Mortell, 2020) and clinical health psychology (Keen et al., 2021). By allowing participants to free associate on a given topic, the research focus is on participants' immediate, uncensored and spontaneous thoughts or images, and exploring what is pertinent to them.

This methodology feels valuable when considering IBD. Power dynamics may be important to consider when conducting research in IBD, as it is not uncommon for people with pain, and specifically chronic pain, to have negative experiences with healthcare staff and processes, being met with a lack of empathy or interest (Hadi et al., 2017). Power dynamics in individuals’ healthcare appointments are also influenced by the person’s identity and social graces (Burnham, 2012), for example, the added burden and struggle experienced by women with chronic pain when trying to appear credible and be listened to in healthcare appointments (Werner & Malterud, 2003). In IBD specifically, healthcare appointments are heavily focused on disease markers, and symptoms and illness experience are often not discussed (Czuber-Dochan et al., 2014; Dibley & Norton, 2013). Given the power that clinicians have in determining the agenda of healthcare appointments, it is possible that many individuals with IBD have not been given much opportunity to discuss their pain and learn more about it to support their understanding and management. Furthermore, the use of the GEM may be of particular value in this context, given that pain can be often confusing and lead to dissonant ideas (Keen et al., 2021). The use of four separate boxes in the GEM allows research participants not to be concerned about connecting ideas or creating a coherent narrative; instead, they can fill the grid how they wish with minimal constraints and diverse and even discordant ideas.

Consequently, by using a qualitative design and the GEM methodology specifically, the study aimed to amplify individuals’ voices and elicit rich and uninhibited data, adding valuable information to this research area and clinical understanding of IBD pain.

Method

Design & Setting

The study planned to recruit through two organisations: the Crohn’s & Colitis UK charity (https://crohnsandcolitis.org.uk/) and the IBD Registry, if necessary. An adequate number of participants was recruited via Crohn’s & Colitis UK, so it was not necessary to recruit from the IBD Registry.

Given the COVID pandemic and the vulnerability of many people with IBD, interviews were conducted online only, using Microsoft Teams, lasting approximately one hour. This may have excluded some individuals without access or confidence with technology, but at the same time, this approach meant that participants beyond the study location (London) could take part.

Participants

The study planned to recruit 15 to 20 participants. The GEM is typically used with considerably larger samples in the fields of health and social psychology in order to make comparisons between subsets of the sample (Joffe & Elsey, 2014). First, this approach was not feasible for this study, given time and resource limitations. Second, the study aimed to amplify participants’ voices and tap into the nuances of understanding IBD pain, which would not be possible with a larger sample and the study did not aim to form comparisons.

Inclusion criteria

Participants were adults, aged 18 or older, with a diagnosis of Crohn’s or ulcerative colitis for at least 6 months, who could speak English and did not have any significant cognitive impairment, which was self-declared on the participant consent form.

Ethical considerations

The study was reviewed and approved by UCL Ethical Committee (REF: 19517/001: Appendix A). Ethical considerations were explored and adhered to, following best practice guidelines (Braun & Clarke, 2013).

Pilot study

Involvement of experts by experience in research is seen as an integral and valuable part of any research process (Lindenmeyer et al., 2007). A pilot study was conducted with two volunteers, known to the researcher, who have IBD. The feedback and discussions from this pilot were used in the study design and implementation.

In brief, the GEM was carried out with both individuals, separately. Overall, feedback was positive; specifically, both individuals felt the GEM allowed them to feel centred in the research and gave them an opportunity to discuss associations that felt relevant and important to them, with respect to understanding their IBD pain. Both individuals were also involved in sharing ideas about the research topic more broadly and developing the study protocol. Their input was invaluable in gaining a better sense of how the GEM may be received and the level of detail in its instructions, which were refined as a result of the pilot feedback. The discussions also highlighted some assumptions that the researcher was making, which are reflected upon in part three of this thesis.

Procedure

The researcher liaised with Crohn's & Colitis UK about the study and once the research advertisement was approved (Appendix B), participants could access it on the Crohn's & Colitis UK research participation page. This was linked to a Qualtrics webpage, containing the participant information sheet and consent form (Appendix C). Once a consent form was submitted, the researcher scheduled each interview via the participant's preferred method of contact (phone or email). An email template, which contained interview instructions and copies of the information sheet and consent forms, was used to ensure consistency. Further communications were tailored as necessary, but aimed to be polite, professional and neutral, to reduce differential priming. Participants needed paper and pen for the interview, but could contact the researcher if that was difficult.

At the start of the interview, the researcher introduced herself and checked the participant's preferred name, consent and any questions prior to starting. The researcher explained that in the interview there are no right or wrong answers and that she was interested in participants' opinions, believing them to be expert in their condition.

The interview began with the researcher sharing her screen to show a simple, numbered, two by two grid and asking the participant to copy it onto a piece of paper. The instructions were then read out and shown on the screen for participants to read and refer to (Appendix D). The instructions stated:

"Instructions:

We are interested in your understanding of your IBD pain. Please express what you associate with this, by way of images and/or words. Please elaborate one image/word per box. Sometimes a simple drawing or word can be a good way of portraying your thoughts or feelings."

Once participants had completed the grid, the researcher took a print screen when the participant held it up to the camera. If the participant was unsure or asked for clarification, the researcher said that the participant should write or draw the first four things that come to mind when thinking about their understanding of their IBD pain, and they should go with their initial, instinctive reactions.

The researcher explained that each box would be discussed in turn and proceeded to work through each box, prompting “tell me about X” and “tell me more about that” to gain further detail. Reflections such as “you mentioned X…(pause)” were also used to encourage participants to continue their elaborations. Participants often discussed upsetting or vulnerable topics; therefore, validation and empathic statements were sometimes used to create a safe environment and ensure participants felt comfortable enough to continue. As elaborations progressed, the researcher encouraged further detail until the participant felt confident they had nothing else to add.

The demographic form was completed following participants’ elaborations and included basic information, such as age, gender and ethnicity. The form also asked four, brief questions about participants’ pain, which were not used formally in the analysis, but added contextual information. Some participants spontaneously elaborated further detail relevant to their grid during the demographic form part of the interview. When this occurred, all participants confirmed they would like this to be included in the analysis. Following completion of the form, the researcher thanked participants, offered an opportunity to ask questions and re-iterated where to find the study outcomes.

Interviews were promptly transcribed by the researcher and the interview files permanently deleted, as per data protection requirements. Transcripts were anonymised and potentially identifiable information, such as locations or hospitals that participants referred to, were removed. As discussed by Braun and Clarke (2013), transparency in how transcription is approached is crucial, and the transcription key used is included in the appendices (Appendix E).

To aid reflexivity and analysis, the researcher reflected on each interview and noted pertinent information following each interview (Phillippi & Lauderdale, 2018). This included details such as how the interview felt, impressions of the participant or any difficulties (e.g., internet connection issues). Additionally, initial ideas about potential patterns were also noted. Collectively, this information was saved as an introduction to each transcript.

Researcher perspective

It is important for researchers to state and reflect on their position, from which they are approaching and viewing qualitative research (Barker & Pistrang, 2005). The researcher was a White, Eastern-European/British, middle-class female in her early 30s. The context for conducting the research was her Clinical Psychology Doctorate. Professionally, the researcher had not worked specifically in IBD, but had a history of being interested in Clinical Health Psychology, had studied Health Psychology at a Masters level and had briefly worked in the field of pain management and chronic fatigue. Personally, the researcher had a diagnosis of IBS, a condition that is less severe but overlaps with IBD, as well as ongoing gut-related problems which were being investigated during the research period. She also developed long-COVID muscle and joint pain prior to starting interviews, which continued for the duration of the research and influenced her perception of chronic pain.

The researcher had two friends with Crohn’s disease, which may have also led to prior development of certain beliefs and ideas about IBD. Whilst conducting the research, the researcher kept a reflective journal, received regular supervision from a Consultant Clinical Psychologist with extensive experience in the field of pain, and also engaged in a bracketing interview to explore any underlying beliefs and assumptions about the research in greater depth (Hill et al., 2005). Furthermore, an idea which stemmed from the bracketing interview involved the researcher conducting a GEM on herself, in relation to her IBS pain, which was completed and reflected on. The researcher acknowledged that she was approaching the interviews with a belief that visceral pain has been deeply neglected in the research literature and therefore, held a desire to amplify participants' voices.

The researcher perspective is explored in more detail in the critical appraisal found in part three of this thesis.

Data Analysis

Thematic analysis has been described as a highly flexible approach, which facilitates finding themes within a data set and can be applied to different frameworks and epistemologies (Braun & Clarke, 2006). The research study design was in alignment with a thematic analysis approach and as previously discussed, thematic analysis is typically the method of choice in GEM research (Joffe & Elsey, 2014).

The researcher's philosophical and epistemological stance is rooted in a contextualist epistemological framework, sitting between positivism and constructivism (Braun & Clarke, 2013). This framework in the context of the research felt appropriate and fitting, given the study planned to explore how individuals with IBD make sense of their pain, whilst acknowledging that individuals come from their own contexts which are relevant and that influence their experiences. The analysis was inductive, meaning no pre-existing theory was imposed on the analytical stages, although researcher biases and assumptions inevitably affect analysis (Braun & Clarke, 2013).

The analysis followed the well-documented, six-step method in thematic analysis (Braun & Clarke, 2006). First, the researcher familiarised herself with the data, through transcription and multiple readings of each transcript. All GEM grids were also examined for potential preliminary patterns, but were not used formally in the analysis. Second, Nvivo software was used to code the data set, in an inductive, data-driven manner. Third, codes were analysed and refined further to start to develop themes (Appendix F). Fourth, continued immersion in the data was used to continually review and revise themes, whilst creating visual mapping of potential overarching themes, themes and sub-themes (Braun & Clarke, 2013). Fifth, once finalised, themes and associated sub-themes were defined and named. Finally, extracts were selected and the overall narrative and findings written up in the thesis.

Validation checks

The credibility and validation of the study was ensured through regular supervision and by following the 15-point quality criteria for thematic analyses proposed by Braun and Clarke (2006). Adherence to the GEM method was ensured by accessing example transcripts from studies by the creator of the GEM and discussions with postgraduate colleagues who had used the GEM. Once data were collected, external checks were carried out by the researcher supervisor and a postgraduate colleague with GEM experience: codes were reviewed for patterns and then discussed and mapped into potential themes and sub-themes. The research supervisor, experienced in qualitative work, frequently gave feedback on evolving findings and helped to ensure adherence to the GEM and thematic analysis processes. No inter-rater reliability checks were conducted, as this was not in line with the study’s epistemology.

Findings

The findings have been divided into two sections. First, contextual information has been presented to situate the sample and give context to the findings. Second, thematic analysis findings are presented.

Contextual information

Altogether, 20 participants took part in the study (table one). Participants ranged from 20 to 66 years old (mean = 36), 13 females and seven males. The majority of participants identified as 'White British' (16 participants), one identified as 'White Irish', one as 'White' and two as 'Mixed White & Asian'. Finally, 11 participants had Crohn's disease, seven had ulcerative colitis and two had both. The interview length ranged from 39 to 72 minutes (median = 52.5 minutes).

Table 1: Participant demographic information

Participant number	*Age*	*Gender (as defined by participant)*	*Ethnicity (as defined by participant)*	*Type of illness*
P1	54	Female	White British	Crohn's disease
P2	26	Female	White British	Ulcerative colitis
P3	62	Female	White British	Both
P4	35	Male	White British	Ulcerative colitis
P5	25	Male	White British	Crohn's disease
P6	47	Male	White British	Ulcerative colitis
P7	20	Male	White British	Both

P8	26	Female	White British	Crohn’s disease
P9	29	Male	White British	Ulcerative colitis
P10	21	Female	White Irish	Crohn’s disease
P11	28	Female	Mixed White & Asian	Ulcerative colitis
P12	66	Female	White British	Crohn’s disease
P13	37	Female	White	Ulcerative colitis
P14	54	Female	White British	Crohn’s disease
P15	22	Male	White British	Ulcerative colitis
P16	25	Female	Mixed White & Asian	Crohn’s disease
P17	51	Female	White British	Crohn’s disease
P18	48	Female	White British	Crohn’s disease
P19	28	Female	White British	Crohn’s disease
P20	22	Male	White British	Crohn’s disease

Interview-based contextual information

Important contextual information also came directly from participants’ transcripts. Summaries of these patterns and reflections are presented below, to further situate the sample.

Pandemic. Twelve participants made references to the COVID pandemic. Comments varied but clustered around the challenges and the benefits of the pandemic, in the context of

IBD and pain. Most participants reflected on the difficulties, including the struggles with receiving healthcare during the pandemic or it being of worse quality. For some, pain had increased due to an increase of stress or a decrease in typical distractions from their pain. In contrast, for some participants benefits included having fewer plans, less stress and exhaustion, making IBD more manageable. Broader reflections included how the pandemic facilitated societal recognition of how it can feel to live in fear of infections or illness, and how it highlighted ongoing discrimination against people with long-term conditions or disabilities.

Gender. Three participants reflected on their gender, in the context of pain. One participant offered extensive reflections on her experiences in healthcare settings, as a woman presenting with pain, and discussed how a lack of research on women's pain has led to an impact on care, for example, receiving medication doses that have been tested on men. This participant also reflected on intersectionality and her position as a woman from a minority ethnic background (see 'ethnicity' section). Others reflected on gender in the context of managing the emotional burden of pain, and how this can be approached differently by women and men.

Ethnicity. One participant spoke about her ethnicity in the context of pain and also its intersectionality. The participant reflected on how belonging to certain minority groups can influence how a person is treated and what assumptions people make. For example, seeing a person's name and making assumptions about religion or making assumptions about a person's pain on how they look, without taking individual differences and culture into account.

