

**Men's experiences of sexual health, well-being, and
healthcare when living with inflammatory bowel
disease: an interpretive qualitative study**

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ABSTRACT

Background: Inflammatory bowel disease (IBD) is a chronic condition of the gastrointestinal tract with a peak age onset of 15-30 years. The condition has a significant impact on sexual health and well-being. The predominant focus of research to date has been on women, with studies on men generally limited to erectile dysfunction. Research that is male-specific and considers the physiological and psychosocial impacts of the disease on sexual health is needed to direct accessible, appropriate, and positive healthcare.

Aims: To describe and interpret: (1) the sexual health experiences and care needs of men with IBD, and (2) health professionals' experiences and understanding of sexual health and care needs in men with IBD.

Methods: A systematic scoping review mapped out the existent literature. Subsequently, two interpretive descriptive qualitative studies were conducted. Data was collected using semi-structured interviews and auto-photography, then analysed using thematic analysis.

Findings: The scoping review demonstrated men's sexual health in IBD is currently evaluated by assessing erectile function. The qualitative studies revealed that the sexual health of men with IBD is not limited to effects on erectile function. Men reported negative impacts on intimate partnerships, self-identity, sexual engagement and a lack of specialised information and healthcare support. Data gathered from healthcare practitioners highlighted difficulties in raising sexual health discussions with men with IBD and the need for support to deliver specialist care in this domain.

Conclusion: This is the first study to investigate and describe how the symptoms and chronicity of IBD can profoundly affect the sexual activities and well-being of men in a gender-specific way. Further research is required to identify the care preferences of men, the training needs of healthcare practitioners, and refine theoretical conceptualisation of the intersection of gender, chronic disease, and sexual well-being.

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AUTHOR'S DECLARATION

I declare that this thesis is a presentation of original work and I am the sole author. This work has not previously been presented for a degree or other qualification at this University or elsewhere. All sources are acknowledged as references.

Material from this thesis has been presented in the following publications:

Ma, S., Veysey, M., Ersser, S., Mason-Jones, A. and Galdas, P. (2020) The impact of inflammatory bowel disease on sexual health in men: a scoping review. *Journal of Clinical Nursing*, 29(19-20), pp.3638-3651. Available at: doi:10.1111/jocn.15418.

Ma, S., Knapp, P., & Galdas, P. (2024). My sexual desires, everything, my normal life just stops'; a qualitative study of male sexual health in inflammatory bowel disease. *Journal of Clinical Nursing*, 33. pp. 4034-4047. Available at: doi:10.1111/jocn.17292.

CHAPTER 1: INTRODUCTION

This thesis investigates men's sexual health, well-being, and healthcare in the context of the long-term condition inflammatory bowel disease (IBD). This chapter outlines the background and justification for the research through elucidating the complexities and challenges associated with the manifestations and management of IBD and sexual health in men.

A brief context of the research is provided (Section 1.1) followed by an overview of IBD (Section 1.2) and sexual health provision in the UK (Section 1.3). Next, the rationale for gender-specific research is introduced alongside a brief overview of masculinities (Section 1.4). The chapter closes by outlining the overall research aims and structure of the thesis (Section 1.5).

1.1 Context of the thesis

The research presented in this thesis was conducted by a clinical nurse specialist (CNS) during a doctoral fellowship. At the time of writing, the NHS Foundation Trust that hosted the fellowship ("The Trust") served a population of approximately 800,000 people, with an estimated IBD caseload of 8,000 patients. The IBD CNS team within The Trust provide a Monday to Friday service that includes 11 nurse-led clinics, a telephone line service, in-patient support, and the ongoing monitoring and prescribing of medical therapies.

The IBD CNSs employed by The Trust operate as autonomous practitioners and are responsible for disease assessment, intervention planning, medication prescribing, and evaluation of treatment response. Their expanded scope of practice helps ensure the provision of safe, effective, and cost-efficient specialist care that is highly valued by those living with the disease (Younge, Mason and Kapasi, 2020; Leach et al., 2014; Hernández-Sampelayo et al., 2010; Nightingale et al., 2000). Advanced nursing practice is delivered alongside 'fundamental nursing care' as defined by the second European Crohn's and Colitis Organisation (ECCO) nursing consensus statements (Kemp et al., 2018) which consists of psychosocial support and self-management coaching.

The UK's National Institute for Health and Care Excellence (NICE) and the British Society of Gastroenterology (BSG) endorse medical research priorities focused on the safety profile and effectiveness of medical therapies (Lamb et al., 2019; NICE, 2019a; NICE, 2019b). Although vitally important to disease management and service provision, these priorities do not always address how patients experience and manage their chronic condition within their current social environment. Describing and interpreting the experiences of ill-health is vital to raising awareness to those working in healthcare and identifying patient need. Furthermore, exploration of patient experiences can inform further research and service development that seeks to advance and improve healthcare systems and services (Thorne, 2016).

This research is grounded within the discipline of nursing by seeking to generate knowledge that will inform nursing practice, research, and theory. This is achieved by adopting a relativist epistemological stance that is congruent with nursing and pursues knowledge that offers an understanding of the “complexities of human subjectivity and social behaviour” (Thorne, 2016, p44). The utilisation of a constructivist-interpretive methodological framework (as described in Chapter 3) has enabled the nurse-researcher to utilise their professional knowledge to collect qualitative data that will identify the healthcare needs of men with IBD. Finally, the application of a nursing lens has enabled the development of interpretations that are informative to healthcare practitioners and may support the enhancement of patient care and future research.

1.2 Introduction to inflammatory bowel disease

Inflammatory bowel disease (IBD) is a chronic, relapsing-remitting condition of the gastrointestinal (GI) tract. IBD can cause distressing and embarrassing symptoms including urgent defecation, bloody diarrhoea, abdominal pain, fatigue, perianal disease, and malnutrition. The disease is also associated with extra-intestinal manifestations that can adversely affect the joints, liver, skin, and eyes. The chronic and often multifocal nature of IBD can cause poor physical and psychosocial ill-health.

The two most common presentations of IBD are Crohn's disease (CD) and ulcerative colitis (UC). There are also less prevalent subtypes including microscopic colitis where inflammation may not be observed macroscopically, and IBD-unclassified (IBD-U) where there are clinical features of both UC and CD.

Disease onset can occur at any age but there is a bi-modal peak onset. The first and highest peak onset is between the ages of 15 to 30 years, followed by a second peak between the ages of 60 and 80 years (Whayman, Duncan and O'Connor, 2011). As IBD affects working age populations there is an economic burden and reduction in quality of life due to absence from employment (Rankala et al., 2021; Van Gennep et al., 2021; Le Berre et al., 2019; De Boer et al., 2016). Employment is often described as a key component of male identity (Kimmel, 2008; Connell, 2005; Kimmel, 2000).

The main focus of IBD treatment is inducing and maintaining disease remission while providing ongoing support. Bowel surveillance is also important due to an increased risk of colorectal cancer as compared to the general population (King et al., 2020). When moderate to severe, the disease can necessitate intensive medical therapy, hospitalisation, and surgical intervention. Disease treatment can lead to a substantial impact on quality of life and require considerable health service utilisation across both primary and secondary care. IBD is associated with an increased annual risk of mortality as compared to age- and sex-matched controls; for UC the adjusted hazard ratio is 1.17 (95% CI 1.14-1.21, $p < 0.001$) and for CD it is 1.42 (95% CI 1.36-1.48, $p < 0.001$) (King et al., 2020).

1.2.1 Epidemiology

In 2019, there were approximately 5 million people worldwide with IBD (Wang et al., 2023; Meier, 2019). Global incidence rates are reported to be the highest in Northern Europe, North America and Australasia, and are rapidly increasing in China, India and North Africa (Ng et al., 2017; Ng et al., 2013). The highest prevalence rates are reported in North America, Western Europe, and high-income areas within the Asian-Pacific region (Wang et al., 2023).

Although incidence of IBD is thought to be plateauing in high and middle income countries (Wang et al., 2023), it is rising in the UK. Rubin et al. (2000) reported a rate of 13.9 per 100 000 person years for UC and later King et al. (2020) reported it to be 23.2 per 100 000 person years. The same studies also demonstrate an increase in CD from 8.3 (Rubin et al., 2000) to 14.3 per 100 000 person years (King et al., 2020).

Pooled analysis of high and middle-income country populations indicates the incidence rate of UC is similar in males and females (Shah et al., 2018). CD is more complex, there is male predominance until the age of 25 and then females carry a 16% to 47% higher risk of CD as compared to males (Shah et al., 2018). The variation in incidence rates across age groups has been argued to demonstrate that sex hormones may be implicated in the pathogenesis of IBD (Shah et al., 2018). The fact that men are more likely than women to be diagnosed with CD during puberty and periods of sexual maturation is possibly an important consideration for sexual healthcare delivery. There are no studies exploring the effect of age at onset on puberty or sexual development in men; this is an evidence gap within the existing research (see the scoping review Chapter 2, section 2.4.3.1).

Overall prevalence of IBD in the UK is increasing at a rate of 2%-3% per year and the number of people living with IBD in the UK is estimated to be 744,120 or 1.1% of the population by 2025 (King et al., 2020). This represents an increase in UC prevalence from 390 to 570 per 100 000 and in CD from 220 to 400 per 100 000 between 2000-2017 in the UK (King et al., 2020). Crohn's and Colitis UK (CCUK), a national charity for the disease, claims that 1 in every 123 people in the UK lives with IBD (CCUK, 2022). The rising incidence rate and prevalence of IBD in the UK represents a significant challenge for NHS healthcare services. Advancing nursing practice so that IBD CNSs can deliver safe, timely, and patient-led care from the point of diagnosis and continuing throughout the life span should be a key objective of NHS services (Duncan et al., 2024). This thesis aims to support this objective through the development of nursing knowledge that can be utilised by IBD CNSs in practice.

1.2.2 Aetiology

The aetiology of IBD involves a complex combination of genetic susceptibility, microbiome disruption, dysregulation of immunity, and possible environmental influences. The various subsets of the disease and presentations are likely due to the multiplicity of mechanisms for the disease.

One hundred and ten genes have been identified as having a role in both CD and UC (Zhang and Li, 2014) but the genetic coding of IBD remains insufficiently understood. In the future, it is expected there will be further categorisations of IBD according to genetic subtype, offering the potential for more specific treatment pathways. For example, molecular studies indicate that ileal and colonic CD are independent subtypes with variants in nucleotide-binding oligomerization domain-2 (NOD2 gene) being associated with small bowel disease and human leukocyte antigens (HLA) alleles with colonic disease (Cleynen et al., 2016). Currently, CD and UC are treated by the same healthcare teams under umbrella IBD services with clinicians being trained to consider the varying presentations and possible treatments. Likewise, the research in this thesis explores IBD inclusive of both CD and UC while remaining mindful and sensitive to the possible variations between the two presentations.

Familial clustering of IBD is well-documented, and a large cohort study reported that 21-27% of patients have a family member with the disease (Cleynen et al., 2016). Put into context, someone with the NOD2 gene from both parents carries a 1 in 30 chance of developing CD (Whayman et al., 2011). The impact of the hereditary component to IBD on voluntary childlessness is poorly understood and there are currently no known studies that have specifically explored fatherhood, which is discussed further in the summary of qualitative study 1 findings (Chapter 4, section 4.4.2).

The potential environmental influences on disease pathogenesis are seen in the global disease distribution. The highest prevalence rates of IBD are observed north of the equator and in industrialised or newly industrialised areas (Wang et al., 2023). Diet and social stress have been identified as risk

factors for the disease. Smoking increases the risk of CD while having a hitherto unexplained protective effect for UC (Zhang and Li, 2014). Other environmental factors commonly hypothesised to carry a risk but without definitive evidence include; intake of cow's milk, refined carbohydrates and hydrogenated fats, insufficient fibre intake, use of the contraceptive pill, exposure to measles, and E.Coli infection. The lack of clarity on what causes IBD may be a driver to some people with IBD not disclosing their disease. There is evidence of high levels of self-blame in people with IBD (Voth and Sirois, 2009) and of others, including family members, thinking the person with IBD is responsible for their condition or symptoms (Dibley, Williams and Young, 2019; Woodward et al., 2016). This is an important consideration for nursing practice as self-blame is linked with reduced adjustment to the disease, propagates IBD as a hidden illness, and may also affect what is disclosed during clinical consultations (Voth and Sirois, 2009).

1.2.3 Symptoms and diagnosis

The predominant signs and symptoms of IBD include abdominal pain, chronic diarrhoea, and poor nutritional status driven by mucosal inflammation. Fatigue is driven by inflammation, anaemia, and vitamin deficiency.

In the UK, the most common pathway to diagnosis is following self-presentation to a General Practitioner with bowel symptoms. A stool sample test for faecal calprotectin is widely used to aid diagnosis and triage people for further investigation. Formal diagnosis occurs in secondary care following endoscopic or radiological investigation which aids exclusion of infective or malignant causes of symptoms. Genetic testing is not routinely conducted in the UK.

In general, men are more likely to delay seeking help for illness (Galdas, Cheater and Marshall, 2005) and men with IBD have mentioned the embarrassment of bowel symptoms causing a hesitancy to seek medical support (Horgan, Richards and Joy, 2020). A delay in diagnosis can reduce the opportunity for early treatment which is linked to better disease outcomes (Agrawal et al., 2021).

1.2.4 Ulcerative colitis

Ulcerative colitis (UC) is typically confined to the colon starting at the rectum and extending continuously without the skip-lesions which are segments of bowel unaffected by the disease. Ulceration with hyperaemia, granularity, and contact bleeding can be seen macroscopically. Microscopically, the lamina propria is infiltrated with inflammatory cells, crypt abscesses may be present, goblet cells may be depleted, and the mucosa will be oedematous (Whayman et al., 2011). Pseudo-polyps are common in UC and long-term inflammation can increase the risk of dysplasia and colonic carcinoma. Early remission is the goal of treatment, with UK patients being enrolled in a colon surveillance programme 8 years after diagnosis (NICE, 2015). When severe, UC can lead to medical and surgical emergencies such as toxic megacolon and perforation. Due to being confined to the large colon, surgery remains a common treatment option. Although stoma formation is used across all sub-types of IBD, clinically it is more common in ulcerative colitis. A total colectomy inclusive of a proctocolectomy (removal of the entire colon and rectum) is deemed a 'curative' option, however the stoma is permanent which can mean ongoing complications and an ongoing need for healthcare intervention in the absence of disease. Stoma formation in general is associated with sexual, psychosocial and physical problems (Di Gesaro, 2016). The impact of living with a stoma is discussed further in the literature review (Chapter 2, section 2.4.3.4) and within the findings of the first primary study of this thesis (Chapter 4, section 4.3).

1.2.5 Crohn's disease

The American gastroenterologist Dr Burrill Crohn first described Crohn's disease (CD) in 1932 (Hindryckx et al., 2014). CD can occur in any part or multiple sections of the GI tract. In approximately 50% of people with CD, the disease is limited to the terminal ileum and some of the colon (Whayman et al., 2011). Small aphthous ulcers and cobble-stoning are common macroscopic features of colonic CD. When inflammation is limited to the colon, skip lesions, observed as areas of healthy intestinal lining, are an

important observation when trying to distinguish CD from UC; an important consideration when deciding upon treatment options.

Inflammatory cell infiltration with ulceration throughout the intestinal epithelial layers may be visualised microscopically in CD. The transmural nature of CD can lead to the development of fistulas and perianal disease. A fistula is an abnormal channel, commonly between the intestine and skin. Perianal disease is defined as inflammation at or near the anal sphincter and includes fissures, fistula, abscesses, and stenosis. Perianal disease can lead to pain, bleeding, purulent discharge, incontinence, and discomfort. The locality of perianal disease means that it is highly likely to have a role in sexual well-being and this is discussed further in Chapter 2 (Section 2.4.3) and Chapter 4 (Section 4.3). Areas of scarring can cause stricturing disease which is a narrowing of the intestinal tract causing abdominal pain and constipation. There is an increased risk of bowel obstruction and the need for surgery when stricturing disease is present. These complications are putative disruptors of sexual health and well-being.

1.2.6 Extra-intestinal manifestations and complications

Extra-intestinal manifestations (EIMs) of IBD are brought about by systemic inflammation and commonly affect the liver, eyes, skin, and joints. Occurrence varies from 6-47% (Rothfuss, Stange and Herrlinger, 2006) while the prevalence of at least one joint, ocular, or skin extraintestinal manifestation in IBD is 25% (Kilic et al., 2023).

Disease-related complications include medication side effects, surgery, and the associated psychological impact of IBD. Many IBD medications have a large side effect profile. Immunosuppressant medications can lead to hair loss, nausea, and fatigue. Long-term steroids can induce diabetes and osteoporosis. Biologic therapies can increase the risk of developing certain cancers such as breast adenocarcinoma and lymphoma. Surgical intervention can leave temporary or permanent stomas, setons (a surgical thread passed through a fistula), and ileal pouches. All of these surgical outcomes which have been associated to poor sexual health (see Chapter 2, section 2.4.3 for

further information). The disease is also associated with an increased risk of thrombus and persistent colonic disease is a risk factor for colonic cancer.

Table 1.1 on the following page provides an overview but not an exhaustive list of EIMs in IBD and complications organised by bodily system.

Table 1.1 Extra-intestinal manifestations by body system. Data extracted from Magro et al. (2014), Harbord et al. (2016) and Rothfuss et al. (2006).

	Extra-intestinal manifestations	Extra-intestinal complications
Dermatological/ Mucocutaneous	Erythema nodosum Pyoderma gangrenosum Oral ulcerations Aphthous ulcers Scleritis	Anal fissures Fistulising disease Hair loss, brittle nails Angular cheilitis Acrodermatitis enteropathica Purpura Sweet syndrome
Haematological/ Vascular	Thromboembolic events Anaemia	Thromboembolic events Anaemia leading to fatigue Mesenteric or portal vein thrombosis Atherosclerosis
Hepatobiliary and pancreatic	Primary sclerosing cholangitis Granulomatous hepatitis Peri-cholangitis Steatosis Cirrhosis Pancreatitis – acute or chronic	Fatty liver Hepatic abscess Hepatic amyloidosis Gallstones Bile salt malabsorption Pancreatitis – acute or chronic
Musculoskeletal /Rheumatic	Osteoporosis Arthropathy Ankylosing spondylitis Sacroiliitis Metastatic Crohn's disease	Osteoporosis/osteomalacia Immunosuppression side effects including septic arthritis and bacterial infection of joints
Neurological	Demyelinating diseases	Peripheral neuropathy Stroke secondary to thromboembolic event Drug induced progressive leukoencephalopathy Guillain-Barre syndrome, tremor, epilepsy, paraesthesia, ataxia, aphasia
Ocular	Conjunctivitis Uveitis/Iritis/Episcleritis	Night blindness and/or keratopathy
Pulmonary	Chronic bronchitis Tracheal stenosis Bronchiectasis Granulomatous interstitial lung disease	Drug induced pulmonary fibrosis Pleuritis
Renal	Tubular proteinuria	Nephrolithiasis Nephritis Renal Amyloidosis Drug induced renal insufficiency
Others	Pain	Malnutrition, weight loss & growth failure Lymphadenopathy Psychological impact Sexual dysfunction Erectile dysfunction (surgery) Surgical complications Medication side effects

1.2.7 The psychosocial impact of IBD

The chronicity, severity, and often 'invisible' nature of the disease can lead to a poor psychosocial status. Psychological distress in IBD reduces quality of life independently of disease severity (Guthrie et al., 2002) and therefore needs careful consideration by treating healthcare teams. A systematic review found the reported prevalence of psychosocial comorbidities in people with IBD was between 39.5% and 44.4%, with those suffering from psychological conditions more likely to be admitted to hospital and have surgery for their disease (Dubinsky et al., 2021). Disease activity is associated with depression and anxiety (Byrne et al., 2017) while surgery and extraintestinal manifestations of the disease have been cited as independent risk factors for anxiety and depression (Navabi et al., 2018).

The relationship between the disease and depression may be bidirectional with some researchers reporting depression being associated with disease recurrence (Mikocka-Walus et al., 2016). The scoping review reported in Chapter 2 shows that depression is associated with sexual dysfunction, and a decrease in sexual interest and satisfaction in men with IBD (see Section 2.4.3.1).

Despite the importance of the psychosocial impact on people with IBD and the possible interaction with disease relapse, treatment of the condition has traditionally focused on the physical aspects of the condition (Casati and Toner, 2000). In order to provide care that is holistic and comprehensive, further understanding is required that considers the psychosocial impact of living the disease and the associated support required.

1.2.8 Medical interventions

As stated above, the primary aim of clinical treatment in IBD is symptom control, induction of remission, and intestinal mucosal healing. Corticosteroid therapy is the mainstay of rescue therapy when there is an exacerbation of the disease.

The drug class 5-aminosalicylates (5-ASAs) are first line therapy for mild to moderate UC (NICE, 2019b). They are not recommended for the induction of remission in CD but are well-tolerated in the CD patient group (Torres et al., 2020). Available in both oral and rectal preparations, 5-ASAs have a good safety profile, are relatively cheap, and can be managed in primary care. Side effects can include diarrhoea, abdominal pain, and pancreatitis. The implication of rectal therapies on sexual well-being has not been well investigated.

Immunomodulators such as thiopurines are widely used due to their low cost and effectiveness. However, immunomodulators require ongoing blood monitoring and have a wide side-effect profile including hair-loss, nausea, and leucopenia. There are several biological and small-molecule therapies with a UK license and NICE approval for UC or CD. Rapid advancements in these types of medications and a reduction in their costs due to the expiry of patents and manufacture of biosimilars means that they are now common treatment for those with moderate to severe disease. Biological therapies and steroids were found by one study (see Chapter 2, section 2.4.3.3) to be an independent risk factor for sexual dysfunction in men with IBD (Marin et al. 2013).

Acute medical management may be required in either UC or CD. In CD, small bowel obstruction can occur due to intestinal stenosis. Bowel obstruction is preferentially managed with bowel rest and gastric decompression (Adamina et al., 2019) but may require surgical intervention if severe or in the event of perforation. In acute severe UC, intravenous steroid therapy is the mainstay of treatment alongside biologic or small molecule therapy. When disease is severe or refractory to medical therapies, surgical intervention may be required. Low residue diets are used for patients in severe flares or at risk of obstruction, but overall there is limited evidence for the use of dietary interventions in the treatment of IBD (Limketkai et al., 2023).

1.2.9 Surgery

Although medical therapy has overtaken surgery as the primary treatment option for IBD, there continues to be a 9.8% risk of colectomy in UC and a 26.6% risk of surgery in CD within 10 years of diagnosis (Tsai et al., 2021).

There are several surgical procedures for IBD, all associated with perioperative risks including bleeding, infection, and mortality. The most common procedures involve the removal of a section of bowel. Bowel continuity might be preserved, or an ileostomy formed. Following removal of the terminal ileum there is an increased risk of bile salt malabsorption which causes chronic watery diarrhoea and vitamin B12 deficiency. The colon absorbs water so when sections of the colon are removed, faecal matter may also become watery. Emergency surgery presents an increased risk of morbidity and mortality (Hajirawala et al., 2021) but is unavoidable in acute bowel obstruction, perforation, or pelvic sepsis.

Strictureing disease in CD may require surgical resection or strictureplasty, alternatively endoscopic balloon dilatation is also an option for some people. All of these interventions are associated with risks including perforation. Although dilation is less invasive than a bowel resection, in 74% of cases it will result in need for further re-dilation within 24 months, and 43% of cases will progress to surgical resection (Adamina et al., 2019).

Perianal fistulas can cause pain and continuous soiling from exudate. Perianal fistulas can be treated conservatively or with the use of a seton stitch, fibrin glue, collagen plugs, rectal advancement flaps, fisulotomy, or ligation of the inter-sphincteric fistula tract. Unfortunately, incontinence rates are higher after flap surgery (Stellingwerf et al., 2019). In cases of severe perianal disease, the entire rectum may be removed or a pouch left, leaving a non-functional orifice that should not be used other than to insert rectal therapy in the event of ongoing inflammation.

Although surgery carries several perioperative risks and complications, some of which can affect sexual health (see Chapter 2, section 2.4.3.4), there may

also be positive outcomes aside from the removal of disease. There have been reports of surgical intervention being a trigger to good health behaviours including smoking cessation and improved nutritional management alongside other positive effects such as viewing the stoma as a form of symptom control (Morris and Leach, 2017).

1.2.10 IBD healthcare provision in the UK

There is a total of 230 IBD specialist services in the UK providing care for adults and children (IBD-UK, 2021). Services are mostly based within acute hospitals and are delivered by gastroenterologists, surgeons, radiographers, endoscopists, junior doctors, CNSs, dietitians, and clinical psychologists. The organisation IBD-UK was launched in 2017 and consists of a partnership of 17 professional bodies, Royal Colleges and patient organisations. The partnership aims to improve the quality and consistency of IBD care in the UK and has developed national standards for IBD service provision (Kapasi et al., 2020) alongside three-yearly benchmarking activities (IBD-UK, 2021). This strategy for service provision runs alongside guidance for the medical and surgical management of IBD produced by NICE (NICE, 2019a; NICE, 2019b), the British Society for Gastroenterology (Lamb et al., 2019) and the European Crohn's and Colitis Organisation (Raine et al., 2022; Spinelli et al., 2022; Torres et al., 2020; Adamina et al., 2019).

IBD-UK also undertakes UK-wide surveys to help assess the quality of services provided and draw attention to key areas of improvement. Although patient satisfaction is generally good, with 72% of 10,222 patients in 2019 rating their care as good, very good, or excellent (IBD-UK, 2021) there remains significant improvements to be made to reduce levels of reactive care and raise the quality of service provision. In the most recent survey, four key areas for change were identified: (1) improvements in diagnosis and information, (2) personalised care and support of self-management, (3) faster access to specialist advice and treatment and (4) effective multidisciplinary team working (IBD-UK, 2021). These objectives are considered further in Chapter 7.

1.2.11 Specialist nursing in the context of IBD care

Clinical nurse specialists (CNSs) are expert practitioners that provide care in a specialism of knowledge, whether that be within a field of practice or specific disease (Fulton, Lyon and Goudreau, 2014). CNSs represent the “professional evolution of nursing, and the foundation of today’s advanced nursing practice” (Barton and Allan, 2015, p3). CNSs work to improve patient access to care, utilisation of services, treatment compliance, and specialist advice. The concept of specialist nursing precedes advanced care practice and the role of the Advanced Care Practitioner (ACP). Although there is significant overlap, the roles have become more defined recently with a validated qualification in Advanced Practice that may also be accessed by Allied Health Professionals. In comparison, a CNSs expertise is usually achieved through a bespoke and often individualised pathway dependent upon their specialism and local service need. While there is an expectation for CNS to have extensive clinical experience and engage in post-graduate study, the IBD Nurse national audit found that only 20% had been educated to Master’s degree level and 50% had worked within the specialism for less than 5 years (CCUK, 2024).

There has been little high quality economic analysis to support the cost-effectiveness of the role of the CNS but a systematic review from Canada draws attention to reduced resource use when CNSs provide care in outpatient settings (Kilpatrick, 2014). In rheumatoid arthritis, a specialism that is comparable to IBD in regards to UK NHS service delivery, a RCT has demonstrated that nurse-led care is comparable to rheumatologist-led care in regards to cost and patient-satisfaction (Ndosi et al., 2014).

There is limited research quantifying the clinical or monetary value of IBD CNSs. What research has been published is mostly single-centre audits that are now out-dated. However, this work is worthy of mention for exemplifying the types of benefits brought to patients by a CNS service. One IBD CNS in an Australia hospital demonstrated an avoidance of 27 admissions and 32 ED presentations in a 12 months period, with a net saving of \$136,535 (Leach et al., 2014). In the UK, there was a 40% reduction in out-patient attendances

and a 20% reduction in in-patient stays following the introduction of an IBD CNS (Nightingale et al., 2000). An audit of a nurse-led IBD telemedicine service showed an overall cost saving of £42,890 over 5 months (Squires, Boal and Naismith, 2016). Possibly the greatest indication of the success of IBD CNSs is the increase in UK posts with 394 identified in 2019, a 32% increase from 2016 (Younge, Mason and Kapasi, 2019). Furthermore, the BSG consensus guidelines on the management of IBD recognises the vital role that CNSs have within the IBD team, providing disease management, therapy monitoring, patient support, rapid access, and continuity of care (Lamb et al., 2019). Pertinent to the topic of this thesis, the N-ECCO consensus statements on nursing roles for patients with IBD states that nurses have a key role in fostering confidence in patients to raise sexual health concerns and subsequently identifying and supporting issues in sexual function and sexuality, referring to specialist services when appropriate (Kemp et al., 2018). The ongoing provision, evaluation, and updating of education and evidence-based guidelines for IBD-CNS services is required to ensure the provision of holistic, patient-centred IBD care that is both relevant to the current socioeconomic environment, and inclusive of sexual health provision.

1.3 Sexual health, care and research

Sexual health is widely accepted as a basic human right and a component of overall well-being and quality of life. In the UK, sexual health has a history of being neglected, in part due to now obsolete ideas of sexual morality that prohibited and constrained the delivery of healthcare in matters of sexuality (Bancroft, 2005). It was not until 2011 that a Multidisciplinary Joint Committee of Sexual Medicine (MJCSM) was established to set the standards of care, training, and assessment for doctors working in the field of sexual medicine. In 2011, only one of the first 283 specialists to be granted the title of Fellow of the European Committee of Sexual Medicine had all of their clinical role dedicated to practicing sexual medicine (Arbanas, Reisman and Andrews, 2015). To date, 625 medical doctors (MJCSM, 2024) have sat the exam demonstrating an ongoing limited number of practitioners working in the field.

Men's sexual health in particular is a neglected issue with an absence of measures and gender-disaggregated data in sexual health research and a lack of attention to men's sexual health within policies that promote gender equity (Shand and Evoy, 2024). This has led to a recent call for a positive focus on men's sexual health that not only considers sexual infections, fertility, and dysfunction but also pleasurable and healthy sexual relationships that is inclusive of men who are older, disabled, live with serious health conditions, have varying sexual orientations, and transgender people (Shand and Evoy, 2024).

1.3.1 Sexual activity and orientation in the UK

The National Survey of Sexual Attitudes and Lifestyles (Natsal) provides an insight into sexual activity in the UK. The most recently available results are from Natsal-3 and have been summarised in Table 1.2. In summary, approximately 60% of the UK population are in a sexual partnership and on average adults engage in sex once a week.

Table 1.2 Summary of UK sexual engagement data from Natsal-3, adapted from Mercer et al. (2013)

	Men (n=6293)	Women (n=8869)
In a partnership	63%.1	61.1%
Median age of first intercourse	17 (16-19)	17 (15-22)
Mean number of episodes of heterosexual intercourse in last 4 weeks	4.3 (SD 5.7)	4.0 (SD 4.9)
Vaginal intercourse in last 4 weeks	62.6%	58.4%
Masturbated in last 4 weeks	66.4%	33.9%
Paid for sex within last 5 years	3.6%	0.1%
Report of any sexual experience or contact with same sex partner	10%	6.6%
Report of one same sex partner in last 5 years	2.3%	1.0%

The UK 2021 national census asked about sexual orientation for the first time and found 89.4% of the UK population over the age of 16 identified as straight or heterosexual while 3.2% (1.5 million people) identified as gay or lesbian, bisexual, or 'other' (ONS, 2023). Although this data provides information on how people in the UK openly identify with a given sexual orientation, it does

not necessarily reflect the true level of same-sex attraction or engagement. Importantly, it is only since the millennium that laws in England and Wales have been introduced that address disparities across varying sexualities, including lowering the age of homosexual consent to 16 in 2000, the Civil Partnership Act in 2004 and the Marriage (Same Sex Couples) Act in 2013. As perceptions and attitudes change towards sex and sexuality in the UK, sexual activity patterns and people's readiness to seek healthcare support may also change. It is essential that those working in healthcare respond to societal changes by ensuring knowledge, processes, and facilities are available to care for all genders and sexualities in a fair, unprejudiced, and equitable way. The considerate care of people with varying sexual preferences, is particularly pertinent in IBD care due to the possibility of rectum and perianal region being affected by the disease, which may play a role in sexual activity.

1.3.2 Defining sexual health

The World Health Organisation (WHO) defines sexual health as; *“state of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence”* (WHO, 2006, p5).

Sexual health encompasses disease, infections, and functionality of the reproductive and sexual organs, but such issues are not the focus of the research presented in this thesis. Rather, this research is primarily concerned with the human nature of being sexual and having healthy sexual interactions, inclusive of but not limited to; sexual behaviours, sexual rights, sexual pleasure, sexual engagement, and sexual identities (WHO, 2006). The idea of sexuality, sexual expression, and sexual pleasure as a healthcare matter is contentious (Lottes, 2013). The World Association for Sexual Health (WAS) urged governing organisations to promote the treatment of sexual concerns, dysfunctions, and disorders while also recognising sexual pleasure as a component of health (WAS, 2005). A more inclusive and broader definition of

sexual health is especially important in the context of chronic diseases, such as IBD, where healthy sex may be compromised by both the physical and psychological impacts of the condition. Currently, there is no standardised definition of men's sexual health (Shand and Evoy, 2024). This work seeks to provide a better understanding of how men with IBD experience their sexual health and whether their experiences align with the WHO (2006) definition of healthy sex that is pleasurable, esteem raising, aligns with a person's self-selected gender identity, and should not cause physical or mental harm.

1.3.3 Sexual healthcare in the UK

In Nastal-3¹, 41.6% of sexually active men and 51.2% of women reported at least one sexual function problem in the last three months (Mitchell et al., 2013). Low sexual function is associated with depression, poor health status, non-volitional sex, an STI diagnosis, and paying for sex (Mitchell et al., 2013). The association between poor sexual function and other poor health outcomes substantiates the need for sexual health to be incorporated in general healthcare assessment and provision. The integration of sexual health into general health provision is particularly important in populations of people with long-term conditions who are at increased risk of low sexual function.

In 2001, the UK Department for Health recognised and set out a much needed strategy for sexual healthcare in the UK that aimed to develop specialist sexual health services and training for a wide range of practitioners (DOH, 2001). This strategy was followed by the World Association for Sexual Health recommendations for universal access to sexuality information and treatment (WAS, 2005). Unfortunately, there continues to be a lack of accessible and integrated provision of sexual healthcare, particularly with regards to psychosexual health (Christophers, Mann and Lowbury, 2008), confirmed by Natsal-3 survey findings where only 10.5% of men and 21% of women in the UK report seeking help for sexual health problems (Mercer et al., 2013). Despite a further independent declaration on sexual pleasure as a

¹NASTAL-4 closed in 2024 but data not available at time of writing.

fundamental sexual right (WAS, 2021; Ford et al., 2019), sexual pleasure and well-being are still not comprehensively considered within UK health policy. The Integrated Sexual Health Service Specification (DHID, 2023) places the focus of sexual health on screening for, and treatment of sexually transmitted diseases, and contraception, with little focus on psychosexual function and sexuality. In the context of IBD, deficits in disease-specific understandings may lead to inequitable access to, and provision of information that supports safe sexual interactions and positive attitudes towards sex. The lack of knowledge in this field expedites the need for research into sexual well-being and for clearly defined treatment pathways in matters of sexual health that affect quality of life, sexual engagement, sexuality, and sexual relationships, so that the evidence base may inform future policy development in this field.

1.3.4 Sexual health in IBD

Intimacy and relationships are a concern for people with IBD, with recent work commissioned by CCUK identifying them as one of 12 socioeconomic priorities for people with the disease (Equality Research, 2024). Two systematic reviews with meta-analysis have demonstrated that both men and women are impacted by sexual dysfunction when living with IBD (Chen et al., 2022; Zhao et al., 2019). Reported rates of dysfunction in men range from 10% to 50% and younger male IBD patients were found to experience the greatest impact (Chen et al., 2022). This finding shows that the impact of IBD may be greatest during a crucial period of sexual maturity and functioning in men (Park and Kim, 2020).

The second European evidence-based consensus on reproduction in IBD (Van der Woude et al., 2015) briefly touches on the influence of IBD on sexuality but does not provide a comprehensive evaluation of how IBD impacts on sexual health and well-being. IBD is described to have a greater impact on women because of issues such as penetration pain and menstrual abnormalities (Van der Woude et al., 2015). These are undoubtedly important issues that have been raised by female-focused research (Weber et al., 1995). However, it is problematic to make direct comparisons of genders due to the inherent differences in how genders experience sex; in doing so there is

the risk of misrepresentation of the potential impact of the disease. For example, the statement “*Women with IBD report significantly reduced sexual activity and libido compared with men*” (Van der Woude et al. 2015, p115) is not inaccurate statistically when directly comparing the data presented by Muller et al. (2010). However, direct comparison of the genders using non-gendered variables in this way does not adequately address the gender-specific impact of IBD on men who live with the condition and who participated in the first primary study of this thesis (see Chapter 4). This includes, for example, the negative impact on men’s body image (51.4%), libido (41.9%) and sexual activity (40.5%) and the finding that overall relationship status and quality of life were similarly affected in both men and women (Muller et al. 2010). Furthermore, while penetrative pain is mentioned in the context of women, there is an absence of information on receptive anal intercourse (RAI) which can affect both sexes. The lack of information on RAI also means there is insufficient evidence to guide healthcare in sexual minority groups including gay and bisexual men which is particularly pertinent within the context of a disease that can affect the anal canal. Furthermore, there is evidence that while women’s sexual health may be more greatly affected by the physical complications of IBD, men’s sexual health is more likely to be disrupted by psychological factors, such as depression (Marin et al., 2013). This comparison is important when considering healthcare interventions as men are less likely than women to seek advice for psychosocial health (Möller-Leimkühler, 2002).

To comprehensively understand and evaluate the evidence base of men’s sexual health in IBD and clarify how IBD may impact men specifically, a systematic scoping review of research is reported in Chapter 2.

1.4 Gender-specific research

Sex and gender are important determinants of health (Evans et al., 2011) and must be incorporated into health research design in order to produce ethical, sensitive and applicable findings (Greaves, 2012). While sex is a biological concept that incorporates anatomy, physiology, genes, and hormones; gender is a social construct grounded in culture and time that considers experiences,

roles and identity (Johnson, Repta and Kalyan, 2012; Johnson, Greaves and Repta, 2009; Lorber and Moore, 2002). Sex differences shape and inform constructs of gender, making them inherently interlinked but not interchangeable. Unlike sex, gender is a self-identification linked to the social context and expressed in varying statuses across the social domains including work, family relations, and expression of illness (Lorber and Moore, 2002). Post-genderism has moved beyond a dyadic and binary classification of gender (Johnson and Repta, 2012). Currently, multiple definitions and revisions of gender exist. These include, but are not limited to, male, female, non-binary, pangender, genderqueer, and gender-fluid.

Recognising and addressing the sexual health needs and concerns of people based on biological sex and gender differences is a key objective of the WHO Action Plan for Sexual and Reproductive Health (WHO, 2016). The WHO guide on gender-analysis and health sector planning suggests examining *“how gender norms, roles and relations influence male behaviour and health outcomes”* (WHO, 2011, p8), encapsulating the gendered-approach taken to this work. Gender-transformative interventions that seek to challenge gender-inequalities and alter harmful gender norms have also been called for (United Nations Fund for Population Activities, 2023; WHO, 2016). These can only be achieved through research that provides gender-specific (or gender-considered) knowledge, and represents a key reason why this work focuses solely upon people who identify as male.

While there is currently no standardised definition of ‘men’s health’ (White et al. 2023), the UK-based Men’s Health Forum (MHF) provides one that is useful to this work: *“A male health issue is one arising from physiological, social, cultural or environmental factors that have a specific impact on boys or men and/or where particular interventions are required for boys or men in order to achieve improvements in health and well-being”* (Men’s Health Forum 2004, p5). Although many policy makers and governing bodies have attempted to define the scope of men’s health, none have been able to describe the population their definition includes (White et al. 2023). Studying men’s health or adopting a male-gendered approach where the concept of

gender and definitions of varying genders are evolving, is not without its challenges. To manage the men's health approach in this work in an inclusive and contemporary way, the concept of male-gender in this thesis was not pre-defined using biological or social concepts. Instead, 'men' and 'male' were the adopted search terms within the literature review, and participants who self-identified as 'male', regardless of sex-assigned at birth or sexual organs, were invited to participate within qualitative study 1 (Chapter 4, section 4.2). This approach recognises that male gender exists across a diverse range of bodily characteristics, self-expressions, social behaviours and sexualities (Lindqvist, Sendén and Renström, 2021; Carrera, DePalma and Lameiras, 2012). This strategy was deemed appropriate for establishing a nuanced understanding of men's care needs and how male identity intersects with IBD gender norms and sexual health.

While men's health as a clinical discipline remains in its infancy, it has emerged within the 21st century as a key concern within the field of health sciences (Gough, 2006). Men on average have a lower life expectancy and are at higher risk of diseases such cardiovascular disease and colon cancer (Baker, 2018; White and Cash, 2004). While there have been calls to tackle gender inequities and pay attention to the social and economic drivers to men's (ill-)health (Marmot, 2014) this has not yet been realised within healthcare research, policy and practice (Griffith, 2024). Not only is there a moral, ethical, social, and economic benefit to delivering research that seeks to improve men's health, doing so can have a consequent effect of improving the health and well-being of partners and children through enabling employment, educational, and child-caring opportunities (Baker, 2018).

Both men and women with IBD have an increased risk of sexual health problems (Zhao et al., 2019; Maunder et al., 1999), however the biopsychosocial differences between sexes and genders have significant implications for engagement in and experiences of sex, meaning that the causes of poor sexual health between men and women may be different. A gendered approach to investigating sexual health is more likely to provide knowledge that establishes the gender-specific determinants of sexual ill-

health in IBD and moves towards the WHO goal of gender-mainstreaming and understanding the needs of men in a grass-roots fashion (WHO, 2011). It is also important to make explicit that although the argument for research that focuses on men is being made, research into the experiences of other genders is also required and it is anticipated that this work will inform similar work across other genders.

Men face gender-specific barriers and stigmas to seeking and utilising healthcare services (Galdas, Seidler and Oliffe, 2023). Historically, male-gender norms have directed men to present themselves as brave and tough, and to disregard pain, leading to the idea that expressing health concerns is 'less-masculine' (Wakley, Cunnion and Chambers, 2003). This representation of masculinity may have contributed to the phenomenon that men may be more reluctant to access healthcare due to masculine norms and ideals of autonomy and not displaying vulnerabilities (Sloan, Gough and Conner, 2010). Reluctance to access healthcare can have implications for health screening and involvement with preventative measures, which is particularly pertinent to sexual health concerns with 48.6% of men² reporting they do not think sexual problems are a medical problem (Moreira et al., 2008). Additionally, men do not access social networks for problem-sharing in the same way as women (Wakley et al., 2003). To address these possible issues, men may benefit from models of service delivery that are tailored to their specific physiological and psychological needs and preferences (Galdas et al., 2014). However, there are gaps in the current evidence on the specific needs of men with IBD, which this thesis seeks to address.