Age. Age was typically discussed in the context of historical information and reflections on participants' diagnosis journeys. Some participants spoke about their struggles to have their pain and symptoms taken seriously and struggling to receive the right diagnosis when they were younger. Two participants also discussed the difficulties around navigating adolescent care and neither paediatric nor adult care being suitable for their needs at that time.

Thematic analysis

GEM grids

Most GEM boxes were completed with a single word or idea; only 12 out of 80 grids contained images. No formal analysis of the boxes was conducted, but patterns were noted. This process was biased by the researcher knowing the context of each GEM grid from the interview elaborations. Nearly half of the boxes (37/80) described pain or its qualities, using either concrete or abstract words or images (figure one). A quarter of the boxes (20/80) reflected the impact of IBD pain (figure two). Feelings and emotive language were also common and appeared in 13 boxes (figure three). Other boxes described comorbid difficulties, management or had ambiguous meanings that did not easily categorise. For further example of GEM grids, please see appendix G.

Figure 1: A selection of different participant GEM boxes, showing pain qualities/descriptions (“deep”, “hidden”, “stabbing”, “intense”, image of a bent over stick person)

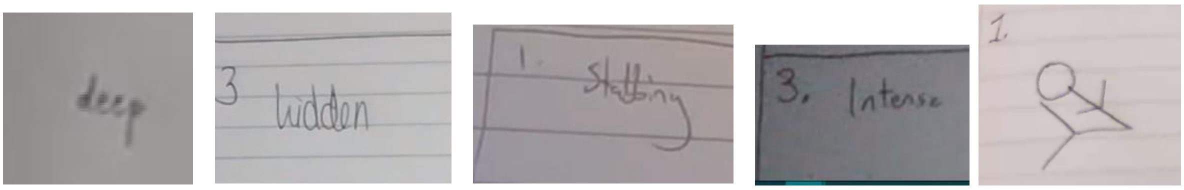


Figure 2: A selection of different participant GEM boxes, showing impact (“takes over”, “exhausting”, an image of a brain with a X through it, “inconvenient”)

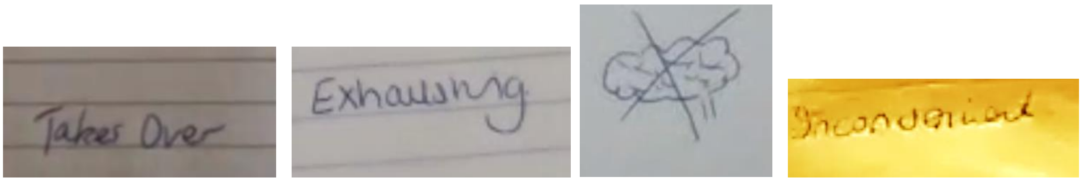
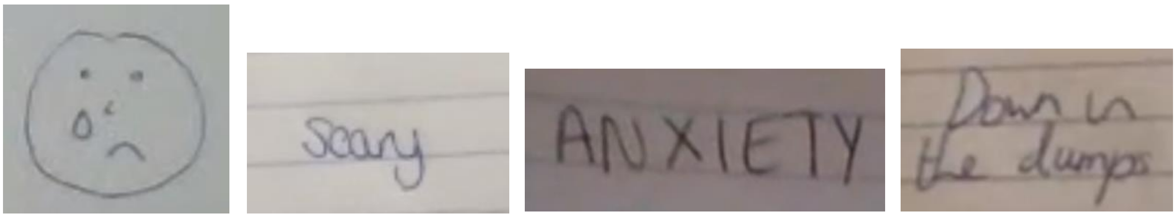


Figure 3: A selection of different participant GEM boxes, showing feelings or emotive language (an image of a sad, crying face, "scary", "anxiety", "down in the dumps").



Interview elaborations

Thematic analysis of interview transcripts resulted in three themes, which comprised seven sub-themes, as presented in table two below.

Table 2: Overview of themes and sub-themes, as well as their rate of occurrence

Themes	Sub-themes	Number of participants (sample = 20)
1. Making sense of my pain	1.1 How it feels	20
	1.2 When it's there	18
	1.3 Why it happens	15
2. Navigating my care & support	2.1 How I cope	20
	2.2 Navigating healthcare and others	19
3. It takes its toll	3.1 The impact on my life	20
	3.2 The emotional and mental strain	20

The themes have been conceptualised as overlapping patterns, which are inextricably linked and influence one another (figure four). In brief, participants made sense of their pain in the context of their healthcare, support and management approaches. Equally, this overlapped with how they felt about their pain (and IBD more broadly) and how much it impacted their lives and mental wellbeing. Details of each theme and subtheme are presented below.

Figure four: Conceptualisation of the three themes as an overlapping Venn diagram. Bold text indicates central theme.

Theme 1: Making sense of my pain. *Making sense of my pain* was considered a central, overarching theme, which outlined the different components of participants trying to understand their pain; *how it feels, when it's there* and *why it happens*. Whilst notable patterns are reported and explored, all three subthemes contained variation across participants, emphasising the spectrum of differential effects of IBD and idiosyncratic experiences.

Subtheme 1.1: How it feels. Many participants spoke to the overall difficulty of describing and explaining their pain. This was often connected to its fluctuating, unpredictable and elusive nature, but also due to a lack of adequate language:

‘...it's a sensation, but I cannot describe it. It's not pain, it's like a dull ache, it's not numb, it's not hot, it's not cold, it's not tingling. It's something that is causing complete discomfort. But it's trying to explain something like that to the doctors...is hard, because there's no word to describe that specific thing’ [P5]

‘indescribable’ [P19]

Nonetheless, all participants described their pain and in various ways. Attempts were made to describe pain in tangible, concrete terms, such as describing the location of the pain and the sensations:

‘Where I experience the pain, it was just above where my... it felt just above where my belly button is. It was a constant, sort of sharp and stabbing pain.’ [P7]

On contrast, many chose to use more abstract ideas; metaphors and comparisons to other pains were common to explain how the pain feels:

‘…like a blender in your stomach or in your colon - which is where I have my colitis - it's something like that basically. It feels like your insides are being ripped out completely…’ [P11]

‘the intestinal pain, it's similar to menstrual cramps.’ [P13]

The researcher felt many participants were keen to convey the severity of their pain and strikingly, numerous participants compared IBD pain to childbirth:

‘oh my gosh, it's awful. It really burns your bottom and it's explosive, and the pain literally takes... just... it's awful. It's, it's even worse than having a child’ [P3]

Whilst gastrointestinal tract pain was at the forefront of participants’ minds, elaborations often delved into other types of pain that participants associated with their IBD, such as joint and eye pain, or pain as an unpleasant side effect from medication:

‘For example, I self-inject my adalimumab and that can be painful because it's a needle that you're injecting and that stings and swells after I do that. And then I've had other treatments. I've had, I had ones, a prescription of suppositories that just were agony to use and they were really painful and so obviously stopped using those.’ [P2]

Pain was rarely described in isolation. Many reflections spoke to the spectrum of symptoms that came alongside pain, such as bloating, nausea, brain fog, diarrhoea and most commonly, fatigue. These influenced recovery from pain, day-to-day functioning and quality of life.

‘I get very bad fatigue and often the pain correlates with the fatigue and it feeds into the fatigue and the fatigue feeds into the pain and then it becomes a bit of a cycle I think. I think for probably quite a few people pain and fatigue are two of the things that are just not as understood or spoken about really.’ [P16]

‘it's the combinations of all the symptoms that makes it unbearable…’ [P19]

There was a sense that the pain had the power to shape individuals’ sense of self, in terms of how they judged their wellbeing and health. Many participants reflected on their baseline of pain or symptoms and how it began to feel like normality.

‘I would normalize a kind of level of pain. Like I'd... definitely a level of pain that nobody else feels - unless it's like a fellow IBD sufferer who’s not looking after themselves…’ [P10]

'...of course normal is interpretable as well - but you almost don't know what normal is anymore. And it's only when you actually feel better that you're like "oh yeah, that's how it's supposed to be"...' [P18]

Subtheme 1.2: When it's there. Making sense of when the pain occurred appeared central to understanding it and served many roles; understanding flares, current disease state, choosing management approaches and reducing the impact on one's life. Many participants spoke about the difficulty and confusion of flares, often mentioning the unpredictable nature of pain and how it does not necessarily correspond to being in 'remission':

'in terms of when and how severe - that is unexpected. Because it's so... it can happen in the blink of an eye..' [P8]

'I think it's almost the surprising element of it as well, because even when you're not necessarily like very ill - like your IBD is in remission or whatever - you can still occasionally get this pain.' [P15]

In contrast, others spoke about identifying certain triggers or patterns. Whilst these varied, they clustered around overactivity, food, stress or medication/treatment, although there were individual differences within and across these categories. Understanding triggers was a trial-and-error process, that developed over time through paying attention to flares, their circumstances and warning signs.

'It's normally food, stress, alcohol related.' 'So it's yeah it's knowing your body, knowing the triggers when you've got it.' [P6]

'you do look back through what you've done to try and figure out how you can stop it happening again. And you also know that if you do that, do those things again, then you can expect... you're ready for... this surprising pain.' [P15]

However, these two patterns were not always mutually exclusive and it was common for the unpredictable nature of pain to co-exist alongside more noticeable triggers.

Different types of pain typically corresponded to different timeframes; most commonly, participants spoke of two types of pain; first, a low-level, dull, aching pain, that was often constant or present for long periods of time and second, acute, intense bursts of short-lived pain that was more unexpected, but passed more quickly. The former was often more manageable, albeit very uncomfortable, whilst the latter was all-consuming and incapacitating:

'... for me, there's that sort of gnawing everyday pain, which moves slowly and then sometimes you have a really big peak within a few seconds' [P16]

The nature of short, intense pain was sometimes compared to waves, or as one participant described it:

'It's like having contractions really... once the first one happens, just prepare for the next ones.' [P5]

Subtheme 1.3: Why it happens. When considering why pain occurs, there seemed to be a consensus that understanding IBD pain continues to be a neglected area, with some participants giving specific examples of how pain has been dismissed in the past, which further undermines their efforts in making sense of it.

'I guess whenever you talk to them [clinicians] about the pain, any of them, it's kind of like, "Oh yeah, that's just part of it." and they don't always tell you what it is that's causing it. Or I guess, just more understanding what is... for example, what is the gut pain?... what is it inside me that's actually hurting? And what is, what's aggravating it? What can I do to alleviate it?' [P2]

There was often confusion about the meaning of pain and a desire to understand pain better (*'I'd like to know really… what kind of... what causes it, why it occurs, why it happens.'* [P9]) However, a few participants felt confident that they knew their body and described a level of attunement to their pain; where it stems from and what it means, developed over time:

'it's sort of always changing and it can change very rapidly, or it can be sort of a low-level kind of gnawing pain that's there all of the time, really, especially if you've got issues with maybe scar tissue or something sort of internal like an ulcer. So you can kind of feel it a lot of the time. Especially, I think, like foods passing by the damaged area, I think, I'm quite aware of how it feels within my gut and sort of where the pain is. Like, I get a lot of kidney pain because I get kidney stones a lot and I know like what's a kidney pain, I know what's a liver pain, I know what's an intestinal pain and there's all of these different pains which will fluctuate and change.' [P16]

Across the sample, pain was attributed to a variety of causes, including passing of food, inflammation, ulcers, obstructions, and strictures. Some reflected on the meaning of pain in broader terms, for example, seeing it as a warning sign and the start of a flare. In some reflections, different pains were matched to different explanations, typically attributing duller aches to less serious causes:

'… the sharp pains would be from the - I had like an abscess, so like an infection - so that was the causing of the sharp pain, so that would be sort of unbearable pain. And that's sort of what made me go into hospital. But the dull, achy pain I get, it's probably just from the condition and I've got a stricture, so it's probably just from food passing through' [P20]

Vivid imagery was also used to convey how painful sensations are perceived:

'… the main source of the pain... is feeling tubes and stuff inside of me just start to close up' [P5]

‘It does feel like you're sort of gnawing away at yourself, kind of thing - very strangely. And I suppose it has some truth to it, because of course it is the wall of your bowel, you know, closing in on itself and becoming so inflamed that it could close.’ [P7]

Many reflections showed a strong link between making sense of the pain and the emotional, psychological impact of not being sure of what the pain means. For example, anxiety; fearing that the pain signifies serious complications:

‘... the really, really painful times, you don't know what's happening. You think "oh has my bowel perforated?"’ [P11]

Reflections on the meaning of pain were typically followed by comments about pain management. This, once again, highlighted the interrelatedness of making sense of one’s pain and navigating how to approach it, emphasising the search for effective coping:

‘... although I wouldn't bet my house on it, I think it's because that's where I've got a bit of a stricture, and I think sometimes that's what the pain is. That's how I imagine it as well in my head. That I just need whatever it is to move past that part of my bowel and then things are going to go OK again, so that's part of how I try and relax into it a bit, because I know it's not going to be there for 24 hours a day. It will pass.’ [P14]

Some participants alluded to the difficulties with teasing out what belongs to IBD versus other problems and how that can affect help-seeking. Sometimes pain and health problems were mistakenly attributed to IBD:

‘...from the pain standpoint, I was hospitalized 18 months ago with a bowel infection that I thought, because of the way it was manifesting, that I thought was a really bad Crohn's, I thought it was a burst bowel, basically.’ [P17]

Theme 2: Navigating my care and support. *Navigating my care and support* refers to the landscape in which participants find themselves. This landscape comprises the multi-faceted healthcare and management process that individuals move through, as they work towards understanding and managing their IBD and pain symptoms. Participants were in various places within this landscape, which was dynamic and changing over time.

Subtheme 2.1: How I cope. This sub-theme spoke to how individuals approached their pain and managed it. When discussing pain, most participants often recounted specific memories and examples of pain, following this recollection by stating how they managed it in the moment. This suggested that accessing experiences of pain was intrinsically linked to coping and getting through the pain.