1.5 Summary

1.5.1 Justification for the research

In summary, the authors observed lack of sexual health consultation within IBD care ignited an interest in the field. The second nursing ECCO statements (Kemp et al., 2018) direct IBD nurses to recognise and support sexual health

² This is based on data from a UK survey of 750 randomly selected men between the ages of 40 and 80 years.

but there is currently no formal guidance, educational resources, or specialist support on how to do this. A recent bibliometric study demonstrated an increase in publications on sexual healthcare in the last 20 years (Fu et al., 2023) but there remains much to be done in order to address the dearth of sexual health research within the context of chronic disease. A recent scoping review that sought to summarise the sexual health needs of people with long-term conditions (Igerc and Schrems, 2023), located only two research articles that explicitly referenced nursing practice and only two that explored sexual health and IBD - one of which was a publication from this work. Additionally, a snapshot review of papers published in the *Clinical Journal of Nursing* between 2008-2013 also revealed a lack of work on how gender influences sexual health and LGBTQ+ themes (Hayter, Haigh and Jackson, 2013).

As discussed in detail in the literature review (Chapter 2), the research literature on sexual health in IBD has typically focused on fertility and function (Chen et al., 2022; Hammami and Mahadevan, 2020; Bulut and Toruner, 2018; Purewal et al., 2018; Shin and Okada, 2016; Mantzouranis et al., 2015; Rosenblatt and Kane, 2015; Feagins and Kane, 2009; Giese and Terrell, 1996; Park and Kim, 2020). A limited number of studies have begun to more broadly explore sexual health in IBD by gathering personal experiences and considering psychosocial well-being in IBD (Fretz, Hunker and Tripp, 2024; Fourie et al., 2024; Fourie, Jackson and Aveyard, 2018; Wilburn et al., 2017; Casati et al., 2000; Hall et al., 2005). The shortage of studies concentrated on understanding the needs of men has created a gap in the evidence base that can guide nursing practice.

A gendered-approach (as defined in 1.4) to sexual health research enables the identification of gender-specific needs, supporting the reduction in gender disparities within healthcare systems. Sexual health research across all genders in IBD is limited but men's health is a particularly neglected area (Allocca et al., 2018). The barriers to health service access and subsequent inequitable health outcomes experienced by men have been recognised in two key documents; 'The health and well-being of men in the WHO European Region' (WHO, 2018) and 'Men and HIV: evidence-based approached and

interventions' (WHO, 2023). In IBD specifically, a meta-analysis has shown an increased risk of sexual dysfunction in men with IBD (Zhao et al., 2019). Only 10% of men with IBD report being asked about their sexual health (Timmer et al., 2007b) and only 14% of gastroenterologists report routinely assessing or enquiring about sexual health (Christensen et al., 2022). The research reported in this thesis aims to develop a male-gender and disease-specific understanding of sexual health, to raise healthcare professional awareness and identify nursing and research priorities that address gender inequalities and patient needs in this field.

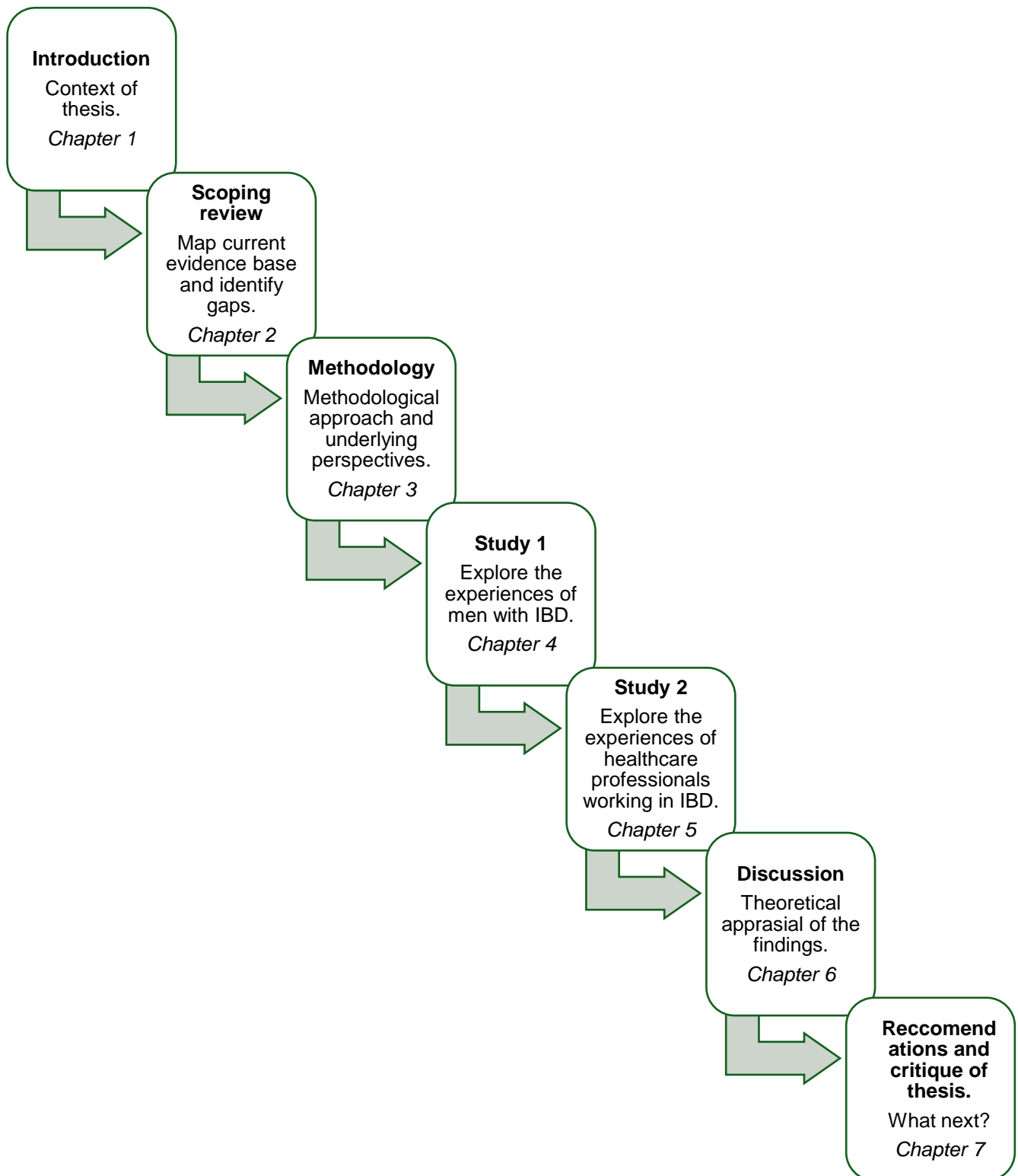
1.5.2 Research aims

The overarching aims of the thesis were:

- 1) to map the current research literature that describes, reports, or evaluates the impact of IBD on the sexual health of men, and identify current gaps in knowledge of relevance to informing nursing practice;
- 2) to describe and interpret the sexual health experiences, activities, and needs of men with IBD;
- 3) to describe and interpret health professional experiences and understandings of the sexual health and care needs in men with IBD;
- 4) to identify recommendations for nursing practice, education, and research in the field of men's sexual health in IBD.

1.5.3 Structure of the thesis

Figure 1.1 Structure of the thesis



CHAPTER 2: SCOPING REVIEW

The impact of inflammatory bowel disease on sexual health in men: a scoping review

This chapter presents the original review conducted in 2019 that shaped the direction of the research presented in the thesis. The resultant peer-reviewed publication can be found in Appendix 1. The literature searches were updated regularly during the course of the doctoral fellowship programme. Relevant and pertinent literature published after the review have been incorporated into the discussions in the subsequent chapters, in particular Chapter 6.

2.1 Introduction

There is currently no published consensus or best practice guidance on how nurses can detect, assess and provide care for sexual health and well-being in patients with IBD (White, 2013). An initial rapid review of the literature revealed six prior literature reviews that included men's sexual health in IBD. Three reviews concentrated on reproductive matters (Allocca et al., 2018; Shin and Okada, 2016; Feagins and Kane, 2009) and one on female issues (Rosenblatt and Kane, 2015). Purewal et al. (2018) reviewed the psychosocial effects of IBD on reproductive health but only found one exclusively male study. Finally, O'Toole, Winter and Friedman (2014) found 12 papers addressing psychosexual function and categorised their results into relationship status, fear of infertility, discussion with physician, active disease, psychological factors, surgery, medications, and testosterone. Only one article was published within a nursing journal and provided a very broad account of sexual health in IBD inclusive of fertility matters and both genders (Giese and Terrell, 1996). The need for a comprehensive literature review that followed a robust method and was male-specific, was identified. The primary question was; what is known about the impact of IBD on sexual health in men?

2.2 Aim and objectives

The primary aim of the scoping review was to systematically identify and summarise peer reviewed, published research reporting the impact of IBD on sexual health in men. The secondary aim was to map out knowledge deficits or unmet patient needs that may be amenable to nursing research and intervention.

The review objectives were to:

- clarify how the impact of IBD on sexual health in men is described, interpreted, and defined in the current literature;
- identify whether the prevalence of sexual dysfunction in men with IBD has been reported;
- investigate the unmet or poorly met support needs in this population regarding sexual function;
- examine assessment and management of sexual function in IBD;
- explore whether any interventions for sexual health and dysfunction have been tested in men with IBD.

2.3 Methodology and methods

2.3.1 Design

Scoping reviews enable researchers to examine the breadth of a field while clarifying concepts to refine further focused study and maintain rigour (Levac, Colquhoun and O'Brien, 2010). An established scoping review method was utilised to ensure rigour and transparency (Munn et al., 2018; Levac et al., 2010) while aiding the refinement of a clinically important research question.

The seminal 5 stage scoping review framework described by Arksey and O'Malley (2005) was selected for its easy to follow, systematic, and reliable approach.

2.3.2 Stage 1: identifying the research questions

To ensure breadth and depth of literature, several questions were formulated. The primary question provided the basis of developing a search strategy. The secondary questions met the objectives outlined in Section 2.2.

Primary research question: what is the impact of IBD on sexual health in men?

This question sought to identify whether any physical, psychological, and social factors commonly associated to IBD have a negative impact on sexual health in men. The breadth of this question demanded that qualitative, quantitative, and mixed methods studies were included in the review.

Secondary research question: how do men with IBD experience sexual health?

Sexual health is a multi-factorial and subjective feature of personal well-being shaped by biological, physical, psychological, societal, and cultural factors. Through understanding people's experiences, an understanding of the most pertinent issues that require further investigation and deepen the guidance given by nurses may be provided. The ability to understand and empathise with a person's experience of disease is central to nursing practice and enables the nurse to be an effective and holistic supporter in a person's health journey. To enable the inclusion of personal experiences, exploratory qualitative studies were included within the review.

Secondary research question: how is sexual health in men with IBD defined and assessed in research and by healthcare professionals?

Sexual health may encompass several health issues including erectile function, anal canal changes, psychosexual disorders, and inability to engage with sexual activities. It is important to see whether the quality of sexual health, as defined and assessed by healthcare professionals' parallels men's own descriptions and experiences of their sexual health. The inclusion of studies that consider service delivery is essential for identifying disparities

between what is provided by healthcare services and what people need. It was important to determine whether there was commonality and homogeneity among measures of global sexual health in IBD that would permit a robust systematic review of research, which demanded the inclusion of descriptive, correlational and quasi-experimental studies.

Secondary research question: what is the prevalence and risk of sexual ill-health and dysfunction in men with IBD?

Prevalence and risk of sexual health problems are useful when developing strategic plans that allocate nursing and healthcare resources. The clandestine nature of sex and sexual dysfunction means true prevalence and impact on patients may be under-reported in nurse-led clinics. This question was essential to seeking a better understanding of the prevalence of sexual dysfunction and demanded the inclusion of cohort studies using quantitative methodologies.

Secondary research question: what health interventions can improve sexual health in men with IBD?

There were no known nursing interventions designed specifically to support sexual health in IBD and therefore the review sought to identify whether this was a gap in personal, local, or (inter)national practice. Identifying interventions was needed to make decisions on whether to pilot or test an intervention in the subsequent research project.

2.3.3 Stage 2: identifying relevant studies

The Sample Phenomenon of Interest Design Evaluation Research (SPIDER) tool (Cooke, Smith and Booth, 2012) was originally selected to develop the search strategy for the identification of descriptive, interventional and epidemiological studies. SPIDER was later replaced with the Population, Intervention Comparison, Outcome (PICO) framework that was found to provide a more open search strategy (Table 2.1). Methley et al. (2014)

support this finding, arguing that PICO supports a comprehensive search strategy in qualitative systematic reviews.

Table 2.1 Search terms using SPIDER and PICO

S	Sample	Inflammatory bowel disease, IBD, Crohn(s), ulcerative colitis, colitis	P	Population	Inflammatory bowel disease, IBD, Crohn(s), ulcerative colitis, colitis
PI	Phenomenon of Interest	Sexual dysfunction, sexual function, sexual intercourse, sex life, sexual behaviour, erectile function, fertility, psychosexual disorders, sexual health, men's health, intimate relationships, sexuality	I	Intervention	N/A
D	Design	Qualitative and quantitative research designs inclusive of cohort studies, descriptive, correlational, and quasi-experimental designs, semi-structured interviews etc.	C	Comparison	N/A
E	Evaluation	Experiences, perceptions, quality of life, disease course,	O	Outcomes	Sexual dysfunction, sexual function, sexual intercourse, sex life, sexual behaviour, erectile function, psychosexual disorders, sexual health, men's health, intimate relationships, sexuality
R	Research	Qualitative and Quantitative			

Sexual health, function and well-being can be reported and coded within a range of clinical fields including gynaecology, urology, sexual diseases, psychology, chronic illness, and general practice. It was beyond the remit of this scoping review to explore all these fields within database searches and therefore IBD, Crohn's disease or ulcerative colitis were selected as key disease search terms. The search terms were kept purposely broad and did not include gender or sex terms to ensure the inclusion of mixed-sex studies in which outcomes were disaggregated by sex or gender.

Following evaluation by an information scientist, the search strategy was amended to suit medical subject headings and ‘explode’ terms across the database searches (Table 2.2). OVID MEDLINE ALL [R], OVID EMBASE [R], OVID PsychINFO, EBSCO CINAHL Complete and the Cochrane Library were selected for searching. To aid verification of the search strategy and for completeness, the reference lists of included and topical studies that did not meet the inclusion criteria were also reviewed. No date restrictions were applied but searches were limited to publication in the English language and available access through the University of York library and inter-lending service as there was no funding for translation or purchasing of papers. The searches were conducted between the 6th and 8th of February 2019.

Table 2.2 Database search strategies

OVID MEDLINE [R] All 1946 – to February 06 2019	OVID EMBASE [R] 1980 – 2019 week 6
exp inflammatory bowel disease/ or colitis/ inflammatory bowel disease*.mp. colitis.mp. crohn*.mp. IBD.mp. 1 or 2 or 3 or 5 exp sexual dysfunction, physiological/ exp men's health/ or exp sexual health/ or exp erectile dysfunction/ or exp sexual abstinence/ or exp sexuality/ or exp homosexuality, male sexual function.mp. sexual dysfunction.mp. sex life.mp. (sexual behaviour or sexual behavior).mp. erectile.mp. (psychosexual OR psycho-sexual).mp. sexual health.mp. sexualit*.mp. 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 6 and 17 (animals not (humans and animals)).sh 18 not 19 Limit 20 to English language	exp inflammatory bowel disease/ or colitis/ inflammatory bowel disease*.mp. colitis.mp. crohn*.mp. IBD.mp. 1 or 2 or 3 or 4 or 5 exp sexual behavior/ or exp sexual function/ or exp male sexual dysfunction/ or exp sexual dysfunction/ or exp male by orientation exp “international index of erectile function”/ or exp erectile dysfunction/ psychosexual disorder/ sexual function.mp. sexual dysfunction.mp. sex life.mp. erectile.mp. (psychosexual OR psycho-sexual).mp. sexual health.mp. sexualit*.mp. 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 6 AND 17 Limit 18 to (human and English language)
<i>continues on next page...</i>	

PsycINFO (OVID) 1987- Week 1 Feb 2019	CINAHL Complete (Ebsco) Feb 06 2019
exp ulcerative colitis/ crohn*.mp. colitis.mp. IBD*.mp. 1 or 2 or 3 or 4 exp Psychosexual Behavior/ or exp Sexual Function Disturbances/ or exp Erectile Dysfunction/ or exp Sexuality/ or exp Sexual Arousal/ or exp Sexual Satisfaction/ sexual function.mp. sexual dysfunction.mp. sex life.mp. (sexual behaviour or sexual behavior).mp. erectile.mp. sexual health.mp. sexualit*.mp. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 6 and 14	S1. (MH "Inflammatory Bowel Diseases+") S2. inflammatory bowel disease# S3. (MH "Crohn Disease+") S4. Crohn* S5. (MH "Colitis+") S6. Colitis S7. IBD* S8. S1 OR S2 OR S3 OR S4 OR S5 OR S6 or S7 S9. (MH "Sexual Dysfunction, Male+") OR (MH "Sexual and Gender Disorders+") OR (MH "Psychosexual Disorders+") S10. Sexual function S11. (sexual dysfunction or sexual difficulty or sexual problems or sexual satisfaction) S12. Erectile S13. Sexual behavior? S14. (psychosexual OR psycho-sexual) S15. Sexualit* S16. Sexual health S17. Sex life S18. S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 S19. S8 AND S18
Cochrane Library (Feb 2019)	ProQuest (Feb 2019)
MeSH descriptor: [Inflammatory Bowel Disease] explode all trees Crohn*:ab,ti Inflammatory bowel disease:ab, ti Colitis: ab, ti #1 or #2 or #3 or #4 MeSh descripton: [Sexual Behaviour] explode all trees sexual function;ab,ti sexual dysfunction;ab,ti sex life:ab,ti sexual behavior\$:ab,ti erectile:ab,ti psycho*sexual:ab,ti sexual health:ab,ti sexualit*:ab,ti #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 #5 AND #15	ab(("inflammatory bowel disease*" OR crohn* OR "ulcerative" colitis OR IBD) AND ("sexual function" OR "sexual dysfunction" OR erectile OR sexualit* OR "sex life" OR psychosexual)).Limited to English, Dissertations and Theses.

2.3.4 Stage 3: study selection

Two reviewers (SM and PG) screened articles using pre-defined inclusion and exclusion criteria (Table 2.2). Disagreements were resolved through discussion to reach a consensus. Levac, Colquhoun and O'Brien (2010) note that this stage should be iterative and non-linear so it was expected that the inclusion criteria would be modified to improve specificity of studies during the review. Modification of the inclusion criteria was not required as after initial study selection there was a manageable number of studies for analysis, all of which were of interest. Careful consideration was given as to whether surgical studies should be included. Of the 236 articles reviewed in full, 187 were surgical. Many surgical studies did not present sexual function as a single or separate outcome measure and were subsequently excluded. Fifteen surgical studies were eligible for inclusion.

Table 2.3: Scoping review inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Peer reviewed.	Included participants under the age of 18 years.
Available in English.	Data on sexual function on men is indistinguishable from female data.
Included participants; aged ≥ 18 years, identify as being male, a diagnosis of IBD (Crohn's disease, ulcerative colitis, Indeterminate Colitis or Collagenous colitis).	Data in relation to men with IBD is not distinguishable from data on other diseases.
Presented primary research data	Studies on fertility, sexually transmitted diseases, sperm or fecundity without investigation of sexual function.
Included sexual function/dysfunction or engagement in sexual activity or erectile dysfunction or sexual behaviour or physical and/or emotional intimacy as a primary outcome measure or focus of the study.	Vaginoplasty studies.
	Surgical studies where sexual function is not a primary outcome, measured within a wider quality of life measure or has not been clearly defined within the study.
	Does not present primary research data (commentary articles/protocols etc).
	Case studies.

2.3.5 Stage 4: charting the data

Key demographic and research findings were charted in two Microsoft Excel tables: surgical and non-surgical. Data included aim, design, population, sample size, measurement of sexual function, prevalence in men, key findings, researcher-reported limitations, and areas identified for future investigation.

Descriptors of sexual dysfunction, IBD-related impact factors and potential interventions identified across the included studies were extracted. Mediators, moderators and sexual health outcome descriptors were presented graphically (figures 2.2 and 2.3). The categorising of common issues and topics into these groups supported the synthesis of data while highlighting significant gaps for further investigation. This process also supported analytical thinking and conceptual clarity, allowing the data to be fractured and reassembled in a way that illuminated patterns and relationships relevant to the scoping review aims and objectives. As can be seen in Figure 2.2, within the mediator, moderator and outcome categories, sub-categories were developed through grouping congruent issues. These categories went on to shape the design of the question framework and interview guide used in qualitative study 1 (Chapter 4). Charted findings were thematically analysed and summarised narratively (Sections 2.4.3 and 2.4.4).

2.3.6 Stage 5: collating, summarising, and reporting results

A PRIMSA diagram (Figure 2.1) was created to visually show the process of article selection. After data were extracted into charts, key themes were collated and organised by the identified questions. Findings were reported in line with each research question identified and graphically illustrated for publication (see Appendix 1).

2.4 Findings

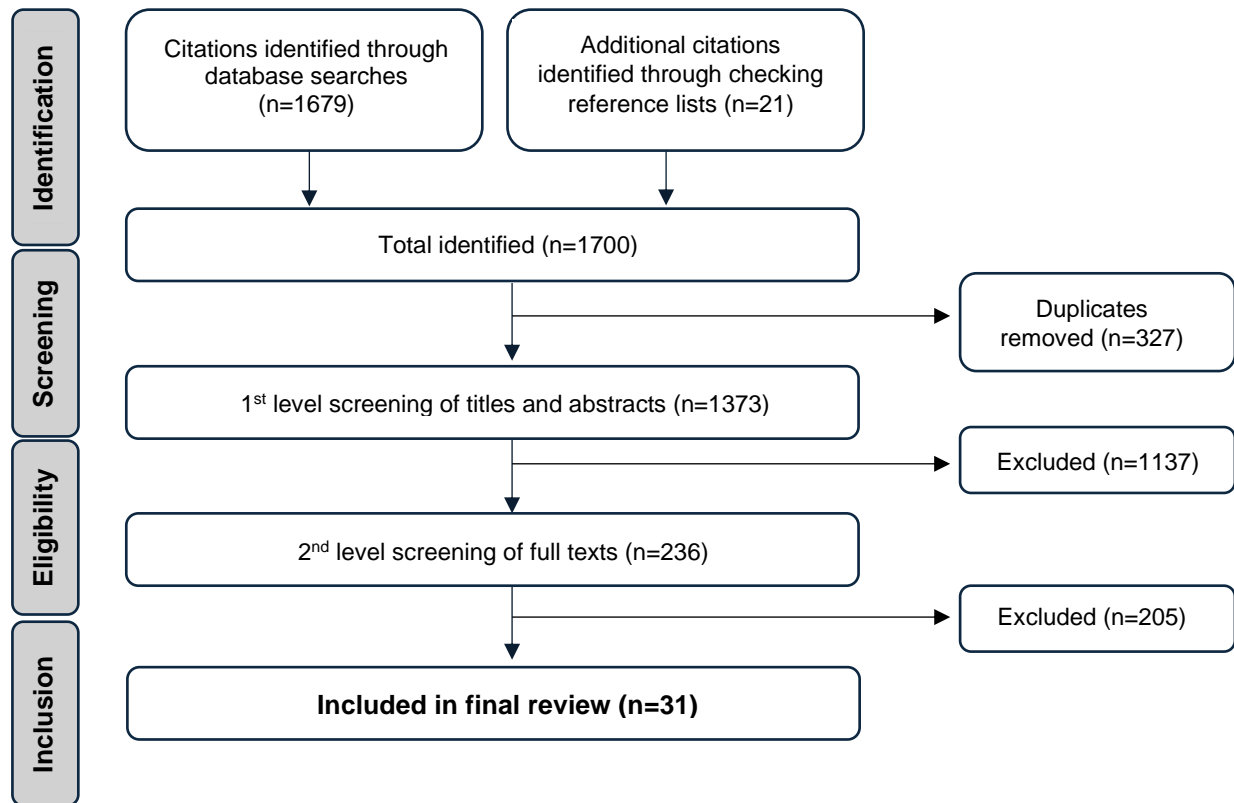
2.4.1 Search outcomes

The database searches yielded 1679 titles (OVID EMBASE [R] n=1118, OVID MEDLINE ALL [R] n=374, EBSCO CINAHL Complete n=98, the Cochrane Library n=56, OVID PsychINFO n=17, ProQuest n=16). A further 21 articles not found in the initial search were identified through review of reference lists. Duplicates were removed leaving a total of 1373 unique citations. 236 articles were reviewed in full of which 31 were eligible for inclusion (Figure 2.1). Two hundred and five articles were excluded for having exclusively female cohorts. Only eight of the studies included in the review had male-only cohorts. This finding confirms that the published and peer-reviewed research evidence is disproportionately female focused. There was a single RCT (Lindsey et al., 2002) that was excluded due to involvement of participants with other gastrointestinal diseases.

The 31 studies in the review originated from 16 countries (USA, UK, Denmark, Germany, The Netherlands, Sweden, Spain, Australia, Austria, Canada, Finland, France, Italy, Japan, Taiwan and Turkey) and included a total of 35,990 men with IBD. The included studies were predominantly single centre (n=20) and cross-sectional (n=26). The most frequently used research method was cross-sectional surveys (n=22). Two studies used a pre-existing patient database to analyse relationships between IBD and sexual function. There was a lack of qualitative research and only two studies presented patient narratives. These studies were the only nurse-led papers included in the review.

Studies were weighted towards exploring UC and 10 of the 15 included surgical studies exclusively recruited UC patients. Fifteen of the 16 non-surgical studies recruited both UC and CD participants with only one study including partners.

Figure 2.1: Scoping review PRISMA Diagram



Reason for exclusion	No. excluded
Irrelevant subject matter	487
Female only cohort	198
Not sexual function	235
Not primary research or review, conference abstract, editorial, case report	164
Non-IBD	134
Includes participants <18yrs	44
Surgery for other diseases included or reason for surgery not clear	30
Female data not distinguishable from male data	28
Vaginoplasty	15
Case reports	5
Not available in English	3
Data duplicated in included paper	2
Correction piece	1
Unable to obtain paper	1

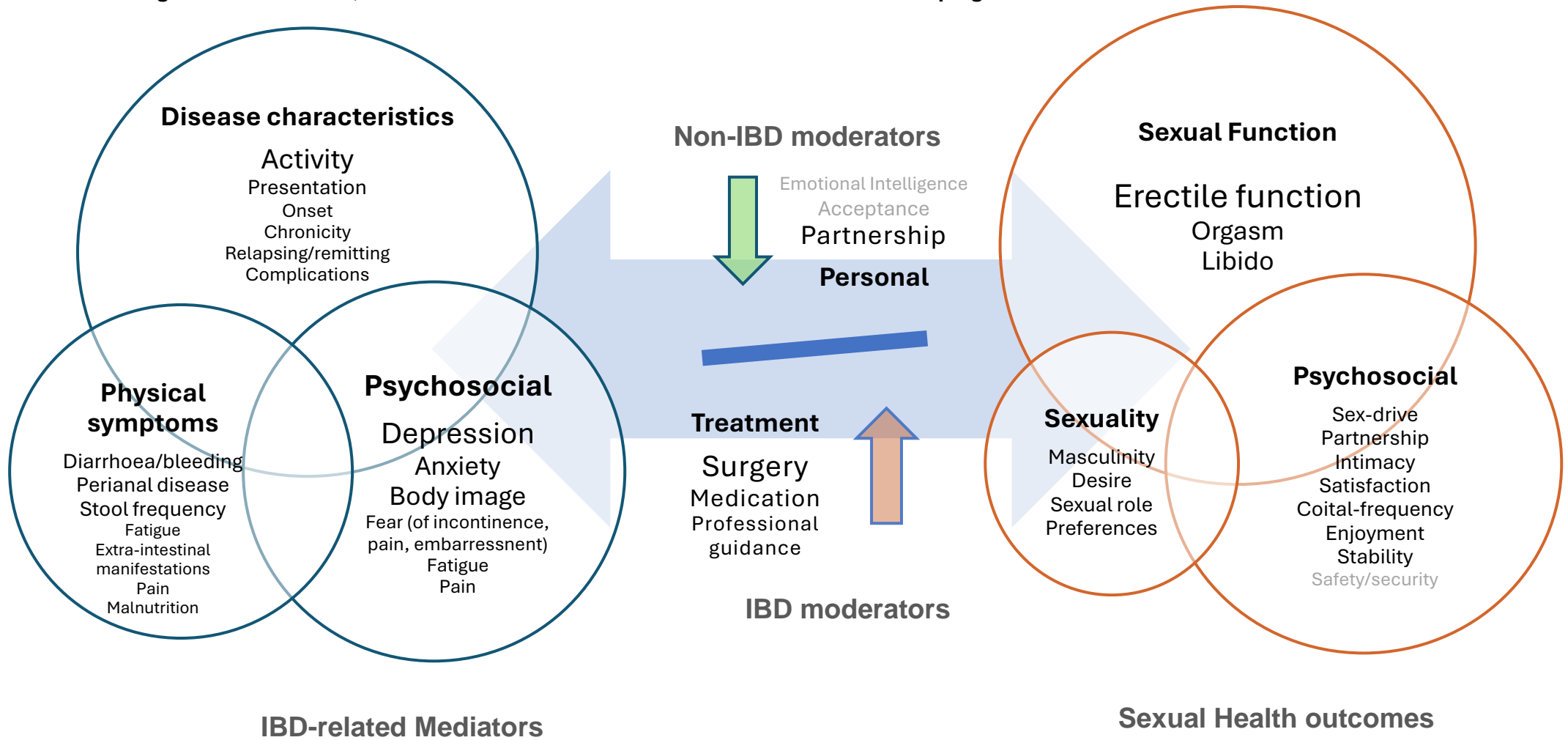
Table 2.4: Papers including in the scoping review

Authors	Year	Aim	Male <i>n</i>
Stahlgren & Ferguson	1959	Investigate changes in sexual function post abdo-perineal resection.	25
Donovan & O'Hara	1960	Explore whether removal of the rectum causes sexual dysfunction.	21
Fazio, Fletcher & Montague	1980	Evaluate the effect of conservative vs radical resection of the rectum on sexual function.	9
Hendriksen & Binder	1980	Evaluate the social/emotional status in UC.	52
de Bernardinis et al.	1981	Explore incidence of sexual dysfunction after colorectal resection.	15
Leicester et al.	1984	Identify the incidence of sexual function after rectal excision.	23
Salter, M.	1992	Identify body image problems for those undergoing a continent procedure vs stoma.	4
Moody & Mayberry	1993	Assess evidence of sexual dysfunction amongst men and women with UC and men with CD.	100
Damgaard, Wettergren & Kirkegaard	1995	Assess quality of life with emphasis on social and sexual function in patients with a pelvic pouch.	26
Tiainen, Matikainen & Hiltunen	1999	Document the kinds of change that take place in sexual functions and fertility after IPAA.	44
Maunder et al.	1999	Evaluate differences between men & women regarding sexual performance & intimacy.	147
Berndtsson, Oresland & Hulten	2004	Assess sexuality in UC patients pre and post IPAA.	25
Timmer at al.	2007	Examine the nature & extent of sexual dysfunction in IBD.	153
Timmer at al.	2007	Assess physical & psychosocial determinants of sexual dysfunction.	280
Muller et al.	2010	Explore perspectives of the impact of IBD on relationships/body image/libido/ sexual function/sexuality	74
Bengtsson et al.	2011	Compare sexual dysfunction in patients with functioning vs failing pouches.	13
Wang et al.	2011	Examine sexual function and QoL before & after proctectomy.	41
De Zeeuw et al.	2011	To pilot whether close rectal dissection is safe.	6
Riss at al.	2013	Evaluate the impact of surgery for anal fistula on QoL, sexual function and behaviour.	22
Marin et al.	2013	Evaluate prevalence and predisposing factors of sexual dysfunction among IBD patients.	153
Yoshida et al.	2014	Evaluate sexual activity after restorative proctocolectomy with ileal J-pouch-AA.	30
Dibley et al.	2014	Explore the parallels between 'coming out' and sexual identity and IBD.	33
Cohan et al.	2015	To examine relationship parameters in patients with UC and their partners.	25
Bel et al.	2015	Evaluate prevalence of sexual dysfunction in IBD.	119
Kao et al.	2016	Determine whether IBD is associated to increased risk of ED.	1845
Riviere et al.	2017	Determine the prevalence of sexual dysfunction.	166
Valer et al.	2017	Secondary aim: evaluate impact of IBD on sexual function.	52
O'Toole et al.	2018	Determine IBD specific psychometric properties that can be used for assessment.	175
Bulut & Toruner	2018	Evaluate anxiety, depression and sexual dysfunction in IBD.	69
Eluri et al.	2018	Evaluate interest and satisfaction with sex.	745
Friedman et al.	2018	Examine the use of ED medications in men with IBD	31498

Table 2.5: Study characteristics of papers included in the scoping review

		Single	Cross-sectional	Retro-spective	Survey	Other	Male only study	UC	CD	Control group
Surgical studies	Stahlgren, L. & Ferguson, L. (1959)	X	X	X	X			X		
	Donovan, M. & O'Hara, E. (1960)	X	X	X			X	X		
	Fazio, V., Fletcher, J. & Montague, D. (1980)	X					X	X	X	
	de Bernardinis et al. (1981)	X	X	X	X	X	X	X		
	Leicester et al. (1984)	X	X	X		X		X	X	
	Salter, M. (1992)	X	X					X		
	Damgaard, B., Wettergren, A. & Kirkegaard, P. (1995)	X	X					X		
	Tiainen, J., Matikainen, M. and Hiltunen, K. (1999)	X	X	X	X			X		
	Berndtsson, I., Oresland, T. & Hulten, L. (2004)	X	X					X		
	Bengtsson et al. (2011)	X	X	X	X			X	X	X
	Wang et al. (2011)	X			X			X	X	
	De Zeeuw et al. (2011)	X			X			X		
	Riss at al. (2013)	X	X	X	X				X	
	Yoshida et al. (2014)	X	X		X			X		
	Cohan et al. (2015)	X						X		
	Hendriksen, C. & Binder, V. (1980)	X	X					X		X
	Moody, G & Mayberry, J. (1993)	X	X	X	X			X	X	X
	Maunder et al (1999).	X	X	X	X			X	X	
	Timmer at al. (2007a)		X	X	X			X	X	X
	Timmer at al.(2007b)		X	X	X		X	X	X	
General studies	Muller et al. (2010)	X	X	X	X			X	X	
	Marin et al. (2013)		X		X			X	X	X
	Dibley et al. (2014)		X	X	X			X	X	
	Bel et al. (2015)		X	X	X			X	X	X
	Kao et al.(2016)		X	X	X	X	X	X	X	X
	Riviere et al. (2017)		X	X	X			X	X	X
	Valer et al.(2017)		X		X		X	X	X	X
	O'Toole et al. (2018)		X	X	X	X	X	X	X	
	Bulut, E. & Toruner, M. (2018)	X	X		X			X	X	X
	Eluri et al. (2018)		X		X			X	X	
	Friedman et al. (2018)		X			X	X	X	X	X

Figure 2.2: Mediators, moderators and outcomes of sexual health from the scoping review



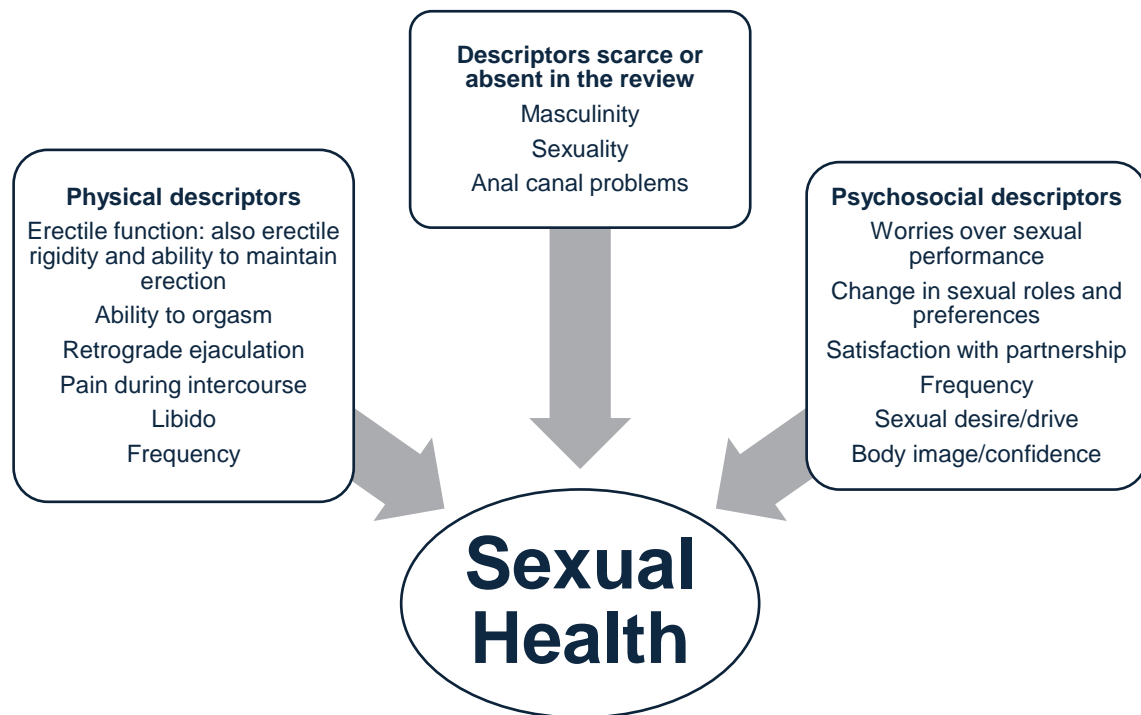
2.4.2 IBD related mediators and moderators of sexual health

Mediators, moderators and sexual health outcomes that were unearthed across the included studies are represented in Figure 2.2. The circle sizes within the figure provide a visual representation of the relative prominence of these issues but are not proportionately scaled and intended only for illustrative purposes. The figure demonstrates the focus of the included literature on erectile function, disease activity and surgery. The ideas or descriptors represented in grey (emotional intelligence, acceptance and safety) were not direct findings and were extracted from discussion sections, drawing attention to gaps and possible areas for further investigation. The see-saw in the centre of the diagram symbolises the potential for IBD moderators to influence sexual health outcomes either positively or negatively. The included studies predominantly portrays IBD treatments such as surgery and medication as having a potentially negative impact on sexual health.

2.4.3 How men with IBD experience sexual health

There were no in-depth qualitative studies that reported extensive patient narratives or the experiences of sexual health in men with IBD. The understanding of patient experiences in the studies was limited to reported descriptors or measures of sexual function (Figure 2.3).

Figure 2.3: Descriptors and measures of sexual function



2.4.3.1 Masculinity

Disease activity may prohibit feelings of masculinity, but masculinity was not shown to be compromised when in remission (Timmer et al., 2007b). It is possible that this perspective was not found within other studies or explored in depth because the surveys did not include concepts of masculinity or gender.

2.4.3.2 Sexuality and sexual orientation

Sexuality was not a common theme. The impact of IBD on men's sexuality, as defined by orientation, pleasure, behaviours, and relationship roles, was largely limited to the measurement of 'satisfaction' and 'desire' within the International Index of Erectile Function (IIEF). The decision was taken to omit studies that looked at vaginoplasty but upon reviewing these they would not have met the other inclusion criteria. Vaginoplasty studies looked specifically at surgery-related issues regarding re-construction of the genitalia. Although

vaginoplasty has not been explored within this thesis, it should be highlighted as an area for further development and understanding.

Dibley et al. (2014) studied the wider impact of IBD on gay men and reported a number of issues including fear of judgement, the lack of inclusion of same sex partners in healthcare interactions, the absence of information on the safety of anal sex, concerns that sexual habits could trigger the disease, and the possible change in sexual role due to disease of the anal canal.

2.4.3.3 Partnership

Partnership is often a precursor to sexual health. The level to which IBD influences partnership and prohibits new sexual relations may be under-represented in the included studies due to study design and possible selection bias. There was a tendency for studies to recruit participants in established relationships. No significant differences were found in duration of marriage or divorce rates between IBD patients and controls or general population data (Muller et al., 2010; Timmer et al., 2007a; Moody and Mayberry, 1993).

Muller et al. (2010) found that 43.2% (n=32) of male patients thought that IBD had affected their relationship. O'Toole et al (2018) reported 21% (n=47) were hesitant to start a new relationship because of their IBD. Salter (1992) found that partners played a role in helping people to adapt, supporting the idea that partnership could also be protective against some of the adverse impacts of IBD such as impaired body image.

2.4.3.4 Sexual libido and frequency

Libido and frequency were mentioned in several studies and are evidently considered an important aspect of sexual health. In Muller et al. (2010) a substantial number of men reported a negative impact on libido (41.9%, n=31) and reduction in frequency of sexual interaction (40.5%, n=30). In controlled studies, no statistically significant difference was found in sexual frequency (Moody and Mayberry, 1993) between IBD patients and controls. Interestingly, Marin et al. (2013) found higher levels of sexual activity in patients as

compared to controls even though IIEF scores were worse in patients. Although there may be a relationship between libido and frequency, they may also be independently impaired.

2.4.3.5 Erectile function

A national cohort study conducted in Taiwan found a 1.64 relative risk increase of IBD patients developing erectile dysfunction (Kao et al., 2016) compared to sex- and age- matched controls. Friedman et al. (2018) reported a crude hazard ratio of men with IBD (who had not undergone surgery) for needing an ED prescription of 1.22 (95% CI: 1.18-1.27).

The International Index of Erectile Function (IIEF) evaluates erectile function, orgasm, sexual desire, sexual satisfaction and overall satisfaction. No significant difference between patients and controls was found if dysfunction was defined as an IIEF of <42.9 (a widely used cut off when using the tool); but mean scores were significantly lower in the IBD group (Bel et al., 2015; Marin et al., 2013). (Table 2.6).

Table 2.6: Comparison of IIEF scores in % <threshold for dysfunction and overall mean.