'... collapsing on the floor, unable to move, having to sort of go into the foetal position as well. I think that comes to mind the most.' [P11]

On other occasions, participants discussed broader views of coping and management of their condition and pain. These discussions were varied, but often clustered around diet, activity pacing and medication/treatment. Stress was also frequently mentioned (explored further under *it takes its toll* subtheme). There were considerable individual differences within the sample; for some participants, coping with the pain continued to be very difficult, whilst others had established strategies or felt their medication was effective.

'... then you start on a different...um, pathway of finding a cure. Which, I, still to this day haven't found.' [P3]

'I just feel quite unlucky with it. But with the right management or with the, you know, with managing it the way that I do, I can deal with it pretty well.' [P9]

More than half of the participants discussed the idea of control and controllability. The desire for control over the disease was dominant. Participants ranged from finding it difficult (*'...it's* *uncontrollable.'* [P1]), to finding it easier (*'I'm getting a lot better at controlling it and I feel quite on top of it right now.*' [P10]). This often interlinked with the psychological impact of the disease and uncertainty.

'... control is a big, big issue. So I know, that I like order. It's something that gives me comfort. And with Crohn's, you just don't have any. You don't know from one day to the next, one hour to the next - I'm sure you know this. So there is no control.' [P14]

A quarter of participants spoke about the internal conflict they experience when managing their condition or needing help. Specifically, there was a pattern of delaying help or medication, either reflecting pain medication stigma or showing the lack of acute support in chronic conditions:

'... when you've got a chronic condition, you would tend to leave things to the very last minute before you sought help, rather than someone who'd become acutely unwell - they'd straightaway seek help. So I think we do allow ourselves to suffer more than we should sometimes.' [P8]

'I tend to wait a bit too long, because I don't feel like taking it [pain medication] and then I've let it get a lot worse than it should be. But I think that's part of the stigma of needing pain medication' [P16]

'... you don't know when to escalate it' [P17]

Fundamentally, most participants felt that there was a lack of support or treatment for IBD pain. There was a noticeable longing amongst a quarter of the participants to try other ways of managing their condition. These reflections centred around wanting more holistic, joined-up approaches, better communication across health teams, new treatments or preferences to avoid current management options:

'Every time we kind of suggested something, we were told there's not enough research and to try and just get on with what we, what I was kind of given... as prescriptions.' [P2]

'... there's lots of options like, um, things like alternative therapies or even counselling therapies... ways of helping you manage pain in the moment... that they just don't really offer.' [P8]

'My IBD doctor… he... because I felt I didn't want to go on these very, very strong drugs, which can give some really bad side effects - he sort of brushed his hands with me really....' [P1]

Subtheme 2.2: Navigating healthcare & others. This sub-theme highlights the healthcare context and the fluid, multifaceted journey that participants found themselves on, when trying to understand and manage their pain. This was also underpinned by power dynamics and the patient-doctor relationship, which was alluded to by many and explicitly discussed by one participant:

'... going to A&E in your pyjamas, feeling a bit vulnerable ((laughs)) and you just want to feel like you're on the same level and having a conversation, rather than a dictation of what you're going to do. Because often I've been told what to do with my management of my disease and I don't really like that approach personally. I like them to talk to me about the different options and say "what would you like to do?".' [:P16]

Most interviews involved participants talking about their IBD journey and reflecting on their earlier history with the condition. There was a sense that a chronological account of the condition and pain underpinned sense-making. Most commonly, diagnoses and specifically, difficult and time-consuming diagnoses, were discussed. This was often linked to aggravated pain and confusion about what they were experiencing.

'... my whole diagnosis was a bit of a mess' [P2]

'... when I was eventually diagnosed, I said to the consultant "I could literally kiss you, because it's such a relief to be given a reason for what I'm going through"'. [P3]

It was striking that almost all participants discussed their experiences with healthcare professionals, ranging from GPs to specialist IBD team staff, at great length. The high number of reflections made on this topic suggested the importance and prominence of healthcare interactions in participants' minds. Reflections were mixed, showing both difficult experiences with being heard and receiving the right support, and appreciation and relief for caring staff and helpful treatments.

'... at least with my doctor, it's difficult to talk. My appointments were cancelled, and then in the end I was changing doctors. I'm not sure why... maybe because of the pandemic they were assigning them to something else. So in the end, I was only followed up by my IBD team, by the nurses mainly, but they seem to be too busy, so... and they have their own agenda and it's difficult for me to make them really listen. So we never discussed much specifically about the pain' [P13]

'... but my consultant - I've got his direct line number at the hospital. If there is a problem, give him a call, you know, I can do that. So, I'm alright.' [P6]

Further, healthcare experiences often shaped individuals' motivation to understand pain. Participants often communicated a sense of resignation and hopelessness about understanding what pain means, as they have been repeatedly informed by healthcare professionals that it is simply an inherent part of the disease. Some also reflected on the lack of support for acute problems within chronic conditions, highlighting a felt gap in the healthcare system and a lack of acknowledgement of acute pain:

‘I was in so much pain and I just felt very much brushed aside. I think when you have a chronic illness you are expected to be able to deal with it better than someone who's acutely unwell.’ [P8]

‘... you've not got any way to get anything on an acute basis for IBD, your next choice is going to be potentially an out of hours NHS service, and that puts you all down that road that can end up with A&E.’ [P17]

Navigating support transcended healthcare and was also discussed more broadly. Unsurprisingly, living with pain was seen as being easier when participants were able to draw on support, for example, from close networks such as family and friends, or wider support systems, such as the Crohn’s & Colitis UK charity. Communication, being heard and understood by others were patterns in many narratives. It was common for participants to find it hard, historically or currently, to open up about the condition. Participants often acknowledged the challenges around having an invisible disease and pain, including the unique challenges around relating to visceral pain, such as IBD pain:

‘I think it's not just that it's not visible. I think it's also that... there are plenty of other types of pain that aren't visible, like migraine, for example, which I also get every now and again. But people understand what it is to have a migraine or headache, you know or back pain, for example, or kidney stones or something. These are types of pain that people can understand better, and I think this is a pain that is less understood.’ [P4]

Equally, the nature of having a bowel condition continued to pose challenges, including frustrations about frequent comparisons to IBS, embarrassment and misunderstandings about the severity of IBD. In contrast, some participants discussed significant progress in this area, showing a reduction in stigma, and increased ease with which the condition can be spoken about.

‘I get a bee in my bonnet, when people say "oh yeah, I've got IBS, I know what that's like" and I'm like, I totally sympathise with you, IBS is uncomfortable and what have you, but it's not the same as IBD.’ [P19]

‘... when you want to tell them about your pain and the Crohn's disease in general, there can be sort of stigmas and stereotypes that come along with that. So it can be quite hard to get around I think, and to help people understand. I think, especially with bowel disease. I mean, I think a lot of people get quite embarrassed talking about that.’ [P16]

Theme 3: It takes its toll. The theme *it takes its toll* describes the pattern of reflections that related to the impact of IBD, pain, its co-existing symptoms, management and healthcare navigation on participants’ lives.

Subtheme 3.1: The impact on my life. Participants’ sensemaking of their pain was closely interlinked with how it affects areas of their lives, including impact on their day-to-day life, going out, relationships, education and work. Most reflections were inextricably linked to coping (see theme two), as effective management and understanding influenced the level of impact.

‘It's also to do with "oh, I had a plan next weekend and I'm obviously not going to be able to do that" or "oh, am I going to have to take time off work?"’ [P11]

‘... when I was on the Infliximab and I did feel normal, it meant I could go places without worrying about toilets, I could go places, I could eat what I wanted and I felt free to do whatever I wanted instinctively. Since I've been... had the flare-up come back after I've been off the Infliximab, I have been wearing nappies and getting a lot of pain…’ [P12]

‘... somebody suggesting you do something - I'll run through the whole list of instant check lists about "well can I, would I, should I? Well, if I do that, will it fit? What's the cost of that? What might that mean?”’ [P17]

Comparisons and analogies were also common, allowing individuals to describe how they felt the pain affects their lives:

'Like a car, it runs out of petrol, which is my getting to the toilets, so when you're going down the motorway you're thinking where is the next petrol stop? Where's the next toilet stop where you're going. You're thinking check everything before you go on the trip, to make sure that everything is in working order, but you can't be sure that everything is, till you get there ((laughs)).' [P12]

One participant also chose to discuss the impact on sexual wellbeing:

'I started experiencing pain during orgasm, which is terrible. Because it's something that should be enjoyable. But after that I was having a pain and pulsing pain from my vagina to my anus and pulsing pain. So there was something so strange that I have never experienced ever before.' [P13]

Whilst most individuals commented on current and/or historical negative impact of pain and IBD, some were optimistic or hopeful. For example, some acknowledged that distraction sometimes provided respite from the pain:

'I can feel that whenever I'm doing something I enjoy very much, the pain goes away a little bit.' '… so whenever I do something I enjoy, limitations are… less - less pain I would say.' [P13]

Subtheme 3.2: The emotional and mental strain. All participants discussed the vast array of mental and/or emotional impacts of pain, powerfully illustrated by one participant's comment:

'I know that when I'm feeling that pain - when I've got the inflammation in my gut - it's scarring. And it's leaving a scar. And as those scars build up, more problems build up, so I

know that. But I also think psychologically, it leaves a mark, and I think that that needs tending to as well' [P14]

Anxiety, worry and fear that is linked to the unpredictable nature of IBD and/or the pain were common. Often, this was closely linked to imagining what the pain is linked to and what that means, as previously mentioned.

'it's really just the uncertainty of not knowing how your IBD will present itself' [P10]

'... it has fear attached to it. It's the fear that I'm going to get a blockage there.' [P14]

However, a sense of resilience and growth was present in many reflections; some participants spoke about their fear and anxiety decreasing over time, as they learnt more about their condition and pain. This demonstrated a level of acceptance that many acquired through trial-and-error approaches:

'... when I first got diagnosed and I had the excruciating pain and crippling pain it... I didn't know, so it was that word "scary" - I think was very much more prominent.' [P11]

'I've learned that trying to fight on through a bad episode of IBD will only make it worse. So actually, there's no point trying to... you have to surrender to it and you know, accept that whatever you might have had planned for the next few hours or days or weeks is not going to go ahead.' [P4]

Anger or frustration was typically apparent in relation to having the condition or sometimes directed at specific areas, such as not being listened to or frustrations with healthcare. This once again demonstrated the overlaps with navigating care and being heard:

'... the usual things... "why me?"' [P12]

Stress was discussed by almost all participants and was typically seen as a factor in both triggering and stemming from pain. Consequently, discussions around stress appeared across all themes, in the context of triggers and flares, difficulties with management and healthcare and the broader nature of having a long-term condition.

'I think stress is a little bit of a kick in with it, but I think it works both ways. I think the Crohn's gives me the stress, I think it's... it's... which is first? The chicken or the egg.' [P12]

'I've had other consultations where I've been told that my pain is due to stress, but then been offered no way of dealing with that stress or the pain associated. So yeah, it's just the small things like that, that make you feel that the pain is not part of the disease they're going to treat.' [P8]

More than a quarter of participants discussed feelings of embarrassment or shame, either in relation to having a bowel disease generally or about specific problems that it brings, especially connected to toilet use:

'I had the embarrassment of having to poo in the woods. You know, it's not something that anyone likes to do…' [P12]

However, a sense of empowerment was evident in some elaborations, whereby participants' perspective around shame and embarrassment has shifted over time:

'I've decided, well… I'm not going to feel like I should be ashamed of having a disease that makes me sometimes ill.' [P17]

Feeling down or depressed showed the impact of the pain and sadness about not being able to do things. For some, this overlapped with guilt and a sense of being a burden and limiting people around them, which could further fuel their depression.

'… "depression" - I get pretty down with it. You know, my husband would like to go out for a walk. I can't go very far, because I'm worried about having this pain and not being able to walk any further.' [P1]

'... sometimes with the pain, it feels like I'm not going to be able to relax and be OK and sleep well and be a normal person ever again. Yeah, I feel hopeless sometimes.' [P13]

Whilst comments about the negative impact of pain was widespread, nearly half of the participants spoke about hope or positivity. Sometimes this was directly in the context of their pain and symptoms, their treatment or it spoke to broader ideas of acceptance. Some also reported periods of being pain-free.

'I currently present zero symptoms of Crohn's, you could meet me on the street and you'd have no idea.' [P10]

Relatedly, the majority of participants (16/20) also compared themselves to others. Some felt their condition was worse than others, but for most, the comparisons seemed to reflect self-reassurance, providing comfort that others' conditions were more severe or giving them hope that remission is possible:

'I always think, consider myself not as bad as many people because some people's conditions are way worse than mine. So I often try and stay positive. I think it could always be worse.' [P18]

Discussion

This study aimed to deepen our understanding of how individuals with IBD make sense of their pain. By using the novel GEM methodology, it was hoped that participants would be able to discuss what felt pertinent to them, without restriction, when asked to consider their understanding of their IBD pain.

The study has shown that people with IBD make sense of their pain experientially, often within the context of their IBD more broadly, given the range of symptoms that typically co-exist alongside pain. This in line with other research, showing the co-morbidity of pain and other symptoms in IBD (Norton et al., 2021; Trivedi et al., 2019). Fundamentally, the current study has shown the interrelatedness of IBD pain with the experience of having IBD, which was seen as impacting the whole body. The findings showed the integration of IBD pain and IBD generally in participants' minds; participants often moved fluidly from one to the other in their elaborations. Further, the findings showed that, for many, IBD pain is not limited to pain within the gastrointestinal tract. Discussions around pain often included other parts of the body such as joints, eyes and various pains stemming from medication or treatments. Past research has highlighted the prevalence of various pains in IBD (e.g. Palm et al., 2005), but to our knowledge, no research has explored a whole-body view of IBD pain. This highlights the importance of a holistic approach to conceptualising IBD pain and co-occurring symptoms in order to reduce discomfort and increase quality of life.