Study	Groups		Patients	Control	P
Marin et al. (2013),	IBD patients (n=153) vs controls (n=73)	% of participants scoring <42.9	14%	7%	0.14*
		Mean score	59.1 ±14.9	63.1 ± 11.8	0.03*
Bel et al. (2015),	IBD patients with active disease (n=36) vs healthy controls (n=91)	% of participants scoring <42.9	36.1%	25.3%	>0.05 ($\chi^2(1) = 4.09$)
	patients in remission excluded here	Mean score	47.36 ±20.60	53.84 ±20.39	<0.05 ($t=2.04$)
Riviere et al. (2017),	IBD patients (n=166) vs health controls (n=56)	% of participants scoring <42.9	16.9%	7.1%	$p=0.57^*$
	(IBS n=53, excluded)	Mean Score	n/a	n/a	n/a

* χ^2 and t values not reported in papers

The IIEF has not been assessed for ‘floor’ (worst case) and ‘ceiling’ (best case) effects in the IBD population (that is, if there is an effect of the index that causes bunching of scores at one end of the scale causing an inadequate measure of central tendency). Therefore, the suggested cut off for impaired function may not be applicable in this cohort of patients. The lack of validation of the IIEF in IBD cohorts may explain why no significant difference was found when this was used to define dysfunction, whereas a difference in mean was identified.

2.4.4 IBD related factors that impact on sexual health in men

Understanding the impact of IBD on sexual health requires uncovering whether IBD induced symptoms or complications that can lead to sexual dysfunction or ill-health. Potential factors remarked on in the included studies are listed in Table 2.7.

Table 2.7: IBD-related factors that could potentially have an impact on sexual dysfunction

Symptom/Impact	Related to IBD	Cite in
Depression/low mood	Indirect	Moody and Mayberry (1993), Timmer et al. (2007a), Timmer et al. (2007b), Muller et al. (2010), Marin et al. (2013), Bel et al. (2015), Riviere et al. (2017), O'Toole et al. (2018), Bulut and Toruner (2019), Eluri et al. (2018)
Feelings about body image/attractiveness	Indirect	Salter (1992), Maunder et al. (1997), Timmer et al. (2007b), Muller et al. (2010), Bengtsson et al. (2011) Marin et al. (2013), Dibley et al. (2014), Bel et al. (2015), O'Toole et al. (2018)
Tiredness	Direct or indirect	Moody and Mayberry (1993), Muller et al. (2010), Marin et al. (2013), Bel et al. (2015), O'Toole et al. (2018), Eluri et al. (2018)
Disease activity/generally unwell	Direct	Timmer et al. (2007a), Timmer et al. (2007b), Bel et al. (2015)
Pain	Direct or Indirect	Moody and Mayberry (1993), O'Toole et al. (2018), Eluri et al. (2018)
Diarrhoea and urgency	Direct	Moody and Mayberry (1993)
Increased bowel frequency	Direct	O'Toole et al. (2018)
Incontinence	Direct	Moody and Mayberry (1993), Riss et al. (2013), Yoshida et al. (2014)
Concern over stoma	Direct or indirect	Salter (1992), Moody and Mayberry (1993), Muller et al. (2010), O'Toole et al. (2018)
Feeling dirty, unpleasant odours	Direct or Indirect	Maunder et al. (1997)
Rectal bleeding	Direct	O'Toole et al. (2018)
Perianal disease	Direct	Marin et al. (2013)
Pouch failure	Indirect	Bengtsson et al. (2011)
Biological agents	Indirect	Marin et al. (2013)
Use of steroids	Indirect	Marin et al. (2013)
Lack of guidance from professionals	Indirect	Dibley et al. (2014)

2.4.4.1 Disease onset or presentation

Data on the impact of disease onset on sexual function in men is sparse. Muller et al. (2010) found no significant association between sexual dysfunction and age of onset or time since diagnosis. There were no studies evaluating the effect of the disease on puberty or sexual development. The effect of testosterone levels have been discussed in earlier reviews (Allocca et al., 2018; O'Toole et al., 2018) but had not been studied in any of the included papers.

Crohn's disease (CD) and ulcerative colitis (UC) are forms of IBD but can vary in their presentation and treatment. Understanding whether this variation

translates into varying effects on sexual function is necessary to understand whether assessment, treatment, and support should also be disease-specific. CD and UC were jointly reviewed in 19 of the 32 included papers but there was no in-depth exploration into the consequences of the heterogeneity of the disease on sexual health.

Bulut and Toruner (2018) found that men with CD or UC both have higher mean scores for erectile dysfunction than controls (without disease) but this difference only reached statistical significance in CD ($p=0.04$). It could be that the study was underpowered to show an effect or that measuring erectile dysfunction does not sufficiently assess the impact of UC on sexual health. Alternatively, it could be that CD has a greater negative effect than UC. As CD is transmural (meaning inflammation can transcend all the layers of the gut), it would be reasonable to consider whether the effect of the disease may vary between CD and UC. Perianal disease in CD can be complicated by fistulas and abscesses causing pain, discharge and bleeding. Perianal disease has been reported to be not associated with (Riviere et al., 2017) and not an independent risk factor for (Marin et al., 2013) erectile dysfunction. It is possible that a negative impact of perianal disease was not found due to small sample sizes and mixed cohort analysis. It is also possible that perianal disease does not directly affect erectile function but could still impact negatively on sexual satisfaction and enjoyment. There have been case-reports of penile lymphoedema in CD (Vint et al., 2012) but the potential impact of this disorder was not reported in the included studies. Conversely, UC more frequently requires surgical intervention that can involve dissection of the pelvic nerves or stoma formation, which are discussed in more detail ahead. In summary, it is not currently possible to deduce whether sexual health and function in men is worse in CD compared with UC. The common and varying risk factors between these two phenotypes of IBD, may require consideration in future research and clinical practice.

2.4.4.2 Disease activity

Most studies investigated or alluded to the importance of disease activity when considering the general impact of the disease. The relapsing and

remitting nature of IBD may complicate understanding of its impact on sexual health. It would not be unreasonable to hypothesise that experiences of sexual ill-health would run in parallel to the relapsing and remitting disease course. Active disease can cause fatigue and bowel symptoms including urgency, frequency, rectal bleeding, and abdominal pain, all of which have been suggested as having an impact on sexual activity (O'Toole et al., 2018). This assumption was supported in the review and patients with active disease (as measured by the Simple Clinical Colitis Activity Index or the Harvey Bradshaw Index) were reported to have poorer sexual function than those in remission or controls (Bel et al., 2015). This finding was replicated when self-reported disease activity scores were used (Eluri et al., 2018). In both univariate and multivariate analyses sexual dysfunction was associated with anaemia (Riviere et al., 2017), which clinically can be an indicator for active disease. Moody and Mayberry (1993) noted several symptoms of active disease that reduced frequency of sexual intercourse, including tiredness, diarrhoea, fear of incontinence, and abdominal pain.

Interestingly, when in remission, men with IBD were found to have better sexual functioning than healthy controls (Bel et al., 2015; Timmer et al., 2007a) further supporting the idea that the potential effect of the disease on sexual health is changeable. In summary, the studies demonstrated that active disease and its symptoms are key determinants of impaired sexual function in IBD.

2.4.4.3 Medication

IBD is frequently managed with medications that can induce unpleasant side effects. Interestingly, these received little attention within the review. There was certainly no exploration of the influence of medication schedules and procedures on sexual well-being. The night-time rectal administration of medication can require preparation and sometimes the assistance of a partner, could imaginably disrupt sexual interest and activity, but this was not explicitly stated within the included papers.

Eluri et al. (2018) showed that prednisolone did not impact upon sexual satisfaction but the data for men in this study was not presented separately from women. Thiopurines, methotrexate and biological therapy were found not to increase the risk of needing an erectile dysfunction prescription (Friedman et al., 2018).

The need for biologic therapies was found to be an independent risk factor for sexual dysfunction in one study of 153 male patients (Marin et al. 2013) but this finding was not duplicated in the larger cohort study that included 31,498 men (Friedman et al. 2018). It is possible that within the study conducted by Marin et al. (2013), biological therapies were a surrogate indicator of disease activity rather than the medication itself causing a change in sexual function.

This review did not find substantial evidence that IBD medications are a major factor in the sexual health and well-being of men with IBD; however, it is noted that medications may be omitted by patients due to a perceived impact on libido and sexual activity (Muller et al. 2010). This should be addressed with patient education as poor medication compliance can lead to disease activity, which has been shown to negatively impact on sexual health.

2.4.4.4 Surgery

There was convincing evidence that surgery can have a negative impact on sexual function in IBD. For example, the largest study (of 31,498 men with IBD), found that previous surgery in men with IBD increased the likelihood of being issued a medication prescription for erectile dysfunction (Friedman et al., 2018).

Reports of post-operative erectile dysfunction ranged from 0% (De Zeeuw et al., 2011; De Bernardinis et al., 1981) to 48% (Leicester et al., 1984).

Unfortunately, all the surgical studies had small sample sizes (fewer than 50 patients) and several large surgical studies were excluded from the review due to the inclusion of non-IBD diseases. The disparity in findings of post-operative erectile dysfunction may also be due to the heterogeneity in population, measure of dysfunction, surgery, and research methodology. Pre-

and post-operative erectile function or frequency of intercourse were also uncovered and have been summarised in Table 2.8.

IBD surgery often necessitates the formation of a stoma. Timmer et al. (2007b) found no association between previous resecting surgery and a low sexual function. The presence of an ostomy did have a negative impact on several domains of the IIEF, including on erectile function and satisfaction (Timmer et al. 2007). Conversely, Eluri et al. (2018) demonstrated that the presence of a stoma was not related to a reduction in sexual activity in men although it is important to note that the measurement used (SexFS) was different to the score used by Timmer et al. (2007b). It is possible that the scores are not able to accurately convey the impact of stomas on men's sexual health.

Damgaard, Wettergren and Kirkgaard (1995) noted that men were more likely than women to continue having sex when they have a temporary stoma. However, Berndtsson, Oresland and Hulten (2004) highlight that frequency of sex does not afford insight into the quality of sexual function and intimate relationships. An ileo pouch-anal anastomosis (IPAA) may offer patients a stoma reversal but pouches can become diseased or function inadequately. Anatomically, pouch formation frequently necessitates deep pelvic dissection and can therefore be more complex with a greater risk of pudendal nerve dissection than a laparoscopic resection or formation of ileostomy. Unsurprisingly, ileo-anal pouches were found to be associated with sexual dysfunction (Bengtsson et al. 2011).

In summary, the review found evidence that surgery increases the risk of sexual ill-health but two studies also reported that surgery can improve sexual function and quality of life (Cohan et al., 2015; Wang et al., 2011). The improvement in sexual function is possibly due to the reduction of disease activity and symptoms.

Table 2.8: Measures and rates of sexual dysfunction (SD) after surgical intervention

Study	Surgery	Male Sample	Measure of SD	Rate of SD
Stahlgren and Ferguson (1959)	Abdo perineal resection of rectum	25 (UC patients, no comparator)	Erectile or ejaculation impairment	20%
Donovan and O'Hara (1960)	Removal of rectum	21 (UC patients, no comparator)	Disruption to erection, ejaculation or frequency of intercourse	10%
Fazio, Fletcher and Montague (1980)	Resection of rectum	9 (IBD patients, no comparator)	Ability to maintain erection, coital frequency, attainment of orgasm and occurrence of retrograde ejaculation	10%
De Bernardinis et al. (1981)	Proctocolectomy vs anterior resection	15/45 (UC patients vs Cancer patients for comparator)	Impotence and retrograde ejaculation	0%/30%
Leicester et al. (1984)	Excision of rectum	23 (IBD patients, no comparator)	Sexual dysfunction including; pain, loss of desire, erectile or ejaculation dysfunction and orgasm intensity	48%
Damgaard, Wettergren and Kirkegaard (1995)	Proctocolectomy and ileal-J-pouch for UC	26/23 (UC vs women as comparator)	Decreased frequency of intercourse	8%/0%
Tiainen, Matikainen and Hiltunen (1999)	Restorative proctocolectomy	44 (UC, no comparator)	Erectile rigidity issues	14.6%
Berndtsson, Oresland and Hulten (2004)	Proctocolectomy	25 (UC, no comparator)	Loss of ejaculation post-op	12%
Bengtsson et al. (2011)	Failed IPAA	13/40 (IBD failed pouch vs working pouch)	No sexual intercourse in last four weeks	23%/15%
Yoshida et al. (2014)	IPAA	30 (UC, no comparator)	Poor sexual activity	23%
De Zeeuw et al. (2011)	IPAA with close dissection	6 (UC no comparator)	Patient reported ejaculation or erection problem	0%
Wang et al. (2011)	Proctocolectomy	41 (IBD pre and post op)	IIEF: global improvement in scores	
Riss et al. (2013)	Surgery for anal fistulas.	22 (CD, health control group)	IIEF: no significant differences in score	
Cohan et al. (2015)	Ileostomy or IPAA surgery	25 UC (pre and post op)	IIEF: Significant improvement in score after surgery.	

2.4.4.5 Depression

There was evidence that depression is associated with sexual dysfunction in men with IBD in both univariate (Bulut and Toruner, 2018; Bell et al., 2015; Timmer et al., 2007a; Timmer et al., 2007b) and multi-variate analyses (Riviere et al. 2017; Marin et al., 2013). Depression was also associated with decreased sexual interest and satisfaction scores (Eluri et al., 2018). Interestingly, in a mixed-sex study, while women attributed physical disease symptoms to the disruption in intimacy, men held psychological factors such as depression responsible (Marin et al., 2013). This reported difference between genders further supports the need for gender-specific research and targeted interventions.

2.4.4.6 Body image

IBD patients can have a distorted perception of their body image (Bel et al., 2015) which may lower self-esteem and confidence, and therefore intimate relationships. Muller et al. (2010) found that 51% (n= 38) of male patients had impaired body image and although all of those who had a stoma reported a negative impact on body image, there was no statistically significant difference between operated and non-operated patients. Further exploration into the impact of body image on non-operated patients is required.

2.4.4.7 Non-IBD related factors

Sexual dysfunction and ill-health can occur independently of the disease. Although the IBD specialist will be focused on disease-orientated interventions, a broader health assessment that includes consideration of other morbidities that can affect sexual health is more likely to aid identification of sexual ill-health and lead to appropriate sign-posting or onward referral to appropriate services. Even when IBD does not directly cause sexual ill-health, there may be a subsequent effect on well-being, ability to cope, and management of their disease. It is therefore important for IBD healthcare practitioners to identify and support sexual ill-health even when IBD is not the direct cause. Diabetes (Marin et al., 2013; Timmer et al.,

2007b), smoking (O'Toole et al., 2018; Riss et al., 2013), and older age (Riviere et al., 2017; Kao et al., 2016) were significantly associated with sexual dysfunction in IBD.

2.4.5 The prevalence or risk of sexual ill-health and dysfunction in men with IBD

The prevalence of sexual dysfunction in men is difficult to determine as there is no agreed measure. Table 2.9 demonstrates the disparity in findings, partly caused by the non-standardisation of assessment of sexual health and well-being. In the two largest cohort studies, 12% of men with IBD were reported to have been issued a medication prescription for erectile dysfunction (Friedman et al., 2018) and there was a reported erectile dysfunction incidence rate of 2.23 per 10,000 person years, with a 1.64-fold higher risk of developing erectile dysfunction than the non-IBD comparator group (Kao et al. 2016).

The lack of clinical and methodological homogeneity in the included studies makes a meta-analysis in this area difficult. However, such an approach has been undertaken by Zhao et al. (2019) in a study published after the searches had been undertaken for this review. The papers used by Zhao et al. (2019) in the meta-analysis were all included within this review, which ratifies the search strategy and study selection. The authors found considerable heterogeneity ($I^2 = 80.2\%$); nonetheless they reported a combined relative risk of 1.41, (95%CI 1.09-1.81) for sexual dysfunction, meaning that men with IBD have an average 41% higher risk of sexual dysfunction than their healthy counterparts. To manage heterogeneity, the authors removed the data from the Friedman et al. (2018) study which accounted for 92% of the participants in the meta-analysis. The relative risk increased to 1.51 and heterogeneity (indicated by the I^2 statistic) decreased to 36.1%, demonstrating that using erectile dysfunction prescriptions as a proxy- measure for male sexual function may lead to an under-representation of the true risk and prevalence of sexual health problems in men with IBD.

2.4.6 Assessment of sexual health of men with IBD

Undertaking an appropriate clinical assessment is fundamental to providing adequate treatment and support. There is currently no consensus on how healthcare professionals should measure sexual health. There was also no evaluation in the published research of how sexual function is currently being assessed in clinical practice. A list of recognised tools used in the included studies is presented in Table 2.9. The IIEF was the most used validated assessment tool. It is relatively quick, easy to use, and assesses domains outside of erectile function including desire and satisfaction. Conversely, the IIEF has not been validated in the IBD population and may not be sufficiently sensitive to identify the layers of sexual dysfunction that are specific to IBD patients.

Without a tool designed for, and validated in the IBD population, it is possible that sexual health co-morbidity that is directly moderated by the disease is overlooked. Moody and Mayberry (1993) reported no significant difference in rates of sexual activity between patient groups and buddy³ controls, yet several IBD-related symptoms were attributed by patients to sexual inactivity. It is possible that there is a mismatch between the perceived and actual impact of the disease, or that a single measure cannot adequately relay the impact of IBD on sexual health.

The IBD-Male Sexual Dysfunction Score (O'Toole et al., 2018) assesses IBD-specific issues such as fatigue, abdominal pain, incontinence, and bowel frequency. Due to its recent publication at the time of the review, it had only been reported within its presenting paper within the review. The tool was developed using an expert panel and reviewed by a patient group. It could provide a much-needed aid to nurses wishing to assess sexual function during consultations but an evaluation of its effectiveness and applicability in clinical practice is still required. The tool focuses upon sexual function and, as with the tools mentioned in Table 2.9, does not assess the impact of the

³ 'Buddy' controls were participant selected controls within the Moody and Mayberry (1993) study.

disease on sexuality, masculinity, and sexual preferences, role and well-being; although it is recognised that these can be difficult concepts to define and quantify.

Muller et al. (2010) make an interesting observation that many studies attempt to quantify sexual function with objective measures or specific categorical answers; however, sexual health and function is largely a subjective matter. It is possible that traditional, validated assessment tools may not be the most appropriate method of assessing the impact of disease on patients, or they may require supplementation with novel approaches to ensure a complete assessment.

A further aspect for consideration is the appropriateness and acceptability of sexual health assessment in IBD clinics. Timmer et al. (2007a) claimed that because only 25% of male patients wanted to discuss sexual issues with a physician, they would not recommend routine discussion of the matter. This finding could reflect the possibility that many men do not view sexual health as a medical matter and do not understand the support clinicians may possibly be able to provide. Recommendations against assessment of sexual health and well-being do not encourage the breaking down of taboos and normalisation of good sexual health and well-being. It is also worth noting that the rate of 25% of men was substantially higher than in the control group (16%), demonstrating an increased need in the IBD population. What this finding does stress is the need for sensitive assessment or identification of problems, that facilitate patient ease, comfort, and improve receptiveness to discussion of sexual health matters.

In contrast to the factors above, Marin et al. (2013) reported that 46% of men thought information about the impact of IBD on sex should be given at diagnosis and 44% believed that the clinicians specialising in IBD are the appropriate person to do this. Furthermore, 78% of IBD patients reported they would be comfortable talking to a doctor about sex (O'Toole et al., 2018) and 52% of male participants with IBD expected to discuss sex with a physician (Riviere et al., 2017).

Table 2.9: Assessment tools for sexual function used within studies included in the scoping review

Tool	Study(s)	Description	Pros	Cons	Common issues
International Index of Erectile Function (IIEF)	Timmer et al. (2007a), Timmer at al. (2007b), Bengtsson et al. (2011), Wang at al. (2011), Marin et al. (2013), Riss et al. (2013), Bel et al. (2015), Riviere at al. (2017), Valer at al. (2017), O'Toole et al. (2018)	Questions in the domains of erectile function, orgasmic function, sexual desire, satisfaction and overall satisfaction.	Validated in wider population. Patient input used to develop measure. Assesses some aspects of wider function such as desire and satisfaction. Quick and easy to use.	Does not account for other specific issues such as premature ejaculation.	<p>Not been validated in an IBD population.</p> <p>Questions do not relate to specific IBD issues.</p> <p>Do not consider wider sexual health domains such as sexuality, personal expression, masculinity, intimate partnership, sexual role.</p>
Sexual Function Questionnaire (SFQ)	Wang at al. (2011)	7 domain questionnaire : desire, enjoyment, orgasm, sensation, arousal, pain, partner.	Addresses aspects of the sexual response cycle.	Developed and validated in women not men.	
Arizona Sexual Experience Scale (ASEX)	Bulut and Toruner (2019)	Assesses desire, arousal, erection/lubrication, orgasm and satisfaction. Score is 5-30, higher indicating more dysfunction.	East to use. Designed to be self-administered. Not dependent on user being in a current partnership.	Based on domains most commonly impaired by psychotropic drugs not chronic disease. Not specifically designed for men.	
Patient Reported Outcome Measurement Information System Sexual Function and Satisfaction Scale (PROMISE SexFS)	Eluri et al. (2018)	Comprehensive assessment including sexual activities, interfering factors, therapeutic aids as well as satisfaction and erectile function.	Derived from literature review, expert opinion, focus groups and qualitative data. Considers anal discomfort.	Originally, developed using cancer populations that may have differing experiences to IBD.	

2.4.7 Sexual health interventions

No interventions were tested or evaluated in the included studies. Suggested or noted interventions are listed in Table 2.10. O'Toole et al. (2018) found that 23% (n=40) of participants were taking erectile-enhancing medications and 5% (n=9) were using testosterone to improve sexual function. Timmer et al. (2007a) argued that treatment should focus on inducing remission of the disease and psychological maladaptation rather than sex therapy.

Psychosocial approaches that include treatment of depression or rebuilding intimate partnerships, such as couples counselling, may develop resilience, coping, and self-management that may also have a benefit on overall disease course. There is a need for defined treatment strategies that can be trialled and tested within this population.

Table 2.10: Potential interventions for male sexual dysfunction in IBD

Intervention	Cited by
Physicians should be aware of risk and inform	Kao et al. (2016)
Reverse/treat the disease	Timmer et al. (2007b)
Provide a safe environment for discussion	Dibley et al. (2014); Muller et al. (2010)
Treatment of depression as a first line intervention	Timmer et al. (2007a)
Psychological assessment or clinical psychology	Bel et al. (2015); Moody & Mayberry (1993)
Referral to couples counselling	Moody and Mayberry (1993)
Involving partners in care	Dibley et al. (2014)
Nurse led co-ordination of rehabilitation and aiding acceptance of body.	Salter (1992)
Sex-therapeutic treatment	Bel et al. (2015)
Erectile enhancing medications and testosterone	O'Toole (2018)

2.5 Discussion

This review found that the majority of research on sexual health in men with IBD has focused upon the assessment of erectile function using the IIEF. The literature reviewed demonstrated several aspects of sexual function that may become impaired in men with IBD. These factors included erectile function, libido, retrograde ejaculation, orgasm function, and sexual satisfaction. Disease activity, depression, and surgery were commonly discussed and are associated with erectile dysfunction. The literature on the impact of medical therapies is sparse and conflicting, for example Friedman et al. (2018) reports there is no association between biologic therapy and sexual dysfunction while Marin et al. (2013) found them to be an independent risk factor. One study showed that only 10% of patients had been in a consultation with an IBD specialist about sex and most importantly no sexual health interventions were found or tested, with sexual health remaining surreptitious in the field of IBD.

This review confirmed that there is a paucity of studies investigating men's sexual health in IBD. Unexplored areas include the experiences of men with IBD and the impact of the disease on masculinity, sexuality, and intimacy. This review did unearth a single detailed personal narrative reporting a negative impact of disability on masculinity and the male social role (Tepper, 1999) that did not meet the inclusion criteria. Little was found on sexual preferences including the potential impact of the disease on receptive anal sex which is somewhat surprising considering IBD causes perianal disease and anal ulceration.

This review has also demonstrated that surgical studies currently form the largest proportion of research in this field. The surgical studies that were included in this review spanned a period of 1959 to 2015 when surgery and medical therapies underwent significant advancements. Most notably was the introduction of laparoscopic surgery which has reduced the need for pelvic dissection and complication rates. Concurrently, the increased use of biological and small-molecule immunomodulating therapies has reduced the overall need for surgery (Olivera et al., 2017). These changes alongside

methodological and data heterogeneity make a met-analysis of the data challenging.

The review suggests that surgery is associated with sexual dysfunction. The predilection for relatively simple retrospective cross-sectional surveys means that the potential causes of dysfunction cannot be distinguished and therefore there is space to more exhaustively investigate the direct impact of surgery (e.g. possible impairment of erectile function due to nerve dissection), post-operative physical effects (e.g. wound healing, stomas, weight loss, fatigue), psychological impacts (e.g. body image impairment, embarrassment, sense of loss) and contextual implications (e.g. disease extent, stage of recovery, social support network). Furthermore, surgery was not always reported to have a negative impact on sexual function. Exploration of the potential benefits of surgical intervention is required and may be an important narrative to patients trying to make decisions on or come to terms with surgery.

This review has not been able to clearly map out the role of IBD medical therapies on sexual health. Papers in the review did consider whether medical treatment brings about side effects that induce sexual dysfunction (Eluri et al., 2018; Friedman et al., 2018; Marin et al., 2013; Muller et al., 2010). This question should be expanded to consider whether medical regimes have an effect which is pertinent in IBD when the timing and routes of therapies (for example the night-time administration of rectal medications) may influence intimate relationships. The role of medication route and regime was not raised within any of the included studies.

Although the studies that used the IIEF have undoubtedly laid the foundations for further research in this area, this tool has not been validated within the IBD population and is rarely used outside of research. This review did unearth the newly developed IBD-Male Sexual Dysfunction Score (O'Toole et al., 2018) that assesses IBD-specific issues such as fatigue, abdominal pain, incontinence, and bowel frequency. One criticism of the scale is that it was generated through an expert panel and then reviewed by a patient group rather than the reverse approach that may have been more patient-centric. The searches did not reveal any studies in which the IBD-MSDS had been

implemented and it is not known whether it has been implemented in clinical practice. As the only IBD-specific tool available, further evaluation to assess whether it may be of use to nursing practice is needed. Additionally, the existing literature does not explore the barriers and facilitators to clinical assessment of sexual health in IBD care which is required to inform clinical approaches and pathways.

It may be prudent for researchers to consider whether there is a trilateral (and complex) association between depression, disease activity, and sexual health. To clarify; men with active disease were found to have higher anxiety and depression scores (Bulut and Toruner, 2018), so it is conceivable that depression could be both the trigger to and the result of sexual dysfunction or poor sexual health. If this is the case, it is possible that an approach that blends treatment of physical symptoms and psychological effects would be the most beneficial. As this statement is based upon presupposition, further work is required to understand what men with IBD would find to be the most appropriate and suitable strategies for care.

Further research is needed to clarify whether sexual health in men is affected by disease-specific symptoms such as rectal bleeding, incontinence, malnutrition, arthralgia, fissures, and fistulas. Such investigation is well suited to research methodologies that facilitate those with a diagnosis of IBD leading the identification of the symptoms and aspects of the disease that effect sexual health rather than being clinician/researcher led. Alternative approaches to cross-sectional methods, which are not best for investigating labile, unpredictable, relapsing and remitting conditions should also be considered. There is currently a shortage of longitudinal studies that may be more suited to the study of chronic disease; this has also been identified by Eluri et al. (2018) and O'Toole et al. (2018).

All the gaps identified here point towards a need for further exploratory qualitative studies that may illuminate the lived experience of people with the disease. Qualitative research would support capturing the multifactorial and subjective nature of both the disease and sexual health that may be shaped by biological, physical, psychological, social, and cultural factors.

Furthermore, qualitative data may provide the information richness needed by nurses to operate within a biopsychosocial care framework and deliver truly holistic care.

2.6 Literature excluded from the review

Several other papers influenced the conceptualisation and design of the two research studies presented in this thesis that did not meet the inclusion criteria or were published after the review. Firstly, Groome et al. (2017) was one of the only studies found in the database searches that explored sexual behaviours in the context of IBD. The authors found that rectal pain was significantly worse in women who engaged in receptive anal intercourse (RAI) but as only two men in the study engaged in RAI they could not draw any conclusions from the effect on men. This paper demonstrates a need to explore sexual behaviours across various sexualities.

A nurse-researcher team in the south of England conducted a qualitative study exploring IBD patient experiences of discussing sexual well-being with their healthcare professionals (Fourie et al., 2021). They used hermeneutic phenomenology and applied Van Manen's framework for thematic analysis (Van Manen, 2016). As well as asking about patient interactions with health-professionals they also asked "Can you describe your experience of intimacy and sexuality from your perspective of living with IBD?" (Fourie et al., 2021, p2). The following patient quote from their semi-structured interviews supports the need for further research and clinical development in this field;

"I feel like people in my HCP team either haven't got the knowledge to discuss with me, the ways that it [IBD] affects it [sex], or haven't been willing to discuss. And I sensed a certain reluctance among them cos I'm bisexual."

[Mark 26 M, CD]", (Fourie et al., 2021, p3).

Ruan, Wu and Zhou (2020) are another nurse-researcher team who employed qualitative methods to explore body image changes in IBD. Four of their 16 participants reported a decrease in sexual drive and activity after diagnosis. This article was one of the only publications that argues for nurses

to design psychosocial interventions in contrast to the other literature reviewed that favoured focusing upon resolution of disease activity. This recommendation aligns with the authors clinical experience of caring for people with this disease, having frequently observed that the psychosocial impacts of the disease may persist during periods of clinical remission.

Three qualitative studies (Sarabi, Navipour and Mohammadi, 2007; McDermott et al., 2016; Tepper, 1999) unearthed by the review that did not meet the inclusion criteria, provided supplementary substantiation of the possible negative effects of IBD on men's sexual health and supported the need for further investigation in this field. The following qualitative data extracted from these studies provided an insight into the sexual health issues possibly faced by men with IBD:

"After surgery I became cold in terms of sexual relations, not because of surgery, I did not have a sexual problem, it was just the embarrassment".

(Sarabi, Navipour and Mohammadi, 2017, p. 175)

"I avoid eating out, socialising and physical intimacy".

33yr old male patient with Crohn's disease

(McDermott et al., 2015, p. 356)

'It takes many painful steps to recover sexual pleasure after a disability. But it can be done. I've done it'.

(Tepper, 1999, p. 51)

2.7 Strengths and limitations

This review provides an exhaustive and systematic search of the academic databases using a recognised scoping review framework. As is common practice with scoping reviews, included studies were not critically appraised using a validated tool. Only papers available in English were reviewed but this decision led to the exclusion of just one (possibly eligible) paper. The search strategy did not include fatherhood or LGBT synonyms. Several surgical studies were excluded for including proportionally small numbers of familial

adenomatous polyposis or participants <18 years. In retrospect, it may have been valuable to include studies with participants <18 years as this cohort will include the period where sexual development and maturity occurs.

The formalised systematic approach adopted by this review supported a rigorous approach and in part led to its publication (Appendix 1). However, for the purposes of creating a complete grounding for this work there is a possible flaw in the exclusion of non-published, non-peer reviewed literature. There may be informative service improvement projects, audits, grey literature and research that has not been published or peer-reviewed, especially as busy clinicians working in the field do not always have the time or support to publish their findings within the academic literature. Furthermore, there will undoubtedly be research from other chronic disease and fields that is applicable to this work that was excluded to ensure the search process was manageable.

Thorne (2024) describes two possible issues with the normalisation and expectation of a formal and structured review; (1) the potential exclusion of an important body of information and evidence which does not meet a strict inclusion criteria and (2) the descriptive reporting of the findings. It is recognised that this work is also subject to these limitations but there are some important ways in which they have been moderated. Firstly, the nurse-researcher was situated within the field of practice at the time of the review and was well acquainted with the non-academic literature and clinical practices. Secondly, as discussed in Section 2.6, several articles that were excluded from the published review were still carefully considered within the context of developing subsequent research questions. A comprehensive body of literature and clinical experience informed the development of the qualitative studies presented within this thesis and the researcher's thinking. Thirdly, although the review focused upon the IBD literature, the researcher also scoped literature discussing sexual health in other diseases and fields of practice to guide the overall discussion of findings (Chapter 6). Finally, although the review itself is predominantly descriptive, this was essential

knowledge and required to conceptualise and design the empirical work presented within this thesis (Chapters 3).

2.8 Public and patient feedback

The findings of the scoping review were shared with three people from a public and patient panel for feedback. One member described a preference to move away from statistical correlation as this does not necessarily determine causes of dysfunction or usefully inform the development of treatment plans for the individual. This point further supported the move towards qualitative approaches for the research conducted. One member felt that there may be space for adapting novel interventions that are used in other domains, such as the 'men in sheds' concept introduced to reduce male isolation in older age. The idea of using the information from the review to develop a prototype intervention was carefully considered and later rejected, recognising that this would be premature at this point and further exploration of the field was required to ensure any suggested intervention was both appropriate and needed.

2.9 Conclusions

The scoping review set out to identify the potential impact of IBD on sexual health in men and identify whether there is scope for nursing research and intervention. Findings showed that research in this field predominantly focused on the evaluation of erectile function using the IIEF. A comprehensive systematic review in this area was completed by another research group while this scoping review was being undertaken and demonstrated an increased risk of erectile dysfunction in men with IBD (Zhao et al., 2019). A key gap in the current evidence base relates to why and how IBD brings about this increased risk.

As well as the need for a more detailed understanding about how IBD may impact on erectile and sexual function, research is also required that considers the broader definition of sexual health and includes aspects that may play a significant role in personal well-being. These factors include

sexual preferences, masculinity, and psychosexual health and are most appropriately examined through qualitative methods that allow the gathering of personal experiences of men with IBD, something that is currently absent in the academic literature but is highly relevant to clinical practice. Qualitative data in the form of personal narratives allow researchers to expose problems that may not yet have been identified in the clinical environment which is required in topics of a clandestine nature such as sexual health. Narratives also enable the identification of issues pertinent and relevant to people that may unconsciously shape disease management and treatment choices. Mapping out the possible social factors that influence disease, treatment, and individual experience allows us to drive forward clinical practice and create patient information and support that is needed and valuable.

Nurses should be able to confidently and sensitively discuss sex and intimate relationships to ensure that men with IBD do not have sexual health problems that are left unaddressed (Kemp et al. 2018). Personal and sensitive communication and collaboration is already at the heart of nursing practice and is important to the successful development of a therapeutic patient-nurse relationship. Unfortunately, many nurses do not feel that they have the knowledge, competence, or organisational support to undertake this task in matters of sexual health (Fennell and Grant, 2019). Perhaps the most important care that nurses offer is “awareness of the sexual issues that often go unspoken” (Giesen and Terrell, 1996, p16) and this can only occur if good exploratory research is available to inform it. Awareness of the physical, psychological, and social IBD-related factors that influence sexual health in men will allow for the identification of needs that can be met through nursing intervention.

2.9.1 Next steps: design the study

In summary, this scoping review has drawn attention to varying impacts of IBD on men's sexual health and the opportunity to develop further training tools and clinical pathways that specifically allow nurses to identify and manage men's sexual health needs in IBD. However, to design interventions that are both appropriate and efficacious, a greater depth of understanding is

required into how men with IBD experience sexual health that is inclusive of the wider psychosocial contextual factors. Absent in the current literature are the experiences, views and needs of healthcare workers who deliver care to men with IBD. It is essential to also gather this knowledge to create interventions that are appropriate, feasible, and deliverable. Subsequently, the principal question arising from the key gaps identified in the scoping review was; what are the experiences of men with IBD and their health professionals? A qualitative approach is best matched to gathering and interpreting lived experiences. Interpretive description (Thorne, 2016) was identified as the most suitable and accessible methodological framework for delivering outcomes that can be translated and integrated into clinical knowledge and practice. This approach and how it informed the conceptualisation of the primary research within this thesis, is described fully in the following chapter.

CHAPTER 3: METHODOLOGY

This chapter first details the underlying theoretical perspectives of the research presented in this thesis (Section 3.2) and the rationale, justification, and application of the selected methodological approach (Section 3.3). The overview of the methodological framework is followed by an outline of the adopted methods (Section 3.4) and the chapter closes with consideration of how research quality was ensured through the design process (Section 3.5).

3.1 Introduction

The scoping review (Chapter 2) revealed a paucity of research into the sexual health and well-being of men with IBD, particularly qualitative investigation into lived experiences. The lack of qualitative research has led to a dearth of in-depth understanding of the sexual health experiences of men with the condition, clarity of male-specific needs, and evidence of how best to deliver nursing care in this area. A more developed understanding of the intersections between disease, sex-life, and sexuality is needed so that disease and gender-specific needs can be identified by nurses and addressed in a patient-centric way. The main aims for the PhD research were formulated from the findings of the scoping review and were:

- (1) to describe and interpret the sexual health experiences and activities of men with IBD. This aim is achieved through an exploratory qualitative study involving men with IBD (Chapter 4);
- (2) to describe and interpret health professional experiences and understanding of the sexual health and care needs in men with IBD. This aim is achieved through a qualitative study with health professional participants (Chapter 5);
- (3) to draw together the findings from the literature review and two qualitative studies to set out recommendations for nursing practice, education, and research in the field of men's sexual health in IBD (Chapters 6 and 7).

As the aims focused on the investigation of personal experiences in order to inform clinical recommendations, a pragmatic qualitative research design was considered most appropriate. The theoretical perspectives that underpin the methodological framework are described in the next section.

3.2 Theoretical perspectives

Interpretive description (Thorne, 2016) is a pragmatic qualitative methodology grounded within nursing and focused upon producing rich and meaningful data that is valuable to clinical practice. Interpretive description (ID) was chosen as the methodological framework for this study as it supports the collection and interpretation of data that is applicable to nursing practice. ID is designed for applied research, aimed at generating insights that can influence real-world practice. Prior to exploring ID in detail (Section 3.3), it is first important to set out the ontological and epistemological assumptions that underpin the research aims and how they align with an ID approach. Furthermore, although ID is intrinsically atheoretical, this section also identifies the theoretical frameworks that influenced the study conceptualisation and design.

3.2.1 Adopting a relativist ontological lens

A nomothetic approach to this work would seek to objectively quantify and define the sexual health of men with IBD. Objective quantification of health aligns with a realist perspective in which reality is considered independent of the mind or personal experience (Ormston et al., 2014). Objective measurement is valuable in health research, particularly in the evaluation of medical interventions, public health, epidemiology, health economics, and service planning. Research that exclusively focuses on objective truths does not readily facilitate an understanding of the human experiences of living with chronic illness, which is essential to providing good healthcare (Kleinman, 1988). The findings of the scoping review (Chapter 2) demonstrated how the dominance of objective measures in sexual health has led to a gap in knowledge regarding the specific needs and priorities of men with IBD, as reflected in the research aims addressed in this thesis.

Relativism rejects objectivity in favour of subjectivity and the possibility of multiple realities that are created and shaped by social interactions (Baghrarian and Coliva, 2019). A relativist perspective to health research supports exploration of subjective illness experiences in relation to the physical, psychological, socio-economic, and cultural contexts in which they are experienced. Nursing praxis involves “an interplay between objective and subjective information” (Thorne, 2016 p28) and both realist and relativist ontological positions have informed nursing philosophy, research and practice (Hirani, Richter and Salami, 2018).

Subtle-realism (Hammersley, 1992) has been offered as a middle-ground in the realist-relativist continuum. Arguments over the utility of relativist-directed research has led to the application of subtle-realism in nursing-focused inquiry (Andrews, 2016). However, the idea that relativism does not create applicable and useful nursing knowledge is rejected here. Adopted in this thesis is a relativist perspective which acknowledges that men with IBD have diverse sexual health and well-being experiences influenced by varying social realities. Through understanding the diversity in illness experiences it is possible to illuminate the differing priorities of people. Understanding diversity forms the essence of nursing knowledge, which is built upon individual experiences, often shared between the patient and their care-givers (Thorne, 2016). Developing personal knowledge can lead to meaningful communication, shared-decision making, and patient-centric care which are important to both patient experiences and effective healthcare and provide justification for the adoption of a relativist ontological lens in this work.

3.2.2 An underlying constructivist paradigm

Positivist epistemological paradigms operate within realist ontologies, creating studies that seek replicability and generalisability (Denzin and Lincoln, 2000). Positivism continues to influence the majority of clinical and healthcare research, where the randomised control trial and systematic review with meta-analysis are regarded as the gold standards from which to inform evidence-based practice (Backmann, 2017; Holloway and Freshwater, 2009). Clinical environments that are task-based and outcome driven inevitably perpetuate

the idea that data is best collected through instruments based on measurement, and best used to ascertain statistical relationships between variables. The social sciences, including nursing, have embraced alternative epistemological positions that facilitate the study of real-life experiences and situations that are not subject to controls or considerations of probability. This creative and imaginative way of researching health and clinical interactions is needed within evidence-based practice to drive care that is individualised rather than rule based (Greenhalgh, Howick and Maskrey, 2014).

In rejecting positivism, this work has adopted a constructivist approach which aligns with relativism and the premise that there is no single valid finding but many useful contextual interpretations (Crotty, 2020). Constructivism is befitting of the collection and understanding of personal health experiences. In constructivism, the context, interaction, and shared experience in which the data is collected and analysed form part of the findings. This approach parallels the participatory nature of nursing where the nurse is not merely a bystander but an agent and partaker of the care experience (Holloway and Freshwater, 2009). Constructivism has not been applied to legitimise the nurse-researcher's influence and possible biases they may introduce, but to provide a paradigm in which reflexively engaging in the researcher's involvement in the production of findings can enhance understanding and knowledge. Through employing a constructivist approach, it has been possible to incorporate the nurse-researcher's clinical experience of working with men with IBD and the healthcare environments in which they are cared for, to provide insights that would otherwise be lost. Research rigour and trustworthiness of the findings in constructivism is achieved through reflexive and transparent research processes, which are detailed further in Sections 3.4 and 3.5.

3.2.3 Conceptual and theoretical frameworks

Conceptual and theoretical frameworks are frequently used in the development and structure of nursing research (Grant, Kinney and Davis, 1993). The literature of sexual health in men with IBD is scant. To employ a specific theory or conceptual model to underpin the study design could limit

the exploratory scope and discovery of new knowledge. In line with ID, the methodological design of this work has not been governed by an existent model or theory. Instead, clinical nursing knowledge and experience have been used to support the development and selection of study processes and techniques. Thorne, Stephens and Traunt (2016) argue that 'disciplinary epistemology' can be used to frame the study conceptualisation through to the selection of methods. By locating methodological decisions within the nurse-researcher's clinical knowledge of what can be done to support the health of men with IBD, it is possible to produce knowledge that may have tangible outputs or could pave the way for further inquiry.

It has been argued that no research is truly atheoretical (Creswell and Poth, 2017) and therefore in order to remain truly transparent and rigorous it is important to consider knowledge and theories that may have informed the "direction of preliminary decisions" (Thorne, Kirkham and MacDonald-Emes, 1997;p197). To clarify, the naming of theory in this section is not for the purpose of validating the study design; the pragmatic qualitative design of ID does not demand this justification. Instead, the discussion of pertinent models in this field provides pragmatic consideration of how this work is situated within the wider field of qualitative applied health research and how it has implicitly impelled this work.

A principal aim of this work is to translate the research findings so that they may inform nursing practice in a tangible way. Recognising the challenge of implementing new clinical knowledge, Graham et al. (2006) developed the Knowledge To Action (KTA) theory. Divided into two parts, knowledge creation and action cycle, the theory considers the two most difficult aspects of bridging the gap between clinical research and practice; (1) the challenge of creating knowledge that is relevant to healthcare, (2) overcoming the barriers to the application of new knowledge. The KTA model has readily been utilised in health services research and have been noted to facilitate the selection of appropriate study designs (Milat and Li, 2017; Field et al., 2014). Within the model, the knowledge creation cycle involves three processes; knowledge inquiry, knowledge synthesis, and knowledge tools/products. In

the initial stages of the project it was envisaged that the output of the thesis would be a new tool to better support the identification and care of sexual health in men. When the scoping review (Chapter 2) confirmed the scarcity of data and lack of clarity over the problems experienced by men with IBD, it was realised that there was insufficient knowledge to immediately produce tools that were ready to transform practice. Consequently, the broader goal of this work became to develop new knowledge that may later help inform nursing intervention rather than to develop an intervention itself. Situating this work within the domain of knowledge inquiry within the KTA model, supported and further validated the adoption of an exploratory qualitative approach.

The conceptual framework of chronic disease and sexuality (Verschuren et al., 2010) was a further informative model within the conceptualisation of the study design and validates the need for the research conducted and reported within this thesis. Verschuren et al. (2010) identified a lack of qualitative inquiry within the existing sexual health literature in chronic disease and a focus on erectile dysfunction in men. Within their literature review, no papers accounting for people with IBD were included (Verschuren et al. 2010) further highlighting the lack of attention to the needs of people with IBD in regards to sexual health. Through their model, Verschuren et al. propagate the idea that people who are chronically ill are sexual human beings and this needs attention within clinical care. The model maps out the potential relationships between the biological, psychological, and relational factors that may influence sexual health within the context of chronic disease. However, societal and cultural factors have not been considered within the framework with the authors claiming that these can be challenging to quantify or operationalise within a study design. This work aims to explore all possible factors that may influence men's sexual health in order to identify their specific needs and therefore further justifies the utilisation of a relativist-constructivist approach that does not seek to quantify but rather to illuminate and interpret contextual relationships. In summary, the model produced by Verschuren et al. (2010) highlights the possible intersections between chronic disease and sexual health and the need for data collection methods that permit both investigation of these points and exploration beyond them.

Gender is an important consideration within health research as it can shape lives and aid or limit individual health (Johnson and Repta, 2012). Through the adoption of a gendered approach, this work seeks to consider the implications of gender on experiences of sexual health when living with IBD. It would therefore be judicious to consider gender theories in relation to the study design. Gender theories commonly explore the way in which humans socially classify sexual differences (Gerish, 2005) and importantly consider classifications or constructions beyond biological differences (Kimmel, 2000). Theories of gender include ideas of gender identity, gender roles, and gender inequality. Originally rooted in feminism, many theorists have contributed to the notion that gender affects all people and that gender inequality is not solely a concern of women (Connell, 2005; Butler, 2004; Hooks, 2000; Kimmel, 2000). The way in which we conceptualise sex and gender impacts the way in which studies are planned and delivered (Oliffe and Greaves, 2012). In contrast to biological sex, contemporary understandings of gender favour a fluid construct dependent upon the social context (Connell, 2005; Butler, 2004). Comparably, masculinity can also be considered multi-dimensional and socially bound (Connell and Messerschmidt, 2005). Sexual autonomy permits individuals to detach their biological sex from their gender identity, supporting varying sexualities (Butler, 2004). To propagate sexual autonomy in health, the overt and covert societal, cultural, and healthcare barriers faced by people of all genders, including transgender and intergender, must be identified and resolved. This demands a flexible research approach that supports the collection of varying experiences led by the participants and not the researchers. Research must also openly address how to consider and include data from varying genders and sexualities. Subsequently, in the first qualitative study (Chapter 4) people who identified as male regardless of biological sex were included, diverging from existent work in this field (inclusive of all work within the literature review) that categorises participants according to biological sex.

In summary, to subjectively explore and interpret personal health and care experiences, this work has adopted a relativist ontological position utilising a constructivist epistemological approach. As the existent research in this field

is limited, this work has been purposely situated within the domain of knowledge inquiry as per the KTA framework (Graham et al., 2006), and through the selection of an appropriate methodological approach has sought to produce findings to inform nursing practice. Although the study design has not been underpinned by a specific theoretical framework, framework of chronic disease and sexuality (Verschuren et al., 2010) and gender-based theories (Connell, 2005; Butler, 2004; Kimmel, 2000) have provided further justification for the chosen methodological approach and have guided design decisions that are now set out in the following section.

3.3 Methodological approach

3.3.1 Qualitative methodologies

Qualitative research methodologies are suited to eliciting rich and meaningful information and are best applied to studying experiences (Holzemer et al., 2010). The strength of qualitative approaches in clinical research is that the person with the illness is enabled to express what is most relevant to their health (Morse and Field, 1996). The flexibility of study design permitted by qualitative methodologies empowers inductive and interpretive approaches where researchers can follow leads that emerge from participants' perspectives (Charmaz, 2014). Research that is participator-led also allows the exploration of areas that may not have previously been identified but are important to people with the illness. This approach was essential for the research presented in this thesis, where the sensitive and often concealed nature of sexual health has left much to uncover.

This idea of data being derived from the person with the disease, particularly through immersion within the social and cultural setting, is a hallmark of naturalistic inquiry (Lincoln and Guba, 1985). Such an approach can be executed through ethnographic methods and that allows the researcher to capture emic perspectives to develop contextual understandings.

Ethnographical approaches are often utilised to understand cultural and social meaning and patterns (Creswell and Poth, 2017; Brewer, 2000; Roper, 1999). In nursing, this approach would be useful for studying patient-practitioner

interactions and clinical interventions. The exploration of sexual health experiences does not lend itself well to the immersive fieldwork characteristic of ethnographical approaches due to practical and ethical considerations. However, the essence of a naturalistic paradigm has been adopted within this work through knowledge being obtained through observation and social interaction to gain the emic perspectives of men with IBD and their health practitioners.

Phenomenologically-informed approaches are widely used in qualitative health research and support the interpretation of the essence of human experience (Van Manen, 2007; Benner, 1994; Cohen and Omery, 1994; Colaizzi, 1978). Benner's interpretive phenomenology (1994) specifically sets out to illuminate how phenomenology aligns to both nursing philosophy and research. Van Manen's (2007) phenomenological framework of four existential elements (lived time, lived body, lived space, and lived human relations) has guided a vast amount of nursing research (Rich et al., 2013), including previous work in the field of sexual health in IBD (Fourie et al., 2021). Phenomenology was not deemed the most appropriate approach to address the research aims in this thesis for a number of reasons. The application of phenomenological methodologies is not always clear, particularly in the assignment of meaning (Paley, 2016). Phenomenological approaches traditionally require the researcher to 'bracket' existing knowledge. Bracketing does not easily align with constructivist approaches or the reflexivity inherent to nursing utilised to enhance research rigor and validity. It can be argued that a specialist nurse researcher, with many years' experience of working with the study population, cannot truly be "*tabula rasa*" (Savage, 2003). Phenomenological approaches aim to depict the essence of human behaviour rather than explore social and contextual experiences. The research aims were to interpret how IBD influences the sexual health within the context of being male and not to describe or understand the root of sexual behaviour in men with IBD.

Grounded theory (Strauss and Corbin, 1997; Glaser and Strauss, 1967) seeks to develop a theory of the social and health processes related to the subject

being explored. Although grounded theory is commonly applied in qualitative sexual health research (Sinković and Towler, 2018), this approach was rejected as the aim was not to develop a social theory of sexual health in men with IBD. Unlike traditional grounded theory, Charmaz's (2014) iteration (Constructivist grounded theory or CGT) permits the nurse-researcher to be a part of the social context being explored. However, the main aim of CGT remains to produce emergent theory or theorisation of human behaviour which did not align with the aims of the study.

3.3.2 Interpretive description

Interpretive description (ID) (Thorne, 2016) is a qualitative methodology that encourages the borrowing of methods to best suit the research objectives. To this extent, ID provides an alternative to prescriptive qualitative methodological approaches and does not impose a specific sequence of steps. ID provides a framework in which health and illness can be described and interpreted from the perspectives of those experiencing the phenomena in order to create knowledge that can be utilised in nursing (Thorne et al., 1997). Therefore, what phenomenology is to philosophers, grounded theory is to sociologists and ethnography is to cultural anthropologists, ID has become to nurse-researchers. Unlike other principal qualitative methodologies, ID does not require bracketing and instead supports enquiry through a constructivist-interpretive lens. In ID, when the researcher draws upon their existing clinical knowledge as 'foundational forestructure' (Thorne et al., 1997) this is not considered to contaminate the data or compromise the trustworthiness of the findings. Instead, reflexivity within the research process ensures that interpretations remain faithful to the participants' narratives while producing transformative knowledge. However, within the constructivist paradigm, the researcher must reconsider and challenge their existent understanding and be open to reinterpretation (Crotty, 2020). During this process of interpretation and reinterpretation, attention must be paid to unpicking patterns that have explanatory power. Remaining focused on extrapolating specific contextual findings from 'the general', ensures findings are meaningful for nursing practice (Thorne et al., 2016). Consideration of

how individual accounts can tell us about shared experiences or patient needs informs study design decisions and the selection of methods. For example, because ID accepts that there are infinite possible variations within the population, sample sizes are not calculated using statistical methods concerned with diminishing variability and producing replicability. Instead, sample sizes are determined during the course of the study and dependent upon whether the collected data is rich and detailed enough to meet the aims of the study.

To ensure that the study design is most likely to produce findings that contribute to nursing knowledge, ID permits adoption of sampling, data collection, and analysis methods that best suit the research question. In summary, ID provides a generic, atheoretical approach to qualitative research that is not only grounded within nursing but enables the researcher to draw upon varying methods to create an overall design best suited to the study aims.

3.4 Study design

Although ID does not prescribe specific methods there are some common characteristics of studies that are guided by the methodology. These characteristics include purposive and theoretical sampling, triangulation of data sources, inductive analytical processes, and constant comparative methods. The studies presented in this thesis adopted all of these design principles and methods, which are now described in the following sections.

3.4.1 Sampling

3.4.1.1 Sampling strategies

In qualitative research, valuable data is derived from ‘good informants’ (Coyne, 1997) and therefore it is essential that sampling strategies support the selection of participants who are most likely to provide rich and valuable information. Purposive sampling is a common approach that allows for the targeted selection of participants that have (possibly untold) experiences specific to the area being explored. This approach provides ‘information

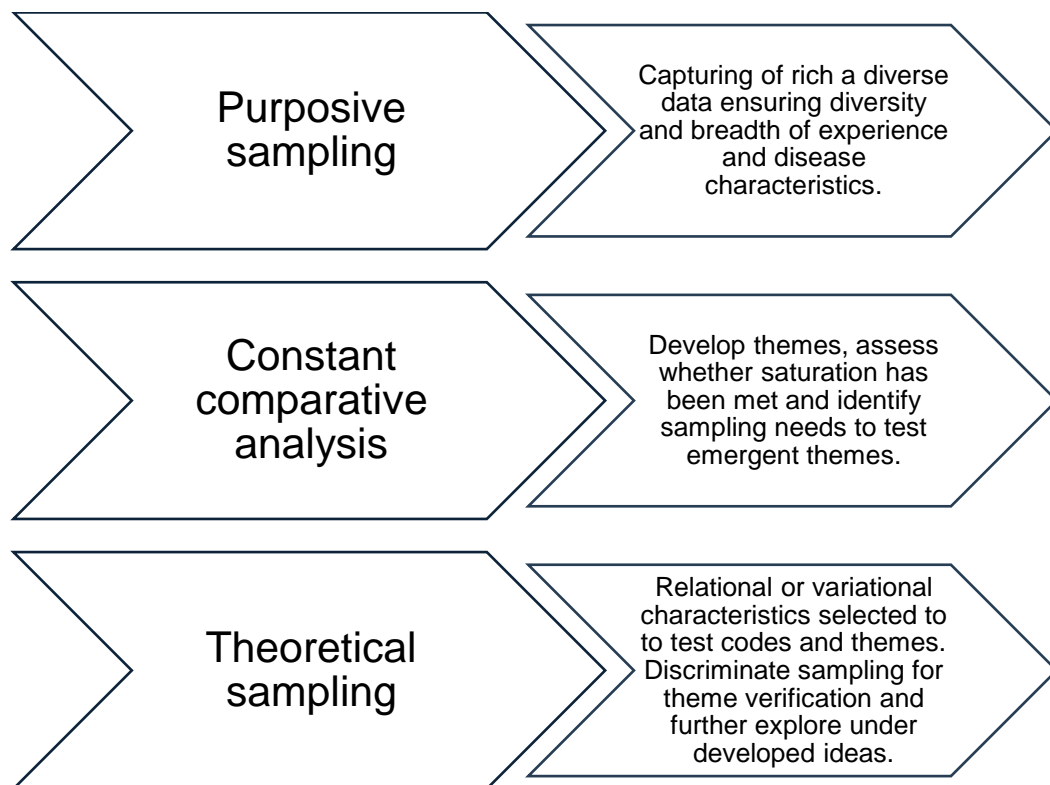
power' (Malterud, Siersma and Guassora, 2016) and improves the credibility of the findings.

Theoretical sampling is a further popular approach utilised in qualitative studies that originated from Grounded Theory (Glaser and Strauss, 1967). In theoretical sampling there is no predefined sampling framework, and so decisions are iterative and evolve as the study progresses. This iterative approach enables the refinement and testing of findings and is reliant upon a study design that prescribes concurrent data collection and analysis.

Thorne (2016) advocates for both purposive and theoretical sampling, applying purposive sampling to identify informants that may provide rich information, and theoretical sampling to obtain variation and challenge the themes derived from inductive analysis (Figure 3.1). In this approach, although variation is important, maximum variation is not always necessary or pertinent because the aim is not to obtain a representative sample but one that provides the most relevant, applicable, and transferable information.

Quota sampling is a form of purposive sampling that specifies categories and the minimum number of participants required in each category (Campbell et al., 2020). Although this approach is more prescriptive it also provides flexibility as no final sample size is specified and recruitment may continue within each quota to allow further depth of understanding or until no new themes are generated.

Figure 3.1 The sampling process



In qualitative study 1 (Chapter 4) a generic purposive sampling was considered to provide the most appropriate approach to initiating data collection. Concurrent data collection and analysis meant that theoretical sampling could be utilised as the work progressed. Further details on this process are provided in Chapter 4, section 4.2.1.

In qualitative study 2 (Chapter 5), quota sampling was considered the most appropriate strategy. The reason for the differing approach was that, while qualitative study 1 focused primarily on the collection of novel knowledge in this topic, qualitative study 2 concentrated upon information that could transform the findings into tangible recommendations for nursing theory, practice, and research. The nurse-researcher's understanding of clinical systems and processes was utilised to decide on the varying participant quotas that would be required to develop this clinical knowledge. Key members of the multi-disciplinary team who may have or could have an important role in providing sexual health provision to men with IBD were

selected for the categories. Further detail of this can be found in Chapter 5, section 5.2.1.

3.4.1.2 Sample size

When using an iterative sampling strategy, a sample size it not usually pre-defined. However for the research ethics application and research planning, an estimated total sample size of 20-50 participants was determined. This figure was derived from the assertion of Green and Thorogood (2018) that 20 interviews will provide sufficiently detailed information alongside the knowledge that more than 50 participants can create a data set that is difficult to manage (Ritchie et al., 2013).

Defining the point at which to stop recruitment was based upon a pragmatic interpretation of saturation (Low, 2019). Presented by Glaser and Strauss (1967), 'theoretical saturation' in its original form is the idea that data collection has been completed when no new theoretical insights 'emerge' from the data. Aligning a relativist perspective that embraces infinite possibilities to the idea that no further insights can be made, is problematic. Thorne (2016) states that nursing requires "I never close a door on new variations and diversity on a theme" (p107). However, in rigorous research it is imperative to set out a clear and transparent process through which data collection is closed. There have been varying terms and interpretations of saturation within the literature that try and make explicit the processes followed by researchers; they include data saturation, code saturation, thematic saturation, and meaning saturation (Low, 2019; Hennink, Kaiser and Marconi, 2017; Charmaz, 2014; Guest, Bunce and Johnson, 2006). Although Thorne (2016) prefers to avoid the term saturation, the proposal that data collection and analysis is complete when there is sufficient quality to provide comprehensive knowledge, is important. In this work, saturation has been utilised pragmatically to mean that this criterion was met. In practice, saturation became the point at which codes and themes were beginning to repeat. The decision to stop interviewing participants was based upon the principles of 'adequacy' and 'appropriateness' (Cleary, Horsfall and Hayter, 2014a) meaning there was sufficient in-depth and rich data to support key findings.

3.4.2 Data collection

Inherent to ID approaches is the triangulation of naturalistic data collection methods that gather contextual, subjective, and individualised information. This process is usually done so that personal narratives can be obtained to provide an opportunity to understand what it means to live with illness (Greenhalgh and Hurwitz, 1998). Thorne (2020) reasons that through gathering individual experiences it is possible to develop a broader understanding of illness. In this section the rationale for either the use or rejection of data collection methods commonly used within ID is provided.

3.4.2.1 Interviews

Interviews are commonly utilised to gather personal narratives as they provide a way to ignite discussions on personal topics and generate rich data on individual experiences. The flexibility of semi- or unstructured interviews supports far-reaching and rich dialogues (Chabot and Shoveller, 2012). Within a constructivist approach, interviews can offer nurse-researchers the opportunity to explore or delve deeper into experiences that may best inform their clinical practice.

Interviews provide a private and confidential space for the discussion of sensitive topics which is more preferable than focus groups (Guest et al., 2017). Additionally, interviews are less likely to trigger exaggerated forms of masculinity that are sometimes observed in groups (Gough, 1998). More recently, a study involving men discussing intimate partner relationships found that online interviews provided participants with privacy, comfort, and control while also improving recruitment and inclusivity due to not having to travel (Olliffe et al., 2021). Interviews are also more likely to be inexpensive (Namey et al., 2016) which was an important practical consideration within this work due to limited funding resources.

The strength of interview data relies upon detailed, focused, and honest responses which are often dependent upon the personality and social identity of the interviewer (Davidson and Layder, 1994). Nurses commonly engage in

private and sensitive conversations and are proficient listeners (Holloway and Freshwater, 2009). These skills support building rapport and trust with participants, which is particularly important when talking about potentially sensitive topics. The nurse-researcher also prepared to manage the interview so that it did not become a clinical consultation. This was achieved by ensuring an informative consent process, providing a detailed participant information sheet, and conducting the interview within a non-clinical environment. The nurse-researcher also ensured that participants could take charge of, and lead the conversation by utilising open interview questioning, providing space and time for participants to speak freely, and speaking only to acknowledge what was being said, maintain focus on the topic, or clarify something. Seeking clarification is an important part of the research interview and provides an inherent form of member-checking that ensures credibility of the data.

As a gendered centric project, the influence and role of the nurse-researcher's⁴ gender required consideration. Previous researchers have found that some young men are uncomfortable with engaging in studies when there is a female interviewer (Chabot and Shoveller, 2012). In contrast, O'Toole et al. (2018) found that 72% of men with IBD in their study had no preference for the gender of the healthcare professional when discussing sexual health clinically. The interviewer's female gender was considered by the research team and the public engagement group during the design phase. It was decided that the combination of the nurse-researcher's identity and their clinical experience of discussing private matters, would sufficiently moderate this potential barrier of gender-mismatch. The interviewer position is discussed further in section 3.5.2.

3.4.2.2 Focus groups

Focus groups have been used successfully in sexual health research (Frith, 2000) and provide a way to canvas collective experiences and opinions. Interaction between participants can provide an increased depth of insight and

⁴ The researcher was also the sole interviewer within the studies presented in this thesis.

allow similar and opposing experiences to be brought to the foreground (Clarke and Braun, 2013). Furthermore, collecting data through focus groups can reduce the researcher's influence over the data.

Thorne (2016) supports the use of focus groups and this would have been a potentially useful method to gather insights into healthcare practitioner experiences. However, focus groups can be difficult to schedule (Guest et al., 2017) and the covid-19 pandemic further exacerbated this challenge. While social distancing restrictions could have been mitigated with online group sessions, the additional clinical pressures experienced by healthcare workers was not as easily moderated. To safeguard recruitment and offer participants greater choice in date and time for participation, individual semi-structured interviews were selected as the primary data collection method across both primary qualitative studies. Although semi-structured interviews may not provoke inter-participant discussion, the interviewer was able to simulate some of the discursive elements seen in focus groups by sensitively and confidentially drawing on their own personal experiences and that of earlier participants.

3.4.2.3 Photography as data

Visual data captures information that may otherwise go unseen (Glaw et al., 2017). In particular, photographs aid exploration of the social and cultural environments of participants, supporting gathering of contextual information (Collier and Collier, 1996). To date, visual research methodologies have most readily been used within sociology, but also in psychology and education (Harper, 2002). It is likely that visual methods have not been as readily adopted in health research due to confidentiality issues and also the private nature and stigma of ill-health. However, visual methods and photography are becoming more prevalent and have been utilised in sensitive men's research. Examples of the use of photography in men's research include the exploration of prostate cancer to strengthen narratives and destigmatise illness experiences (Oliffe and Bottorff, 2022; Oliffe, 2005), within gender research to explore the perspectives of groups who are less often reported (Haines-Saah

and Oliffe, 2012), and most recently within men's accounts of anxiety to illuminate experiences of suffering and stigma (McKenzie et al., 2023).

Auto-photography is a visual form of ethnography in which participants take photos to capture their lived experiences, which was originally developed from action-based research with marginalised groups (Rose, 2016). Allowing participants to photograph their lives provides an additional depth of description that cannot always be conveyed verbally. Photo-elicitation is the use of photographs within interviews to provoke discussion and create what Collier and Collier (1996) call 'communication bridges'. Using auto-photography in conjunction with photo elicitation can clarify experiences and reduce misinterpretations (Glaw et al., 2017) while giving control to the participant to provide their own narrative. It was decided that utilising participant-provided photographs in qualitative study 1 would provide further social and cultural insights while evoking emotions and memories that might otherwise go untold (Glaw et al., 2017; Harper, 2002). Photographs were not used within qualitative study 2 in which the focus was on professional experiences that can be difficult to ethically and practically capture and burdensome to participants, potentially affecting recruitment.

3.4.2.4 Questionnaires

Questionnaires are occasionally used within qualitative studies to provide a private and confidential space for participants to express their experiences or opinions. However, for true qualitative work their use involves open-ended questions with spaces for participants to write freely. Closed questions are useful for the collection of demographic data that helps provide a contextual background for the data set.

For qualitative study 1, a short closed-ended questionnaire was devised for the collection of demographic data. This information was used to support sensitive interviewing and developing rapport. For example, having a general understanding of the participants' surgical and medical background meant the research could avoid asking inappropriate questions. The background

information also reduced the time spent on collecting demographic details, and ensured that the focus of the interviews was on lived experiences.

In this work two validated scoring systems on sexual function (the International Index of Erectile Function (IIEF) and the IBD-Male Sexual Dysfunction Score (IBD-MDSD) were also collected. It was felt that these scoring systems could provide a route to discuss this sensitive topic and prepare the participant for the interview. As with the photos, the intention was that completing these assessment scores might trigger memories or highlight issues for discussion. These data were not collected with the intention of performing any quantitative analysis. Some basic statistics (percentage, mean and median) were calculated for summarising and presenting the sample within the study.

3.4.3 Data analysis

“Using inductive analytic approaches characteristic of interpretive description, researchers seek understanding of clinical phenomena that illuminate their characteristics, patterns and structure in some theoretically useful manner”.

(Thorne, Kirkham and O'Flynn-Magee, 2004, no pagination)

Inductive analysis is a trait of ID, which is achieved through a concurrent data collection and a constant comparative analytical approach. Thorne (2016) describes this process as identifying patterns then transforming them using an inductive but critical reasoning process. This process parallels clinical reasoning and is therefore well-suited to the nurse-researcher. Furthermore, as there is limited published work in this field, an inductive analytical approach was thought essential to ensure the findings remained true to the perspectives of participants.

Analytical methods in ID are informed by, and borrow from other qualitative methodologies. Thematic analysis (Braun and Clarke, 2006) provides a systematic but flexible and accessible method for supporting the researcher to bricolage the data (Crotty, 2020). In thematic analysis (TA) the researcher

may also employ their expertise and prior knowledge during the analysis to produce findings which can be understood through a nursing perspective.

TA sets out a strategy for identifying, categorising, and translating patterns relevant to the research question and reporting collective and 'obvious' semantic meanings (Braun and Clarke, 2012). The structured approach is beneficial when it comes to managing and analysing large data sets (Nowell et al., 2017). The six phases of TA are detailed in Figure 3.2. Within this work steps 1 to 4 were also understood by the nurse-researcher through Charmaz's (2014) model of 'initial coding', 'focused coding' and 'memoing' (Figure 3.3).

Although the combination of two methods can be subject to criticisms of method slurring, Thorne (2016) welcomes method blending that enriches the research process. Additionally, the analytical process set out by Braun and Clarke (2006) and Charmaz (2014) are further developed within ID when considering Thorne's (2020) 'transforming data' which seeks hermeneutic composability within the findings (Holloway and Freshwater, 2009). In essence this means reconstructing the data into a coherent, clinically applicable narrative. This has been achieved in this thesis through relaying the narratives obtained in a way in which healthcare practitioners may best understand and by making explicit the implications of the findings for practice. This also aids transferability with readers being provided with enough information to determine whether the findings might be applicable within their own context.

Figure 3.2: Thematic analysis (Braun and Clarke, 2006)

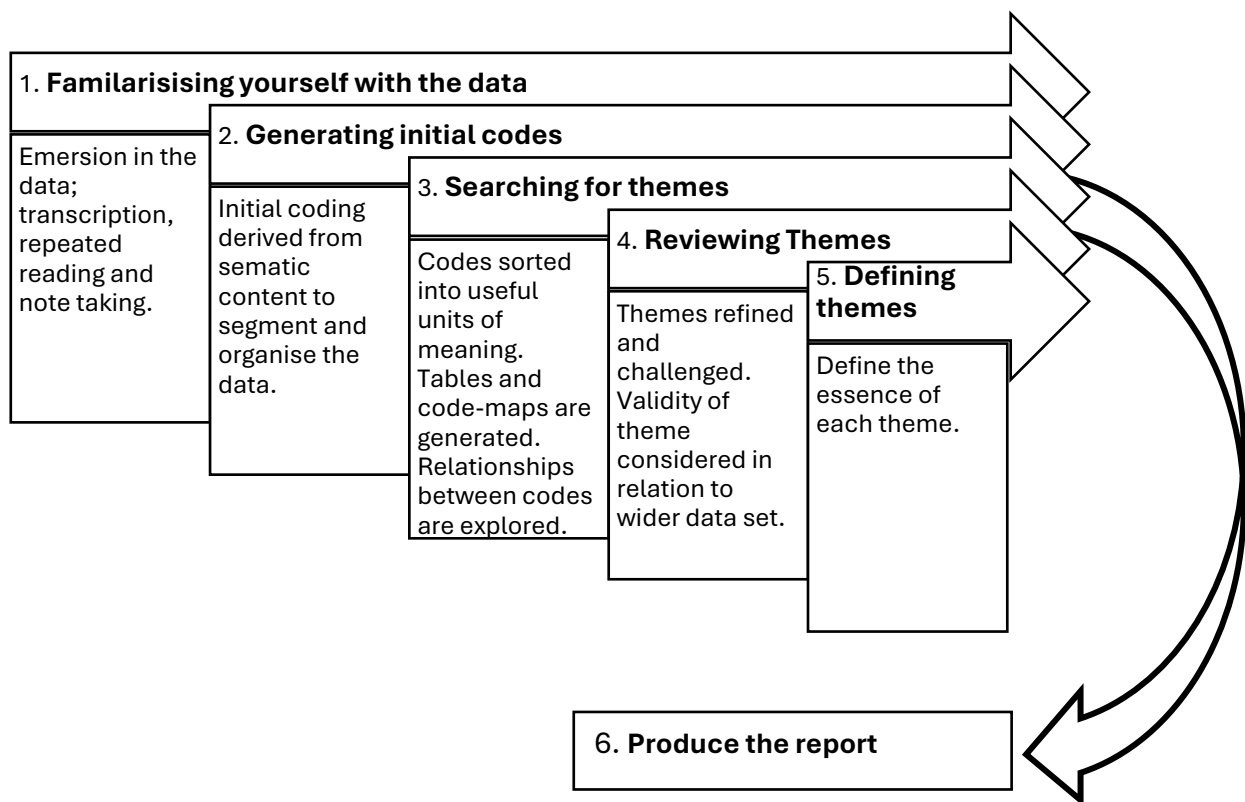
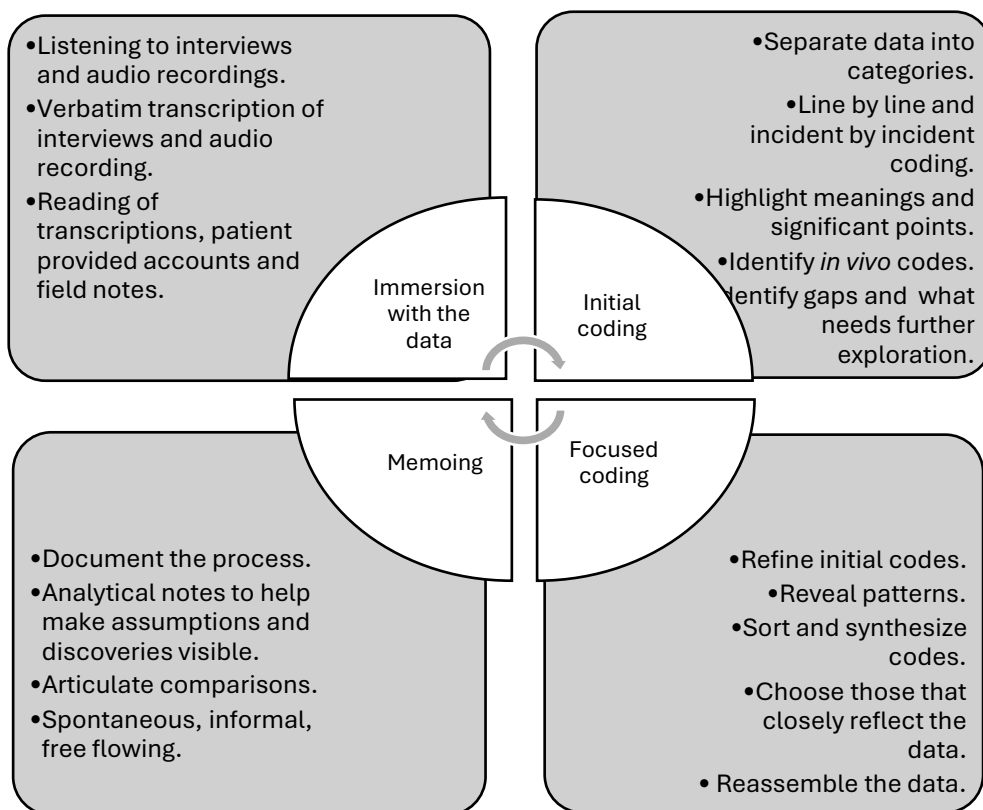


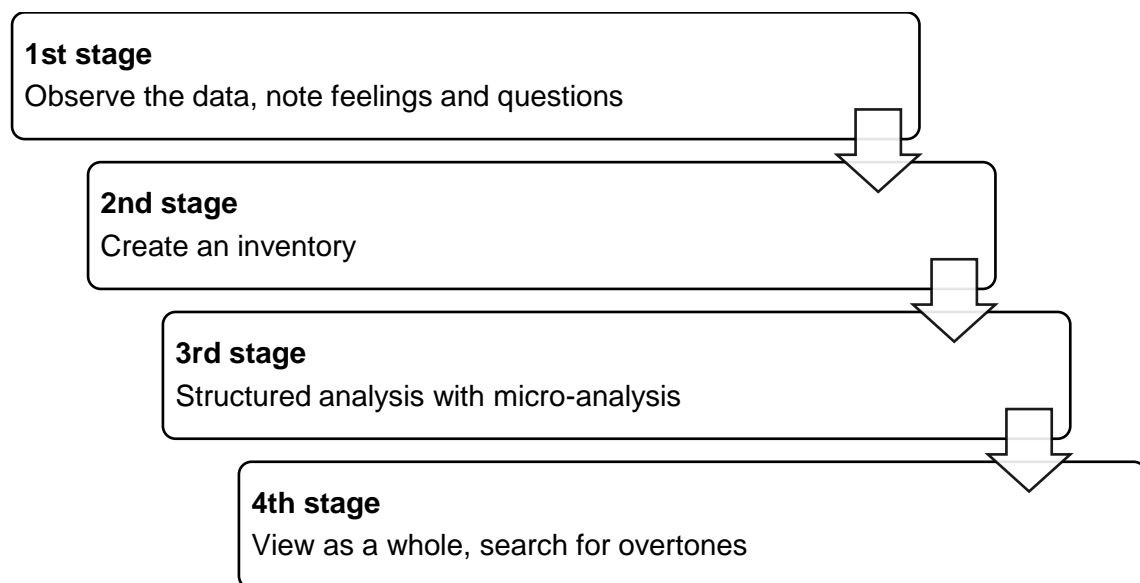
Figure 3.3: Data analysis approach informed by Charmaz (2014)



3.4.3.1 Photo-analysis

Extracting data from photography can be challenging (Collier and Collier, 1996). Glaw et al (2017) suggest organising photographs to generate and compare categories. Collier and Collier (1996) set out a similar process (Figure 3.4) whereby an inventory is created alongside a structured analysis. Unfortunately, this was not achieved as not enough photographs were collected to effectively apply the 2nd and 3rd stages. Rose (2016) suggests that interview data and photographs can be treated as one body of data, devising a coding system that includes both. Photographs were observed and considered in line with the model presented by Collier and Collier (1996) and then linked into the coding log produced following analysis of the interview data.

Figure 3.4: Photo-analysis as proposed by Collier and Collier (1996)



3.5 Research quality

In quantitative approaches scientific rigour is assessed by considering accuracy to ensure validity of the findings and consistency for reliability. These markers of research rigour are not appropriate for the idiosyncratic nature of qualitative inquiry. Instead, rigour in qualitative research encompasses the trustworthiness of the data, its applicability and

transferability to practice and, what Charmaz (2014) describes as the 'conceptual density' and 'explanatory power' of the findings. This section describes the way in which rigour was insured through research design, reflexivity, and public and patient involvement. Also detailed are the application of ethical design and conduct to protect the rights and safety of the participants, the researchers, and the public.

3.5.1 Research rigour through design

Trustworthiness in qualitative research is the degree to which findings accurately represent participants' experiences and are supported by transparent and systematic methods (Nowell et al., 2017). Trustworthiness can be ensured by paying attention to credibility, dependability, transferability, and confirmability which together describe how likely the findings reflect the participants' experiences and whether they may be applicable to or align with other contexts (Ahmed, 2024). Lincoln and Guba (1985) define credibility as the accuracy of the representations in the study; transferability as the possible applicability of the findings to other settings; dependability as the consistency of the research process; confirmability as the extent to which the results are derived from the participant data and therefore likeliness to be 'confirmable' by others with comparable experiences. A common strategy for ensuring trustworthiness is to collect and compare varying types of data which is referred to as 'data triangulation' (Lincoln and Guba, 1984). In this work, triangulation involved utilising multiple varying data sets including interview transcripts, photographs, and nurse-researcher diaries. Data triangulation contributes to the comprehensiveness of the study and enables the corroboration of findings, which inherently supports trustworthiness (Barbour, 2001). Photograph elicitation intrinsically improves reliability of the findings because photos clarify memories during an interview and provide a form of validation of the collected accounts (Harper, 2002). Importantly, a consistent approach to data collection that enables all participants to contribute relevant experiences and avoid inadvertent omissions, also improves the reliability of the data. To achieve this, an interview guide was utilised and the interviewer

ensured all participants had the opportunity to provide information in a comparable format.

Interpretive credibility, which is the reliability of the patterns identified within the data (Thorne, 2016) can be achieved through the sampling and analytical processes. Firstly, purposive and theoretical sampling enables interrogation and testing of emergent patterns and themes (Barbour, 2001). The iterative and ongoing process of theoretical sampling supports the attainment of saturation which is important in ensuring that the most important avenues of investigation have been exhaustively explored and tested. It is also prudent to note that saturation can be difficult to realise in practice due to constraints on researcher time, availability of resources, and other recruitment challenges (O'Reilly and Parker, 2013). To safeguard against this occurrence, multiple concurrent recruitment processes can be exploited to broaden the pool of participants. In the primary research presented in this thesis, both a local and national participant recruitment strategy was adopted alongside careful research planning with generous contingency plans. To ensure interpretive credibility within the analytical process, a transparent and auditable procedure was maintained with a clear audit trail, inclusive of the coding and theme logs which can be found in Appendix 12 and 23.

Applicability and clinical utility of the findings to nursing was achieved by utilising a methodological approach that allowed the researcher to interpret the data through a nursing lens (see section 3.5.2, below). Collection of detailed information on disease and participant characteristics also provides other researchers and clinical practitioners with the information required to make decisions about the transferability of the findings to their own patient cohorts (Shenton, 2004).

3.5.2 Researcher position and reflexivity

Reflexivity is the process by which researchers overtly consider their relationship with the data, in particular the influence of their position and assumptions on study design, data collection, and analysis (Finlay and Gough, 2008). Reflexivity is an essential strategy within qualitative research to

ensure dependability and therefore trustworthiness of the data. It is particularly important within a constructivist paradigm in which the researcher is the data collection tool and the quality of the data relies upon human interaction (Dickson-Swift, James and Liamputtong, 2008).

Reflexivity has been achieved in this work through several strategies: (i) critical engagement with theoretical frameworks that may have shaped the study conceptualisation and design (Section 3.2); (ii) reflexive journaling throughout the data collection and analytical processes (see Appendices 15 and 25 for exemplars); (iii) internal critical thought throughout the process; and (iv) (presented within the current section) consideration of the nurse-researcher's identity and relationship with the respondents (Doucet, 2008).

The nurse-researcher's professional identity and position as a nurse has inevitably shaped the overall premise and structure of the research presented in this thesis. Nursing research is influenced by the belief that suffering produced by ill-health can be eased and therefore influences the research questions asked (Thorne et al., 1997). The nurse-researcher's clinical experiences led to the identification of patient need leading to the focus on sexual health. Further meetings with public involvement members and academic supervision directed the selection of study methods. The nurse-researcher's training, clinical experience, and professional values all made possible the ethical delivery of a study that collected personal and emotive narratives of health. Drawing upon clinical experience and knowledge also supported the design of a study to produce findings transferable to nursing practice. However, while endeavouring to produce findings that are transferable to clinical practice it is also important to ensure that the nurse-researcher's influence over the narratives did not compromise credibility, dependability and confirmability and therefore trustworthiness of the data. This outcome was achieved through an open and reflexive interviewing process that inherently sought participant clarification and verification.

The relationship between the researcher and participant is also an important consideration. Whether the researcher is already acquainted with the interviewee can shape the direction of the questioning and the information

provided. The narratives provided by participants can also be influenced by gender, power, and authority (Holloway and Freshwater, 2009) and how the participant views the researcher (Charmaz, 2014). In the current study, a decision was made to recruit both participants known and unknown to the nurse-researcher to balance the possible effect of existing research-participant relationships. Additionally, a contemporaneous reflective diary was maintained, and the findings were periodically reviewed by an all-male supervisory team and a male member of the public involvement group.

Finally, although this research is not grounded in feminist theory, there are inherent aspects of feminist philosophy that the author aligns with which are evident within this work and which should be made explicit in order to maintain transparency. Feminist features of this work included seeking to establish collaborative and non-exploitative research relationships (Creswell and Poth, 2017) and a willingness of the nurse-researcher to show emotion, engage in active listening, and be sensitive to the needs of the participants (Carroll, 2013). These aspects are mostly likely to improve applicability of the findings through elicitation of meaningful accounts. However, the use of emotive data collection techniques may induce adverse emotions. Although adverse emotion can be an aspect of the participant's experience that bring about transformative knowledge, the possible emotional burden of the research on both the participant and researcher must be carefully managed to ensure ethical research delivery (Hanna, 2019). Balancing participant well-being while allowing the participant to share their emotions can shape data collection as the interviewer may limit questions that might induce stress. The sampling strategy (described in Section 3.4.1) mitigated the possible limiting of interview questions to reduce participant stress, by ensuring ongoing recruitment of homogeneous and heterogeneous cases to provide a sufficient sample to achieve an in-depth understanding of the issues raised.

3.5.3 Public and patient involvement (PPI)

Public and patient involvement (PPI) helps to ensure that research design and conduct is ethical, appropriate, sensitive, and relevant (Hanley et al., 2004).

PPI activity was funded by a National Institute for Health and Care Research grant provided through a local research design service.

Group members were identified through the host NHS Trust's research public advisory panel and IBD patients known to the nurse-researcher. A four-member group ensured a range of feedback was achieved, while being small enough to co-ordinate meetings, offer training, and develop an effective working relationship with each member. Three members had first-hand experience of living with IBD and the fourth member had experience of living with another chronic health condition. All members were aged 40 or over which unfortunately does not reflect the peak onset of IBD which is 15 to 30 years of age (Whayman et al., 2011). However, two PPI members with IBD had received a diagnosis in adolescence and therefore had valuable experience from a younger age. There was a range of socio-economic and relationship statuses in the group and two members had previously participated in similar public involvement groups. The selective recruitment of members meant that the group were able to provide a range of experiences and reviewed the project from multiple perspectives.