The experiential, multi-faceted elaborations in this study, are in line with other GEM pain research. Whilst not focused on IBD pain, Keen et al. (2021) also found a strong experiential component within GEM interviews that explored how individuals with chronic pain understand their pain. This further suggests that exploring 'understanding pain' using the GEM moves beyond a cognitive dimension and taps into broader, multi-faceted reflections about how pain embeds itself within the individual’s life. Nonetheless, other studies that have used other research paradigms have also reported finding that individuals understand IBD through its psychosocial impact, context, illness history and the multi-layered reality of living with this condition (Huisman et al., 2022; Trivedi et al., 2019).

The study integrated and conceptualised the patterns in participants’ elaborations as three overlapping themes. How individuals made sense of their pain was interconnected with their reflections around navigating their care and management, as well as the impact of the pain. For example, participants often spoke about topics such as diagnoses, journeys, experiences with healthcare, psychological effects of the pain and the overall impact on their lives. This suggests that the GEM prompt (‘understanding IBD pain’) often triggered emotive memories and historical accounts of how they came to have the condition. The majority of interviews contained a strong, recurring social component; lengthy reflections about navigating healthcare, seeking support and trying to be heard (subtheme 2.2: navigating healthcare and others) and various negative interpersonal consequences of pain (subtheme 3.2: the impact on my life). Past IBD inpatient research also revealed similar interpersonal challenges around not being heard and feelings of frustration (Bernhofer et al., 2017). These findings may reflect the social dimension of pain (Williams & Craig, 2016), specifically, highlighting pain as an inherently “social and threatening human experience”, that can challenge interpersonal needs such as the need to belong, need for autonomy and need for justice (Karos et al., 2018). Given the nature of IBD, it is unsurprising that many reflections were connected to a social dimension of pain. This further emphasises the need for a holistic, multi-dimensional view of each individual presenting with pain, to increase the likelihood of good outcomes. For example, many participants reported difficulties with healthcare staff, felt dismissed or in some cases, were initially misdiagnosed and research has shown that feelings of injustice can lead to increased pain experience and unpleasantness (McParland et al., 2016; Trost et al., 2014). The study further highlights that social experiences and threats to social needs should not be deprioritised, and instead, considered alongside health-related needs (Karos et al., 2018).

Explicit explanations of the meaning of IBD pain, e.g., inflammation, were not at the forefront of participants' minds and were never free associations in GEM grids. However, they indirectly appeared in many elaborations. First, participants described different types of pain (namely low-level, constant, dull ache and intense, acute, short-lived bursts of stabbing pain), alongside different patterns of pain (common triggers, often co-existing alongside an unpredictable pattern of pain and flares). Some explicitly named the difficulties with describing visceral sensations and used various ways to convey their pain; concrete descriptions of locations and sensations of pain and more abstract methods, such as comparisons and metaphors. Second, when reflecting on what pain means, some participants openly stated that they would like more information and were not sure why they experienced pain or what it signalled. Across the sample, pain was assigned various meanings, ranging from bodily functions such as food passing through inflamed areas, to serious concerns such as an obstruction or bowel perforation. The confusing nature and variability of pain was emphasised. When trying to make sense of pain, many participants discussed the limited utility of the term 'remission', given that pain often occurs whether or not they are judged to be in remission. This is in line with other research in IBD, showing that 'remission' can mean improvements in certain disease activity markers, but many individuals with IBD continue to experience pain (Bielefeldt et al., 2009).

What pain meant to participants was sometimes linked to different types or sensations of pain, which interlinked with different levels of fear and coping strategies. This demonstrates the interlinking nature of all three themes and mirrors the processes in the Common-Sense Model of Self-Regulation (CS-SR model; Leventhal et al., 2016). This well-established theoretical framework shows the multifaceted journey from experiencing a health-threat, e.g. painful stimuli, through to formulating the meaning of the threat, alongside its affective components, and deciding how to act. Illness representations, how individuals perceive their illness, are a central part of the CS-SR model and inform coping strategies. The findings in this study emphasise the difficulties individuals face in formulating a cohesive narrative of their IBD pain and the subsequent challenges in knowing how to manage it. The model posits individuals as ‘common-sense scientists’, as they navigate their journey in understanding and self-regulating their health (Leventhal et al., 1984; Leventhal et al., 1980). This strongly reflects the findings in this study, which showed individuals’ ‘trial and error’ efforts to examine what works best for their pain, with mixed results. As a result, an improvement in IBD pain communication and information could help to facilitate management. This mirrors conclusions and recommendations in other recent research (Huisman et al., 2022).

Given that IBD pain can carry different meanings and is often unpredictable, it can be difficult to decide on the best course of action to manage pain. Rest and temporary avoidance of activities may be effective in some circumstances, but research has consistently shown the cumulative, negative impact of long-term, pain-related avoidance in perpetuating disability and decreasing quality of life (Zale & Ditre, 2015). In some interviews, vicious cycles of pain and avoidance were evident, mirroring findings in past qualitative research (Sweeney et al., 2019). Cycles of pain and avoidance often stemmed from threatening conceptualisations of what pain may mean, leading to understandable negative impact on mood and confidence. Conversely, for some, engagement with meaningful activities sometimes alleviated pain and emotional suffering. This was also often seen in interviews where participants experienced an increase in pain during the pandemic, due to a lack of distraction and decrease in daily activities and sense of purpose. The Fear-Avoidance Model of Chronic Pain (Vlaeyen et al., 2016) explains the difficulties that can develop when pain is repeatedly interpreted as threatening and the associated fear leads to decreasing levels of activity and increased hypervigilance. This further shows the importance of how pain is perceived and conceptualised in the context of activity, for example, how individuals decide when to rest and when to acknowledge the pain but continue with daily life. Some interviews showed individuals' despondency about their pain and automatic, subsequent avoidance of activities. This demonstrates that more information about IBD pain and a biopsychosocial approach that draws on cognitive-behavioural principles could be helpful for certain individuals, to address the vicious cycle of long-term chronic pain, fuelled by pain-related beliefs that rest is always necessary. Nevertheless, individuals' experiences were heterogeneous and not all participants were avoidant of activity; for some, a careful examination of each situation and pacing was evident.

Moreover, the study showed that a large proportion of GEM grids were completed with feelings, showing the emotional charge of this topic and the importance of psychological factors. Further, no GEM grids were completed with meta-cognitive, medical or specific words/images about understanding pain, for example, inflammation or perforation. One explanation could be that the emotive nature of pain overrode cognitive conceptualisations on IBD pain. The free associative nature of the GEM may have therefore allowed participants to tap into uncensored emotional reactions, such as 'anxiety' and 'overwhelming'. Furthermore, participants disclosed emotive memories of their illness, diagnoses journeys and other past experiences at great length, without prompting. It is possible that the GEM allowed a quicker, deeper access to illness 'prototypes', memory structures encompassing individuals' histories of illness, as described in the CS-SR model (Leventhal et al., 2016).

Making sense of the psychological and emotional components discussed in the interviews is also important when considering the expanding field of research on the brain-gut axis in IBD (Barbara et al., 2014). Even though most participants discussed emotions as stemming from their IBD pain and the impact of the condition, some reflections alluded to the bi-directional nature of emotions. Specifically, stress was often discussed in the context of both triggering and stemming from IBD pain. Further, many participants did not explicitly discuss a connection between psychological factors and pain, but this link was implicitly present in their narratives. Given the bi-directional communication system between the brain and the gastrointestinal tract, as outlined in brain-gut axis research, this is an important finding that further emphasises the need to take a biopsychosocial approach to IBD pain and ensure that attention is paid to psychological components which could influence pain in IBD (Bonaz & Bernstein, 2012). Nonetheless, as previously mentioned, there were individual differences across the interviews and the findings cannot be generalised to all individuals with IBD.

Strengths & Limitations

To date, this is the first study to specifically explore how individuals with IBD understand their pain. IBD pain has historically been a neglected area, despite the extensive impact of pain on many people's lives. The study quickly recruited 20 participants and further individuals came forward to express their interest. This shows the popularity of the topic and many participants expressed their desire for more research to be conducted on IBD pain.

Further, this is one of the first clinical health studies to utilise the novel GEM methodology, excluding Keen et al. (2021), which has historically been predominantly applied in social psychology settings (Joffe & Elsey, 2014). The application of this method in this area yielded rich and detailed data and showed the value of a free associative approach in the field of pain. Whilst not formally collected, participants gave positive feedback on their interviews and the nature of the GEM. Further research could build on this study in various ways; comparing different visceral pain conditions with larger samples, altering the detail of the GEM prompt to explore the effect on elaborations or endeavour to formally collect feedback on the GEM experience from clinical health populations to explore its applicability and acceptability.

Given the COVID-19 pandemic, limitations were unavoidable in terms of the study design. All interviews were conducted online, which may have excluded some participants and in some interviews, challenges were encountered, such as internet connection problems. In contrast, this setting allowed for participants to take part wherever they lived, without the need to travel to be interviewed, more convenient for some. Furthermore, internet-based therapy can be as effective as face-to-face interventions (Andresson, 2016), with comparable levels of rapport and openness; a similar equivalence may be possible in research interviews.

The pandemic context of the research may have also influenced the findings. Participants had different views on how the pandemic affected their IBD pain, but most had negative experiences, which may reflect the strong focus on impact and negative healthcare experiences within the interviews. Participants frequently commented on the difficulties in being listened to, or simply scheduling an appointment. For some individuals, the interviews may have been an opportunity to be heard and to convey their distress and experiences.

Moreover, the study is based on a self-selected sample of individuals, who may tend to hold particular views on pain. Participants were aware from the advertisement that the study was focused on IBD pain and also knew the researcher was a Trainee Clinical Psychologist. This could have inadvertently skewed the participants' elaborations towards areas such as psychological impact of pain and difficult experiences with healthcare, which were very common. Further, when considering the study's sample, it is important to acknowledge that the majority of participants identified as white. The researcher had originally hoped to acquire a diverse sample, as past research has shown that IBD presents similarly in Black and White populations, but its impact and healthcare use can differ (Straus et al., 2000).

Additionally, research has consistently shown the underrepresentation of ethnic minority groups in medical research (e.g., Smart & Harrison, 2017) and the inequalities of pain support across different ethnic backgrounds (Peacock & Patel, 2008). Due to practical considerations, this study did not use targeted, strategic recruitment, however, future research should endeavour to utilise methods that help to engage and represent ethnic minority groups in IBD. Reflections from one mixed-race participant in this study spoke to the importance of ethnicity and culture and how this shaped their own experiences with pain and navigating healthcare. It highlights the importance of exploring topics such as ethnicity and culture in future IBD pain research and ensuring the amplification of ethnic minority voices.

Finally, like any methodology, the GEM carries both advantages and disadvantages. The GEM facilitated unstructured, uncensored free associations around understanding IBD pain. Whilst this resulted in rich and interesting data, the researcher was not able to ask specific or follow-up questions or clarifications on the topic. This meant that interviews were not tailored to the research question in a specific, controlled way. This was felt to be an inherent trade-off that exists in using a free associative methodology, such as the GEM. Further detail on the researcher experience of the GEM is discussed in part three of this thesis.

Implications

The purpose of qualitative research is not to be generalisable, but it is helpful to consider the study's insights within this specific group of participants and how this may translate to a wider context (Braun & Clarke, 2013).

First, the study would argue that IBD pain is important to assess in clinical settings. The study has highlighted the widespread impact of pain, which is not limited to the gastrointestinal tract. Pain assessments are typically not part of routine care in IBD clinics (Bakshi et al., 2021). Whilst pain is included in the clinical severity scale for Crohn's disease

(Kemp et al., 2018), it is not present in the four-item scale for ulcerative colitis (Torres et al., 2017). Although there is no widely-accepted, fully validated pain assessment tool for IBD, it has been proposed that pain assessment should be an inherent part of IBD consultations (IBD UK, 2019; Bakshi et al, 2021). This study gives further weight to this proposal and suggests a holistic view of pain that extends beyond the gastrointestinal tract. Moreover, the interrelatedness of IBD pain and other symptoms has been highlighted in this study and others. Therefore, a holistic assessment of individuals' pain should incorporate co-existing symptoms to ensure the best chance of alleviating discomfort and improving quality of life. Finally, many participants spoke about the difficulty of both describing pain and gauging pain due to an altered baseline due to pain chronicity. This should be considered within clinical work, but also in further research.

Second, the study demonstrated the spectrum of different conceptualisations and ideas about IBD pain, as well as outright confusion for some. Moreover, many participants discussed difficulties with pain management and a desire to try a wider range of approaches. This may reflect many factors, such as the heterogeneous nature of IBD pain. However, clinical settings can aim to discuss how individuals make sense of their pain, if relevant to the individual, and provide appropriate information, if possible. IBD teams could also signpost individuals to reliable resources and information, especially if this cannot be provided directly within the service. This is also in line with the CS-SR model (Leventhal et al., 2016), which emphasises that accurate information can support coping. Research shows that pain education approaches are promising (Watson et al., 2019), but as stated by Huisman et al. (2022), future research should also endeavour to examine what individuals retain after receiving pain information and how, if at all, this influences their coping and levels of distress. Personalised information, that is tailored to the individual's experience and symptomology should be prioritised, to increase the likelihood of retention and application. Moreover, based on resources and availability, IBD services may be able to offer referral to pain management programmes or other support. Another important intervention could involve IBD teams supporting individuals to systematically monitor their triggers, symptoms and pain, alongside the management strategies that they are trialling; this was something that participants often felt very lost and alone with. Given the prominence of musculoskeletal pain over visceral pain in many pain management settings, clinicians can proactively ensure individuals with visceral pain are not neglected. Some participants explicitly discussed the lack of acute pain support for chronic pain conditions, such as IBD, which suggests that this area requires attention.