The group advised on the practicalities of the research processes, which may have improved accessibility and acceptability of the project. For example, one member wondered what his wife would think about the information leaflet, and this led to in-depth consideration about postal methods during the study. Three members expressed concern that recruitment of participants may be challenging and were concerned about toilet facilities during face-to-face interviews. This input led to offering online interviews, diary collection (which unfortunately was not taken up by any participants), and photographs.

The study documents including the study protocol, participant information sheets, consent forms, interview guide, and ethics application were reviewed by the PPI group. The PPI contributions improved readability and accessibility of patient-facing documents which may have improved recruitment, but this was not formally evaluated. A slight but important semantic shift within the patient-facing documentation from 'sex' to sexual well-being and identity was also made following PPI recommendations. Another member noted that the

nurse-researcher needed to be flexible when offering interviews and one member highlighted the importance of remaining neutral which led to the rephrasing of the primary research question from 'what is the impact of IBD on male sexual health?' to 'how do men with IBD experience sexual health?'.

The group felt the interviewer should wear their nursing uniform for the interviews as it was a symbol of professionalism and trustworthiness. However, this was not adopted as it was felt by the thesis supervisory team that a clear distinction between a clinical interaction and research interaction was needed. The group did struggle with the idea of photo-elicitation which focused the nurse-researcher's attention on ensuring that it was properly explained. On reflection, greater work could have been done to improve the uptake of photo-elicitation, which was possibly not well understood by participants reflected by its limited uptake.

The PPI group supported an application for research funding from the charity CCUK, which was shortlisted for the second application stage. Unfortunately, due to the covid-19 pandemic the funding call was withdrawn completely. At this point the doctoral fellowship was suspended while the nurse-researcher was redeployed in their clinical role in IBD to work on the intensive care unit. Upon returning from the leave of absence it was decided that reapplying for funding would delay the project and so alterations were made to the project plan so that it could progress in the absence of funding. Most significantly this meant the lack of reimbursement for ongoing PPI time, no participant incentives, and no professional transcription services. Subsequently, only one member of the PPI group was asked to feedback and review the themes but this did improve trustworthiness of the findings and enable a form of member checking.

3.5.4 Ethical considerations

Ensuring the rights, safety, and well-being of patients is fundamental to ensuring ethically conducted research. The study design aligned with the relevant research legislation including the UK policy framework for health and

social care research (HRA, 2017)⁵, The Data Protection Act (2018), Freedom of Information Act (2000), Mental Capacity Act (2005) and the General Data Protection Regulations (2016). Prior to commencing, both primary qualitative studies underwent review by the Health Sciences Research Governance Committee at the University of York. The first study also underwent review by the North East – York Research Ethics Committee and received Health Research Authority approval. The study ethical applications and approval letters can be found in Appendices 4 and 17 and provide full details of how the study processes were designed and carried out. Importantly, these documents assess the possible risks and set out strategies to mitigate risk to participants and nurse-researchers including a data security plan, protection of anonymity, recruitment processes free of coercion and influence. The ethical implications of conducting gender-specific work and utilising photographs are specific considerations in this study design and are discussed here.

While it is essential for research to consider gender differences in order to identify needs that may be gender-specific and overcome gender inequalities, it is also important to not overgeneralise findings which can lead to gender profiling (Johnson et al., 2012). An important consideration within this research was to minimise the risk of the study processes or findings leading to marginalisation of men, women or other genders in regards to sexual health in IBD. On a participant level this was managed by careful interviewing and interaction with participants. The interviews were intended as safe spaces, free of prejudice and this was facilitated by the nurse-researcher's clinical experience. The researcher also explicitly stated that experiences could be shared free of judgement by the interviewer. The risk of the research outputs provoking marginalisation has been mitigated through considered reporting and dissemination of findings. Contemplation of how findings may be misinterpreted or reconstructed in a way that could potentially disadvantage groups within the study was important but also needed to be balanced against truthful reporting of findings. One way in which this was mitigated was to have

⁵ The UK Policy Framework for Health and Social Care Research was updated in 2023 after the completion of the study.

a PPI member review the themes and identify any possible pejorative terminology or misinterpretations. Studies, reports, and publications also overtly sought to discuss the issue and identify the need for further sensitive and unprejudiced accounts of the subject matter. It is important to note that throughout the thesis the quotes extracted were not edited for content to ensure they remained true to the participants account. Although quotes were sensitively selected, as they were not edited they may have the potential to offend readers.

Data collection via photo methods requires additional considerations. Firstly, consideration is needed of vicarious trauma through photographs triggering negative emotional responses in viewers (Creighton et al., 2017). As the nurse-researchers professional training had equipped them with the resilience to discuss sensitive issues, this risk was assessed as being low. A Clinical Psychologist dedicated time for debriefs with the nurse-researcher but this was not required. Photographs shared publicly or with the study team were carefully considered regarding their emotional impact alongside balancing the need to portray an accurate account of the participant's narrative.

Providentially, none of the photographs collected were deemed as too sensitive for sharing. Additional consent for publication of photographs was required. Ensuring the participant retains the copyright of their photograph is ethically important but can reveal the participants identity if not managed appropriately. To overcome this, the nurse-researcher has taken on the role as gatekeeper for data sharing. Furthermore, photographs also needed to be anonymised but it has been argued that pixilating photographs can decontextualise and obscure meanings (Creighton et al., 2017). Initial data analysis of the photographs occurred prior to pixilation but the participants anonymity was paramount so all aspects of a photograph that might reveal a participant's identity were pixilated for printing and archiving. The photographs included in the thesis were carefully selected as to not dehumanise the participants.

3.5.5 Methodological limitations

In qualitative approaches, the data collected and the interpretive findings are contextually defined, relevant to the time and context in which they were captured. Although findings may be transferable to other cultures, diseases, healthcare systems, and periods of time they should not be considered as generalisable. It is recognised that a study of this design would allow for some commonalities to be detected but not an exhaustive list of experiences or potential patient needs. As is argued with similar work exploring masculinity in testicular cancer, it is not necessary to exhaust all possible realities in order to provide useful insights (Gordon, 1995).

Trustworthiness of interview data is limited by the participants' ability to articulate their experiences and the researcher's proficiency at eliciting and interpreting those experiences. Member checking would have mitigated this but was rejected to reduce participation burden. Instead, an approach was favoured of continuing data collection until a data set was achieved that provided in-depth exploration of themes and therefore secure dependability of the themes.

A longitudinal study could have supported exploring changes over time considering the possible effects of the relapsing-remitting nature of IBD. Indeed, a paucity of longitudinal studies was identified within the scoping review (Chapter 2). However, IBD is not always progressive in nature and the timeframe needed to truly explore changes would have exceeded that of the study period of the PhD. To try and mitigate this, it was decided that participants in qualitative study 1 would be provided with a three-month period to provide additional written, audio-recorded, or photographic data if they felt anything had been missed at interview or arose following that was important. It was also identified within the theoretical sampling strategy that it may be important to recruit men of different ages with varying lengths of time from diagnosis and healthcare professionals with differing years of professional experience to capture some of the variation a longitudinal study may have provided.

3.6 Next steps: exploring lived experiences

In summary, this work adopts a relativist ontological perspective within a constructivist paradigm which is well-suited to research that seeks to illuminate lived experiences within social contexts. This theoretical position is supported by ID (Thorne, 2016) which has offered an established methodological approach upon which to scaffold a research study that is grounded in nursing. The adaptable algorithm provided by ID has supported the selection of sampling, data collection, and data analysis methods best suited to gathering rich, contextual understandings that can be transformed into clinically-actionable knowledge. This chapter has described and justified the theoretical perspectives and methodological framework harnessed within this research and provided an outline of the study design for the two exploratory studies within this thesis. The following two chapters provide further detail of how the methods were applied within the two primary research studies and the resultant study findings. The first study (Chapter 4) explores the lived experiences of men with IBD, while the second study (Chapter 5) explores healthcare practitioner understanding and needs in regards to sexual healthcare provision within this field.

CHAPTER 4: QUALITATIVE STUDY 1

An exploratory qualitative study of male sexual health, identity and activity in inflammatory bowel disease

This chapter sets out the study design and findings of the first primary study of this thesis. The peer-reviewed publication that resulted from this work is in Appendix 2. Reporting of this study takes into consideration both the COnsolidated criteria for REporting Qualitative research (COREQ) (Tong, Sainsbury and Craig, 2007) and the Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014).

4.1 Introduction

The scoping review reported in Chapter 2 set out the need to better understand the influence of IBD on sexual health in men and informed the development of the primary research question: what can be learned from the sexual health experiences and activities of men living with IBD? The study aim was to describe and interpret the sexual health experiences and activities of men with IBD to provide interpretations that contribute to clinical knowledge, education, and practice.

The study objectives were to:

- (1a) explore how men with IBD identify, perceive, and make sense of their sexual experiences;
- (2a) describe the interaction between disease, sex life, sexuality, and gender role;
- (3a) identify whether men's sexual experiences and activities tell us anything about their sexual health and welfare that may be amenable to nursing intervention and support.

As detailed in Chapter 3, Interpretive description (ID) (Thorne, 2016) provided the methodological framework and informed the development of the study design and analysis. A qualitative framework was best suited to the research

question and is a valid approach for gathering and interpreting the lived experiences of men with IBD. Utilisation of existing nursing knowledge and clinical experience throughout the research process was permitted through the adoption of a constructivist approach.

4.2 Methods

4.2.1 Study population, sampling and recruitment

Men with a diagnosis of IBD were recruited via three NHS hospitals and online advertising through the national IBD charity Crohn's and Colitis UK (CCUK). The sampling framework and recruitment processes were reviewed for acceptability by the study public involvement group and are described below.

As discussed in Chapter 1, modern constructions of gender are not binary and may not reflect the chromosomally determined biological sex of a person. In Chapter 2 it was identified that erectile function has been the mainstay of male sexual health research in IBD to date. The broader aspects of sexuality and sexual well-being have been largely overlooked in the field of IBD. To capture the multifactorial nature of sexual health while encompassing both biological and psychosocial considerations, the study population included people that identified as male regardless of biological sex.

The participant inclusion criteria were as follows:

- a diagnosis of Crohn's disease, ulcerative colitis, IBD-U or microscopic colitis;
- ≥ 18 years at time of enrolment;
- identify as male;
- able to give informed consent;
- English speaking;
- medically well enough to attend an interview.

Chapter 3, section 3.4.1 provides a comprehensive description and justification for the sampling framework utilised. Purposive sampling provided

a “starting point to launch the data collection process” (Butler, Copnell and Hall, 2018, p562) and enabled the recruitment of male participants with relevant experience of sexual health in IBD while ensuring diversity and breadth of personal and disease characteristics.

This approach was followed in the later stages of the project with a theoretical sampling approach, as described by Thorne (2016). This method supported rigorous exploration, refinement, and testing of emergent themes produced by concurrent data analysis. Theoretical sampling was achieved through screening demographical information and disease presentation of potential participants through an NHS IBD clinic. For example, it was identified that a further participant with young children was needed to explore coding around fatherhood and therefore men with young children were provided with the study contact-us leaflet (Appendix 5). Recruitment was terminated when there were no new emergent themes (saturation).

Two different recruitment processes (NHS and Non-NHS) were adopted to ensure:

- a demographically varied group of potential participants;
- a sufficient sample size to meet saturation;
- a diverse sample to allow theoretical sampling decisions to be made.

NHS site recruitment

Participants were recruited at three NHS teaching hospitals in North Yorkshire, England. Hospitals A and B were selected because the nurse-researcher was employed by the NHS Trust for these hospitals and could screen patients on site. This was particularly advantageous for the theoretical sampling stages where screening of participant characteristics and demographics was required for maximum variation in the sample and testing of emergent themes. Hospital C served approximately 1.7 million outpatient visits a year (compared to 0.5 million outpatient visits per year for hospitals A and B combined) and was added as a patient identification centre (PIC) to ensure further demographic diversity in the NHS recruited stream. A fourth

small district hospital was identified as a PIC but did not advertise the study due to capacity constraints on site. This did not hinder overall recruitment to the study.

During initial purposive sampling, patients were identified and checked for eligibility by IBD specialist nurses and Consultant Gastroenterologists when they attended outpatient clinics or called the telephone advice line. At this point no other patient or disease characteristics were reviewed. Over a period of 4-weeks, approximately 100 potential participants were provided with a contact us leaflet (Appendix 5). Patients were asked to email or telephone the nurse-researcher if they had any questions about the study or wanted to participate. They were then provided with the participant information sheet (PIS) (Appendix 6). The process and subsequent numbers of participants recruited are detailed in Figure 4.1.

Theoretical sampling involved screening potential participants for eligibility alongside other characteristics available on the hospital central patient database or revealed during clinical consultations. The following disease and demographic characteristics were sought to test emergent themes or capture variables not yet captured within the data set:

- rectum removed due to disease;
- limited disease extent (proctitis confined to the rectum);
- medical therapy failure/awaiting surgery;
- new diagnosis;
- divorced;
- parent;
- penile disease/possible manifestation of the disease.

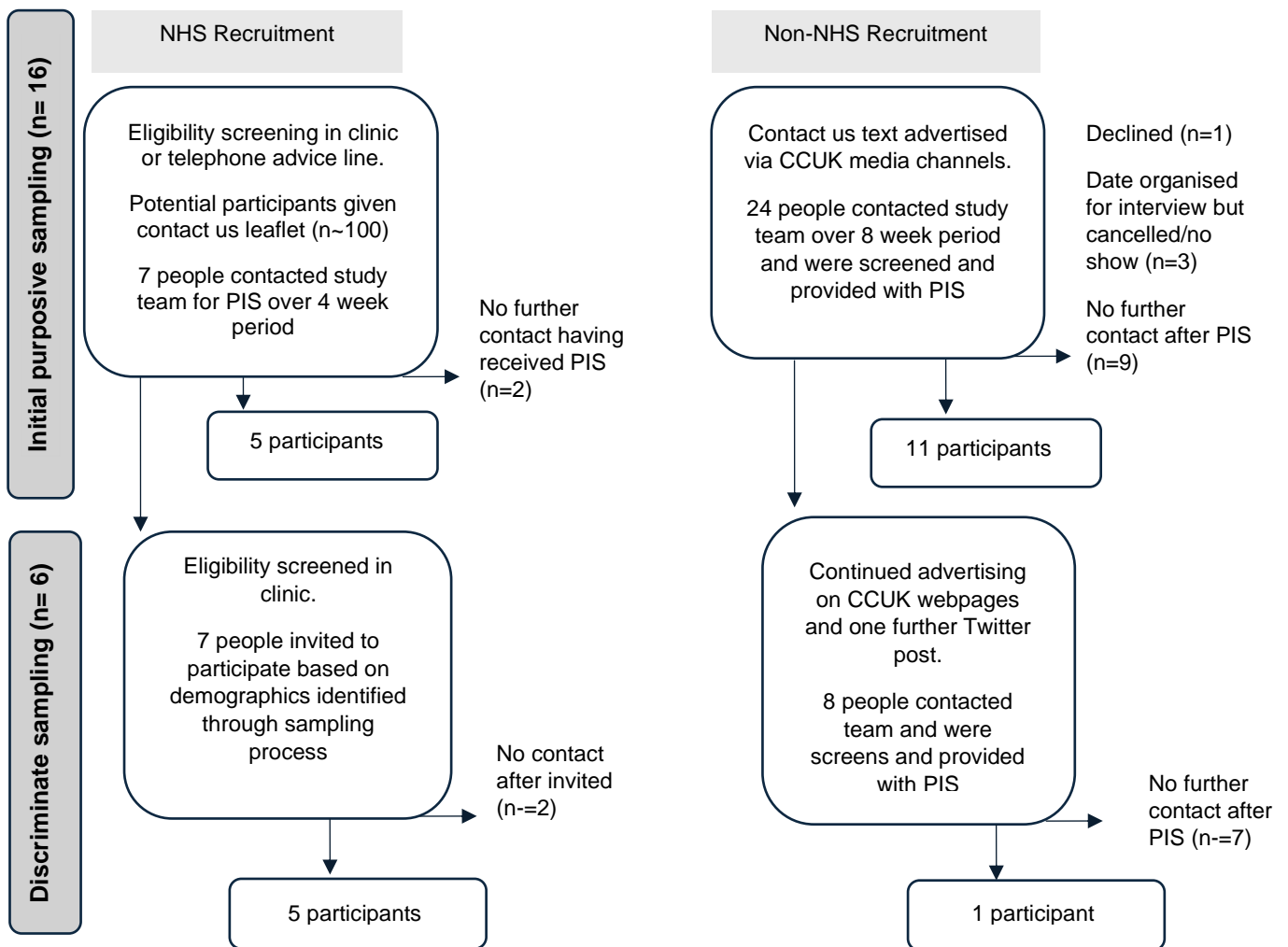
Non-NHS site recruitment

Concurrent to NHS recruitment, CCUK made a call for participants through their social media platforms and website. People interested in participating could either complete an online contact form or contact the nurse-researcher directly via telephone or email. Following contact from a potential participant, a study PIS was provided either by email or post. One follow-up call or email was made to discuss the project following provision of the PIS.

After initial advertisement of the study via CCUK, 24 people contacted the nurse-researcher over a period of 8-weeks and 11 men in this cohort elected to participate (Figure 4.1). The advert remained live and a further 8 people contacted the nurse-researcher with one person electing to participate. One participant saw the CCUK advert and was coincidentally a recently diagnosed patient at Hospital A. He was recruited during the theoretical sampling stage to provide an additional perspective of someone who had been recently diagnosed with Crohn's disease and undergone surgery.

All potential participants were provided with at least 24 hours to consider the information, ask questions, and discuss the project with others. Eligibility was reconfirmed and written informed consent obtained, either by post or email. The recruitment processes followed Good Clinical Practice guidelines (ICH, 2017) and the UK Policy Framework for Health and Social Care Research (HRA, 2017). It was made explicit that participation in the study was voluntary and that non-participation did not change or affect clinical care.

Figure 4.1: Recruitment process for qualitative study 1



4.2.2 Data collection

Qualitative data were collected using individual, semi-structured interviews. Clinical and demographic details were retrieved via a questionnaire completed by the participant. Participants were also provided with the opportunity to submit photographs or written accounts to support or describe their experience narratives.

Demographic data and questionnaires

A questionnaire (Appendix 7) was supplied to participants prior to interview. This was used to construct a contextual background of the participants including how long they had lived with the disease, whether they had received prior surgery, and their current treatment. This information provided insight into the participant's current situation and supported the conduct of sensitive interviews.

The International Index of Erectile Function (IIEF) (Rosen et al., 1997) and IBD-Male Sexual Dysfunction Score (IBD-MSDS) (O'Toole et al., 2015) measures were incorporated into the questionnaire. These scoring systems provided a platform for discussing this sensitive topic and prepared the participant for the interview and for reflecting on their sexual health experiences. Considering the responses to the measures alongside the participant's narrative also aided interpretative analysis of their experiences.

Participant interviews

Semi-structured interviews were conducted via video call (n=18), face to face (n=3), or over the telephone (n=1) and always privately. The option for remote interviews meant that participants across the UK could be recruited. Remote interviewing was strongly favoured by the public involvement group who felt that this method provided a more comfortable setting for the participants to answer sensitive and personal questions. Interviews were audio recorded and transcribed verbatim for analysis. The interviewer also took notes during the interviews to aid thinking and help return to points raised for further clarification. One interviewer performed all interviews and transcription, both for consistency and to aid constant comparative analysis.

An interview guide (Appendix 8) contained questions relevant to the research objectives along with key words and prompts to support the interviewer to delve deeper into discussions that could develop the researcher's understanding of the participants' experiences of sexual health. The guide was reviewed for legibility, applicability, and acceptability by the public

involvement group. Initial background questions covered the participant's disease journey to help contextualise the sexual health questions, build rapport and improve participant comfort. Questions included, 'Can you start with telling me a bit about your journey with inflammatory bowel disease?' and 'Can you tell me a bit about your day-to-day life?'. This was followed with questions based on the four categories: being a man, relationships, sex, and support with sexual well-being.

The interview guide supported the elicitation of desired narratives specific to the research questions and did not require any formal amendments during the study. However, the interviewer did rephrase or adapt questions according to the patient narrative or based on prior experiences of responses. This was necessary to explore areas that had or had not been covered to expand knowledge and test emerging themes, for example, *"some people worry about incontinence during sex.....is that something you relate to or you feel differently about"*.

Making questions generic is a validated technique in studies of this nature. In a study of health masculinities, Sloan et al. found that men did talk about their health issues but "avoided personal and emotional referents" (Sloan et al., 2010, p789) while Chabot and Shoveller (2012) found that men preferred to use an impersonal tone when being interviewed. Adopting techniques to 'de-personalise' the questions at points during the interview was one way to improve participant comfort and in fact enhanced their story telling.

Semi-structured interviews were on average 60 minutes long and ranged from 24 minutes to 1 hour 58 minutes. The variation in length reflects the differences in the complexity of participants' narratives, how much detail they felt appropriate to provide and individual participant preferences and constraints. Thorne (2016) suggests removing any extraneous data from transcripts but this was not required. During interviews, participants were mostly sensitive to, and aware of the difference between a research interview and clinical consultation, with a good understanding that they were attending to give information rather than receive clinical advice or care. This could have been due to a clear information sheet and thorough informed consent

practices. All participants were aware of the interviewer's role as a clinical specialist nurse but the interviewer did not wear a nursing uniform so as to distinguish themselves as a researcher in the context of the study. The three face-to-face interviews were also conducted in hospital meeting rooms rather than clinical consultation rooms for this reason. There were only a couple of occasions the researcher had to steer the interview back from discussion of other topics or from providing clinical advice.

Participant written, audio or pictorial accounts

Sexual experience is a sensitive and private topic that some participants may find difficult to convey during an interview. As described in Chapter 3, section 3.4.2.3, photo elicitation is becoming a more widely incorporated research technique and data collection tool in qualitative health research. Integrating photographs into interviews can trigger participant recall of events and improve discussion (Glaw et al., 2017). When a participant is asked to bring photographs to an interview it can grant the interviewer insight into the individual and personal aspects of the participant's life, providing a useful springboard to discussion and aiding storytelling. The rationale for photo elicitation was detailed in the PIS and discussed during the consent process. Maintenance of confidentiality and the retention of copyright to the photographs was considered and detailed within the consent process. Participants were given some guidance in the PIS (Appendix 6) and verbally, including clarification that photographs could be of their everyday lives and anything they thought might be relevant to describing the wider aspects of their sexual well-being. Unfortunately, participants did not bring photographs to the interview, this may have been because participants either did not fully understand the rationale for bringing photographs or they did not feel comfortable doing so.

Additionally, the submission of photographs was permitted in the form of auto-photography data as discussed in Chapter 3, section 3.4.2.3. These photographs were intended as supplementary data to give voice to the participant. The opportunity to take or supply photos provided participants with time to consider their experiences and decide how they wanted to express or

represent them. Participants were guided in the PIS towards the types of photos that could be supplied, for example;

“Photographs could be of anything that is important in your life from your family or partner, your hobbies, things you enjoy or pictures at different time points of your life....Photographs that reveal your identity will not be used in any publication.” (Appendix 6, page 3).

The supply of additional data was limited to a three-months period to ensure each participant's dataset could be analysed completely and in a timely fashion. This gave participants time to reflect on the interview and add any further thoughts or experiences. Participants were reminded of this option at the end of the interview and in one follow up email. This strategy had greater success and a total of eight participants submitted photographs following the interview. Having participated in the interview and developed rapport with the interviewer, participants were seemingly more willing to share photographs and possibly had better understanding of the potential insights that photographs can provide. For example, one participant provided a picture of his bicycle which he had sold due to not being able to exercise, prior to the interview he may not have readily considered the impact that giving up social activities and exercise might have on his sexual health.

4.2.3 Data analysis

4.2.3.1 Analytical approach

A constant-comparison analytical approach informed by Constructivist Grounded Theory (Charmaz, 2014) was adopted. Data collection and analysis occurred concurrently. Where possible, audio recordings were transcribed and analysed prior to the next interview but there were a couple of occasions where this was not possible due to the close succession of interviews (for example, on one occasion two interviews were held on the same day). As described in Section 3.4.3, data analysis broadly followed thematic analysis (Braun and Clarke, 2006) supported by the analytical steps of 'initial coding', 'focused coding', and 'memoing' as described by Charmaz (2014). In practice,

immersion and familiarisation with the data was achieved through the researcher undertaking all of the interview transcribing and producing concurrent analytical notes.

NVivo 9.0 QSR NUD.IST was used to sort data and code segment-by-segment, enabling simultaneous comparison of new and previous codes. All codes, sub-themes, and themes were logged using a Microsoft Excel spreadsheet. The code-log provided overview of the development of codes and progression of analytical ideas (Appendix 12). In order to “move beyond thematic analysis and into the more creative and interpretive realms of figuring out options for depicting patterns and meanings” (Thorne, 2016, p. 169), creative and tactile ways of reconstructing the coding outside of the traditional NVivo approach were used. This involved using post-it notes, highlighting captions, printing of quotes, noting key ideas, and drawing diagrams to make connections and visualise patterns and concepts.

Four experienced academics and a member of the public involvement group not involved in data collection, provided feedback on themes and sub-themes given to them in charts containing a description of the code, explanation of how the themes evolved, and excerpts of the interviews (Appendix 13).

The data from the questionnaire were entered into a Microsoft Excel spreadsheet. Basic statistics to report demographic details were calculated, for example, the mean age of participants and the international index of erectile function (IIEF).

4.2.3.2 Analytical process

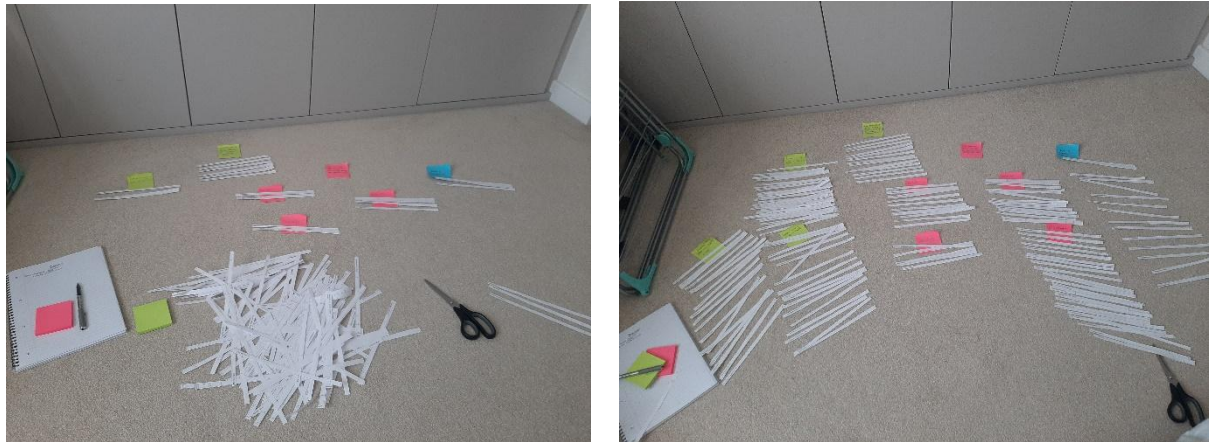
Initial coding of interview transcripts was undertaken line-by-line either with single words or short phrases to label key ideas and descriptors. These are referred to within the analysis as ‘initial codes’. Thorne (2016) recommends against fastidious or over-enthusiastic coding but the depth and breadth of the interviews, alongside the limited experience of the coder led to many initial codes being generated. After the first interview there were 74 initial codes, many of which were ‘de novo’ for example, “being a sicknote” and “crack on”.

Initial codes from the first interview were reorganised into 18 categories. Categories reflected broader ideas such as 'continuing to work' and were an interim step used to help organise the quantity of data.

Analysis continued in this way, with initial codes being retained within categories to support constant comparative analysis. By the 5th interview there were 108 initial codes many of which were synonymous or contained only subtle differences in meaning from other codes. Examples include 'being frustrated' and 'feeling mardy' which sat within the category of 'the emotional baggage carried by IBD'. Retaining the initial codes enabled the coder to articulate and interpret the emerging patterns, for example the initial codes 'being ill as a feminine trait' and 'treatment taking away feeling masculine' were grouped into the category 'the emasculating effects of IBD'.

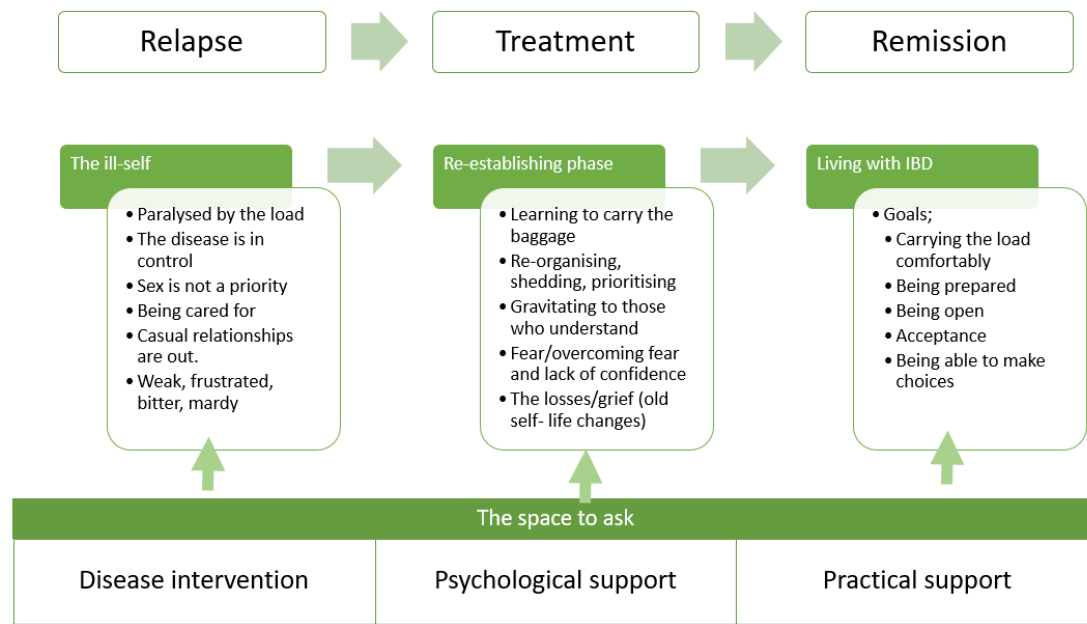
After interview 5 there was sufficient data to begin preliminary focused coding, which required taking a wider view of the initial coding. To support this process, initial codes were physically printed to allow an iterative form of sorting, synthesising, and reassembling the data (see Picture 4.1). Importantly, this process allowed patterns to be clearly visualised while highlighting areas that needed further exploration or clarification in future interviews. Various combinations were tested, while referring to the wider context of the interview transcripts. This was done over several days to ensure careful consideration and reflection over the resulting 7 categories which included 'the interaction between disease and masculinity' and 'the interaction between disease and gender role'. These categories were different to themes and sub-themes in that they did not represent elucidations or fully realised concepts.

Picture 4.1: Sorting, synthesizing and reassembling the data in qualitative study 1



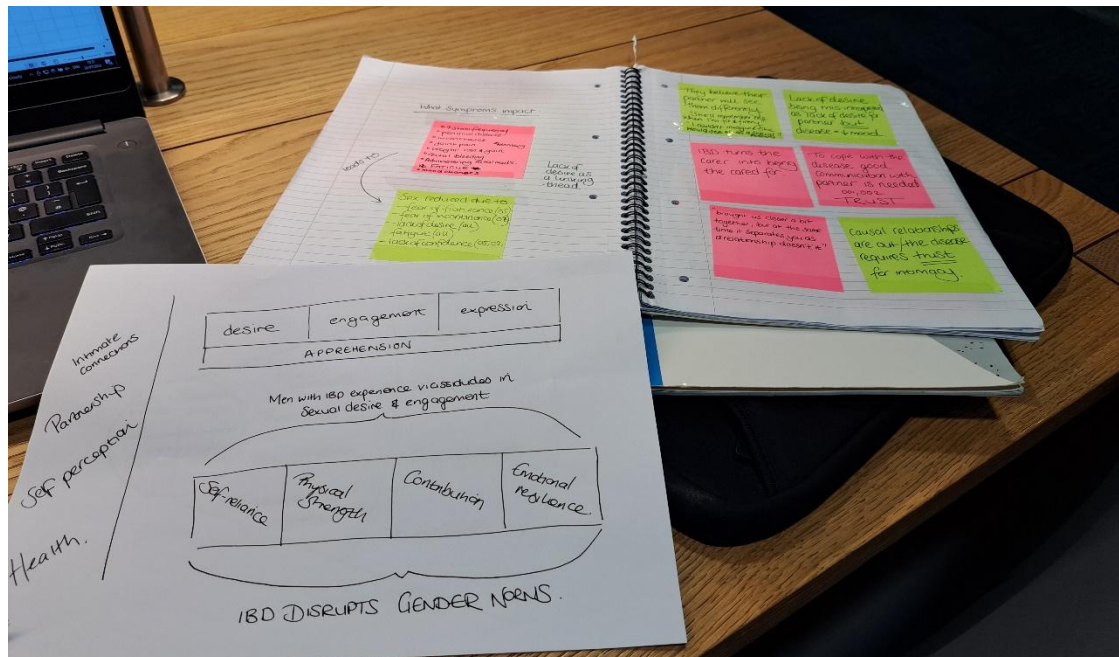
This process was replicated between the 6th and 10th interviews. After the 10th interview there were 94 initial-codes sorted into 9 categories. Analytical thinking cyclically moved between descriptive and interpretive constructions of the data. Recurring patterns were substantiated or negated as more narratives were collected. As the data set increased it was possible to articulate heterogeneous, critical, and deviant cases as described in the findings (Section 4.3). To aid interpretive analysis, intersections between emergent themes and professional understanding of the disease were illustrated. This is depicted in Figure 4.2, where codes are listed and grouped into disease phases and treatments. Fracturing and reconstructing the data in this way facilitated the critical understanding and organisation of ideas into clinically useful, disease specific observations.

Figure 4.2: Early coding visually organised by treatment phase (qualitative study 1)



Following the 16th interview, initial coding became static and there was sufficient available data to begin developing the codes and categories into themes. One example was the category ‘the interaction between disease and masculinity’ that directly evolved into the final theme ‘IBD disrupts male gender norms’. This process involved careful consideration and testing of the codes against interview transcript excerpts and reviewing the data set holistically. The development of themes and sub-themes was supported and tested using diagramming and memoing (Picture 4.2).

Picture 4.2: Diagramming and memoing during data analysis in qualitative study 1



The spreadsheet of data collected from the questionnaires was referred to throughout the analysis to compare demographic details and disease presentations. This technique supported consideration of similar or opposing concepts and ideas through the individual narratives.

Photographs were provided to the researcher at different time points by participants after the interview. This meant that not all photographs were analysed concurrently with the participant's interview transcript. This was not problematic because of the non-linear and cyclical analytical approach applied to the overall data set. The delayed addition of photographs at times improved rigorous testing of the coding as it prompted the researcher to revisit the transcript and re-challenge or further develop the analysis.

Occasionally, participants submitted a photograph with a written description, which was useful when the picture did not show something that had been discussed in the interview. For example, one participant, 'Hugo' provided a picture of a tin which he described as his "pharmacy tin" that had not been mentioned previously. To manage the visual data, all photographs were imported into a single Microsoft Powerpoint presentation alongside a text box

used for memoing and storing corresponding relevant quotes. A descriptive analysis coined by the researcher was added and linked to the code-log. Importing the photographs into a single document aided a constant comparative approach to the auto-photography supplied.

There were not enough photographs to apply the in-depth analysis described by Glaw et al. (2017) that involves organising photographs into tables and a structured analysis through categorisation, frequency counting and comparison across themes generated exclusively from the photographs. This approach is suited to studies with a large corpus of visual data, which was not the case in the present study. Instead, photographs were treated as supplementary qualitative data that contributed to the richness and contextual depth of the participants narratives. They were coded inductively alongside interview transcripts. The inclusion of photographs in this study therefore more closely aligns with interpretive approaches to traditional photovoice where the visual data is valued for its expressive content rather than as an aid to thematic analysis. Given the limited number of photographs, a selection of the most illustrative and conceptually relevant images has been integrated into the finding (Section 4.3) rather than presenting them in a separate photovoice section. This decision was guided by the aim of preserving coherence and flow of the participant stories. These are presented alongside a descriptive commentary to situate the findings and enhance transparency. Additional photographs and related reflections that are not central to the analytical narrative but remain valuable to the overall study can be found in Appendix 14.

The analytical process was integrally reflexive, facilitated through a researcher diary. This process was essential to ensure that the researcher remained close to the data and recognised their role in constructing the data. Appendix 15 provides extracts from the researcher diary to demonstrate how reflection was incorporated throughout the analytical process.

4.2.4 Transparency and trustworthiness of findings

Several strategies (discussed in more detail in Chapter 3) were used to ensure research rigour and the trustworthiness of the findings. In a qualitative study this is achieved through reflexivity and transparency of the data collection and analysis process. Full verbatim transcription of interviews, maintaining a reflective diary throughout the study, and meticulous logging of coding supported the transparency of the analytical processes employed in the study. Peer review of the coding, incorporation of photography, and use of participant words when coding supported trustworthiness of the findings.

4.2.5 Ethical and regulatory considerations

The study was reviewed by the Health Sciences Research Governance Committee at the University of York on the 31 January 2022 and given approval for progression to NHS REC review. Health Research Authority approval was received on the 30 May 2022 following review by the North East – York Research Ethics Committee. Full details of the ethical considerations and risk assessment and management of risk for this study including informed consent procedures can be found in the study protocol (Appendix 3) and data management plan (Appendix 9).

4.3 Findings

4.3.1 Participant characteristics

22 people participated in the study with no withdrawals. Interviews were conducted between the 1 July 2022 and 1 February 2023. 12 participants had been made aware of the study through CCUK and 10 through their NHS secondary care provider. Participants were aged between 20 and 66 years at the time of interview. The number of years between diagnosis and interview ranged from 0 to 53 with a median of 6 (IQR 2-16). Participant age, relationship status and sexual orientation are detailed in Table 4.3, with additional descriptive statistics of participant age and relationship status provided in Tables 4.1 and 4.2 respectively. 21 participants were born male

and 1 participant identified as male and had undergone gender affirming surgery.

Participants were interviewed by video call (n= 18), telephone (n=1), and in person (n=3). Eight participants submitted photographs to be included as part of their data set. All participants spoke English and were residing in the UK at time of interview, but English was not the native language of 4 participants. Occupational data was also not collected in the pre-interview questionnaire but during the interviews occupation and socio-economic status was often discussed and is listed in Table 4.3.

Table 4.1: Participant age in qualitative study 1

Age	Number (%)
18-29	9 (40.9%)
30-39	6 (27.3%)
40-49	3 (13.6%)
50-59	2 (9.1%)
60-69	2 (9.1%)

Table 4.2: Participant relationship status in qualitative study 1

	Heterosexual (n=17)	Bisexual (n=3)	Homosexual (n=2)
Cohabiting (n=9)	7	2	0
Married (n=7)	7	0	0
Single (n=3)	1	0	2
Dating (n=2)	2	0	0
Divorced (n=2)	0	1	0

Table 4.3: Participant demographics, listed in order of interview in qualitative study 1

Pseudonym	Age	Disease	Years since diagnosis	Sexuality	Partnership status	Occupational status
Alex	28	UC	1	Heterosexual	Cohabiting	Working
Andy	28	CD	19	Bisexual	Cohabiting	Working
Arthur	47	CD	0	Heterosexual	Married	Working
Benjamin	20	UC	5	Heterosexual	Cohabiting	Student
Dara	24	CD	0	Heterosexual	Single	Working
David	66	IBD-U	53	Heterosexual	Married	Retired
Ethan	28	CD	12	Heterosexual	Cohabiting	Working
Ewan	34	CD	2	Heterosexual	Married	Working
Frank	31	CD	4	Bisexual	Cohabiting	Working
Freddie	64	CD	16	Homosexual	Single	Working
George	37	CD	21	Heterosexual	Married	Working
Guy	58	UC	7	Bisexual	Divorced	Unable to work
Hugo	24	CD	7	Heterosexual	Cohabiting	Working
Noah	38	CD	22	Heterosexual	Dating	Working
Oliver	52	UC	0	Heterosexual	Married	Working
Peter	26	UC	10	Homosexual	Single	Working
Raphael	43	CD	22	Heterosexual	Married	Working
Sam	28	CD	4	Heterosexual	Cohabiting	Working
Steven	31	CD	16	Heterosexual	Cohabiting	Working
Tim	46	CD	1	Heterosexual	Non-cohabiting	Working
Toby	34	UC	3	Heterosexual	Married	Working
Tom	28	CD	4	Heterosexual	Cohabiting	Working

Disease data is presented in Table 4.4. Participants reported a diagnosis of Crohn's disease (68%), ulcerative colitis (27%) or IBD-U (5%). Most participants (73%) reported mild disease at the point of interview even though the majority (81%) had previously or were currently requiring biological therapy, which is usually an indication of moderate to severe disease. 55% of participants reported previously needing IBD-related surgical intervention. Several extra-intestinal manifestations were reported (Table 4.4) indicating that the study population generally had disease presentations that would require regular secondary care (i.e. specialist) review and follow up.

Table 4.4: Participant disease data in qualitative study 1

Category	Sub-category	Number (%)	Category	Sub-category	Number (%)
Disease	Crohn's disease	15 (68.2%)	Participant rated disease severity	Mild	16 (72.7%)
	Ulcerative colitis	6 (27.3%)		Moderate	5 (22.7%)
	IBD-Unclassified	1 (4.5%)		Severe	1 (4.5%)
Extra-intestinal manifestations	Perianal disease	8 (36.4%)	Co-morbidities	Hypertension	2 (9.1%)
	Ankylosing spondylitis	1 (4.5%)		HIV	1 (4.5%)
	Inflammatory arthritis	1 (4.5%)		Eczema	6 (27.3%)
	Oral Crohn's	1 (4.5%)		Psoriasis	2 (9.1%)
	Uveitis	1 (4.5%)		Non-IBD arthritis	5 (22.7%)
	Erythema nodosum	2 (9.1%)		Depression	4 (18.2%)
Treatment history	History of surgery	12 (54.5%)	Stoma	Prior stoma	1 (4.5%)
	Current or prior biologic therapy	18 (81.8%)		Current stoma	3 (13.6%)

Eight participants (53%) with CD reported perianal disease, which is much higher than the general CD population prevalence of perianal disease reported to be 19% (Tsai et al., 2022). This observation possibly reflects the severity of the perianal phenotype of CD (pCD) and its impact on day-to-day life. This presumption is supported by the finding that all eight participants with pCD had previously had surgery and were current or prior users of biologic therapy. Four out of 22 participants had (or previously had) a stoma, three of whom were in the pCD group. Two of the eight pCD patients had been treated for depression and two were single at the time of interview.