Third, the findings have highlighted the understandable psychological toll of IBD pain. For some, there was an awareness of the important relationship between mental wellbeing and pain. This is in line with biopsychosocial conceptualisations of pain (Turk et al., 2011) and emphasises the role of psychological factors in modulating pain and the need for appropriate psychological support for the emotional and mental burden of pain. Furthermore, research on the brain-gut axis continues to cast light on the importance of considering psychological and emotional factors within IBD pain formulations and inflammation (Bonaz & Bernstein, 2012). A holistic, biopsychosocial focus in IBD is crucial when supporting individuals with their pain. Equally, access to psychological support should be available and psychological components of the condition normalised to reduce stigma and validate individuals' experiences. It is evident that the importance of integrated care in IBD is now more acknowledged, but the move to making this a reality in practice is an ongoing development (Mikocka-Walus et al., 2012).

Conclusion

In conclusion, this study aimed to explore how individuals understand their IBD pain, using a unique, qualitative, free association method; the GEM. Analysis of 20 interviews found three overlapping themes, comprising seven sub-themes. The themes demonstrated that understanding pain is fundamentally experiential and co-exists with other symptoms, experiences of navigating healthcare and management, as well as making sense of the impact of the condition. The findings were discussed in the context of the study's strengths and limitations, as well as clinical implications.

Takeaway messages:

- This study explored how individuals with IBD make sense of their pain, using a novel qualitative method based on free association.
- 20 participants took part in the study and wrote down the first four things (words or images) that came to mind when they thought about their understanding of their IBD pain. The researcher then asked them to elaborate on each one.
- All interviews were transcribed verbatim and analysed using thematic analysis.
- Three overlapping themes summarised the patterns found; *making sense of my pain, navigating my care and support* and *it takes its toll*. These showed that participants made sense of pain experientially, multi-dimensionally and in the broader context of IBD and its symptoms. The psychological impact of pain was evident in all interviews.
- The findings mirror research in other IBD studies and emphasise the need to pay attention to pain in clinical and research settings.
- IBD assessments and management approaches should routinely integrate pain, and holistic, whole-body view of IBD is recommended.
- The study reflected on its strengths and weaknesses and presented ideas for future research.

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PART III:

CRITICAL APPRAISAL

Introduction

The following discussion contains my reflections and experiences of carrying out the empirical study presented in part two of this thesis. This critical appraisal begins by reflecting on my position within this research, including exploring my own assumptions in a bracketing interview and trialling the GEM on myself. Following this, I appraise the process of using the GEM, from piloting this novel methodology with experts by experience, through to my reflections on its relationship with the findings and my original research questions. The discussion ends with my final concluding remarks, in terms of my overall learning and changes in my thinking.

Reflexivity & my position

Choosing the topic & method

When choosing a research area, I was drawn to clinical health psychology, given my background in health psychology and passion for the area. Given my own experiences with IBS, having friends with IBD and a desire to explore an area that continues to be under-researched, I was quickly interested in doing an IBD project. Furthermore, I was intrigued by doing qualitative research, a new area for me, and I became fascinated by my supervisor's suggestion of using the GEM. Having done a limited amount of research myself, I felt open-minded about methodological approaches and did not feel wedded to one approach specifically. I felt the GEM was refreshing; it directly contrasted much of the research I had come across and its design felt like it placed participants, rather than the researcher, at its core.

Building awareness of assumptions & biases

Having had some prior experience in quantitative research, I recognised the need to explore and shift my perception of research, when transitioning to a qualitative paradigm. The term ‘researcher-as-instrument’ has been used to emphasise the unique role of researchers in qualitative approaches and how their subjectivity can shape every aspect of a study (Morrow, 2005). Instead of perceiving this as a flaw or a problem that needs to be overcome, acknowledging this inherent part of qualitative research and working to become more aware of one’s position and what they bring to research is recommended (Braun & Clarke, 2013). Reflexivity, turning one’s awareness on oneself, helps researchers understand how their biases and beliefs may influence how they construct knowledge in their research and reflect on this (McLeod, 2011).

It is recommended to approach reflexivity from multiple angles (Hill et al., 2005). First, I kept a research journal throughout the research process, and wrote down my ideas, thoughts and concerns regularly. I tried to use this journal in an unstructured, organic way whereby I wrote down anything that seemed relevant in an uncensored manner and regularly reflected on the content of my journal. This process helped my own reflections and gave me material to bring to supervision sessions. For example, I wrote about noticing my desire to adopt an activist stance within the research, working to raise awareness and reduce stigma around bowel conditions, which was stemming from both the research interviews and participants’ struggles, but also from my fluctuating difficulties with IBS. It was helpful to discuss topics such as discrimination, disability and stigma within meetings with my supervisor and consider the broader context of this research area. Furthermore, my journaling also revealed to me that I held assumptions about pain knowledge. Specifically, I observed myself thinking that having a detailed, comprehensive understanding of one’s pain is essential if one is to manage it most helpfully. I reflected on the rigidity of this belief and acknowledged that, first, people vary how much information and understanding they would like about their pain and, second, the relationship between understanding and management is considerably more nuanced and complex. Keeping the research journal proved valuable for gaining insight into my thinking, but also helped to monitor the change in my knowledge, skills and concerns as the research progressed.

Second, prior to starting interviews, I underwent a bracketing interview to explore what ideas and assumptions I was bringing to the project. Bracketing interviews have been positioned as a helpful tool to aid the process of reflexivity in qualitative research (Tufford & Newman, 2012). My interview was conducted by two other trainee clinical psychologists and was recorded and transcribed. The process allowed me to reflect on my expectations and wishes for the project in terms of the GEM paradigm, but also my relationship with IBS and IBD, for example:

'… if the participants' symptoms are similar to mine and how that may cause me to act differently with them, for example, being more engaged, having more empathy, wanting to validate or even going into therapist mode when that happens. I definitely think I may feel almost more drawn to this research, have more empathy and feel more invested, because it feels more relevant to me.'

This reflection was pertinent for conducting interviews, but also throughout the data analysis process and when writing the results and overall thesis. I was able to stay mindful of how I might align with some participants more than others and work towards not favouring any transcripts or quotes due to personal solidarity or preference. I chose to monitor how many quotes were in my final thesis for each participant to try to avoid over-representation of some participants, compared to others.

The bracketing interview also delved into exploring the research design and overall research question. I was able to recognise that this was closely interlinked with my ongoing medical investigations into gastrointestinal issues:

'… I am kind of on my own journey of understanding pain and other things - gastro-related. So am I almost, you know, projecting that onto this project, which is all about understanding pain. So I think understanding is a really important word. This sort of 'quest' for knowledge, for answers, almost for closure, weirdly. Which is more my stuff, so I should be careful not to put that onto my participants. So I think I need to be very mindful of that.'

By discussing this in the interview I was more aware of what aspects of my personal life were connected to my research question and how they could influence how I approach my research.

The interview uncovered various personal experiences and motivations, which showed me the value of having individuals pose thoughtful questions about the research, as opposed to solely reflecting on the topic on my own. The interview also generated the idea of carrying out the GEM on myself, when thinking about my own IBS pain. This was an illuminating exercise; I was able to get a sense of how the GEM may feel for the participants and also what my mind is drawn to when considering IBS pain. Specifically, I noticed that my mind was particularly drawn to certain abdominal symptoms, such as bloating, highlighting further biases and the lens through which I think about pain and symptoms.

Lastly, I fostered reflexivity through making prompt field notes after every interview. This allowed me to reflect on each interview on a deeper level and notice the dynamics between myself and each participant. It also allowed me to notice my own feelings, which could affect how the data was then analysed. For example, when a participant presented with very severe IBD and accompanying depression, I felt her distress and helplessness. It was helpful to be mindful of this when working with her transcript and coding extracts. I was more aware of where my attention went to when coding the extract and tried to maintain a nuanced view of her narrative and not view everything in a depressive, negative manner.

In sum, I used various methods to build self-awareness and better understand what I was bringing to the research. The purpose of this was not to attempt to remove all biases, but to recognise my context that will inevitably influence the research process to various degrees. Furthermore, reflexivity and transparency is also valuable for research dissemination, allowing readers to also have a better understanding of the research and how it has been interpreted (Rennie, 2012).

Using the GEM

Pilot study

Prior to carrying out the pilot study, I noticed myself holding black and white ideas about how the GEM might be perceived and filled out. I believed that the GEM instructions would yield homogeneous reflections about individuals' IBD pain: where it comes from, the sensations and experiences, how they understand it, their triggers and potentially reflections about management. By carrying out the pilot study, I was able to see that the GEM can trigger a range of unexpected responses. First, I learnt how I held a strong assumption that the word 'pain' would be automatically interpreted in the physical sense. However, one of the pilot interviews revealed that pain can be interpreted in an emotional sense. I found this quite profound and wondered whether this could arise if the topic was particularly emotionally charged, for example, participants could be going through a flare. Secondly, my two pilot interviewees were extremely different, which showed me how much the interviews may vary. This could have been as a result of a variety of factors, but from my perspective, I wondered whether length of diagnosis, level of pain and effectiveness of management could impact responses. I wondered whether responses could be more raw and emotionally charged if an individual is recently diagnosed, in a flare or their IBD pain is not well managed. In contrast, I noticed myself wondering whether longstanding effective management of the condition and reduced pain and flares could lead to more cognitive content within the grid and slightly more detached, intellectualised free associations. Further, my perception of the interviews and how they were carried out by the two volunteers was inevitably influenced by me knowing them and our friendship. This may have shaped what they chose to reveal and how I interpreted it.

Whilst the pilot study only included two interviews and no significant conclusions were drawn from these, the process was invaluable. I learnt both the practicalities of administering the GEM and was able to gain an insight as to how the GEM is perceived and filled, when considering a clinical topic. The process allowed me to consider how the GEM instructions are phrased and how the free associations may be much broader and richer than I may have anticipated. It also highlighted the importance and value of having feedback and views from experts by experience and how much nuance and insight they bring.

Carrying out interviews

The GEM has typically been used in the field of social psychology (Joffe & Elsey, 2014) and its application in clinical psychology is relatively novel. As a result, it has been interesting to reflect on how this method translated to a different area of psychology. Firstly, the nature of the interview topic, i.e. a chronic condition and its pain, was unsurprisingly a deeply emotive area for many participants. The discussion often included very difficult past experiences or traumas associated with the condition and participants often revealed intimate information, for example, the details of their bowel problems. Whilst it is possible that the use of GEM in social psychology can elicit emotive discussions, it is likely to be less common. Therefore, I wondered whether the nature and identity of myself as a GEM interviewer may have differed somewhat to a typical GEM interviewer in social psychology. I felt that giving empathy and validation was often needed, and without such statements, the interview would be problematically cold, robotic and hinder further elaborations. Participants were exposing parts of themselves that they often do not discuss openly (as stated by many participants). I felt that this vulnerability and trust in me to hold what they have shared, warranted reciprocal sensitivity. By responding with statements that sometimes surpassed ‘tell me a bit more about that…’, I was able to contain the participant and offer a safe space, where they felt comfortable to continue the discussion about their associations. Nevertheless, it is important to reflect on this and tease out how much of this may be related to my position as a trainee clinical psychologist that is often tempted to adopt a more therapeutic role and finds it difficult to maintain neutral and more silent. Being new to qualitative research and the GEM, I initially found it difficult to distance myself from my typical clinical role. I knew it was important to hold onto some of my therapeutic skills, for example, good listening skills, whilst refraining from using others, for example, exploring or challenging beliefs. Being mindful of this from the start was helpful. I ensured I maintained awareness of my position. Sending my supervisor two example transcripts of my interviews allowed us to explore together how I responded in interviews and agreed that my empathic and validating interviewer style was appropriate, given the research topic.

The interviewing phase took a total of 10 weeks and it is interesting to reflect how I and the process developed over time. When I began interviewing, I was very mindful of not wishing to bias my participants into discussing topics I am interested in. However, it is impossible to be a blank slate, as inevitably we bias the discussion through what we say or do not say and body language. To attempt to reduce my bias, I refrained from reading and extensively researching the condition prior to the interviews. Whilst I had foundational knowledge about IBD from writing necessary research documents, I did not delve into further information which could unintentionally prime me to be interested in certain topics that might come up in interviews. I wished to interview from a place of curiosity and openness.

At the start of the interviews, I believe that my bias was reduced in some respects, as I was largely unaware of what might come up in the interviews. However, as the interviews progressed, I naturally became more knowledgeable of IBD pain and IBD experiences more broadly. By acquiring more familiarity and knowledge of the topic, it is likely I became primed to pick up on certain things more readily or even anticipate what may appear. For example, if a participant's grid box mirrored an entry from a past participant, I would be tapping into memories of the past interview, which could have made me less open and "blank" for the participant. Furthermore, although I had not formally begun data analysis until all interviews were completed, transcription is arguably part of data analysis (Braun & Clarke, 2006) and I was already primed to notice certain patterns of conversation. Whilst I always endeavoured to keep the same body language and responses, it is likely they would have been affected by the number of interviews conducted. For example, hearing about the details of difficult experiences such as soiling oneself in public were probably more shocking for me to hear about the first time, compared to later interviews.

Participants' experience of the GEM

I have also reflected on how the GEM might be experienced by participants. No formal feedback was gathered and the following reflections are based on observations only, influenced by my desire for the GEM to feel like a helpful methodology.

Whilst individual differences mean participants may have felt differently about this approach, I noticed patterns amongst interviews. First, participants were typically quieter and more apprehensive at the start of the GEM. Whilst some of this normal anxiety may be attributed to settling into an interview setting and building rapport with the researcher, I believe the nature of the GEM was initially unsettling and the freedom that it offers participants could initially feel uncontaining. Many participants asked for reassurance that they had understood the instructions correctly. Research shows that individuals with IBD are often not asked about their IBD pain and symptoms in healthcare appointments and given NHS pressures, appointments tend to be brief and focused on disease-markers, directed by the healthcare professional (Czuber-Dochan et al., 2014; Dibley & Norton, 2013). The experience of coming into an interview where the participant chooses to talk about whatever comes to their mind for an hour may have felt very unusual. Further, not being asked a series of direct questions, which would mirror healthcare experience, could be an unfamiliar reversal in usual power dynamics. Many participants appeared to be more cautious and unsure about their elaborations initially and sometimes sought reassurance from the researcher about their responses. Demand characteristics, the tendency for participants to want to please researchers in studies, is common (Barker et al., 2015). One participant anxiously stated that she was not sure she could fill the whole hour and it seemed that having space to talk about her IBD pain felt very unfamiliar. Related to this, GEM prompts such as "tell me more about that" could be perceived by participants as them not giving 'enough' or the 'right' type of information. From my experience, however, I noticed that as interviews progressed, participants had a tendency to settle into the methodology, the flexibility of the interview and seemed to find it liberating to speak freely, with many offering longer and more detailed elaborations as time went on.

The GEM and the research question

Like any methodology, the GEM brought with it strengths and challenges. The breadth and richness of the interviews and participants' apparent engagement with the GEM could be in part a testament to the methodology. I also found the change of power dynamics within the GEM refreshing and believe that this approach will continue to produce rich research with unique insights. As mentioned above, I think it is helpful to consider whether slight adaptations or flexibility needs to be adopted when using the GEM within clinical research.

A challenge that I have reflected on throughout the research process is the relationship between research questions and the GEM. By its nature, the GEM does not direct participants during the interview and the only prompt that is directly linked to the research question/s is presented in the brief, initial instructions. I sometimes felt conflicted about this: the GEM resulted in unpredictable, exciting and varied data, but at times I wondered whether it was directly linked to the research question. Other approaches, such as semi-structured interviews, would allow me to tailor my questions to guide the participant to talk about the specific research interest and have more control over the discussion when it becomes distracted or off topic. This is in contrast to the GEM and I often found myself feeling anxious, worrying that some data is not 'relevant'. I reflected on the aims of the research and how I was labelling certain data as 'helpful' or 'less helpful'. Discussions with my supervisor allowed me to recognise that the GEM requires a shift in thinking and a looser hold on the research question. What is elicited by the GEM, however broad and varied, is all valuable and gives us an insight into thinking and conceptualisations. In sum, my perspective on the purpose of the study adjusted and adopted a more exploratory and flexible approach.

Participant interest and numbers

Recruitment can be a struggle and a common dilemma for many researchers. Therefore, I was struck by the study's popularity and how quickly I reached 20 interviews. I have wondered whether the interest in the study reflects the importance of pain and the desire to talk about it for many individuals with IBD. As previously discussed, pain can be highly debilitating, yet often ignored by healthcare professionals. I felt that the individuals interested in the study may have wished to share their experiences and access a space which is not usually available to them. Equally, there was a sense that participants wished to contribute to this research area with hope for future pain interventions and support. The charity which advertised the study was also very important in recruitment; many individuals spoke about how much they valued and appreciated Crohn’s & Colitis UK and the trust they had in the charity for important and reliable information. This may have increased the appeared credibility and trustworthiness of the present study and showed me the value of carefully considered recruitment sources.

Concluding reflections

Being new to qualitative research and the GEM, this research study was a rich and varied learning experience. Each part of the process offered different challenges and opportunities for reflection and I have acquired many new skills and insights, ranging from writing a conceptual introduction through to using the GEM and conducting a thematic analysis.

Carrying out interviews and listening to people’s raw stories of pain, both physical and emotional, felt like a true privilege. I felt honoured to have their story shared with me and I was frequently struck by their resilience and capacity to overcome multiple traumas. Their experiences often stayed with me well beyond the interview and it was a unique experience to relive them numerous times through transcribing and re-reading.

The interviews undoubtedly shifted how I viewed IBD: from seeing it as an unpleasant, problematic condition to a significantly more severe, frightening and often misunderstood disease. Not all participants were experiencing active disease or symptoms, but all carried emotional, and sometimes physical, scars of flares and complications. Many participants described the pain as being worse than childbirth. It made me reflect on my own health and the privilege I carry in living a largely unaffected, healthy life, despite having a bowel health condition myself.

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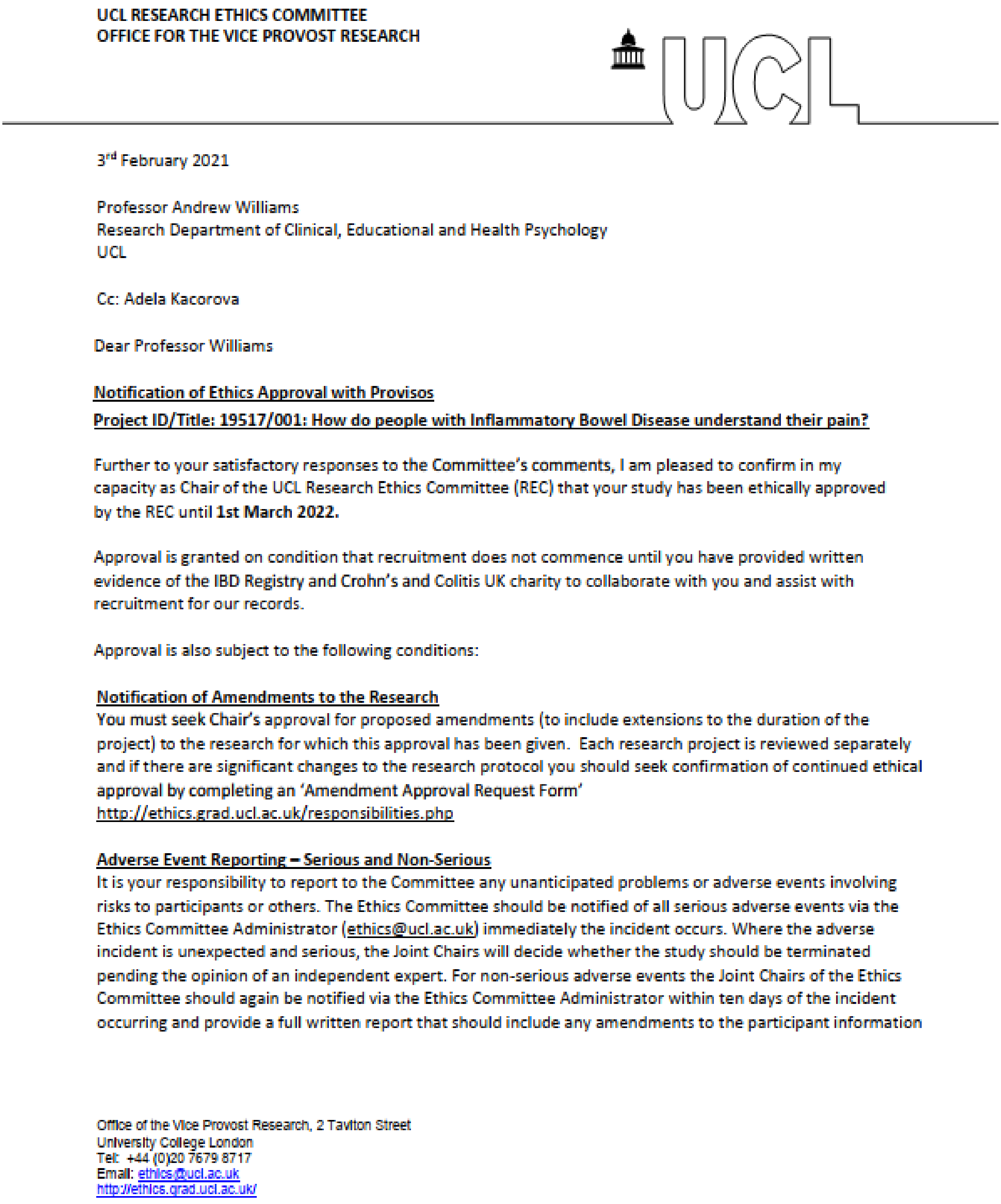
Appendices

Appendix A – Ethical approval



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

3rd February 2021

Professor Andrew Williams
Research Department of Clinical, Educational and Health Psychology
UCL

Cc: Adela Kacorova

Dear Professor Williams

Notification of Ethics Approval with Provisos

Project ID/Title: 19517/001: How do people with Inflammatory Bowel Disease understand their pain?

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the REC until **1st March 2022.**

Approval is granted on condition that recruitment does not commence until you have provided written evidence of the IBD Registry and Crohn's and Colitis UK charity to collaborate with you and assist with recruitment for our records.

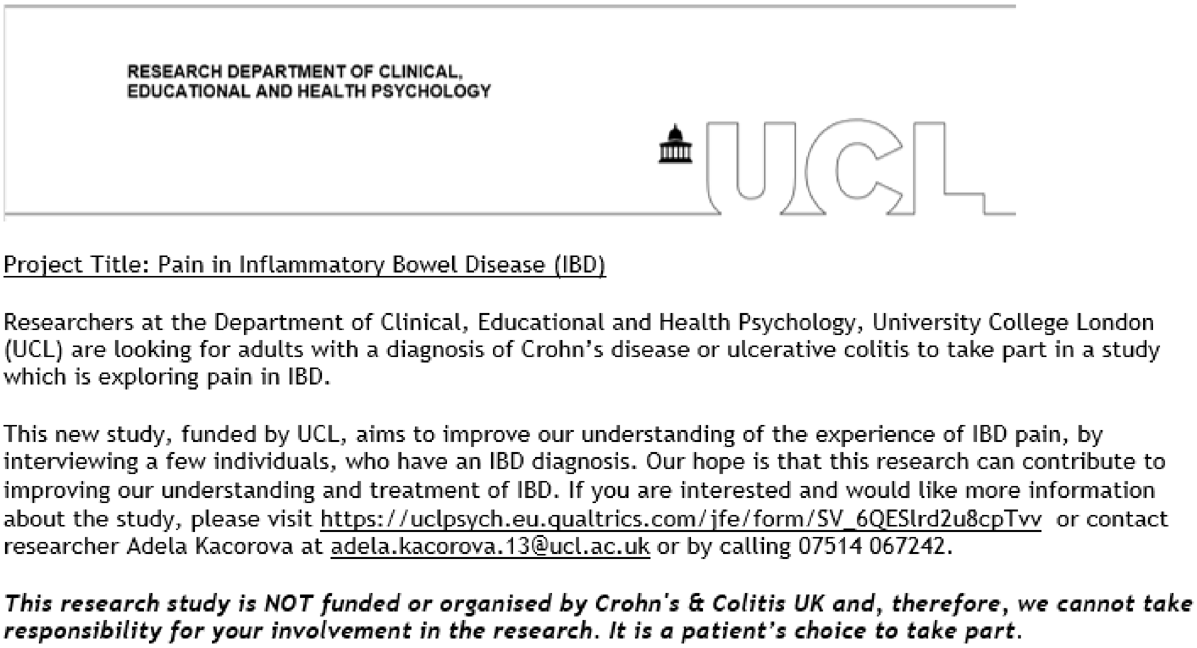
Approval is also subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

Appendix B – Crohn’s & Colitis UK advertisement



RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY

UCL

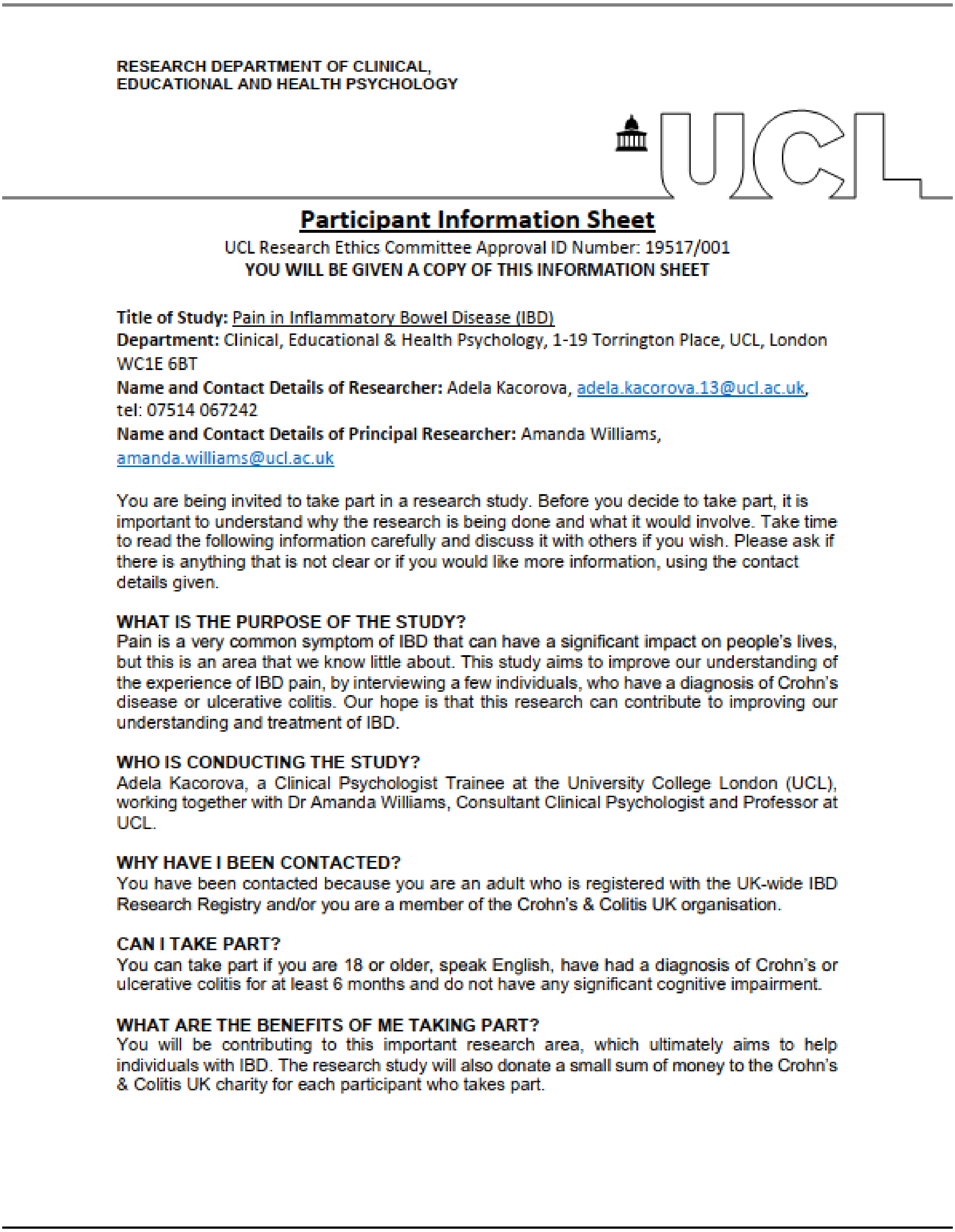
Project Title: Pain in Inflammatory Bowel Disease (IBD)

Researchers at the Department of Clinical, Educational and Health Psychology, University College London (UCL) are looking for adults with a diagnosis of Crohn’s disease or ulcerative colitis to take part in a study which is exploring pain in IBD.