The scoping review (Chapter 2) indicated that pCD was not an independent risk factor for erectile dysfunction (Ma et al. 2020) and this finding was supported further by this data with comparable mean IIEF scores in the pCD and non pCD subsets (54.6⁶ vs 54.9 respectively). IBD-MSDS means were also similar between the two subsets (11.9 in pCD group, 10.6 in non-pCD group). The sample size was too small to undertake a true statistical

⁶ "Freddie's" data was removed from this calculation due to being aphallic and therefore unable to complete the erectile function questions of the IIEF. His data remains in the overall IIEF data as he was able to answer questions from the remaining categories of the IIEF.

comparison between the pCD and non-pCD groups but the presence of perianal disease was considered during the qualitative analysis.

IIEF and IBD-MSDS scores are provided in Table 4.5. The mean score for the IIEF domains are similar to the control group of the original study (Rosen et al., 1997) where erectile function was reported at 25.8 (SD 7.5), orgasmic function 8.8 (SD 2.9) and sexual desire 7.0 (SD1.8). This suggests that the level of Erectile Dysfunction (ED) in this study was comparable to the general population. However, according to the IIEF recommendations, two participants would have been suitable for a trial of sildenafil, seven for psychosexual therapy, and five for androgen and prolactin-testing.

In the IBD-MSDS validation study (O'Toole et al., 2018) the mean score was 4.6 (SD 6.2) in 175 IBD patients, which is lower⁷ than in the study sample (11.08, SD 5.85). This indicates that disease symptoms were impacting on sexual health in the study group, but not necessarily erectile function.

Table 4.5: Sexual dysfunction scores in qualitative study 1

Category	Sub-category	Total possible score	Mean (SD)
IIEF	Total	75	53.4 (±16.1)
	Erectile function	30	23.4 (±7.8)
	Orgasmic function	10	8.1 (±2.9)
	Sexual Desire	10	6.7 (±2.1)
	Intercourse satisfaction	15	7.7 (±4.4)
	Overall satisfaction	10	6.8 (±3.1)
IBD-MSDS	Total score	40	11.1 (±5.9)

4.3.2 Overview of core themes

Interpretation of the sexual health experiences and activities of men with IBD led to the development of three core inter-related themes (Figure 4.3). The first theme, 'IBD shapes intimate connections', draws together descriptions of how the symptoms, treatments, and possible complications of IBD can alter men's relationships with their sexual partners. These experiences were

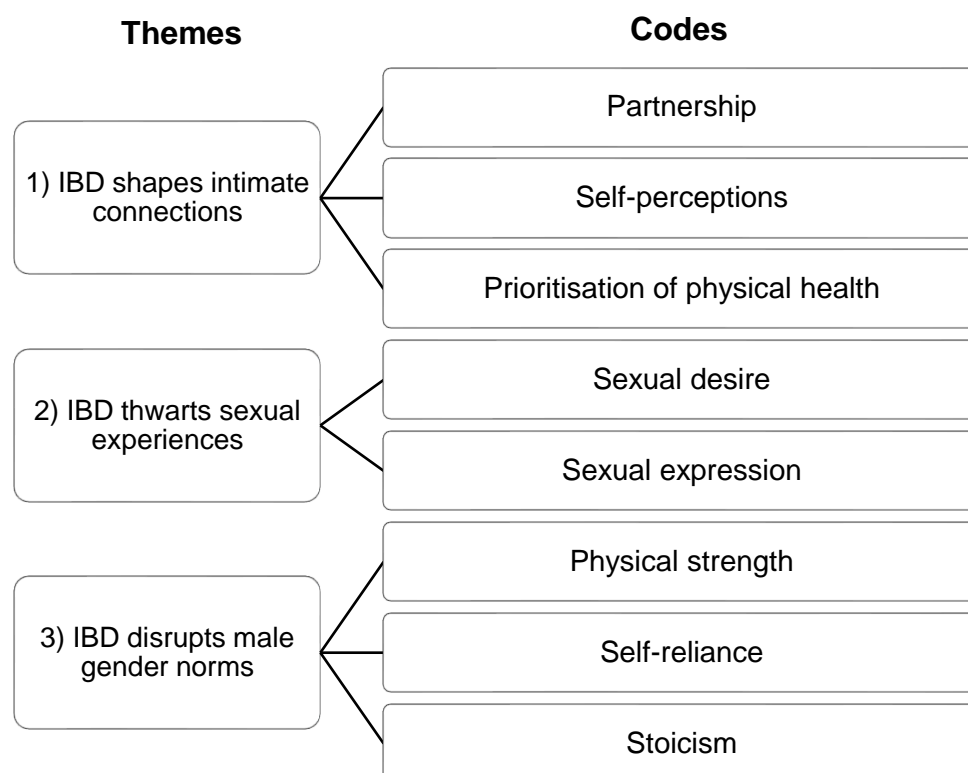
⁷ Low scores are correlated to better sexual health or function in the IBD-MSDS.

attributed to the disease modifying how men engaged in and sustained partnerships, changes to self-perceptions, and the impact of prioritising physical health on relationships.

The second core theme, 'IBD thwarts sexual experiences', conveys the finding that the disease can negatively affect sexual engagement by reducing desire and in some cases constraining or limiting expressions of sexuality.

Finally, the theme, 'IBD disrupts male gender norms', encapsulates men's narratives that expressed disruption to male gender ideas which could occur in a range of ways and to varying degrees dependent on disease presentation, individual life experiences, and social context. Maintaining male gender norms could be detrimental to self-perception and harmful to sexuality but conversely could also aid resilience and disease management.

Figure 4.3 Coding tree of final themes and codes for qualitative study 1



4.3.3 Theme 1: IBD shapes intimate connections

Theme 1 draws together the impact that living with IBD can have on relationships with sexual partners. The experiences discussed in the interviews mainly centred around the communication, interaction, and feelings that occur between intimate partners outside of coitus that could influence engagement in sexual relationships and overall sexual health. Descriptors of intimacy such as passion, tenderness, and affection were largely absent from men's narratives. Instead, men frequently referred to difficulties in communicating to intimate partners the impact that the disease was having and the reasons for their personal lack of sexual desire. The impact of the disease on relationships and partners was described with a sense of self-reproach.

"I felt so guilty that she was having to take on that role for me and that definitely impacted, not just at the time, but you know for quite a while.."

Andy, 28yrs, bisexual, cohabiting

The three sub-themes of partnership, self-perceptions, and prioritisation of health, illuminate how men internalised living with the disease, and were evident in men with varying relationship statuses.

4.3.3.1 Partnership

"a lot of it is finding the right partner"

Alex, 28yrs, heterosexual, cohabiting

An understanding and trusted partner was important to many participants and led to successful sexual engagement, whether that was in casual or long-term relationships. A variety of different sexual partnerships were discussed in the interviews including one-night sexual encounters, group sex, and most commonly monogamous coupling. Common to men's accounts was a view that if sexual partners were understanding of IBD and the disease symptoms, there was more likely to be a level of ease and successful sexual engagement. However, some men discussed the difficulty in explaining the hidden IBD symptoms and unpredictability of the disease to partners,

"I tried casual sex a couple of times and just never gelled with it really. And I think in part that's it, I have to feel really comfortable with someone to be that intimate with them. And that could well be 'cause you know, I mentioned that I wouldn't necessarily go into the gory detail of my Crohn's disease with someone I didn't know particularly. So, I guess subconsciously I'd be oh, you know like if I had this casual hook-up or whatever and then I was unwell halfway through."

Andy, 28yrs, bisexual, cohabiting

The preference for intimate partners to know about their disease meant sexual intercourse was enjoyed more when respondents were well acquainted with the sexual partner. Guy spoke about engaging in multiple sexual relationships simultaneously, implicitly indicating that partners were not always aware of his disease. However, he went on to say that if he wasn't feeling entirely well with his disease, he would turn to the people who understood.

"Those are the people that if they come around to have a chill out now and just watch movies or whatever, but the point is, have a fun time, then there's oral sex and other things you can do. So, that's not an issue, that's not a problem. But that's the people you know, like you, basically it's being comfortable enough. You don't have to explain yourself."

Guy, 58yr, bisexual, divorced

One challenge faced by many men was when to disclose the disease to a new partner. David expressed feeling concerned over whether it would *"make a difference"* to the relationship. Noah described the trouble of *"trying to gauge what they would accept"* and a *"fear that they'll find it quite disgusting"*, although he could explain the disease to acquaintances, he said *"I really, really struggle talking to loved ones about it"*. Peter authenticated the fear of possible rejection and provided an example of a person he had met on a night out withdrawing from a possible sexual encounter upon learning Peter suffered from IBD. As well as the fear of rejection, opening up to partners may also have been driven by not wanting to *"put that emotional physical stress on your partner, to change their role from potentially being cared for to being a carer"* (Arthur).

Participants recently diagnosed with the disease described being lucky to have an existing partner who was understanding. Alex, who was in a relationship when he had been diagnosed, believed that he wouldn't have been able to date if he had been single.

"Guaranteed, you aren't pulling. How are you going to a club where you can't drink, you can't go out for a meal dating... you've lost 10kg of weight, you're shitting blood. How do you explain that?"

Alex, 28yrs, heterosexual, cohabiting

In contrast, Andy who had been diagnosed with IBD as a child, described successful relationships post-diagnosis but did express concerns over the impact of his condition on his partners. Andy was clear that he would not conceal his disease from sexual partners and said; *"it's part of who I am... so I only really associate with people that would accept that"*.

Noah and Alex spoke of relationship breakdowns that were in part a result of not being open to their partners about the disease. Men attributed not discussing the disease to being embarrassed and not wanting to burden their partners. This is reflective of a typical masculine ideal of being strong and resilient, expressed by many participants and discussed in more depth in the theme 'IBD disrupts gender norms' (Section 4.3.5).

"It's my problem, you don't have to worry about it, but I think generalising over sort of failed relationships over a number of years, actually maybe that approach hasn't been very good, because I'm not telling them everything and I think there's an element that I don't open up."

Noah, 38yrs, heterosexual, dating

Tim detailed how not conforming to the hegemonic masculine ideal of stoicism and opening up to his partner had aided sexual engagement and opened the door to better support from his partner.

“Probably, for the first time ever to be really open and vulnerable with somebody and let her know exactly how I was feeling. But along with that is trust in the ability to do that with somebody and it's kinda like, you know what there is, there is nothing I can do now but be brutally honest with my feelings and everything that goes with it. So in some respects, I mean she, when we talk about that cared for period ... you know she had my meals planned, she was making breakfast, tea, snacks in between and she literally had everything documented.”

Tim, 46yrs, heterosexual, non-cohabiting relationship

Healthy and strong partnerships were also reported to have a positive impact on disease management, with good disease management feeding into good sexual health. An example of this happening was Sam's experience of a partner sourcing specialist stoma bags for him to make him feel more comfortable while engaging in sex. However, this was not a universal experience and some men also revealed a change in relationship dynamics when their partners took on caring responsibilities. Alex described the disease as having *“brought us closer a bit together, but at the same time it separates you”*. Alex discussed the shame of his partner having to assist with medications and questioned why she continued to stay with him; *“now she's putting rectal therapies in my bum hole... I would have called it a day if I was her”*. This sense of guilt and embarrassment with partners having to assist with care was echoed in other accounts, for example Andy's partner dressed his perioperative perianal wounds leaving him questioning *“what am I bringing to this relationship?”*.

Being able to meet the sexual and emotional needs of partners was very important to the men in the study. Arthur described this as *“fulfilling his obligations”* and that he would be happy to focus on sexually satisfying his partner even if he did not want to engage in sex. Arthur also explained the importance of sexual engagement in reaffirming and strengthening intimate partnerships, the implication being that if the disease interrupts or prohibits sexual interaction the relationship can breakdown.

"I think just engaging in sexual acts, there there's always a consciousness, and I think we humans know this, if you don't engage in sexual acts with your partner for long enough, you can emotionally and mentally start to diverge... and then you have sex and then a lot of those things just seem to go away again, like you reaffirm your connection."

Arthur, 47yr, Heterosexual, Married

In considering the impact of IBD on the broader aspects of partnership, parenthood was frequently discussed. Some men required medication for their disease that could reduce sperm count or possibly lead to fertility complications. This had contributed to David and his partner making a conscious decision not to have children, reflecting the impact the disease had on a significant partnership decision. Noah had not yet revealed the potential fertility complications to his new partner implying the difficulty in navigating these issues during relationships. Alex, who had a child, highlighted the fact that being unwell with IBD had led to his partner taking on most of the caring responsibilities which should have been a joint endeavour; *"she pretty much raised my son on her own for a year"* (Alex).

Finally, although many men reported that partners were often engaged in their overall IBD care and supporting them with the disease, there were reports that partners were not directly involved with their healthcare team. Noah, who had described previous issues with opening up to partners, voiced the possible benefit of partners being given permission to discuss these issues with his healthcare team or to bring partners to consultations.

"If someone had asked me these questions, I would have actually told them the things I told you today. I would have told them and maybe if someone had asked me 5 years ago in an appointment, and a consultant or an IBD nurse had said at the next one bring your partner, we will explain it to them a little bit, I would have done that."

Noah, 38yrs, Heterosexual, dating

4.3.3.2 Self-perceptions

"At one point, you do think - how is my missus attracted to me?"

Alex, 28yrs, heterosexual, cohabiting

Men frequently referred to the way in which the disease changed their body shape and appearance, leading to an impact on body image and confidence. Weight and muscle mass were reported to be difficult to control with weight gain due to medications and the inability to engage in exercise or weight loss brought about by active disease and malnutrition. Weight changes were mainly described negatively with recurrent use of the term 'skinny' and only Freddie referred to the inability to gain weight as a potential benefit of the condition.

"Sometimes I do look really skinny and especially when we recently went on a holiday, I think it probably did cross my mind just for a moment. It's like 'Oh, I am definitely the skinniest person on this section of beach', but it's never been a really big issue."

Hugo, 24yrs, heterosexual, cohabiting

The combination of weight loss, reduction in muscle mass, and fatigue induced by the disease and surgery were noted to conflict with the perceived norms of masculinity including being healthy, strong, and active. Although participants frequently reported not affiliating themselves with the 'macho-man' persona in both image and personality, changes to their physique did impact on their confidence and self-esteem, which contributed to not wanting to have sex.

"You don't feel attractive yourself, then you know anything is going to be a complete non-starter and it's a very easy condition to feel like that about because you know the symptoms are what they are."

Raphael, 43yrs, heterosexual, married

Participants who had been diagnosed in childhood or adolescence described feeling different to their peers. Some withdrew to non-physical activities like computer games that would not cause embarrassment or discomfort but contributed to the lack of physical exercise and level of fitness. Changes to self-perceptions were also embedded in concerns over how partners might see them, especially when they had taken on caring roles.

"So she was like cleaning the poo off me and then dressing my wounds and that was really challenging for me. You know, I was in tears multiple times, not because of anything she said, but I just felt so guilty that she was having to take on that role for me and that definitely impacted - not just at the time, but

you know for quite a while after I just didn't feel, erm, (pause) I just didn't feel like sex, cause I just felt really self-conscious about it and her having to see me that way..... I just felt small you know, I didn't think that she'd be able to see me as a sexual person, after seeing me like go through that and then like physicality's of wound care and stuff. I guess, I just thought like how on earth is she ever going to see me that way again?

Andy, 28yrs, bisexual, cohabiting

For some men, negative self-perceptions were transient, occurring with disease relapses or during short-term treatment episodes such as non-permanent stomas or setons. Those with permanent stomas or who had been diagnosed in adulthood described a more permanent effect and difficult adjustment to the complications of the disease. Interestingly, Benjamin, who was awaiting stoma-forming surgery did not express concerns over having to live with a stoma. Benjamin viewed the stoma as a route to improved health.

Partners had an important role in supporting positive self-perceptions and an acceptance of body changes:

"She was absolutely fine with it (the stoma), like probably couldn't be more supportive, was just like I'm not bothered, if that's part of you. If you can accept it then so should everyone else"

Ethan, 28yrs, heterosexual, cohabiting

Sam reported having a supportive partner but still struggling to come to terms with his stoma. He described being in good physical shape and very confident prior to his diagnosis. Following a diagnosis of IBD and stoma formation, Sam's physical shape changed with friends referring to him as 'skinny' and the stoma having a profound impact on his body image. Once happy to walk around in public with his shirt off, he reported that it had taken a long time for him to adjust and 4 years into his current relationship he continued to wear a 'dignity' belt and boxers during sex.

"I don't feel as attractive as what I used to"

Sam, 28yrs, heterosexual, cohabiting

Picture 4.3: Being “skinny”⁸



Participant account connected to picture 4.3:

“I had decent muscle on me would be happy to walk around with my top off, I would say that I was very confident”.

“So then, as soon as I was diagnosed and obviously read into things more and thought of the risks, and what might be, if I have to take a long period of time off, or can't be active as such then the risk of my income....all I've wanted to do is sport, and then suddenly feel as though that's being taken away it's a massive knock.”

Researcher reflection on picture 4.3:

Football was an important aspect of his life, and there is some grief in what has been lost. Again I do not know if these pictures are pre or post-surgery. The composition of the photographs being taken from behind I interpreted as a reflection of his reported loss of confidence or something that is difficult for him to look back on.

⁸ Quotes are not labelled alongside photographs so that the participant characteristics table (Table 4.3) cannot be matched with photographs, ensuring anonymity of participants.

Men commonly reflected on feeling unclean because of the disease. Frank recognised it was his own perception and not that of his partner, which was most prohibitive.

"I don't feel I'm clean enough, you know, because with the ileostomy and I had a fistula, which would leak constantly, and obviously with the colonic secretions as well I don't know if I would be able to hold them, so you know this impacted me a lot psychologically. So while my partner really didn't kind care, when I had this problem it was more me kinda stopping myself from you know starting anything. You know I would find excuses just to avoid the kind of situation where we would get more intimate. I would try to initiate things when I was more confident with my body, especially after a shower, that be would have been a good moment for me."

Frank, 31yrs, bisexual, cohabiting

Cleaning rituals and routines before and after sex were commonly described. Although often accepted as probably unnecessary and excessive they were reported to aid confidence and comfort. These practises did reduce sexual spontaneity and impulsiveness and some men reported that their partners found this challenging. A few men were unable to overcome the change in body image or feelings of uncleanness. Freddie, who had fistulising disease, uncontrolled flatulence, and unwanted odours, had decided not to engage in sexual activities with other people. Freddie was sexually satisfied from solitary masturbation and although his case is unique within the study sample, due to the context of gender re-assignment and complexity of his symptoms, his account parallels that of other men with severe disease. George had a severe presentation of Crohn's disease that had caused him to lose weight and have a very low body mass index (12.4kg/m^2), leading to the need for intravenous nutrition and medications that had changed his skin colour. The presence of a Hickman line for parenteral nutrition meant sex needed to be planned around nocturnal feeding regimes dictated by his treating clinicians. George was married, but like Freddie, also reported feeling at times that it was easier to sexually satisfy himself alone.

4.3.3.2 Prioritisation of physical health

“I never really thought about things like dating, going out, being with anyone until probably after the line was fitted... I think I, just so, I would have liked to but in my twenties it wasn't really a priority, it was more just figuring out my health.”

George, 37yrs, heterosexual, married

Although engagement in sex, sexual health, and sexuality were important to participants, resolution of disease symptoms and improving physical health were described as a priority especially during disease flares and relapses. This also reflects the lack of sexual desire experienced during disease relapses, which are described in more detail in the theme ‘IBD thwarts sexual experiences’ (Section 4.3.4). Two men in the study, Arthur (47yrs) and David (66yrs), valued the importance of sexual engagement in contributing to mutual contentment and affirmation of the partnership. They both articulated other important aspects of intimate relationships that could be developed and strengthened outside of traditional sex, even during periods of being unwell. For them, disease and sexual health were linked to overall health but they could also see other routes to being contented in life. It is possible that their maturity meant that they were more readily able to navigate a middle ground and accept the fallible nature of both health and sex.

There was commonality between young, single men with more severe disease presentations completely abstaining from seeking intimate relationships during illness or recovery phases.

“When I had the stoma...it was only a period of 6 months, I don't think from memory I was interested in anything romantic at all. I think because again, I was dealing with this thing.”

Peter, 26yrs, homosexual, single

Dara refrained from sexual engagement due to reported concerns over the impact on a potential partner, although reviewing his interview as a whole revealed that this decision could also have been due to a reduction in self-esteem, which links to the prior sub-theme ‘self-perceptions’.

"I've not really put myself out there since the hospital trip, I haven't at all. I've kind of wanted to but I'm aware my farts are significant. I find my flatulence and all these are things which are just not fun for anyone really and I don't want to subject someone else to that, until I've got on top of it a lot more."

Dara, 24yrs, heterosexual, single

Men in relationships who needed to prioritise their health often reported that this need could lead to problems in relationships and they expressed this with guilt. Noah described it as *"a little bit selfish and prioritising myself and they are coming second"*. Noah also noted that it was a combination of prioritisation his health and how he communicated the impact of his condition to his ex-partner that contributed to the relationship breakdown.

"They think I am not into them, or I'm losing interest when the reality is I'm so preoccupied by my illness, unfortunately, having to be a little bit selfish and prioritising myself and they are coming second. And I think, unfortunately, with Crohn's, I have to put myself first and as a result that sort of miscommunication and lack of me opening up has always been an issue in the past."

Noah, 38yrs, Heterosexual, dating

Balancing the need to prioritise physical health with a desire for children was a difficult challenge for some men. Sam's partner was unsure about whether she wanted children, but he was still reluctant to progress to a proctectomy and remove residual disease, as he wanted to father children and this surgery carries a risk of impotence. For others, prioritising physical health was an important consideration around whether to have children. Frank and his partner had considered adopting children prior to him being diagnosed with the disease and subsequently *"never really put more thought into it"*. Noah articulated multiple complicating disease-related factors that made him reluctant to consider fatherhood at the time of the interview.

"I need to be healthy to be able to after a child or two and already I'm at a disadvantage because of fatigue, because of pain, because of illness if I go to hospital, I can't work etc."

Noah, 38yrs, Heterosexual, dating

Ethan also discussed the need to focus on his health to care for his child which had also become one of the driving factors to him accepting his stoma,

knowing that progressing to further surgery could disrupt his presently stable health.

4.3.4 Theme 2: IBD thwarts sexual experiences

“My sexual desires, everything, my normal life just kind of stops.”
Arthur, 47yr, heterosexual, married

All men expressed how the disease could negatively impact their sexual experiences. For some, this was not a permanent effect and could be variable depending on disease symptoms, treatments or social factors such as relationship status. As discussed in the theme ‘IBD shapes intimate connections’ (Section 4.3.3) some men noted that being single during relapses could cause them to refrain from seeking sexual relationships. The most discussed impact was a lack of desire which men attributed to being caused by bowel symptoms and fatigue. A small number of men identified that erectile function could be intermittently affected but they did not assign this to a physical cause driven by the disease, and generally indicated that erectile function issues were related to fatigue or the psychological impacts of living with IBD.

4.3.4.1 Sexual desire

The majority of men reported that when the disease was active or symptoms were ongoing there was a reduction in both desire and frequency of sex. Ewan detailed how bowel sensations inhibit and over-ride feeling sexual.

“A very uncomfortable feeling and it’s not a sexy feeling. It’s a very distracting feeling and its one that, you know, one doesn’t feel sexy when one feels bloated or like you need the toilet and it’s a sensually, it’s a distracting feeling to have. So that had a big impact, that and being tired and low energy also impacted things, so even if I could get and maintain an erection doesn’t mean that I was particularly kind of energetic or in the mood, so that’s kind of how it impacted sexual health I would say.”
Ewan, 34yrs, heterosexual, married

Fatigue was one symptom frequently linked to a lack of sexual desire. Fatigue was also reported to have a broader impact than just on sexual desire, Arthur

said “*my sexual desires, everything, my normal life just kind of stops*” while Raphael noted it “*indirectly affects everything*”. Hugo reported that sex didn’t “*even cross my mind very often*” when he was symptomatic with the disease. Dara, who was single, continued to feel the desire to masturbate but the fatigue directly affected his ability to get an erection.

“Fatigue was awful, I remember that really clearly, I couldn’t walk down the road without feeling absolutely dead on my feet. I could watch porn but I couldn’t get an erection at all.”

Dara, 24yrs, heterosexual, single

The lack of sexual desire could feed negatively back into partnerships with participants reporting the challenge of trying to convey to their partners that it was not a lack of desire for them.

“You don’t want to come across as sort of not wanting to be with your partner, it’s getting it across in the right way. I think sometimes it can come across in the wrong way.”

Benjamin, 20yrs, heterosexual, co-habiting

Medications, particularly rectal therapies could also reduce sexual desire. Oliver attributed the use of rectal suppositories at night to being a “*buzz-killer*”, reporting staying up late in the evening to mentally prepare himself to insert the suppository and wait for his partner to be asleep so that it could be done privately. For Oliver, who was in a relationship, the reduction in sexual interaction was “*obvious*” and he reported that this “*weighed a bit more on your mind*”. Libido did not immediately return upon cessation of rectal therapy; “*it’s trying to find that spark again*” (Oliver).

4.3.4.2 Sexual expression

IBD could constrain, change, and limit certain sexual activities. Erectile function, anal play, and satisfying a partner were all expressions of sexuality prohibited by the disease. Men experienced sexual apprehension which reflected the mental burden of living with a chronic and hidden disease. The most common concern reported was a lack of feeling clean. As discussed in the sub-theme ‘self-perceptions’, some men would use ritual cleaning

practices, cover their bodies, or avoid intimacy because of bowel sensations, colonic secretions, leaking fistulas, and stomas.

"We've had a nice evening, are we likely to have sex tonight, I need to have a shower beforehand and prepare myself there's so many things I am trying to prepare, mentally prepare for all possible options in my head which is very taxing."

Noah, 38yrs, heterosexual, dating

Partner reassurance and support were noted to be important triggers to regaining confidence in order to engage freely in preferred sexual activities. Sam explained how he covered his body after having a stoma but his partner had supported him in developing his confidence.

"She did have the conversation with me eventually; 'you do realise I wouldn't be here if it bothered me', so I did then start taking my top off. I will still have my belt on, but that's so it doesn't get in the way. Right from there I would then say that I started to rebuild my confidence."

Sam, 28yrs, heterosexual, cohabiting

Many men reported worrying about faecal incontinence during sex even though they had not experienced this directly: *"the stupid thing is, it [being incontinent during sex] has never actually happened"* (David). Sam, who would empty his stoma bag directly prior to sex, reported the *"realisation that I'm full-on over-thinking it"*.

Erectile function was noted to be an important part of sexual expression and also a way to display masculinity. Some men linked erectile function to their masculinity while others conveyed that erectile function was not the main component of either their masculinity or sexuality. All those men who reported having problems with penile flaccidity did not definitively know the direct cause. Fatigue, lack of desire, and medications were suggested by participants as possible causes of erectile dysfunction. For men who had experienced erectile dysfunction, it was mostly reported as transient and coinciding with a relapse of the disease. However, many men reported not really viewing this impact as an IBD issue and, when questioned, most reported they would seek advice from their GP rather than an IBD specialist. Some men had used PDE5 inhibitors but no men reported to take this

medication regularly. It was discussed that use of erectile medications removed spontaneity of sex.

Picture 4.4: Perhaps it's the medications



Participant account connected to picture 4.4:

"I also have an Infliximab Infusion every two months. some of the creams and sprays etc are only used as required, but I'm now feeling ill just looking at them all."

"But I suppose, I had always had slight difficulties maintaining an erection and so on and you know, I have often wondered is this because of the drugs, or is it you know perhaps because as I get older it is probably more difficult, is it just age"

Researcher reflection on picture 4.4:

He does not like the idea of having to use medication, I wonder whether the daily routine of taking them is a reminder of his health issues. In clinic many people do not like the idea of being on long-term medications, it is a reminder that the condition is on-going and they are dependent on something else to keep them well. In his interview he alludes to the side effects of medications including infertility and impotence. This is a common juxtaposition of a patients struggle with taking something to improve your health in one way which then compromises something else. The decision to take medications is a choice made according to personal priorities, bringing me back to the code 'sex wasn't a priority'.

One of the most significant challenges reported was faced by those who wanted to engage in receptive anal intercourse (RAI). Peter noted what when engaging in receptive anal sex *"there is a level of discomfort to be expected. I don't know how badly mine compares to like someone without IBD, I've not lived that life"*. For Peter it was something he had learned to tolerate whereas

Freddie, who had extensive perianal disease, the pain and discomfort was too much to bear: *“just no way could I have coped with anybody down there and then I lost my nerve”*. Freddie’s story echoed that of Andy, who had enjoyed receptive anal play with his girlfriend but the development of an abscess meant that even though he did not currently suffer with pain, psychologically he could not commit to reattempting sexual anal stimulation through fear of triggering or exacerbating the condition. RAI was reported to not be discussed in the IBD clinic, with participants explaining they had not asked about it and information had not been put forward by healthcare providers.

“Pain is never too much of a limiting factor it’s completely psychological. I’m afraid of doing damage I guess and making it worse.”

Andy, 28yrs, bisexual, cohabiting

Receptive anal sex and anal play is affected when the rectum is removed due to severe disease. This was the case for Frank whose pan-proctectomy *“took the options from me”*. When surgery is performed to remove the rectum there is also a risk of erectile dysfunction due to nerve dissection. For Frank, the risk of erectile dysfunction was his foremost concern prior to surgery. Fortunately, this side effect had not occurred for Frank and within his same-sex partnership he was able to enjoy sex outside of RAI. Homosexual (gay) and bisexual participants alluded to a lack of understanding from healthcare professionals, the public, and potential sexual partners about how they might express their sexuality. Peter reported a sexual partner questioning the way he expressed his sexuality and his desires which importantly highlights the need for more specific information for men with IBD who engage in anal sex and anal play.

“He was like; I mean with your condition why are you like this and I’m are just simply like; I like what I like and I have to make it work.”

Peter, 26yrs, homosexual, single

4.3.5 Theme 3: IBD disrupts gender norms

Participants had varying thoughts and feelings towards whether IBD impacted upon their masculinity. Many men discussed not feeling that their personal perspectives aligned with traditional masculine ideals. Regardless of this,

participants did consistently refer to impacts of the disease on aspects of their lives that aligned with traditional masculine ideas. These aspects have been grouped into the sub-themes of physical strength, self-reliance, contribution, and emotional resistance.

4.3.5.1 Physical strength

Physical strength is entwined with the sub-theme 'self-perceptions', and both were reported to be negatively impacted by IBD. Being physically strong and fit was a commonly described aspiration which can be interpreted to be an important attribute of masculinity, especially among the younger male participants. Men commonly stated they had stopped engaging in their preferred physical activities including football, running, cycling, and going to the gym. Group activities were particularly burdensome, especially due to the unpredictability of the disease and for those who reported difficulties in being open about their disease with others. Not all men struggled to talk to others about their disease. Men who were willing to discuss their disease reported feeling that others were not always understanding or sympathetic to their situations.

"Without having a lived experience of a disease like IBD, I don't think you could ever really truly understand, you can sympathise, but not understand."
Andy, 28yrs, bisexual, cohabiting

Some men reported finding ways to adapt, for example Sam transitioned from playing football to refereeing, while Noah had taken up yoga.

'I haven't felt well enough to run for a couple of years now, because it just wipes me out, which is really sad because I love running....I've got weights, so I've been trying to keep my muscles up and I try and eat enough protein'
Freddie, 64yrs homosexual, single

The disease prompted some men to focus more on their overall physical health while others took up new sports and physical interests. However, for many men the inability to retain the aspired or previous level of fitness was

always in the background and was seen to compromise their identity as men. Picture 4.5 shows a bike for sale as one participant⁹ could not longer cycle.

"I used to be in decent shape before it happened. I had decent muscle on me and would be happy to walk around with my top off....we went on holiday ad I had a lot of anxiety about walking around with my top off."

Sam, 28yrs, heterosexual, cohabiting

Some men wanted to be physically strong not only to be involved in parenting but to set an example to their children.

"I found that quite difficult when I had children and trying to be that kind of father figure, especially to my son. When you're trying to be the kind of strong person that's there and especially having to accept that you are going to be weak and that's okay."

Raphael, aged 43yrs, heterosexual, married

⁹ Pseudonym removed to prevent de-anonymising participant in event bike is recognised.

Picture 4.5: Bike for sale: “in the end I just found it too tiring”



Participant account connected to picture 4.5:

“I would always try and go out on the bike as often as I could, but where I live is up a fairly steep hill, which was great going downhill to work on the bike, but then up hill on the way back wasn’t quite so good, so in the end, I just found it too tiring, and one of the problems with IBD is the fatigue, it really is a problem, and that probably indirectly has a bearing on you know my sexual”.....”so during lockdown I realized they were having problems trying to supply bikes so I promptly advertised mine”

Researcher reflection on picture 4.5:

This is a further representation of the code ‘letting go’, and I do not find it surprising to make this association through photography as we often photograph things that we must relinquish, are proud of or that we know will change.

The combination of his disease and other factors puts a stop to cycling and once again we are reminded how the disease can stop people from living their lives. ‘Physical activity’ is a common theme and in the associated quote related the fatigue to both reduced physical activity and sexual engagement and this is important due fatigue being an IBD symptom that is often poorly managed.

4.3.5.2 Self-reliance

"I need to get control of this, because I am not in control at the moment, I am so reliant on them being, you know, them managing this for me."

Ethan, 28yrs, heterosexual, cohabiting

Participants presented narratives of a lack of control and independence when living with IBD while concurrently demonstrating personal perseverance and determination. The variability and unpredictability of symptoms and constraints in treatment regimens often led to men describing a lack of control. This factor also fed into reported disruption in their partnerships and self-perceptions. There was a strong desire across the participants to be in control of their health and lives and also to be self-reliant. Men found ways to be self-reliant through being practical and organised. Three men submitted photographs that demonstrated how they self-managed the condition by being prepared (Pictures 4.6 to 4.8)¹⁰.

Picture 4.6: The rucksack



Participant account connected to picture 4.6:

"My rucksack which always contains a spare change of clothes and a toilet roll. I have to take this bag with me everywhere."

"A lot of anxiety came with it, er like everywhere I go, everything I do".

"I think it, it mostly affects sort of like being able to do things so like we do make an effort to go out and try and do stuff and things, but we probably don't do as much as, much things because I can't go places, like this places she wants to go."

Researcher reflection on picture 4.6:

The majority of photographs did not really directly reflect sexual health and this was expected considered due to the sensitive and private nature of the topic. They do illuminate the way in which men live with the disease. The photo's submitted closely paralleled his story; the anxiety going out, having to be prepared and organised, the disease being part of his everyday life and very much a part of his identity.

¹⁰ Pseudonyms have not been attached to photograph to ensure anonymity

Picture 4.7: The secret compartment

**Participant account
connected to picture 4.7:**

“A little bit is kind of planning things and eating and drinking and then all also access to toilets and that sort of thing. I carry around a change of underwear, just discretely in the side pocket on one of my bags, you know my work bag has that, just in case you know, that should happen. And so it's always, I think you kind of understand, realise your own life, but find it fitting those types of things in around is your own and I certainly have got a lot better at that.”

**Researcher reflection on
picture 4.7:**

This photograph corresponds with other participants stories. It supports the impact on everyday life and the hidden nature of this disease. When he sent me the photograph he says he hopes it was not inappropriate, showing the inherent clandestine nature of matters of the bowel and defecation. Even though he knows I am a nurse he still worries that his underwear is inappropriate, such barriers must be brought down if we are to have open conversations about sexual health and well-being.



Picture 4.8: The pharmacy tin



Participant account connected to picture 4.8:

"I always have it in the bottom of the backpack (which I take to work, out with friends, travelling, everywhere) and kinda nickname it in my head a 'pharmacy tin' it has various tablets in it but also other bits that have ended up in it. I have had some form of this tin in the bottom of my backpack ever since I was diagnosed, although back then it used to have stronger painkillers in it".

"I was quite focused on trying to get myself better, and I think the thought of trying to build a relationship with kind of like new people at that, time was, yeah, I wasn't even really sure what was going on with myself and so I kind of like trying to build a deep connection with someone else was just not, not kind of on the cards, and I think in terms of casual sex, like I was always been a bit wary of that just cause again, especially like when I was first being diagnosed and kind of like first year of uni and and I'm still having those like pains, the thought of like, maybe being overnight somewhere else, at someone else's house, and like all of a sudden being like 'Oh, God, like I feel awful' was just like, I just wouldn't have put myself in that situation, I would rather be at my own uni house, with kind of like my flat mates who I knew I can speak to if I needed to. And yeah, where I knew there was like kind of like painkillers, and like the bathroom and that kind of stuff. So I think it probably, it just it made me like yeah more hesitant like during those early years of diagnosis. But since being in remission, I think the impacts been like yeah, basically none."

Researcher reflection on picture 4.8:

The tin shows tablets but also interestingly a condom and toothpick. He reports being wary of casual sex but carries these items on him – they could have been left there from before his disease or are they there because he's now back in remission? It is enlightening to have both the picture and account together. The picture is a good representation of how the disease and sexual health are both notable aspects in his life.

For many participants, medications provided something they could self-manage, improving their sense of self-reliance. However, IBD medications were also reported to remove choices and autonomy, and induce side effects that could be problematic to self-sufficiency and well-being. Access to medications and treatments were a common frustration. Participants described annoyance with the lack of co-ordination between healthcare providers, inefficiencies in the healthcare system, and a sense of feeling at the mercy of healthcare providers.

Picture 4.9: Realistically it won't work forever



Participant account connected to picture 4.9:

'It got better when I came here because I have access to more drugs. I couldn't get vedolizumab or tofacitinib, it was really bad. I was hospitalised three times, maybe four.....even if this drug did work realistically it won't work forever and it's not great to be on it, a drug that has all these negative side effects from such a young age.'

Researcher reflection on picture 4.9:

His experience of healthcare has been challenging, with limited access to the right medications ultimately leading him to have his bowel removed leaving him with a stoma. The medications, and prior lack of medications has shaped his experience of the disease. Going for surgery has become the way for him to regain control and in the interview he looks forward to that and he believe it will better his relationship and improve his day to day life.

Men's accounts gave insights into the precariousness of feelings of control and the fact that becoming unwell or having to re-engage with healthcare providers could jeopardise that.

"When I get ill and especially if I have to go into hospital, I really hate the kind of 'patient me' that turns up. So even having this MRI tomorrow, I know as soon as I set off from home I'm gonna go into this kind of patient mode, which is much more vulnerable and feels helpless and not in control, because you know, I put a lot of effort into being in control of my life."

Freddie, 64yrs homosexual, single

The desire to be self-reliant did not always have a positive effect and could contribute to an *"I'll deal with everything myself"* (Ethan) attitude. As previously discussed, this had the potential to be destructive to partnerships and also result in disengagement with health services or ignoring of medical advice. Oliver reported not following through with a referral to the clinical psychology team, reporting *"actually like to have a go at solving this myself"*. Similarly, Tim decided not to follow the advice of his surgeon and went back to weight training after his surgery, reported using his own judgment at what his body could endure. For some men the desire to regain control and be self-reliant encouraged regular contact with their healthcare professionals and a need to understand the minutiae of their treatments.

Many men sought information from the internet, for example via 'Reddit' and other social media platforms. Some men reported that they did not always find that this was helpful as at times the information was not relevant to their personal situation or could heighten concerns and anxieties. Importantly, most men reported there was not enough support or the right type of support for them.

Employment was cited as an important aspect in many participants' lives and a way to be self-reliant. Being unwell could threaten employment status which could lead to financial implications.

"This has definitely impacted my finance and the ability to, you know, bring in the money.....had 7 surgeries in one year so by the time I was getting closer to being able to go back to work was either like a push back again, you know push back again, push back again, because it's another infection or that infection, and until the point where I was in hospital for 6 weeks. So I went to nil pay and they had a meeting and we decided to take 6 months break from my career. Obviously the 6 months I didn't have any income and slowly but surely, so you know I wanted to keep doing the same, paying the same bills, paying for food, so I didn't rely on my partner. I kept paying what was due and I think my bank went to 0... I remember using some money from my family... made me feel quite bad because I didn't want to rely on just his income."

Frank, 31yrs, bisexual, cohabiting

Dara reported that he would *"force myself back to work sooner than maybe I should"* and many others discussed the trouble of juggling work with a long-term chronic condition. Being able to work from home and having a supportive employer were reported to be key factors in alleviating this strain. Only Hugo expressed ease with relying on his partner in regard to finances if he was out of work; *"I know that my girlfriend would just like help look after me"*. Hugo was one of the five men who also discussed how the disease changed their career paths and trajectories which could lead to feelings of disappointment, frustration, and regret.

"I've always played with being a paramedic, and actually the beginning of the year I did apply for it, I applied once, years ago... at the time I wasn't very well with my Crohn's and all that. It was probably not like the best idea in the world and then I applied for it again, beginning of this year, like an apprenticeship route. I got through and started doing some bits of training with them... and I think it became quickly, that the lifestyle just wasn't going to suit me and I think that was a lot down to my Crohn's, it was, it was kind of like no regular meal times, and the fatigue just got really badafter days of the 4am start and kind of 12 hours on the road with the driving instructor it was just very clear that like it wasn't going to be possible."

Hugo, 24yrs, heterosexual, cohabiting

Men commonly expressed that they did not want to be a burden and this feeling was conveyed throughout their lives whether that was in intimate partnerships, the wider family, at work, or to society. The ability to contribute was important to a feeling of self-worth and value which could be disrupted by being unwell with the disease.

"I'm just a body lying here that's not contributing."

Andy, 28yrs, bisexual, cohabiting

The widely understood masculine ideal of being financially stable or providing for the family was expressed in several interviews. It was also common for participants to detail wanting to support historically feminine roles including running of the house and parental responsibilities. At times this aspect was given equal value to financial income particularly for those with working partners. As well as wanting to contribute to the home environment, men also expressed feeling responsible for providing stability. Ewan reported *"I do sometimes feel like it's my responsibility to kind of keep things together"* while also explicitly conveying that wasn't because his wife didn't also keep things together.

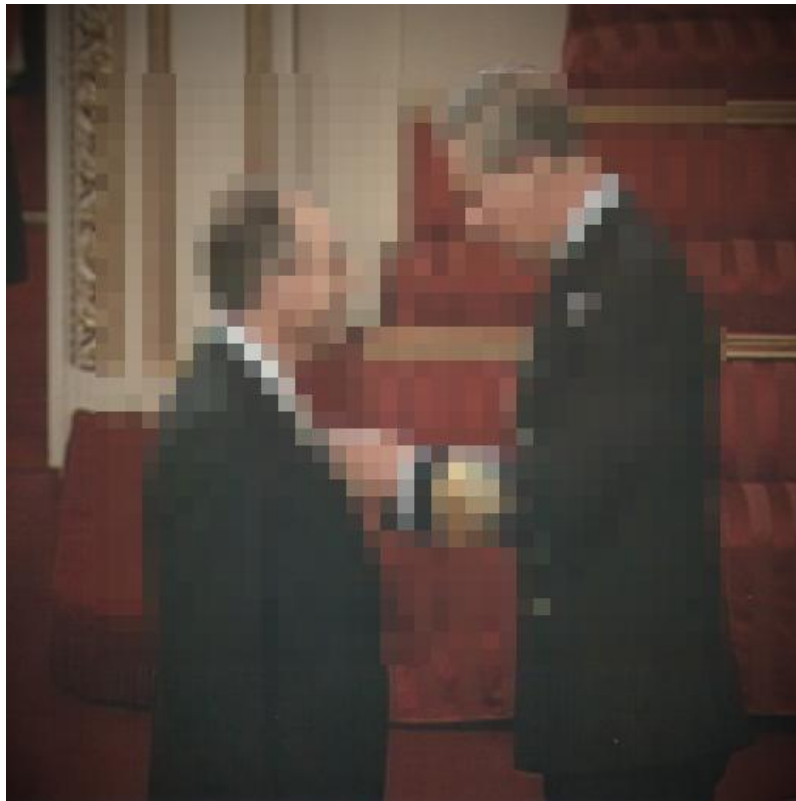
"When you're feeling really unwell and you're not able to do much, you just think, what am I bringing to this relationship really like she's having to do all this work yeah look after me and do more around the house."

Andy, 28yrs, bisexual, cohabiting

Many participants expressed wanting to give back to society with several participants describing volunteering or philanthropic activities. There was a desire to participate in the study itself to help improve research and help others affected by the disease.

Of all the participants, David had lived with his condition the longest and was the oldest. He relayed that IBD had influenced his later childhood, informed career choices, affected work experiences, shaped partnerships, was a factor in not fathering children, and played a role in his sexual health. However, David also conveyed that his life had been fulfilling regardless of these struggles and this was in part due to still being able to contribute to society.

Picture 4.10: Contributing to the world



Participant account connected to picture 4.10:

"I've actually achieved, although I have had all these things going on in my life, because I've kept myself busy or occupied in other ways."

Researcher reflection on picture 4.10:

Being able to achieve in other ways outside of sexual health was an important part of his story. Although he expressed concern that he could not always meet his wives sexual needs he is proud of other aspects of his life (including their love for one another). I have pixelated this picture to protect anonymity but we are still able to see that he is being presented with an award by the then Prince of Wales, now King Charles. I interpret the fact that he chooses to submit this photo, as a reflection of what men may value in their lives and how they may feel rewarded.

4.5.5.3 Stoicism

Living with IBD was described as physically and emotionally challenging. Almost all participants demonstrated emotional resilience, determination, and stoicism even if they did not overtly recognise or report it. The need to be resilient was interpreted as a normative masculinity ideal that was related to the prior sub-themes of 'self-reliance', 'physical strength', and 'contribution'.

"I think being a man is just, get on with it."

Alex, 28yrs, heterosexual, co-habiting

The potential impact on loved ones was also regularly mentioned and was a concern to many men. The concern for, and culpability of, the emotional toll on loved ones was a driver to perseverance and the concealment of personal distress.

"I didn't think I would make it to be honest with you, but just, I had to do it because my mom was next to me. I didn't want to see her sad, had to push myself a bit and my partner as well who would come every day and see me."

Frank, 31yrs, bisexual, cohabiting

For some men, resilience and acceptance increased with time since diagnosis while for other men, the burden of the disease was reported to increase over time. This was dependent upon the disease course and treatment options which were very variable.

"(It) chips away slowly in the background and the more flares you have the worse it will, the more of your identity becomes intertwined with living with IBD and you know I think it does just kind of chip away at that part of yourself, as it does it with the physical nature of Crohn's disease."

Andy, 28yrs, bisexual, cohabiting

The severity of the disease could lead to a profound understanding of the fragility of life and mortality. This was particularly the case for participants who had undergone emergency surgery, been critically unwell, had rare presentations of the disease, or were on advanced medical therapies. Men who understood the improbability of cure, exhibited a desire to live their lives as they wanted to, remain physically strong, be self-reliant, and provide

contribution. For some, this could be achieved through resolution of symptoms, for others, particularly those with unstable and advanced disease, finding ways to adapt to the condition was more important.

"I think you get to a certain point you know something's gonna get you. It's just what it is that's gonna get you it's just something to live with and I'm quite comfortable with that, what I want, which now I think about it, is particularly petty, is to remove the symptoms, because that's what affects the life."

Arthur, 47yrs, heterosexual, married

Picture 4.11: "It's a waiting game"



Participant account connected to picture 4.11:

"it is just, it's it's a waiting game pure and simple. You know I know there's no cure for the Crohn's, I know the Hickman line still there, I'm one, infection, actually, you know one bad connection away from sepsis, you know, so it's like an incredibly vulnerable position to be in",

"there's quite a few accounts for people talk about their stoma bag, but it's very rare, you see any accounts, especially men with Hickman lines you know",

"it was only after the line got put in 2012. I think it's probably more of a case of my general health has improved and you know, some of the desire came back",

"yeah spontaneous things are very, very difficult. If I want to go abroad, f I want to go even a weekend away or anything, everything needs to be planned"

Researcher reflection on picture 4.11:

TPN has saved his life but at a cost. He adapted to the limitations it has put on his life but must live knowing he is "one back connect away from sepsis". The weight of the burden is visualised is the amount of equipment..

Men reported varying perspectives of how to label themselves with the disease. Some men reported that they did not see themselves as disabled and believed they were in a better position than people with other conditions. Some men saw themselves as having a disabling condition. Guy described using a walking stick, even though he did not always need it to aid mobility, to externally display that he was living with a hidden condition so that others might be more considerate to him. No patterns in demographics or disease presentation were identified in relation to how men perceived their disease.

4.4 Summary of the findings

'Knowledge transformation' is an important step in ID where the findings are rendered so that they are applicable to nursing practice (Thorne, 2016). This process begins in this section wherein the qualitative study 1 findings are considered in relation to the aims set out in Section 4.1 and within the context of the extant literature. The literature searches conducted prior to the start of the study were repeated so that the most up to date evidence could be incorporated into the analytical discussion. This process has been repeated in Chapter 5 for qualitative study 2. In Chapter 6 the findings of the literature review and two primary research studies within this thesis are then considered in the context of relevant theory so that they can be critically refined and possible explanations can be proposed. This process supported the development of recommendations for research and practice that align with nursing praxis, which are set out in Chapter 7.

Drawing together the themes and revisiting the study aims revealed two important overall findings. Firstly, through considering how men make sense of their experiences (aim 1) this study has shown that the sexual health needs of men with IBD are more complex than erectile function. This finding is explored in Section 4.4.1. Secondly, in exploring how IBD interacts with men's sex lives, sexuality, and gender roles (aim 2) the study has drawn attention to the importance of partnership, body image, and gender roles as precursors to healthy sexual relationships. This finding is discussed in Section 4.4.2.

4.4.1 What do the study findings tell us about how men with IBD perceive and make sense of their sexual health experiences?

When severe or in relapse, men reported the disease could eclipse normality inclusive of their sexual well-being. This issue has also been reported within other conditions such as malignant blood disease where illness was described as 'overshadowing sexuality' (Olsson et al., 2013). The men's narratives in the current study demonstrated that sexual health experiences could be affected by disease-specific factors (activity, disease presentation, age of onset, body habitus changes, and treatment) and non-disease specific factors (relationship status, life experience, masculine ideals, sexual orientation, and identity). Disease-specific factors could also affect non-disease specific factors and cause an indirect impact on sexual health. However, reporting that IBD can both directly and indirectly affect men's sexual health and well-being but does not convey well the multiple, interconnected layers of experiences that were apparent within men's narratives in the study. In line with ID, this thesis did not set out to provide a complete sociological theory of male sexual health in IBD but instead to provide interpretations that support and develop an appreciation of the complexity of individual experiences that may enhance the agency of nursing practice (Thorne, 2013). In this case, broadening thinking beyond erectile function when assessing and caring for male sexual health is a key finding. This is both valuable and novel in the context of erectile function assessment, which has been the mainstay of research in this field to date (Khan et al., 2024; Ma et al., 2020).

In the current study, participants were forewarned and consented to possible discussions about erectile dysfunction, and also completed an IIEF score prior to interview. Despite this, erectile function was not found to be the principal concern of participants. Instead, many of the participants' narratives centred upon the impact of disease on partnership, engagement in sex, and emplacement within their social contexts rather than the physiological processes of erection, ejaculation, and orgasm. The mean IIEF scores of participants also suggested that the rate of ED in the study sample is

comparable to the general population¹¹. This is an important finding as it indicates that IIEF scoring may not be a discrete marker of overall sexual health and may explain why there have been conflicting findings about whether active disease has a negative impact on men's sexual health in IBD. For example, when correlating disease activity with erectile dysfunction (ED), Bel et al. (2015) reported an association between active disease and lower IIEF scores, while more recently Mules et al. (2023) reported no significant difference in IIEF scores between men with active disease and those in remission. In the current study, active disease was observed to have a negative impact across multiple indicators of sexual well-being and throughout a number of sub-themes presented including partnership, self-confidence, and sexual desire. Importantly, it was also discovered that while active disease induced these effects, resolution of symptoms did not automatically resolve the negative implications for sexual health. The reason for this finding was interpreted to be because of the ongoing fear of relapse and the burden of living with a chronic disease which can worsen over time for some men. Additionally, the fear of sexual activity inducing disease activity was reported by some men in the study. This experience has also been identified in people with cardiovascular disease reporting a fear of sex triggering disease symptoms (Kazemi-Saleh et al., 2007). Transposing this into nursing practice could mean that sexual health problems should be tackled not only through resolving active disease, but through supporting men (and their partners) to adjust to the physical and emotional challenges of a chronic condition; an approach applicable to nursing practice across varying aspects of IBD (Ma, 2020).

Over half of the men in the study had undergone surgery for their disease and although the life-preserving need of surgery was appreciated by participants, it was also described as inducing negative impacts. The possibility of permanent impotence was a common fear for participants who were awaiting or had undergone surgery. Evident across men's accounts were inaccurate

¹¹ The IIEF scores in this study population were comparable to the control group in the original IIEF validation study by Rosen et al. Rosen, R. C., et al. (1997). The international index of erectile function (IIEF): a multidimensional scale for assessment of erectile dysfunction. *Urology*, 49(6), pp. 822-830. [https://doi.org/10.1016/S0090-4295\(97\)00238-0](https://doi.org/10.1016/S0090-4295(97)00238-0).

understandings of the risk of ED post-operatively, which may reflect the differing risk across different types of surgeries, varying risk data from historical studies (Chapter 2, section 2.4.3.4) and a lack of clear information available to patients. For some men, concerns over possible post-operative ED had influenced treatment decisions, drawing attention to the need for accurate information that is accessible and specific to men. One man in the study reported transient erectile dysfunction in the post-operative period. More commonly, surgery was reported to induce fatigue, body image changes, and the need to prioritise physical recovery. All of these factors could lead to a negative impact on overall sexual well-being.

Where sexual health and function has been explored in the context of other chronic diseases, it has mostly focused on conditions that do not necessitate surgery, including arthritis, cardiovascular disease, dermatological conditions, diabetes, epilepsy, multiple sclerosis and Parkinson's disease (Van Pinxteren et al., 2023; Savel et al., 2022; East et al., 2021; Barisone et al., 2020; Basson et al., 2010; Santos, Pascoal and Barros, 2020). Prostate cancer offers an exception but contrasts with IBD in that the peak age of onset is higher and the associated surgery carries a greater risk of physiological erectile dysfunction; that is, up to 85% post radical-prostatectomy (Emanu, Avildsen and Nelson, 2016). Men's narratives around sexual health and masculinity following prostatectomy have therefore focused upon the impact of impotence (Oliffe, 2005). Although this research has produced contrasting focus in men's experiences, these studies present findings that resonate with patterns evident in the narratives of men in the current study. These findings may be applicable to nursing care in men with IBD, namely that sexual intimacy strengthens partnerships and can continue with adaptations outside of penetrative sex (Oliffe, 2005; Beck, Robinson and Carlson, 2013).

Anodysparenunia (recurrent or persistent pain during receptive anal penetration), which is both a symptom of active disease and a side-effect of surgery in the rectal region, was discussed by three men within the study who identified as gay or bisexual. Anodysparenunia was described not only as being prohibitive to receptive anal simulation and sex but also as inducing fear

of disease exacerbations and reducing sexual confidence. Anodysparenunia has not been studied within the context of IBD and has only been identified in one prior study, which included male and female participants (Groome et al., 2017).

While this section has focused upon the reported impacts of active disease and surgery on men's sexual health, an important observation was that many of the issues discussed (including prioritisation of physical health, poor body image, and sexual apprehension) were central to men's experiences outside of surgery or active disease. In the absence of cure, supporting men with IBD in 'sexual adjustment' (Enzlin, 2014) including coming to terms with body changes and learning to communicate the possible implications of their disease to partners, rather than the treatment of erectile dysfunction may be a focus of nursing intervention. This suggestion is discussed further in Chapter 6, section 6.2, where the chronicity of the disease and the impact of the disease stage are considered in detail.

4.4.2 What is the interaction between disease, sex life, sexuality and gender role?

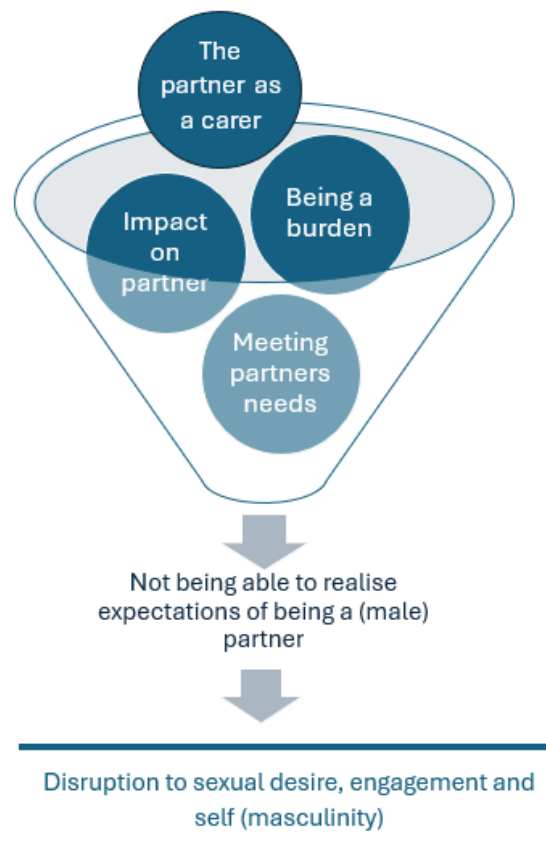
A key novel finding of the current study is that IBD was reported to disrupt partnerships including the communication and connectedness between partners. The negative impact of IBD on relationship status has also been reported in prior studies involving samples of both men and women with IBD (Argyriou et al., 2017; Muller et al., 2010). However, the survey design of these prior studies has not yielded insight into how relationships have been impacted or why. The current study has added to the evidence-base in this area. Participants expressed concerns over not meeting their partner's needs, being a burden to partners, and their partners becoming carers, all of which could lead to feelings of inadequacy that could disrupt sexual engagement (Figure 4.4). Some of these reported issues overlap with the experiences and perceptions of those living with other chronic conditions. For example, in a qualitative study of men with diabetes, one participant said "who would love a broken person" (Barnard-Kelly et al., 2019, p203), a view also expressed across participants within the current study. In a study that included

dermatology patients (Bhatti et al., 2014), participants¹² described difficulties in explaining their disease, not wanting to initiate relationships due to fear of rejection, and having low confidence; all of which were reported by men in this study.

The need to prioritise physical health was described in section 4.4.1 as a barrier to starting new relationships, but participants in relationships also described how focusing on their own physical health could place a strain on existing relationships. Conversely, existing and previous relationships were also reported to be beneficial to men's well-being in terms of practical and emotional support. This has also been reported more generally in chronic disease where long-term partnerships have been associated with improved health (Gray et al., 2017). The idea that the disease could both unite and divide a partnership has also been described in research exploring other chronic conditions. For example a study in which a man with diabetes said that it "creates a connection with your partner" (Barnard-Kelly et al., 2019, p204) echoing a participant's words within this study: the disease "*brings you closer*" (Alex).

¹² Bhatti et al. (2014) included both men and women within their study so these findings are not necessarily male-specific.

Figure 4.4: How men's partnership concerns were interpreted to impact upon sexual health



The finding that partners were not readily involved in men's healthcare provision is important in the context of the possible positive benefits of partnership. Additionally, relationship stress can exacerbate poor health outcomes (Gray et al., 2017) and it has been reported that IBD affects the psychological well-being of the partners of IBD (Jedel et al., 2015b).

Previous studies have identified that IBD can impede positive body image (Ruan et al., 2020; McDermott et al., 2015; Jedel, Hood and Keshavarzian, 2015a) and this finding was replicated within the study across the sub-themes; 'self-perceptions', 'sexual engagement', and 'physical strength'. While body image dissatisfaction was once considered to predominantly affect

females, it is now widely accepted that men can also be affected by body image concerns (Murray and Touyz, 2012). Muscularity in particular is recognised as a masculine ideal (Murray and Touyz, 2012) that has been associated with sexual satisfaction (Daniel and Bridges, 2013). Participants in the current study discussed the loss of muscle mass, and body shape changes that were either brought about by the disease or were caused by the barriers they faced in engaging in physical activity. This could reduce confidence and self-esteem which impacted on sexual engagement. Similarly, body shape changes have been reported to lead to sex avoidance in male patients with chronic renal failure (Keskin, Babacan Gümüş and Taşdemir Yiğitoğlu, 2019). Surgery was also found to change body image, and this finding has also been identified by McDermott et al. (2015), who reported an association between surgery and body dissatisfaction regardless of stoma formation. The current study provides further insight into why this may be the case, including the weight changes caused by surgery and wounds. Interestingly, one participant in the study awaiting surgery was not concerned over the forthcoming changes. Importantly, his surgery was planned in advance, which may have played an important role in his adjustment and acceptance of the resultant body changes, but it also demonstrates that not all men will be negatively affected by a stoma formation.

The collected narratives of men with IBD reveal nuanced ways in which the condition can alter sexual health and wellbeing across varying sexualities and sexual identities. Research into the sexual health of gender minorities and gay men with IBD is especially limited and has been raised by others as an area for further research and clinical provision (Eidelberg et al., 2024; Boyd and Friedman, 2023; Martin et al., 2017). To date there has been only one primary research study focused on the experiences of gay and lesbian patients with IBD (Dibley et al., 2014). In a poster presentation of this study, Dibley, Norton and Schaub (2013) reported that gay men with IBD were hesitant to discuss their sexuality with practitioners due to fear that the disease would be attributed to their sexual practices. Men within the current study did not express a belief that their sexual practices had caused their disease although there was a fear that sex might trigger disease flares. Men from sexual

minorities did, however, express that their sexual practices were poorly understood by practitioners. For example, one participant who was in a relationship with a man, highlighted that their sexual life rarely involved the rectum, demonstrating that anal sex is not always practised in men who have sex with men.

Fatherhood and fertility were not the sole focus of this work but as expected the topics were frequently raised by several participants in the wider context of sexual health. No studies have explored fatherhood specifically in the context of IBD but Mukherjee, Sloper and Turnbull (2002) investigated the experiences of parents. The experiences of fathers cannot be distinguished from those of mothers within the Mukherjee, Loper and Turnbull (2002) study but the overall findings align with the disruptions reported by fathers within this study, including the inability to undertake social activities, concerns of passing on the disease to children, and worries over children seeing them unwell. A qualitative study of men with rheumatoid arthritis identified that fathers could struggle with undertaking parental responsibilities, and participants identified the need to secure their physical health in order to parent (Avrech Bar et al., 2021): these findings were replicated within this study. Infertility has not previously been associated with IBD (Shin and Okada, 2016) even though some medicines carry the risk of impacting on sperm quality and some surgeries might carry the risk of ED. Some participants in the current study expressed concerns regarding fertility but there were no reports of infertility.

Voluntary childlessness was mentioned by two participants within the study; a topic unexplored in the previous literature. In this work all the participants who discussed childlessness also reported additional factors that were not IBD-related but had contributed to their decision to not have children; for example, the complexity of adopting in same-sex relationships or a partner not wanting to have children. Fatherhood is a key signifier of masculine identity whether constructed hegemonically (for example, being the protector of the family and main breadwinner) or non-hegemonically (for example, in a more egalitarian relationship as a primary or equal care-giver). In work on the intersectionality of fatherhood, a theorised junction with race, economic status, and culture has

been discussed (Strier and Perez-Vaisvidovsky, 2021). To date the intersection between IBD and fatherhood has only been considered in regard to fathers caring for children with IBD (Spurr et al., 2023).

Men with and without children sought financial security and discussed the challenges of engaging in employment, resonating with evidence that unemployment and absenteeism from work are a recognised economic burden of IBD (Zhao et al., 2021; Le Berre et al., 2019; Rankala et al., 2021). Employment in the context of IBD has also been investigated and is associated to a negative impact on quality of life (Van Gennep et al., 2021; De Boer et al., 2016). The ability to undertake employment was interpreted within this study to facilitate realising a number of male gender norms, including being self-reliant, being able to provide for the family unit, and contributing to society.

To summarise, the findings presented in this chapter demonstrate that disease-specific factors can directly impact on sexual health and well-being. Importantly, the disease can also impact on social and occupational engagement (including partnership, fatherhood and employment) which indirectly impacts on sexual health through disruption to male gender norms. These issues are discussed in further detail in Chapter 6, section 6.3.

4.4.3 Strengths and limitations of the findings

This section highlights the most pertinent strengths and limitations relating to the findings of the study presented in this chapter. Later in the thesis, Chapter 7 provides a critical reflection of the research presented in this thesis, including the methods used within this study.

A key strength of the research presented in this chapter is that it is the first male-specific study in this field. As such, it contributes new knowledge and insights that adds appreciably to the evidence base, including specifically how men with IBD experience and perceive their sexual health. While the study findings provide additional understandings of the impact of IBD on body

image, it also provides novel insights into how the interplay of disease and gender may alter men's partnerships and sexual interactions.

As an interpretive qualitative study, the purposive sampling strategy was focused on eliciting a rich narrative data. Inclusion of narrative interview excerpts, pictures, thick description, and interviewer reflections (Appendix 15) affords an understanding of the personal context of the findings to enable readers to practically and emotionally engage with the data (Stalmeijer, Brown and O'Brien, 2024). This allows others to comprehend the data in a way which may be applicable to their own contexts and is a key tenet of qualitative research (Cleary, Horsfall and Hayter, 2014b). Additionally, the adoption of a gendered approach and application of a nursing lens to the data means that the findings may be both informative and transferable to other nurses working with men with IBD or men with other health conditions (further analysis of the findings in relation to other chronic conditions is also considered within Chapter 6).

As is expected in qualitative methods, the findings do not indicate the prevalence of sexual health issues raised and the sample is not proportionately representative of the UK IBD population in regard to disease phenotype, treatment, sexuality, and other personal characteristics. One example of this is that 53% of participants with CD in the current study reported perianal disease, which is higher than the general CD population, reported to be at 19% (Tsai et al., 2022). Furthermore, not all presentations of IBD were included which may limit the transferability of the findings to some men with IBD. However, continuing data collection until the point of saturation of themes supports the transferability of the findings to broader theories and concepts relating to gender, sexual health, and chronic illness.

Although the sample included representation from sexual minorities including a trans-man, and bisexual and gay men, the findings indicate that further work is required to develop a fuller understanding of the specific needs of these men. Likewise, this study did not include partners' perceptions or experiences and so this is absent from the data.

Each participant was interviewed once, so this study can only report any changes over time or progressive effects of the disease based on a participant's recall of the account. Although the relapsing-remitting nature of the condition was conveyed by participants and many participants described the impacts of active disease it may be informative in future research to interview men during periods of relapses. This aspect was considered within the theoretical sampling strategy but the researcher did not seek to sample men in relapse due to the ethical and moral obligation to prioritise the well-being of men within the study. In an attempt to provide a longitudinal aspect of the study and enable participants to expand or develop the narratives provided at interview, participants were offered the opportunity to provide oral, written, and visual accounts to the researcher for a period of three months following their interview. This was not taken up by any participant and it would have been interesting to ascertain why uptake of these methods is poor in future work. It is possible that this data collection method was not fully understood by participants, participants may not have felt comfortable recording their experiences, or it was too much of a burden for them. It is also possible that they felt the interviews had comprehensively covered their sexual health issues and they did not feel that there was anything further to add.

As there was only one interview with each participant, there was no opportunity to undertake member-checks of the interpretations. This was mitigated by having a PPI member review the findings, but the theoretical sensitivity of the work may have been strengthened by giving the opportunity for participants to further clarify or have input into the process of data analysis and interpretation.

4.4.4 Next steps

Overall, the current study has identified that the symptoms and chronicity of IBD can have an important, detrimental impact on men's sexual health and wellbeing. The influence of the disease on sexual health could be a 'direct', for example reduced sexual desire and prohibition of sexual expression, or 'indirect' for example changes to partnerships, self-perceptions, and the ability

to attain a desired gender norm which could lead to an impact on sexual health and well-being.

Many men reported that healthcare practitioners did not initiate discussions relating to their sexual health or well-being during routine clinical appointments and interactions. Men were seemingly unsupported with regard to their sexual health needs. To comprehensively explore the field of sexual health in men with IBD and identify the priorities for future nursing practice and research, exploring healthcare practitioner (HCP) experiences to gain insight into their understanding of men's needs, the barriers to sexual health provision, and possible ways in which to improve care, is needed. This conclusion informed the decision to explore HCP views in the subsequent study presented in Chapter 5.

CHAPTER 5: QUALITATIVE STUDY 2

A qualitative study exploring health professionals' experiences and understanding of the sexual health and associated care needs of men with inflammatory bowel disease

This chapter sets out the design and findings of the second qualitative study in this thesis. This study sought to understand IBD healthcare professional (HCP) experiences of providing sexual healthcare to men with IBD. The study is reported in line with the COnsolidated criteria for REporting Qualitative research (COREQ) (Tong et al., 2007).

5.1 Introduction

Findings from qualitative study 1 (reported in Chapter 4) showed that IBD can shift men's emplacement within their personal, social, and sexual relationships which can alter the way in which they engage in sexual activities and negatively affect their sexual well-being. Men with IBD who participated in qualitative study 1 reported that professionals involved in providing healthcare for their condition rarely initiated discussion about their sexual health. This demands the exploration of HCP perceptions and understanding of men's sexual health in men when living with IBD, to identify the barriers to assessment and care. There have been two comprehensive reviews exploring healthcare professionals' perceptions and attitudes toward sexual healthcare in chronic disease (McGrath et al., 2021; O'Connor et al., 2019) but neither has included studies focused on IBD; demonstrating a paucity of understanding in this field and the need for further study.

The aim of this study was to describe and interpret the experiences of HCPs working in IBD to better understand current healthcare practice in relation to the sexual health of men with IBD and further expand upon and develop the findings of qualitative study 1. Acquisition of such knowledge is required for the development of clinical, educational, and research recommendations that

will seek to ensure patient information and healthcare provision are appropriate and accessible to men with IBD while also being practical and feasible within the clinical context.

The study objectives were to:

- (1b) explore current practice in relation to the assessment of sexual health needs in men with IBD and the delivery of relevant care;
- (2b) examine the perceived barriers and facilitators to professionals engaging with men about their sexual health;
- (3b) gather professionals' recommendations for ways to improve sexual healthcare.

Interpretive description (Thorne, 2016), as outlined in Chapter 3, provided the methodological framework for this work and informed the development of the study design and analysis. ID permits a reflexive approach, which enabled the utilisation of existing clinical knowledge and experience throughout the data collection and analysis in this study.

5.2 Methods

5.2.1 Study population, sampling and recruitment

The study population was healthcare professionals in the UK who were involved in the diagnosis, assessment, and treatment of men with IBD. In the UK the core healthcare team in IBD usually includes General Practitioners, Gastroenterologists, Surgeons, Endoscopists, Dietitians and Clinical Nurse Specialists (CNSs). Care is also supported by practitioners working in radiology, pharmacy, medical infusion units, community health teams, acute hospital wards; in the event of extra-intestinal symptoms, other departments such as dermatology, rheumatology, and ophthalmology. IBD CNSs are often the first point of contact once a diagnosis has been made and they are responsible for co-ordinating the patient care pathway.

Purposive sampling was used to select participants that would be able to provide rich and informative data. A range of professional groups were

included in the recruitment process with the aim of promoting sample diversity and ensuring breadth in the data (see Table 5.1). As this work is centred within the field of nursing and because IBD CNSs are both the care co-ordinators and key contact for people with IBD, they were the primary participant group. However, to ensure a comprehensive and rich understanding of the current sexual healthcare landscape in the UK, a key informants list of all HCPs who are most likely to have direct and regular contact with men with IBD, was employed within the sampling strategy (Table 5.1). Although the list was not exhaustive, it was deemed suitable for the subject matter being covered and achievable within the scope of the study.

A prior systematic review of studies assessing sample sizes in qualitative studies (Hennink and Kaiser, 2022) demonstrated that saturation was usually reached between 9-17 interviews. This study aimed to recruit a slightly higher figure of between 12-20 participants to allow for more than one participant from each professional group within the key informants list. This sampling strategy was deemed appropriate for providing sufficient variation to allow consideration of disconfirming evidence and to achieve maximum variation (Kuzel, 1992). During purposive sampling, the researcher also considered other factors to enhance representation, including:

- geographical location; to capture professionals who care for varying populations and within varying clinical frameworks and local policies.
- level of expertise and training; to represent the diversity of experience, training and expertise that occurs in the clinical environment.

Table 5.1: Key informants list for qualitative study 2

Professional Group	Key informants	Registering body
Medical doctors	Gastroenterology Consultants and Registrars Surgeons with a specialist interest in IBD General Practitioners	General Medical Council (GMC)
Nurses	IBD and Gastroenterology Specialist Nurses Stoma Nurses Biologics/Infusion unit nurses Nurse endoscopists	Nursing and Midwifery Council (NMC)
Clinical Psychologists	Clinical psychologists working within gastroenterology departments or with a specialist interest in IBD	Health and Care Professions Council (HCPC)
Dietitians	Hospital based dietitians working in gastroenterology departments	Health and Care Professions Council (HCPC)

The inclusion criteria for the study was:

- adults aged 18 years or above;
- a health professional registered with the GMC, NMC or HCPC;
- currently employed (or employed within the last 5 years) in a role that directly provides care, support or advice to men with a diagnosis of IBD;
- able to give informed consent.

Participants were recruited by advertising through professional organisations, committees, and networks. These specifically included the Royal College of Nursing IBD Facebook group, the local IBD specialist nurse networks, and several IBD specific conferences. Advertising was cascaded to healthcare professionals with specialist nurses giving the advert to colleagues in other professional groups. HCPs who expressed an interest in participating were provided with a participant information sheet (PIS) (Appendix 19) and were followed up via email. Everyone who requested a PIS, agreed to participate. Recruitment was terminated after 19 participants when there were no new emergent themes (saturation) and at which point there was also a diverse

study population in regards to years of IBD clinical experience and professional group.

The recruitment processes followed Good Clinical Practice guidelines (ICH, 2017) and the UK Policy Framework for Health and Social Care Research (HRA, 2017). It was made explicit that participation in the study was voluntary and all participants were given the opportunity to ask questions. Written, informed consent was taken prior to participation in the study. All participants were made aware of the nurse-researcher's professional role as an IBD CNS and some participants were known to the researcher prior to participation in the study. There was no coercion and the researcher maintained a reflective diary and carefully considered the possible influence of knowing participants prior to participation, which is a valid and recognised approach within constructivist research approaches.

5.2.2 Data collection

Qualitative data were collected using individual, semi-structured interviews. Interviews were held via an online video call, duration averaged 32 minutes (range 21 - 54 minutes). All interviews were audio recorded and transcribed verbatim by the researcher. Only the researcher and participant were present during interviews. Participants chose the location of the interview and all were advised to select a private location and maintain patient confidentiality throughout the process. One female nurse-researcher (the author) performed all interviews and transcribing. Notes were taken during the interviews to aid thinking and help return to points raised for further clarification. An interview guide (Appendix 20) contained questions that covered professional background and experience followed by points relevant to the research objectives and informed by the findings of qualitative study 1 including: challenges faced by men with IBD in regard to their sexual health, assessment of sexual health, potential barriers and facilitators, training received, and recommendations for improvements. Transcripts were not returned to participants in order to reduce participation burden, and no repeat interviews were required. During interviews, in accordance with a constructivist approach, the nurse-researcher favoured drawing on their

personal experience of working in IBD care alongside the findings of qualitative study 1 to stimulate discussion. This approach was favoured over 'bracketing' in the traditional Hursserlain sense, in which researchers do not allow their own assumptions to influence data collection (Polit and Beck, 2008). Drawing upon personal experiences was carefully considered by the interviewer and combined with questioning the participants' agreement with statements made. The risk of confirmation bias and leading questioning was mitigated with in- and post- interview reflection.

5.2.3 Data analysis

The data analysis process applied in qualitative study 1 and which is described in detail in Chapter 3, were replicated in the current study. Familiarisation with the data occurred through the nurse-researcher conducting all the interview transcribing and analytical note taking. Utilising NVivo 9.0 QSR NUD.IST, initial coding involved line by line, segment by segment coding. After each transcript was coded, the codes were reviewed and compared to prior transcripts. All codes, sub-themes, and themes were logged using a Microsoft Excel spreadsheet. As with qualitative study 1, to "move beyond thematic analysis and into the more creative and interpretive realms of figuring out options for depicting patterns and meanings" (Thorne, 2016, p. 169) post-it notes, noting key ideas, drawing diagrams, and memoing were also used.

Emergent themes were aligned with the study objectives. Initially four main themes emerged that were labelled: (1) The multiple intersections of IBD and sexual health; (2) It's difficult to discuss sex; (3) Issues induced by healthcare systems; (4) Transforming services. These were eventually merged into two overarching themes, the first focusing on personal experiences and attitudes labelled 'It's difficult to discuss sex', and the second combining service provision and delivery issues labelled 'Service transformation is needed'. Each theme contained several codes depicting the most commonly explored experiences, barriers, facilitators, and recommendations. The final themes were verified by considering them against the original interviews and the researcher's reflective diary (see appendices 24 and 25). The themes were

logged in a table with a description and examples, which were reviewed by the supervisory team (Appendix 24).

5.2.4 Truth, applicability and dependability of findings

Research rigour and trustworthiness was ensured using the strategies discussed in more detail in Chapter 3, section 3.5. Interviews were transcribed verbatim, a reflective diary was maintained, and codes were logged to ensure transparency and replicability. Peer review of the coding supported trustworthiness of the findings.

5.2.5 Ethical and regulatory considerations

The study was reviewed by the Health Sciences Research Governance Committee at the University of York and given approval on the 3rd February 2023 (Appendix 17). The study risk assessment, informed consent procedures, and data management can be found in the study protocol (Appendix 16) and data management plan (Appendix 21).

5.3 Findings

5.3.1 Participant characteristics

Nineteen HCPs consented to participate in the study. There were no withdrawals. Interviews were conducted between 11 April 2023 and 21 July 2023. Ten nurses, 6 medical doctors, 2 clinical psychologists, and 1 dietitian participated, of which 14 were female and 5 male (Table 5.2). Participants had worked with IBD patients between 6 months and 22 years with a mean of 7 (IQR 15).

Table 5.2: Qualitative study 2 Participant demographics

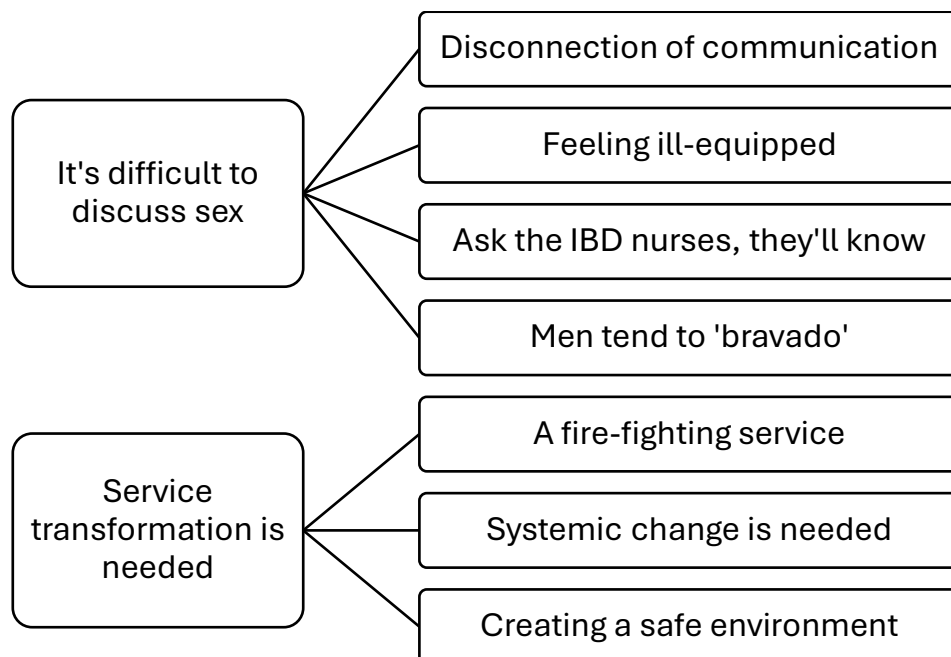
Participant code	Profession	Job title	Gender	Years working with IBD patients
ACP1	Nursing	Gastroenterology Advanced Care Practitioner	Female	20
CG1	Medical	Consultant in Gastroenterology and Lead for IBD	Male	17
CG2	Medical	Consultant in Gastroenterology, Academic Professor	Male	33
CP1	Clinical Psychology	Principal Clinical Psychologist	Female	7
CP2	Clinical Psychology	Clinical Psychologist	Female	0.5
CNS1	Nursing	IBD Specialist Nurse	Female	6
CNS2	Nursing	IBD Specialist Nurse	Female	18
CNS3	Nursing	IBD Specialist Nurse	Female	7
CNS4	Nursing	IBD Advanced Nurse Practitioner	Female	20
CNS5	Nursing	Stoma Specialist Nurse	Female	7
CNS6	Nursing	Clinical Nurse Educator in IBD	Female	29
CNS7	Nursing	Nurse Endoscopist	Female	4
CNS8	Nursing	Infusion nurse team leader	Female	14
CNS9	Nursing	IBD Specialist Nurse (Lead)	Female	22
D1	Dietetics	Gastroenterology Specialist Dietitian	Female	25
GP1	Medical	General Practitioner	Male	3
GP2	Medical	General Practitioner	Male	7
R1	Medical	Gastroenterology Registrar	Male	5
S1	Medical	Surgical Registrar	Female	5

5.3.2 Overview of core themes

Through collecting and interpreting the experiences of HCPs working in IBD, this study aimed to better understand current healthcare practice in relation to sexual health in men with IBD.

The barriers to sexual health discussions, assessment, and provision of care were apparent through two emergent themes. The first theme, 'it's difficult to discuss sex', brings together the personal, professional, and societal barriers to discussing sex that were raised by HCPs. The second theme, 'service transformation is needed', identifies the service-related barriers faced by both patients and HCPs and some possible adjustments that may facilitate the identification and support of men's sexual health and well-being needs within clinical practice.

Figure 5.1: Qualitative study 2 coding tree



5.3.3 Theme 1: It's difficult to discuss sex

Barriers to discussing sex in the IBD clinic were consistently discussed by all participants, who generally reported that it is likely that sexual health issues are under-identified in this population.

Most participants held the view that sexual health was not routinely discussed during clinical consultations.

“This is a huge area that we’re actually missing, we’re not addressing this with patients at all.” (D1)

Commonly reported barriers included a perceived lack of both HCP and patient confidence in raising sexual health matters during discussion. Some participants suggested that patients did not initiate these conversations because male gender norms could prevent men from disclosing sexual health concerns. HCP lack of confidence was attributed to insufficient training and not knowing how to provide adequate support. Four sub-themes were identified including; disconnection of communication, feeling ill-equipped, men tend to ‘bravado’, and ask the IBD nurses, they’ll know. These sub-themes are discussed in the following sections.

5.3.3.1 Disconnection of communication

“I think that’s where maybe there’s a kind of disconnection of communication between us and the patient.” (GP2)

Many participants discussed feeling unsure about whether men would feel comfortable discussing sex and the appropriateness of raising the topic. For example, a Consultant Gastroenterologist with 17 years’ experience in the field of IBD (CG1) stated that it felt ‘intrusive’; this was echoed by other medical and nursing professionals.

“I think there is this two-way thing, where the patient is probably not comfortable asking or we don’t encourage them to ask.” (R1)

Many professionals considered the root cause of the discomfort to be driven by a societal stigma towards sexual health. Many participants also referenced British culture specifically as being inhibited in matters of sex, examples include “*British embarrassment*”, “*the British stiff upper lip*”, and “*we’re a bit prudish*”. One nurse also considered religion as a contributing factor to not raising the topic, but this was not referenced by any other participants.

“There is kind of a level of discomfort, I think, about talking about sexual health just generally kind of within society, isn't there? It kind of feels like a bit of a bit of an uncomfortable thing to kind of go into.” (CP2)

Many participants recognised that leaving patients to raise the topic, or what CNS7 referred to as the *“assumption that I should have let them come to me with the question”* (CNS7), was not beneficial to patients. HCPs considered that not initiating conversations about sexual health could create barriers to discussions rather than open spaces to talk. The ACP participant suggested that a professional-patient power imbalance may contribute to the difficulties in raising discussions about sex. Both male and female HCP participants wondered whether their own gender may present a barrier. Participants often mentioned that there are proportionately more female than male nurses, but there was no clear consensus that a male HCP was better suited to discussing male sexual health matters. CNS4 articulated that there was a professional responsibility to initiate conversations and create a safe space to do so, regardless of the professional's gender or professional background;

“I think that's our responsibility as healthcare professionals. I feel to make that a non-issue, make our sex a non-issue, we're professional. And if we start a conversation about sex, then that will help male, female, either.” (CNS4)

5.3.3.2 Feeling ill-equipped

“You pick up on things when you read, you pick up on things when patients mention them to you or when other colleagues discussed they've come across such and such, but I've never really had any form of training or formal education on sexuality, on sexual health specifically in IBD patients.” (S1)

Participants held a unanimous view that sexual health, well-being, and sexuality were an important aspect of overall health. Yet, the majority of participants reported that they had either not received formal training in sexual health, well-being, and sexuality or, if they had, they perceived it as inadequate. While CNSs generally held a broad view of sexual health to encompass sexuality and well-being, many participants across the professions noted that what sexual health meant could be confusing in practice. For instance, CG1 noted how sexual health is often interpreted to mean genitourinary medicine leading to IBD healthcare practitioners feeling *“completely out of our depths”* (CG1). However, all the participants within the

study discussed how IBD-specific symptoms could disrupt general sexual well-being, including partnerships and body image. Many participants felt that they needed additional support to improve their confidence in raising the topic.

“I think as nurses we have an innate ability to spot people in trouble, it is what we naturally do isn’t it and I think it’s about giving the team the education they need to feel confident enough to have those conversations.” (CNS2)

Although it was clear that participants wanted more training on general sexual health, well-being, and sexuality, the more pressing need was for practical support including disease-specific informational resources, clear referral pathways, and additional specialist services to help tackle specific issues once they had been identified;

“I think more education for us, I think running workshops that you know that work towards how do you bring this into your everyday working life, where do you place it, how do you ask that question, how much should you be checking, how often should you be checking.” (CNS2)

“We feel utterly ill equipped in actually giving quality advice thereafter.” (CG1)

“The fear to open those conversations because you don’t know what to do.” (CNS9)

Unlike other professional groups in the study sample, the two clinical psychologists reported feeling confident in generally discussing matters of sexual identity, relationships, and sexuality broadly. They were also able to clearly define what may be appropriate within role and what would necessitate referral to sexual therapy or other medical services. This finding contrasted with other professional groups within the sample, who were not sure what services might be available or how specific sexual issues may be dealt with. However, the clinical psychologists in the study were also not aware of any IBD specific support or resources that were available. CP2 identified that she did not feel these discussions were raised as frequently as they were in other disciplines, such as patients with renal conditions.

Two participants discussed specific concerns relating to their lack of experience or knowledge to support patients with varying sexualities, particularly with men who had sex with men.

"I haven't got much experience with gay men, and how it affects them. And we have some gay patients, but they haven't brought sexuality up, and certainly I find it quite hard to bring it up." (CG1)

5.3.3.3 Ask the IBD nurses, they'll know

"Whether it's me as a psychologist or somebody like yourself as a nurse, where does that ball start rolling." (CP1)

Although the participants generally felt sexual health and well-being should be addressed in clinical practice, evident across the data was a lack of clarity over which professional group should have responsibility for initiating the assessment of sexual health and co-ordinating any subsequent care.

"Who's taking responsibility for this area of their health, who's leading it, are we both looking over the fence at each other." (GP1)

"Our Doctor colleagues could be leading the way a little more. But I think we all ultimately have a responsibility." (CNS9)

The dietitian interviewed revealed that her initial response to participating in the study was *"no point in interviewing me, I don't know anything about it"* (D1) but having reflected on the role of dietetics in body mass and muscularity, and her previous discussions with patients about body image, she described a role for dietitians in the support of men in this area. Both of the clinical psychologists recognised that their roles provided more time and privacy to have sexual health discussions with patients. Many participants described surgeons as setting an example in having sexual health conversations. Interestingly, the surgeon who was interviewed said *"I will talk about it, to be honest, in very brief superficial terms"* (S1) suggesting that discussions of sexual health in the context of a pre-operative consenting may not explore the potential wider impacts of the disease and surgery on sexual well-being outside of erectile dysfunction.

Many participants considered that IBD nurses were well suited to sexual health assessments because *"patients open up with nurses a lot more"* (CG1), they hold specialist knowledge, and were perceived by some participants as

having more time. This view was not always echoed by the nurse participants, who felt they did not necessarily have the time or the knowledge.

“(the Doctor) would say, you know, oh, ask the IBD nurses they all know. I’m like oh my God, right, okay, I’m gonna look something up here because I don’t actually know.” (CNS6)

5.3.3.4 Men tend to ‘bravado’

“I think with male patients they are more difficult to raise, they don’t want to appear like they don’t know, and they don’t want to ask the questions because they are frightened of the answer.” (CNS2)

Many participants discussed the possibility that there were gender-specific barriers to sexual health assessment and care. Some considered whether male patients were more likely to fear being judged by healthcare workers or find it more difficult to discuss intimate aspects of their lives.

“I think that there is a theme that you see more with men than women, they are harsh upon themselves, and do not give themselves the credit that they have been through this trauma.” (CG1)

Two HCPs specifically mentioned the possibility of male ‘bravado’ as a barrier. One participant (CP2) considered whether men did not (in general) express emotion in the same way as women, meaning HCPs might not be alerted to a possible issue;

‘I wonder if it is more likely for women to kind of have that external expression of what’s going on emotionally for them, than it is for a male.’ (CP2)

Many participants attributed gender and age differences between the professional and the patient to triggering a form of ‘bravadoing’ in patients. This opinion was commonly held by female health professionals in situations when they were older than the male patients:

“Maybe if the younger patient is speaking to somebody my age, it might be like speaking to your mum.” (ACP1)

“Young men, teenagers you know, who would just be absolutely mortified if you know if it’s this old person asked some questions.” (CNS6).

However, concerns over age and sex were not limited to this group and one nurse commented that her younger age could be a barrier:

"I am a young female, quite difficult for any males really to discuss their personal sexual health." (CNS1)

5.3.4 Theme 2: Service transformation is needed

"You look at what it is in your living that makes the lights go on, makes life worth living, what's good about it and in that way you're finding these qualitative elements that's so important and we should be capturing those and then making sure our service supports these elements." (CG2)

IBD care was described by participants as primarily focused on the resolution of active disease, which was either considered the most effective way in which to reduce overall burden of the disease on quality of life or it was the main priority of patients. However, most participants articulated a belief that healthcare services were not meeting the needs of patients with IBD, particularly outside of disease activity. This theme draws together participants' descriptions of how the organisation and operational delivery of the NHS was seen to present a barrier to sexual health assessment, and participants' ideas about how this might be improved.

"An IBD service has to constantly be reinventing itself, modernizing, re-establishing its roles, its responsibilities within a healthcare setting to respond to the needs of patients." (CG2)

5.3.4.1 A fire-fighting service

HCPs consistently described a stretched and under-resourced service. Almost all professional groups referred to a lack of staffing capacity. Medical and nursing professionals most commonly cited lack of time as a critical factor.

"Clinics are so short, and you tend to focus in on the physical things that you need to treat at that point. I think there is a huge risk with that, you know that you don't think beyond what's right in front of you." (CNS6)

"If they have active disease in the limited time that we have appointments, you're very much focused on assessing that formulating a treatment plan for that" (CG1)

One of the Clinical Psychologists expressed a belief that it was the wider system rather than individual skill set or knowledge that was problematic.

"I think sometimes it is about the wider system that you are working in, isn't it? And I, meeting the nurses. I know that I will get the sense that everybody is kind of incredibly skilled about asking about this stuff, and that's the feedback I've been having from people have been seen I suppose it's just how do we, how do we as a service kind of prioritise that time to just check in with somebody's well-being." (CP2)

The varying healthcare professions and specialities were often seen by participants to operate in silos. For gastroenterology doctors and IBD nurses, assessment and resolution of active disease was described as the clinical priority and central to clinical consultations.

"I think we are still running a fire-fighting type service, we're still about just keeping the plates spinning, and I think there is a huge amount of personal, interpersonal family, relationship difficulties that we just leave for people to work out for themselves." (CG2)

Some participants described how disease symptoms that might interfere with sexual activity, such as nocturnal bowel motions, would be discussed as part of the assessment of disease activity. However, there was a failure to translate these assessments into discussions about how the symptoms might impact on quality of life and sexual health.

"We think about overnight disturbance from the bowel point of view, but we don't necessarily think about what that is doing to that relationship" (CNS4)

Waiting lists, shortage of supportive services such as clinical psychology, complexity of caseload, and lack of continuity of healthcare practitioners were all discussed in interviews. Collectively the participant group recognised a mismatch between what they believed should be done, and what could be delivered within the constraints of the service.

"We're in a challenging situation in the NHS at the moment because there's what we would like to be able to provide and what we're actually able to provide." (CNS9)

5.3.4.2 Systemic change is needed

“You know, we have a women's health, women's health examination appointments where women come and have, you know, have double appointments, and full examination, and swabs taken as routine, whereas we don't have that pathway of care for men.” (GP1)

Several participants made suggestions on how sexual health provision within IBD could be improved. A common pattern evident across participants' narratives was a fundamental need for services that are more patient-centric with inclusive access, well-defined referral pathways, and interdisciplinary collaboration.

Mode of service delivery was frequently discussed as a potential solution, including utilisation of tele-clinics and mobile apps. It was often suggested that utilising new technologies may help improve accessibility and efficiency.

“It's something that I've thought about, is the use of digital tools like apps, so that you can pre-screen someone and talk about relationships, sexual health and all of the rest of it and they can answer those questions without actually having to answer you directly.” (CNS4)

Exploiting the possible resources available from the charity sector was considered by some participants as an alternative *“tier of support, which would be person-led rather than driven from secondary care” (CG2)*. Services that were patient-led and offered patient choice were widely seen as important. Common across participants' accounts was a view that a more comprehensive multi-disciplinary approach with increased time and regular contact is likely to be needed.

“This area of men's or sexual health is really important, and we need to start building a structured service beyond just the simple issues of a pharmacy, dietetics and a little bit of clinical psychology.” (CG2)

However, while individualised pathways and flexibility were viewed as a possible route to improvement, it was also highlighted that consistency of care across organisations throughout the NHS could facilitate more cohesive and integrated pathways for patients.

“Why we can't have integrated tools, why can't have kind of integrated pathways. Why, am I doing something different where I am to you?” (CNS4)

5.3.4.3 Creating a safe environment

A common sub-theme underpinning the idea of improving access and inclusivity while being patient-centric was the concept of creating a safe space in which men might discuss their sexual healthcare needs. There were some practical considerations, for example the stoma nurse noted the benefit of being able to visit people at home, which provided a safe and familiar environment. In comparison, the surgeon, medical registrar, ACP, and endoscopist all noted working environments that were not conducive to privacy or comfort.

“So whether they need a more friendly environment where, or dedicated sort of clinics where they can have that discussion in more open discussion.” (R1)

As identified in the theme ‘it’s difficult to discuss sex’, the need to overcome underlying attitudes towards discussing sex was identified. It was frequently recognised that professionals needed to find ways to have open and honest discussions with patients and make them feel emotionally safe and secure enough to do so. Pre-screening aids, posters, and equipping professionals with acceptable questions to open discussions were all suggested as potentially useful tools for facilitating discussions.

“I think the key thing is getting the message out that it's okay to come forward.” (CG1)

Participants frequently raised the issue of including partners. For example, one participant described experiences of patients not talking as much when a partner was present (CNS3) which could be a barrier to having open discussions about sex, whilst several participants considered whether inviting partners into consultations would help to open the door to discussions. For adolescent patients, having parents in the consultation was seen as prohibitive to having discussions of that nature that needed to be managed sensitively.

“We all know kids do it (have sex), they are not going to fess up in front of their parents, that’s the same with drugs as well isn’t it, you are not going to sit in front of your parents and say yeah of course I take those.” (CNS2)

Finally, although it was not always explicitly stated, the idea of creating a safe space for HCPs to discuss sexual health was also embedded throughout the participants’ interviews. HCPs noted that they could be supported to overcome their own anxieties and misapprehensions about discussing sexual health through provision of supporting materials, better training, and open and honest discussions amongst the MDT. For many participants, the first step was a simple one; to talk about it more and reframe sexual health as an important issue to be dealt with by practitioners:

“Just talking about it more even within the nursing teams that we’re in. Just make it a kind of an open discussion to talk about.” (CNS3)

5.4 Summary of the findings (qualitative study 2)

This is the first UK study to explore HCPs’ experiences of delivering sexual healthcare to men with IBD. This study aimed to build upon the findings from qualitative study 1 (Chapter 4) by exploring and interpreting HCPs’ experiences to meet the study objectives: (1b) better understand how current practice is delivered; (2b) examine the perceived barriers and facilitators to delivering care; (3b) gather HCPs’ recommendations for possible improvements. Two key themes were identified: ‘it is difficult to discuss sex’ and ‘service transformation is needed’. This section will explore these themes across the three study aims while also considering how they extend the current evidence base. The scarcity of research within the context of IBD-related sexual health practice in the UK, means that literature from other countries and domains of practice has also been drawn upon.

5.4.1 What do the findings tell us about how current practice is delivered and possible barriers to care?

A key finding from the current study is that HCPs perceived sexual well-being as an important part of overall health and that they had professional responsibility to provide support in matters of sexual health to men with IBD.

However, participants also reported that they did not routinely assess sexual health and well-being with men in the IBD clinic. This lack of routine discussion and assessment has been a consistent finding in research on other study populations living with chronic disease. For example, a systematic review demonstrated that only 14% of professionals routinely discussed sexuality (McGrath et al., 2021). Similarly, a survey of HCPs across the UK (n=813) reported that 90% believed sexual healthcare should be a part of healthcare provision but 94% were unlikely to discuss sex with patients (Haboubi and Lincoln, 2003).

Several additional barriers to the provision of sexual healthcare of men with IBD were identified in the current study that also resonate with those discussed within the wider literature. Primarily these aligned with the findings of a survey of American Gastroenterologists who reported a failure to address sexual health due lack of clinician time and knowledge, and embarrassment (Christensen et al., 2022). Additionally, participants in the current study referred to diagnosis and medical care being the focus of healthcare provision rather than ongoing support and adaptation to living with life-long conditions; a finding also reported by McGrath et al. (2021). In a review of qualitative studies exploring why healthcare professionals don't talk about sex, Dyer and Das Nair (2013), represented the barriers and facilitators to sexual health discussions under three main themes: organisation (healthcare), structural (or wider societal), and personal factors. As these themes align with the findings of the current study, a similar approach has been applied in Figure 5.2 to represent the barriers raised by participants in this study.

The novel findings in the current study build upon and extend the insights of this prior work. Firstly, while the Dyer and Das Nair (2013) review mostly included studies of HCPs working in primary care, this study demonstrates how similar barriers are faced by HCPs working in secondary care and specialist services. This similarities observed demonstrates the likely transferability of the current study findings to practitioners working in both IBD and other healthcare settings or conditions. Secondly, the findings of the current study suggest an additional factor that influences HCP's discussion of

sexuality which has been labelled ‘professional’. While Dyer and Das Nair (2013) found that training and personal views were frequently raised by studies across their review, they do not discuss the possible implication of professional values or perspectives. As the methodology applied in the current study was grounded in nursing with the goal of informing practice, this lens may have enabled additional insights into the contrasting positions of varying healthcare professional groups. Additionally sampling from varying professional groups within the same study has allowed interpretation of how different professional roles may intersect with the barriers faced by HCPs.

Figure 5.2 Barriers to sexual health discussions with men with IBD

Personal	<ul style="list-style-type: none"> •Comfort and confidence •Attitude and beliefs •Gender and age
Professional	<ul style="list-style-type: none"> •Training •Professional values and philosophical perspectives •Professional-patient power imbalance
Organisational	<ul style="list-style-type: none"> •Continuity of care •The healthcare environment: privacy, time •Availability of and access to resources •Cohesion of the MDT
Societal	<ul style="list-style-type: none"> •Stigma •Gender norms

The key theme ‘it’s difficult to discuss sex’ reflected several participants’ accounts of feeling uncomfortable, a finding replicated by HCPs working in oncology (Leonardi-Warren et al., 2016) and diabetic specialist nurses (Yin, Rämngård and Wangel, 2023). In this study instigating discussions about sex were reported to feel “intrusive” with many participants reported that they would leave it to the patient to initiate discussions; a finding also replicated in 88% of HCPs working in rheumatology care (Helland et al., 2017). The personal discomfort with addressing sexual health was suggested by participants in the current study to be driven by societal stigma, which has

also been identified in a prior review of sex in chronic illness (O'Connor et al., 2019). Many participants in the current study referenced British culture as stigmatising sex, however studies with HCPs in Sweden and Turkey have also identified sex and sexual health as social taboos (Saunamäki and Engström, 2014; Evcili and Demirel, 2018; Yin et al., 2023). Healthcare practice will need to transcend the taboos regarding sex in enable people to make informed decisions and lead fulfilling and healthy lives (Tohit and Haque, 2024). A key recommendation of this work is the normalisation of HCP-initiated sexual health assessments in clinical practice that are sensitive and culturally considerate (Chapter 7, section 7.2.1).

Participants considered whether the disparity in age between themselves and patients could be a barrier to discussions. A recent review of the wider sexual health literature found that HCPs were less likely to raise issues with young or older adults (McGrath et al., 2021). Participants also contemplated whether their gender may influence men's comfort with discussing sex and whether having more practising male IBD CNSs might lead to sexual health being more readily discussed. Male HCPs in the UK have been reported to be more likely than female HCPs to address sexual health (Haboubi and Lincoln, 2003) but this was not reflected within this study with many of the male participants expressing a reluctance to discuss sexual health with patients. Many of the HCPs in qualitative study 2 wondered whether increasing the number of male nurses might support the willingness of men to speak to nurses regarding their sexual health. Reducing the under-representation of men in nursing may help to ensure that the profession reflects the diversity of the population it serves to ensure accessible and culturally sensitive care (Martsolf, et al. 2023; Douglas et al. 2014; Entwistle, 2004). However, the fact that both male and female HCP participants described challenges in discussing men's sexual health suggests that reducing the gender gap in nursing should not be the only approach to improving practice. An approach considered by all HCP participants, regardless of gender was improving training and support to engage in sexual healthcare discussions.

A further key finding was the varying perceptions amongst participants about which professional group should be responsible for providing sexual healthcare. The review by Dyer and das Nair (2013) identified five papers in which HCPs expressed the view that sexuality was outside of their domain of practice. A study of 1,211 nurses working with people with renal conditions in the Netherlands, found that 83% felt that doctors should be raising sexual health (Van Ek et al., 2018). While all participants in this current study agreed that their professional role was in some way responsible for supporting sexual health, there was a range of ideas about who should be initiating conversations and leading sexual healthcare in the context of IBD. Importantly, participants in the current study recognised that the lack of clarity on professional roles, could be a possible reason for it being overlooked entirely. In prior work specifically with nurses working in oncology and HIV care, it was reported that although nurses perceived sexual health as an important part of their role they did not know how to incorporate it into their practice (Reynolds and Magnan, 2005). Nursing literature published in countries outside of the UK demonstrates a lack of preparedness for general discussions of sexual intimacy with patients (Evcili and Demirel, 2018; Van Ek et al., 2018; East and Hutchinson, 2013). There is an apparent need to more clearly define roles within the multidisciplinary team and an opportunity to improve inter-disciplinary training on sexual health. As the care co-ordinators of IBD patient journeys, it is likely that specific training for specialist nurses could provide benefit to those living with IBD in the UK.

A barrier that spans all categories is the possible ambiguity over what sexual health and well-being means to both individual practitioners and patients. This lack of understanding is also recognised within the wider sexual health literature. There have been calls to ensure that the domain of sexual health is inclusive of sexual pleasure and justice as well as function, fertility, disease, and well-being (Mitchell et al., 2021). It is possible that the lack of clarity over what sexual health encompasses and what should be covered in a sexual health assessment, feeds into HCPs feeling ill-equipped to deal with it. HCPs reported that they do not have the expertise to deal with the complexity of sexual health and this has also been reported as a barrier in existing work

outside of IBD (Dyer and Das Nair, 2013). In the current study both nurses and clinical psychologists demonstrated a broader understanding of sexual health as compared to other professional groups which were more likely to discuss function and disease of the sexual organs within the interview.

Overall, the findings from the current study suggest that healthcare practitioners working in IBD are likely to understand the need for sexual healthcare in men with IBD but face personal, professional, organisational, and societal barriers to providing assessment and support. Future work should therefore focus upon how HCPs may become comfortable and proficient at initiating sexual health conversations that are inclusive of psychosocial-sexual needs.

5.4.2 Strengths and limitations of the findings

A key strength of the research presented in this chapter is that it is the first study to investigate the experiences of HCPs in relation to the sexual health of men with IBD. As such, it contributes new knowledge to the evidence base, including the barriers to providing sexual healthcare to men with IBD faced by HCPs.

A further strength of the study was the diversity of the study sample in terms of profession, gender, and years of experience working within IBD. The sample diversity secures the dependability of the findings being applicable to the care of men with IBD and increases the likely transferability of the themes to other clinicians working with men with IBD. However, as the sample only included one dietitian, one ACP, one surgeon, and one medical registrar the findings may not reflect the experiences of these professional groups. Further research is therefore required to fully explore the varying experiences between different professional groups.

Information on the locality and type of service provider the participants worked in at the point of recruitment was not collected and therefore no comment can be made on the patient demographic the HCPs in the study served, nor is it possible to assess whether certain barriers were related to certain types of

service. This omission was inopportune as the study was advertised nationally and utilised online interviewing to widen participation from HCPs across the nations. Subsequently, no initial interpretations about experiences regarding patient population or type of service can be made.

The targeted purposive sampling strategy raises two potential limitations. Firstly, it is possible that the participants had a clinical interest in sexual health or felt they faced barriers to sexual health in practice and therefore wanted to participate to facilitate change. On the one hand, this is beneficial in regard to obtaining rich information but it does limit the transferability of the findings. Further research to confirm these findings may be required. Secondly, some participants were known to the interviewer in a professional capacity, and this could have shaped what they were willing to share due to a desire to maintain their professional reputation but also protect the service they worked for from being perceived badly. Attempts to mitigate this effect were made with clear information on confidentiality, adopting an open and non-judgemental approach to interviewing, using reflexive interviewing and diary taking (see Appendix 25 for examples). The interviewer felt that the participants were candid during the interviews, and this is substantiated in the excerpts provided in Section 5.3.

While the interviews were conducted almost three years after the start of the covid-19 pandemic, IBD services were continuing to experience an impact during the study period. In order to streamline care and keep services operational, while also attending to the public health needs of the pandemic, the focus of gastroenterology services became the diagnosis and treatment of urgent disease (Shen, 2021). There was a call for IBD services to keep telephone lines open and better utilise teleservices for care provision (Ma, Rook and Galdas, 2020a) and while this was achieved, nurses faced challenges to disrupted pathways, disjointed multi-disciplinary working, and increased workload (Avery et al., 2021). To provide context, HCPs were interviewed following a time period when they had experienced reduced face-to-face patient contact and a reduction in clinical consultation time. Participants had clinical experience of working in the field from 6 months to 33

years, so some of the experiences collected did extend beyond the covid-19 period but the findings should be considered within this context.

In summary, while this study provides valuable and dependable new insights into HCP experiences of delivering care to men with IBD, there are limitations relating to the sample, participant-interviewer relationship and time period in which the study was conducted, that mean that the transferability of the findings need to be carefully considered. Despite the limitations discussed above, the inclusion of narrative excerpts, thick description and reflexivity (see Appendix 25) enables the reader to engage with the data in such a way that they may be able to make it applicable to their own contexts (transferability). In combination with continuing data collection until saturation of themes has also ensured trustworthiness and dependability of the findings. This strength is confirmed by the themes of the current study aligning with the findings of the review by Dyer and das Nair (2013).

5.4.3 Next steps: knowledge transformation

The two primary research studies presented in Chapters 4 and 5 of this thesis have set out a number of interconnected findings that have extended what is currently known about men's sexual well-being and current sexual healthcare practice when living with IBD. Importantly, this work confirms that not only can the sexual health of men be disrupted by the condition, but there are likely unmet health needs within this population.

The men who participated in qualitative study 1 drew attention to the varying ways in which IBD could affect their sexual health, including partnerships, body image and expression of gender norms. These impacts were affected by active disease but were often psychologically driven and could persist in periods of remission. Although the resolution of disease symptoms is likely to support sexual well-being, this finding identified the likely need for ongoing support with adapting to chronic disease. HCPs in qualitative study 2 reported feeling ill-equipped and underconfident in dealing with sexual issues, in part because they were not supported with adequate training and service provision. They confirmed that the focus of care was on physical disease

symptoms and medical management. Qualitative study 1 highlighted the ways in which men from sexual minorities were affected by the disease and the lack of information available to them. HCPs in qualitative study 2 reported a lack of experience and confidence in dealing with sexual health issues presented by gay, bisexual and men of sexual minorities. Participants across both studies confirmed an overall lack of informational resources and support mechanisms.

The following chapter presents a critical evaluation of these findings in relation to relevant existent theories and frameworks to help provide new insights into ways of understanding the key emergent issues; supporting the transformation of findings into clinically useful knowledge and formulation of pertinent recommendations for future research and practice.

CHAPTER 6: DISCUSSION

In this chapter a theoretical interpretive lens is applied to challenge, contextualise and bring together a coherent interpretation of the findings of the scoping review and two primary qualitative studies presented in this thesis. This crucial step has facilitated the transformation of the findings into clinically useful knowledge that can help inform nursing praxis, and underpins the recommendations subsequently set out in Chapter 7.

6.1 Introducing the key findings of the thesis

The scoping review and two qualitative studies presented in this thesis have yielded novel insights that can help inform the development of men's sexual healthcare in IBD. Three overarching findings identified from a synthesis of the three studies presented within this thesis are introduced within this section. Sections 6.2, 6.3 and 6.4 contextualise these key findings within the existing literature..

6.1.1 Key finding 1: Men with IBD experience sexual health as a multidimensional concept that reaches beyond erectile function

While the existing research has indicated that IBD may lead to physiological sexual dysfunction in men, the first qualitative study demonstrated that IBD can also lead to poor psychosocial sexual health and well-being. These impacts were experienced, for example, as negative effects on partnerships and self-perceptions which have also been reported in men with other chronic conditions such as diabetes (Barnard-Kelly et al., 2019). In qualitative study 1, these negative impacts were reported to be driven by active disease or surgery for men with IBD. However, it was also reported that disruption could occur in the absence of these factors indicating that disease chronicity may be a significant moderating factor of sexual well-being alongside other disease variables such as age at diagnosis, presentation, and treatment. The finding that men with IBD experience psychosocial sexual health impacts that are shaped by disease and treatment pathways supports the idea that sexual health needs to be defined more broadly than erectile function and reframed

within the context of chronic, relapsing-remitting disease. This interpretation may be informative for models of care in IBD but also in other chronic conditions such as multiple sclerosis, stroke, and Parkinson's disease. In these conditions, sexual health recommendations for men often centre around the pharmacological or medical treatment of erectile issues (Basson et al., 2010) rather than an integrated medical and psychosocial pathway; a recommendation recently put forward by Tandon (2023). Section 6.2 further discusses the importance of chronicity of disease when understanding sexual health in men with IBD.

6.1.2 Key finding 2: Male gender norms influence experiences of sexual health and sexual healthcare in men with IBD

The second key finding relates to the influence of male gender norms on men's sexual health and well-being; a hitherto underexplored topic within IBD research. This finding has emerged due to the gendered approach adopted within this work and the consideration of the gender theories discussed in Chapter 3, section 3.2.3. In the broader health research literature, sex-specific approaches, particularly in epidemiological studies and treatment evaluations, are common. However, gendered approaches are uncommon within the qualitative investigation of chronic conditions. Subsequently, the influence of masculinity and gender-norms on men's response and adaptation to ill-health has not been widely examined. Oliffe, Galdas and colleagues have spearheaded this approach within the fields of prostate cancer and cardiac conditions which has informed the gendered approach adopted within this thesis (Galdas et al., 2023; Galdas et al., 2014; Galdas, Ratner and Oliffe, 2012; Oliffe and Greaves, 2012; Galdas et al., 2010; Galdas, Cheater and Marshall, 2007; Oliffe, 2005).

In regard to sexual health and sexuality in IBD, gender norms were found to have a tacit influence on the way in which men perceived and experienced sexual well-being and subsequently the manner in which they engaged with healthcare services. The narratives gathered in qualitative study 1 are an exemplar of the difficulty some men with IBD experience in talking about their sexual health needs. The challenge of discussing sexual health needs has

been reported in other long-term conditions, for example in diabetes (Van Pinxteren et al., 2023), however the findings reported in this thesis for the first time highlight both gender- and IBD-specific issues. In qualitative study 2, societal gender norms were perceived by HCPs to influence both their own and male patients willingness to initiate conversations about sexual health. Conversely, diabetic specialist nurses in a Swedish study (Yin et al., 2023) reported that men were more likely to spontaneously raise matters of sexual health, making it easier to discuss sexual health. This illustrates that while considering the intersectional factors that may be relevant to men's health experiences is informative to nursing practice, the interpretations of a gendered approach remain bound to the data collected. The findings may therefore be useful when considering other diseases or social contexts, particularly in informing further research, but should not be uncritically transferred to other diseases or social contexts. The influence of male gender norms on men's sexual health is discussed in Section 6.3.

6.1.3 Key finding 3: Men's sexual health is currently under-supported in IBD practice

The final key finding is the suggestion that men's sexual health may be under-supported within the context of specialist IBD services. While this is likely to be the case for many varying groups of men with IBD, the findings presented in this thesis have collectively drawn attention to the needs of under-represented groups. As highlighted in the scoping review (Chapter 2), the experiences of gay and bisexual men with IBD are largely absent within the current literature. Similar observations have been made of the evidence-base in other conditions. For example, emergent research in the field of cancer indicates that sexual orientation and gender-minority status negatively affect sexual functioning, response to disease, and quality of healthcare (Kent et al., 2019). This is pertinent in light of wider population studies demonstrating greater health disparities amongst gay and bisexual people as compared to heterosexual people (Kneale, Thomas and French, 2020; Booker, Rieger and Unger, 2017; Fredriksen-Goldsen et al., 2013). Furthermore, there is evidence of stigma and discrimination in healthcare towards those from sexual and

gender minorities (Layland et al., 2020; Ayhan et al., 2019). Although the participants in qualitative study 1 did not describe explicit discrimination, gay and bisexual participants did report that practitioners did not enquire about or understand their specific needs. IBD practitioners in qualitative study 2 corroborated this finding by describing a lack of experience, confidence, and knowledge within the IBD healthcare community when assessing and caring for the needs of sexual minorities; this is discussed further in Section 6.4.

6.2 Sexuality in the context of chronic disease

Consistent with the relativist paradigm in which this study is positioned, men's sexual health experiences were found to be variable, multifaceted, and complex. The overarching aim of the thesis was not to weave into a coherent theory the possible interconnections between the mediators, moderators, and outcomes of sexual health as initially laid out in the literature review (Figure 2.2, Section 2.4.2). In fact, predetermining associations between compounding influences on sexual health could undermine the variability in men's experiences. Instead, the complexity of the findings should be used to "sensitise practitioners to the complexities inherent in patient experience" (Thorne, 2013, p297) and facilitate a more nuanced and individualised sexual health assessment.

While the scoping review drew attention to the predilection of research in this field to investigate erectile function, a key finding from qualitative study 1 was that sexual health was affected more broadly than erectile function.

Psychological elements, social contexts, and disease chronicity were found to be critical intersectional points in men's sexual health experiences. This observation is informative to the way in which nursing practice is delivered and importantly indicates that focusing on the assessment and treatment of erectile function may not meet the sexual health needs of men with IBD.

Testing the epistemological integrity and analytical logic of this idea involves considering current frameworks of sexuality in chronic disease; the Verschuren et al. (2010) framework (described in Chapter 3, section 3.2.3) is an obvious starting point to begin this examination as a seminal theory for

understanding the complex interplay between sexuality and chronic health conditions.

6.2.1 Contextualising the results within existent frameworks of sexual health

Unlike the way in which men's sexual health has been studied within the existing IBD literature (see Chapter 2), common to men's accounts in qualitative study 1 was that sexuality and sexual health were not only experienced or viewed as a physical or functional phenomenon but as a psychosocial practice. This interpretation aligns with and adds further evidence in support of the Verschuren et al. (2010) framework, which places 'physical condition' and 'psychological well-being' as interdependent cornerstones of sexual health. The Verschuren et al. (2010) framework also denotes that relationships, treatment, acceptance, and complications all interplay with sexual well-being which was evident within the men's narratives in qualitative study 1. However, as discussed in Section 3.2.3, the role of societal and cultural factors are omitted in the framework, but were found to be central to many men's accounts in qualitative study 1. Men's upbringing, family, education, work, social activities, attitudes, and values all fed into their self-identities, and the ways in which they adapted to their condition and engaged in sexual partnerships. Importantly the role of gender, which was found to be an important factor in physical, psychological, and social expression, is not represented in the Verschuren (2010) model. In contrast to the model presented by Verschuren et al. (2010), the Katz-Dizon model of male sexuality after cancer (2016) draws focus to 'societal messages' as central aspect of sexuality and sexual well-being. The model was developed by the authors who recognised that standard physiological sexual response models do not always reflect the sexual challenges faced by men who have survived cancer. While the Katz-Dizon model (2016) begins to describe the possible intersectionality of gender, disease, and sexual well-being described in the findings of this thesis, the 'body' and 'treatment effects' (physiological factors) take an inferior position. The lack of emphasis on physiological changes may be relevant to men who have recovered from illness (which the model was developed upon), but the narratives of men with IBD highlighted

the concurrent importance of both the physiological and psychological effects of IBD. This may also be the case of other conditions where disease pathology or treatment carries a significant risk of ED such as in diabetes (Burke et al., 2007), prostate cancer (Bianco et al., 2009) and those on dialysis for chronic renal failure (Keskin et al., 2019). In conditions where there is no pathological basis for erectile dysfunction there may be other physical drivers to sexual ill-health such as joint pain in rheumatoid arthritis (Van Berlo et al., 2007), mobility restrictions in stroke patients (Rosenbaum, Vadas and Kalichman, 2014) and genital disease in men with psoriasis (Ryan et al., 2015). It is important to note that in these health conditions, there is also evidence for psychosocial drivers to disruption of sexual well-being (Van Pinxteren et al., 2023; Barisone et al., 2020; Keskin et al., 2019; Hanly, Mireskandari and Juraskova, 2014; Van Berlo et al., 2007). Crucially, men within qualitative study 1 noted that when the disease was severe, sex was not a priority for them in comparison to treatment for their condition. So, in summary, while the findings of this thesis suggest that the physiological components of sexual health, including erectile function, are not the only affected domain of sexual health, they remain an important consideration. Furthermore, disease chronicity, with either cycles of relapse and remission or progression of symptoms throughout the life-span, was also revealed in the accounts of men with IBD in Chapter 4 and this aspect is not reflected in either the Verschuren et al. (2010) or the Katz-Dizon (2016) models.

6.2.2 Utilising the Chronic Illness Trajectory Model to apply the findings of the thesis in clinical practice

A model that does consider the dynamic nature of chronic illness is presented by Corbin and Strauss (1991). 'The Chronic Illness Trajectory Model' (Corbin and Strauss, 1991) not only adopts a nursing lens but also supports blending biographical, social, and medical perspectives within nursing (Corbin, 1998). Although the model was devised over three decades ago, it continues to provide contemporary relevance by highlighting the importance of the dynamic nature of chronic disease. Significantly, the model also considers periods (labelled 'comeback') where the disease itself is stable yet physical and psychological adaptation continues. Male participants in qualitative study

1 reported ongoing effects on sexual health in the absence of disease symptoms and therefore an important consideration for healthcare provision is the likely need for ongoing healthcare in periods of disease stability. This is a pertinent conclusion that highlights a possible gap in care, with the majority of IBD services in the UK currently being hosted within secondary care where the focus is mostly on treatment of acute disease phases. An example relevant to IBD is adapting to a stoma formation. A stoma may resolve disease symptoms but also bring about additional challenges that continue to threaten expressions of masculinity and self-identity and therefore require ongoing support. A similar discovery has been made in men who have undergone bariatric surgery, where men report ongoing health challenges and fears during and after weight loss (Groven, Galdas and Solbrække, 2015). This observation draws attention to the likely need for an adaptive approach to healthcare provision that take into account men's needs in relation to their current disease phase. To represent this, the stages of the Corbin and Strauss model most pertinent in IBD¹³ have been extracted into Table 6.1 alongside a suggested goal for sexual health management. Table 6.1 is not intended as a prescriptive model of care but to demonstrate the possible utility of superimposing this layer of insight onto nursing care.

To summarise, the models presented by Verschuren et al. (2010), Katz-Dizon (2016) and Corbin and Strauss (1991) do not singularly provide a complete framework that enabled the interpretation of the findings in this thesis; collectively they offer useful guidance for nursing practice in this domain. Theoretical frameworks are more likely to reflect the complexity of sexual health in chronic disease if they consider how specific disease courses may influence the physical, psychological, and social components of sexual health in a gender-specific way.

¹³ Pre-trajectory phase is possibly less relevant as the risk factors for IBD are not understood to be behaviorally driven and downward/dying have been removed as the disease rarely leads to this outcome.

Table 6.1 Goal setting using the Corbin and Strauss (1991) Chronic Illness Trajectory Model

Trajectory phase	Goal of sexual health management for men with IBD
Trajectory onset: diagnostic	Information giving. Assessment of sexuality, sexual activities, preferences and socio-biographical information. Invitation for partner to attend clinics. Suggested focus of care: information gathering and giving.
Stable: illness symptoms are under control and life activities are being managed	Information updating. Assessment – if sexual health issues persist in periods of remission is specialist support and onward referral required? Promoting safe engagement in desired sexual activities. Planning for future aspirations including fatherhood. Suggested focus of care: identification of problems in absence of disease (e.g. fatigue, low mood), adjustment, future planning, information giving,
Unstable: reactivation of illness, difficulty in undertaking daily activities	Consideration of impact of medical intervention to treat disease. Focus on disease activity and need to make adaptations to sexual activities. Increased MDT support to mitigate the psychological and physical needs of active disease including treatment of anaemia and weight-changes. Suggested focus of care: disease stabilisation, MDT collaboration, partner support, preparing for possible acute episode
Acute: hospitalisation, disease complications	Clear information regarding any possible risks of treatments to sexual health and erectile function needed to support informed decision making and reduce unspoken fears of erectile dysfunction for those undergoing surgery. Strong psychological input recognising the distress of risk of life and permanent complications. Suggested focus of care: preservation of life, risk reduction,
Comeback: healing, limitations, re-engagement with adjustments	Providing a space to discuss psychological and physical impact of acute phase. Re-engagement with partner. Suggested focus of care: re-engagement with or adaption to social and sexual activities, adaptation or modification to new treatments.

6.3 The influence of gender norms on men's sexual health experiences in IBD

In the previous section it was argued that exploring men's sexuality in the context of chronic disease can reveal the interdependency of physical, psychological, and social factors within the dynamic and cyclical nature of IBD. This interplay of factors parallels the concept of intersectionality, which has been applied within gendered research to evaluate the relationship between gender and health. Originating from black female scholars (Collins and Bilge, 2020; Crenshaw, 1989), conceptualisations of intersectionality consider how social identities such as race, class, educational status, gender, sexual orientation, and ableness are associated with inequalities in access to healthcare, treatment, and health outcomes (Hankivsky, 2012; Shields, 2008).

Griffith (2012) offers an intersectional approach to men's health disparities¹⁴ that claims to encourage thinking beyond *which* social determinants affect health to *why*. Focusing on gender as a central pillar in this thesis, the Griffith model (2012) links gender to physiological health and health behaviours. In order to examine this association in light of the findings of this thesis, it is first essential to consider what 'gender' represents in the context of this work.

6.3.1 Male gender representation: masculinities

Masculinity, as the gendered representation of maleness, is predominantly viewed as a social construct based upon multiple demographic factors (Courtenay, 2000; Kimmel, 2000). While 'masculine' has previously been viewed as a singular antithesis of 'feminine', Connell's (2005) influential work presents a theory of masculinities as a collection of constructs that are dependent upon social contexts and operate in varying power relationships. Hegemonic masculinity is described either as the most dominant (mostly in power rather than number) and culturally idealised representation of masculinity (Kimmel, 2000) or as the most normative within the local social context (Connell and Messerschmidt, 2005). In the UK, hegemonic

¹⁴ Men's health disparities refers to both the possible health and treatment differences between men and women but also between different social groups of men as well.

masculinity is typically embodied through traits such as emotional restraint, physical toughness, dominance, and breadwinning roles; reflecting societal norms of male power and privilege (Connell & Messerschmidt, 2005). Connell (2005) labels other masculinities as 'marginalised', for example gay men could represent 'marginalised' masculine characterisations. 'Marginalised' or 'sub-ordinate' masculinities have become associated with poorer health outcomes (Evans et al. 2011). Contemporary Western interpretations of hegemonic masculinities have also become associated with behaviours that can be damaging to men's health and those around them; these include traits that may suppress other people such as aggression, dominance, and competitiveness (Gough, 2006; Connell, 2005). Masculinity is commonly understood to be a negative determinant of health, linked with maladaptive health behaviours, both preventatively and adaptatively (Evans et al., 2011).

6.3.2 The association between gender and health behaviour(s)

As noted previously, in his intersectional approach to men's health, Griffith (2012) draws an association between gender and health behaviours. Charmaz (1994) also describes this association in men with chronic conditions, observing that men 'bracket' their condition to deal with uncertainty and strive to maintain a 'normal life'. The findings of qualitative study 2 (reported in Chapter 5, section 5.3) also highlighted that HCPs often believed gender (masculine norms) influenced health seeking behaviours and inhibited sexual health discussions. This idea was not confined to men who embodied 'hegemonic' representations, with HCPs reporting very little experience of gay and bisexual men initiating sexual health conversations. From a sociological perspective, it might be argued that hegemonic norms drive the marginalisation and health disparities across non-hegemonic masculinities. A crude example of this would be the 'hegemonic' driven perception that healthcare for sexual well-being is for women, leading to many men not knowing how or if they can access sexual well-being services.

A compelling interpretation of the association between gender and health behaviours is that there is not a single link, but several layered

interconnections that reflect the plurality of masculinities described by Connell (2005). Additionally, while it may be possible to assign masculinities to groups of men according to social class, race, age, and sexual orientation, a further consideration is that individual men may concurrently hold or identify with several masculinities (De Visser, Smith and McDonnell, 2009). Some men may construct their own 'moasic masculinity' by bringing together 'fragments' of masculinities that are most appropriate to their own ideologies (Coles, 2008). This could be an important consideration for HCPs when treating men, highlighting the need to not assume individual men will align themselves with normative masculinities yet understanding that their self-identity may be intrinsically affected by this societal construct. HCPs may also benefit from