This new study, funded by UCL, aims to improve our understanding of the experience of IBD pain, by interviewing a few individuals, who have an IBD diagnosis. Our hope is that this research can contribute to improving our understanding and treatment of IBD. If you are interested and would like more information about the study, please visit https://uclpsych.eu.qualtrics.com/jfe/form/SV_6QESlrd2u8cpTvv or contact researcher Adela Kacorova at adela.kacorova.13@ucl.ac.uk or by calling 07514 067242.

This research study is NOT funded or organised by Crohn's & Colitis UK and, therefore, we cannot take responsibility for your involvement in the research. It is a patient’s choice to take part.

Appendix C – Participant Information Sheet & Consent Form



RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY

Participant Information Sheet

UCL Research Ethics Committee Approval ID Number: 19517/001

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: Pain in Inflammatory Bowel Disease (IBD)

Department: Clinical, Educational & Health Psychology, 1-19 Torrington Place, UCL, London WC1E 6BT

Name and Contact Details of Researcher: Adela Kacorova, adela.kacorova.13@ucl.ac.uk, tel: 07514 067242

Name and Contact Details of Principal Researcher: Amanda Williams, amanda.williams@ucl.ac.uk

You are being invited to take part in a research study. Before you decide to take part, it is important to understand why the research is being done and what it would involve. Take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information, using the contact details given.

WHAT IS THE PURPOSE OF THE STUDY?

Pain is a very common symptom of IBD that can have a significant impact on people's lives, but this is an area that we know little about. This study aims to improve our understanding of the experience of IBD pain, by interviewing a few individuals, who have a diagnosis of Crohn's disease or ulcerative colitis. Our hope is that this research can contribute to improving our understanding and treatment of IBD.

WHO IS CONDUCTING THE STUDY?

Adela Kacorova, a Clinical Psychologist Trainee at the University College London (UCL), working together with Dr Amanda Williams, Consultant Clinical Psychologist and Professor at UCL.

WHY HAVE I BEEN CONTACTED?

You have been contacted because you are an adult who is registered with the UK-wide IBD Research Registry and/or you are a member of the Crohn's & Colitis UK organisation.

CAN I TAKE PART?

You can take part if you are 18 or older, speak English, have had a diagnosis of Crohn's or ulcerative colitis for at least 6 months and do not have any significant cognitive impairment.

WHAT ARE THE BENEFITS OF ME TAKING PART?

You will be contributing to this important research area, which ultimately aims to help individuals with IBD. The research study will also donate a small sum of money to the Crohn's & Colitis UK charity for each participant who takes part.

DO I HAVE TO TAKE PART?

No, it is entirely up to you to decide to join the study. It is important that you give informed consent to take part. If you do not take part, there are no negative consequences or impact to your care with the NHS. You are free to withdraw your interview from the study, without giving a reason, at any point up until one week after your interview.

WHAT DO I HAVE TO DO?

If you decide to take part and give informed consent, we will contact you to arrange a suitable time to interview you about your IBD. The interview will be done remotely via a video call using Microsoft Teams and will last around 1 hour, although some interviews may be slightly shorter or longer. The interview will be done by Adela Kacorova and recorded. During the interview, we will ask you about some thoughts that you have about your IBD pain, ask you to write them down on a piece of paper and then finally ask you to give more detail about each of these thoughts. If you are unsure about how to use a video call but would like to take part, we can support you to set this up and discuss it in advance to make the process as stress-free as possible. You do not need to download Microsoft Teams for the study, we will simply send you a link that you click on.

We will also ask you for some demographic information, for example, your age and ethnicity. We are collecting this demographic information to have a better understanding of our sample and who has taken part in the study. We are hoping to interview around 20 people altogether. Each interview will be transcribed manually by Adela Kacorova. All interviews will be recorded, to allow us to transcribe interviews and record everything accurately.

During the interview, you do not have to answer every question and the interview can be stopped at any point.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

All information from the interviews will be completely confidential, anonymised and stored securely. When we look at the information gathered from the interviews, we will be looking at patterns. We may use interview quotes in the research, but these will be anonymised to protect your identity.

LIMITS TO CONFIDENTIALITY

Keeping you and others safe is always our priority. If you disclose any information that makes us concerned about yours or others' safety, we may need to break confidentiality, but we would always try to talk to you about this first.

HOW WILL MY DATA BE TREATED?

Identifiable information will be removed from all interviews, to protect participants' identities. Data will be stored electronically in a secure UCL data storage system and password protected. The recorded interview files will be deleted once transcription is complete and all other data will be deleted within a maximum of 5 years, to allow for publication and dissemination of research. Data will not be archived and will not be shared with future researchers or in a repository.

WHO HAS REVIEWED THE STUDY?

The study prioritises protecting your safety, rights, wellbeing and dignity. This study has been reviewed and approved by UCL Ethical Committee (REF: 19517/001).

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

We aim to write up the findings in a doctoral thesis. Following this, the results may be presented in scientific journals and at conference presentations. If you are interested in the outcomes of the research, you can access the results by visiting (website link), where the details will be uploaded at a later date, around October 2022.

WHAT IF SOMETHING GOES WRONG?

The interview will not ask you any upsetting questions, but if you feel distressed talking about your IBD pain, we will be able to take breaks, signpost you to support and resources (if you would find this helpful and appropriate) or stop the interview if you wish. If you would like to complain about any aspect of the study or how you have been approached or treated, you can contact the Principal Investigator Amanda Williams at Amanda.williams@ucl.ac.uk. If you feel your complaint has not been handled to your satisfaction, you can contact the Chair of UCL's Research Ethics Committee at ethics@ucl.ac.uk.

LOCAL DATA PROTECTION PRIVACY NOTICE

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click here

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and' Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

CONTACT FOR FURTHER INFORMATION

If you have any questions or concerns, please contact Adela Kacorova or Dr Amanda Williams, using the contact details provided. Thank you for reading this information sheet. If you feel you would like to take part, please proceed to give your informed consent in the next section. You can return to this form at any time. Many thanks for your time.

RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY

Participant Consent Form

YOU WILL BE GIVEN A COPY OF THIS FORM

Please complete this form after you have read the Information Sheet and you have had an opportunity to think about participation and ask any questions about the study.

Title of Study: Pain in Inflammatory Bowel Disease (IBD)
Department: Clinical, Educational & Health Psychology, 1-19 Torrington Place, UCL, London WC1E 6BT
Name and Contact Details of Researcher: Adela Kacorova, adela.kacorova.13@ucl.ac.uk, tel: 07514 067242,
Name and Contact Details of Principal Researcher: Amanda Williams, amanda.williams@ucl.ac.uk
Name and Contact Details of the UCL Data Protection Officer: Lee Shailer, data-protection@ucl.ac.uk
This study has been approved by the UCL Research Ethics Committee: Project ID number: 19517/001

I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

	Please tick all boxes
1. I confirm that I have read and understand the Participant Information Sheet, for the above study.	☐
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
3. I confirm that: - I am 18 or older - I speak English - I have had a diagnosis of Crohn's or ulcerative colitis for at least 6 months - I do not have any significant cognitive impairments	☐

4. I understand that my participation is voluntary and that I am free to withdraw my data at any time, without giving any reason, up until one week after my interview. I understand that withdrawing my data will not have any adverse consequences. ☐

5. I understand the interview will be recorded and all information will be anonymised. I give consent for information from the interviews (including demographic Information) to be used in research, which may include anonymised quotes from the interview. ☐

6. I understand that my data will be stored electronically in a secure UCL data storage system and password protected. The recorded interview files will be deleted once transcription is complete and all other data will be deleted within a maximum of 5 years, to allow for publication and dissemination of research. Data will not be archived and will not be shared with future researchers or in a repository. ☐

7. I agree to take part in the above research study. ☐

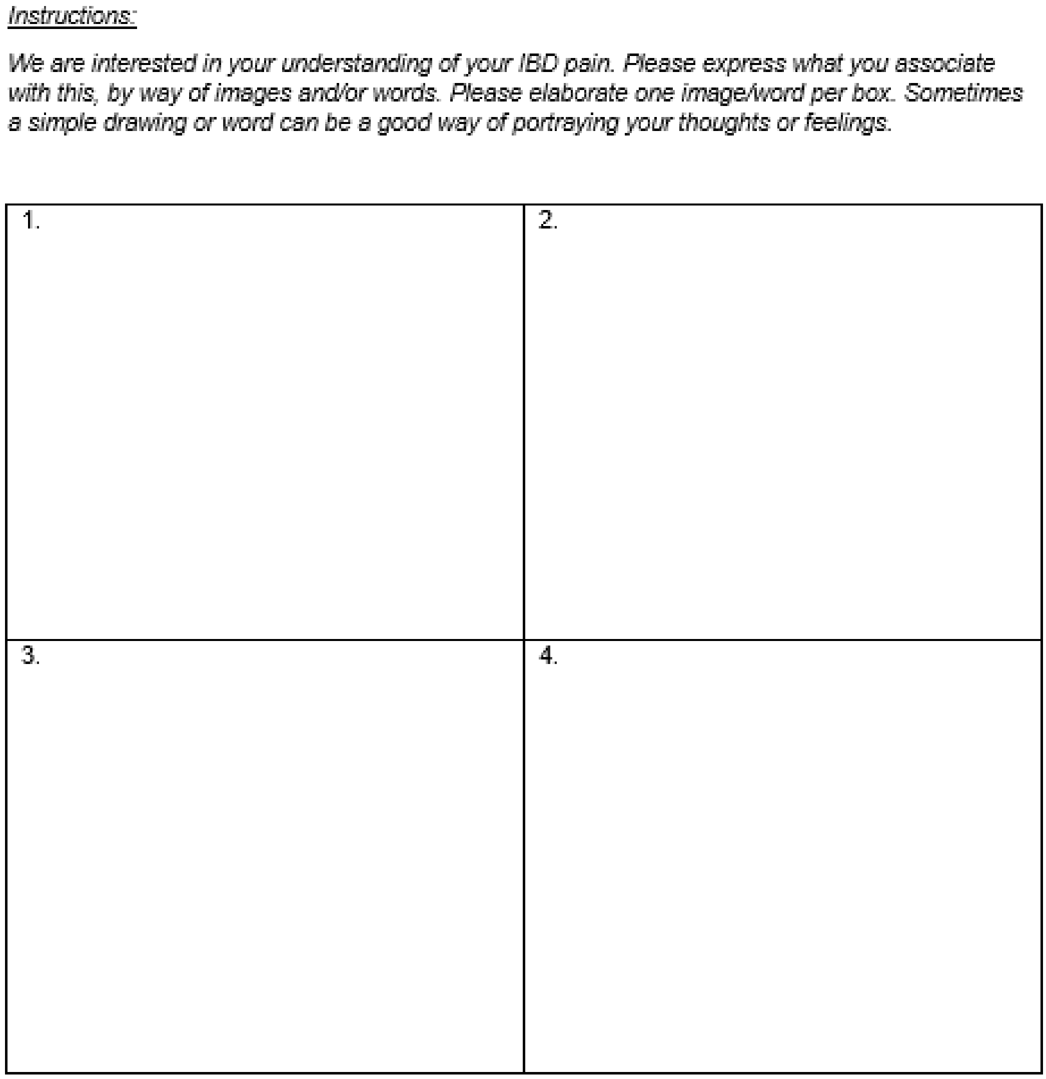
8. I understand that I can access the outcomes of the study by visiting (https://www.surveymonkey.co.uk/r/7QSJLXQ), where the details will be published at a later date. ☐

Name of Participant	Date	Signature
Telephone number	Email address	Preferred method of contact

Thank you for choosing to take part in this study. As a thank you, we will donate £5 to the Crohn's & Colitis UK charity for each participant that takes part.

If you have any further questions or concerns, please do not hesitate to contact the study researcher Adela Kacorova at adela.kacorova.13@ucl.ac.uk or by calling 07514 067242.

Appendix D – GEM participant sheet



Instructions:

We are interested in your understanding of your IBD pain. Please express what you associate with this, by way of images and/or words. Please elaborate one image/word per box. Sometimes a simple drawing or word can be a good way of portraying your thoughts or feelings.

1.	2.
3.	4.

Appendix E – Transcription key

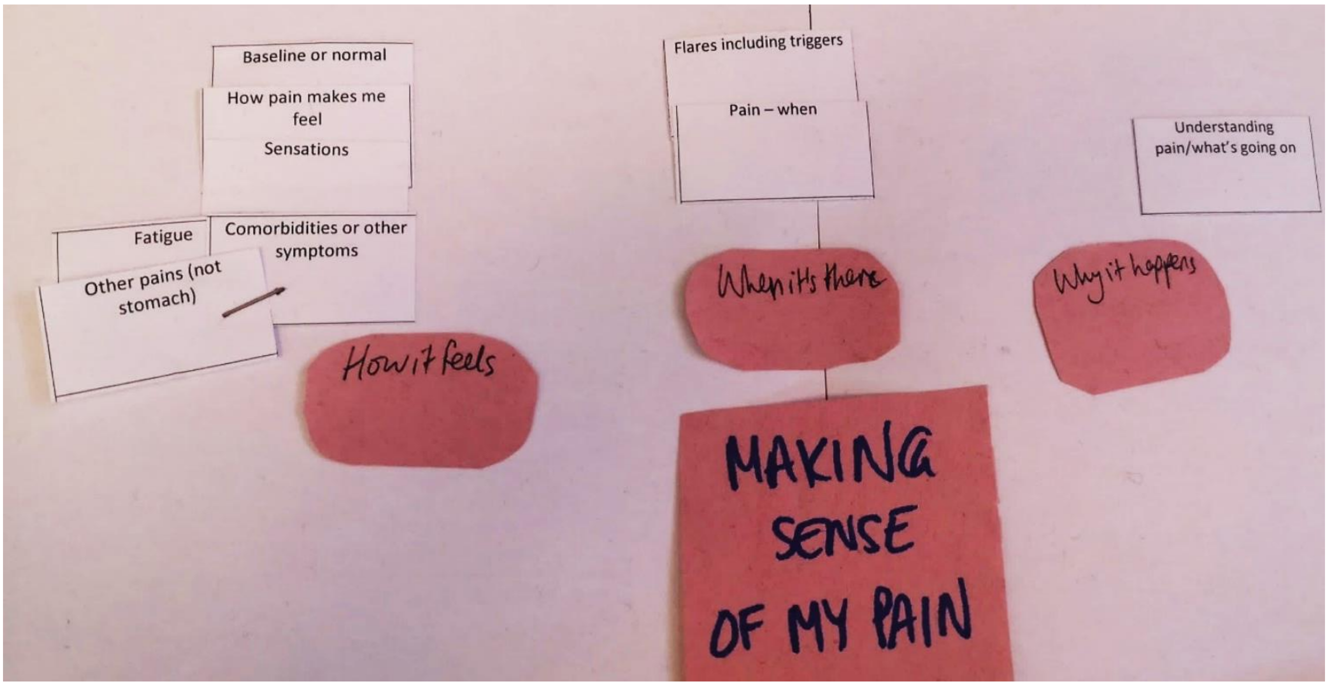
Transcription notation system key (based on example given by Braun & Clarke, 2013).

Feature	Notation and explanation of use
The identity of the speaker	The speaker's name (either participant or interviewer), followed by a colon, signals the identity of the speaker
Laughing, coughing or other incidents in the interview, e.g. internet problems	Double brackets, such as ((laughs)) or ((coughs)) are used to signify such activities. ((General laughter)) is used to signify both the participant and interviewer engaging in joint laughter.
Pausing & ellipsis (…)	The various lengths of pauses have not differentiated in detail in the transcripts. Ellipsis (…) denote participants pausing or trailing off in a sentence. Particularly long and noticeable pauses are depicted by ((pause)).
Spoken abbreviations	Where spoken abbreviations are used, the abbreviation is transcribed as used by participant, verbatim.
Inaudible or unclear speech	When participants' speech is inaudible, ((inaudible)) has been used. When participants' speech is unclear and the researcher has not been confident in the transcription, single parentheses () have been used to denote a best guess.
Non-verbal utterances (e.g. "um")	Non-verbal utterances were transcribed, but not focused on in detail, as the aims of this study were not focused on conversational analysis.
Reported speech	Quotation marks ("") are used to denote any reported speech/words.
Spoken numbers	One to nine have been transcribed as words. 10 and above have been denoted numerically.
Identifying information	Specific information, such as towns or jobs, have been replaced with generic descriptions, indicated by a square bracket. For example, "London" changes to [city].

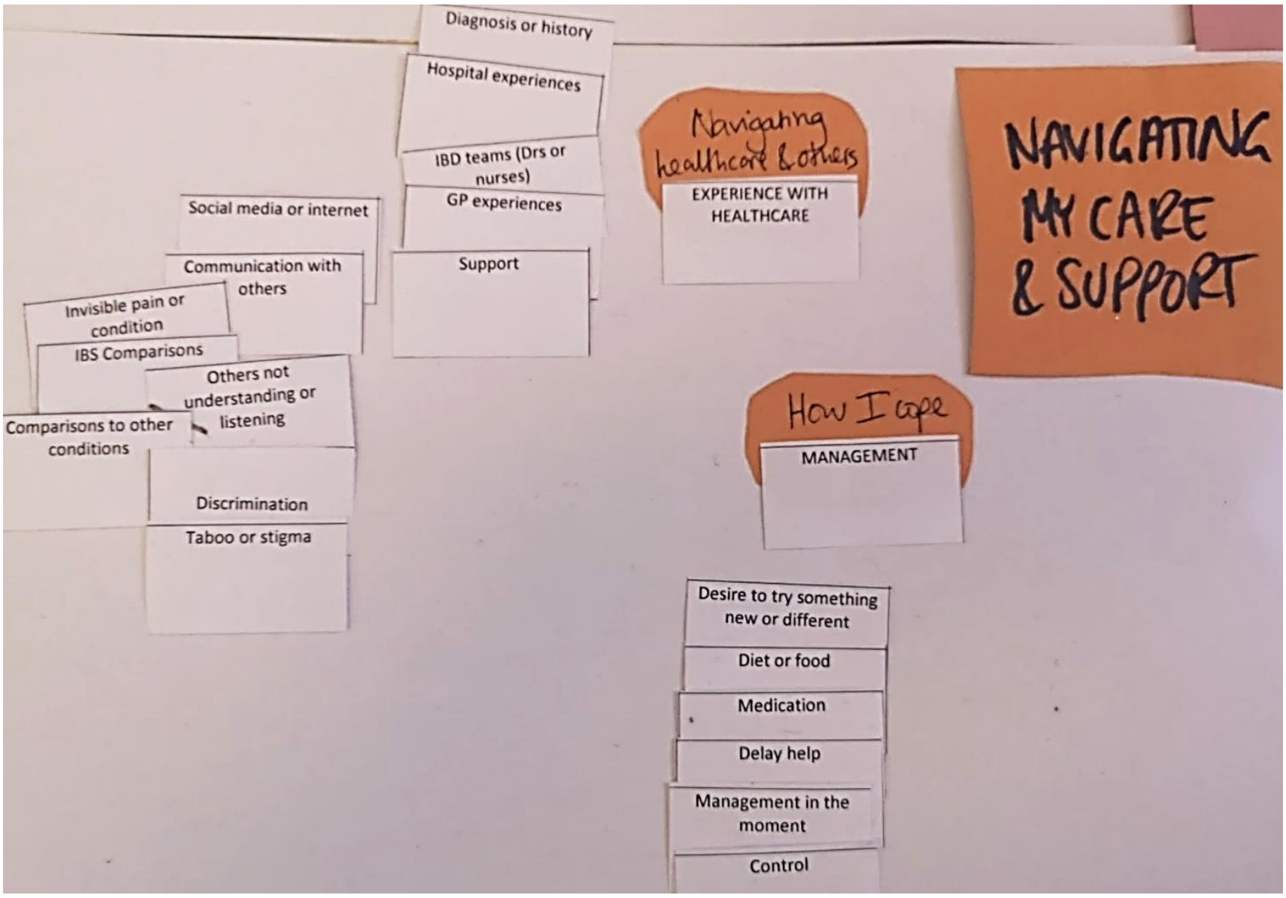
Appendix F – A photograph of the research paper's map of codes and how they collated to create themes and sub-themes

Overall map

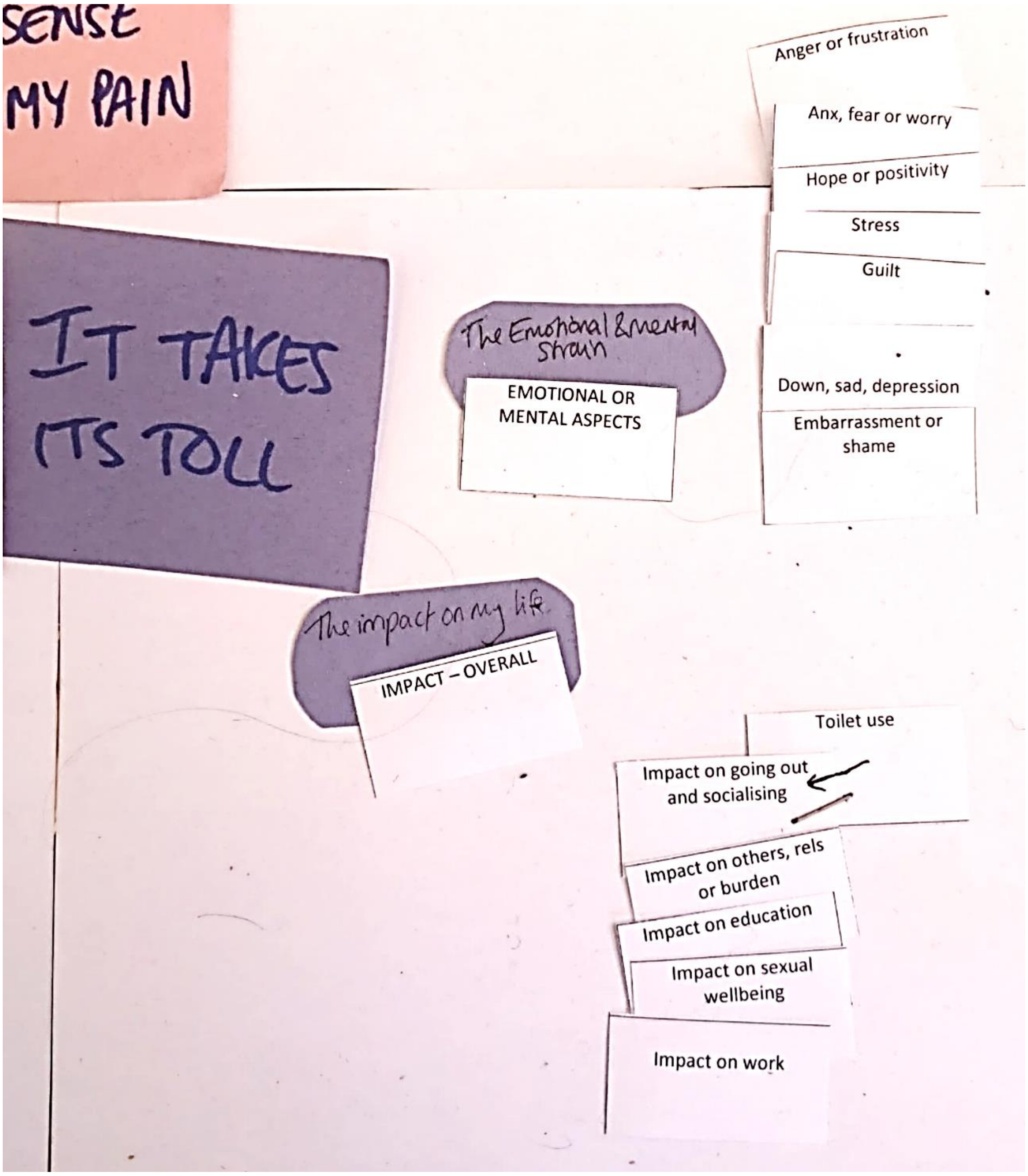
Making sense of my pain (zoomed in)



Navigating my care and support (zoomed in)

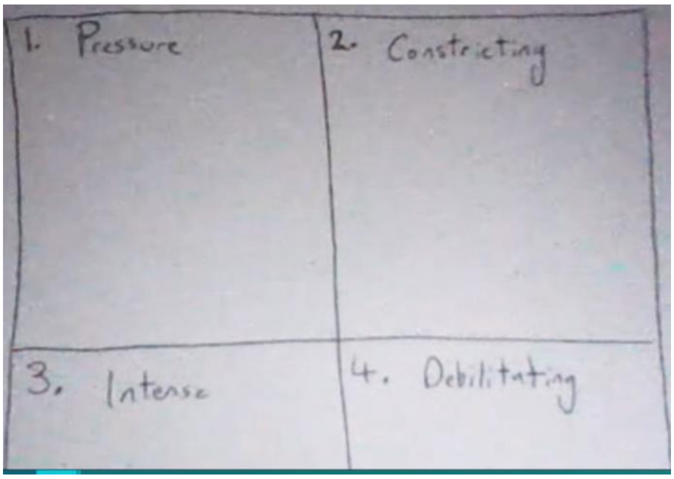


It takes its toll (zoomed in)

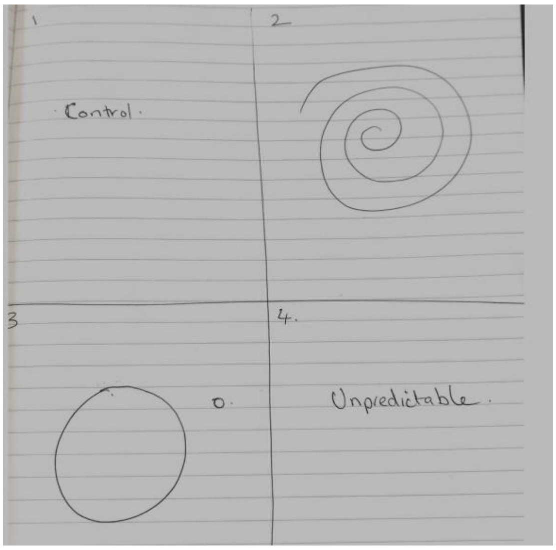


Appendix G – Further examples of completed GEMs

Participant 5:



Participant 17:



Participant 19: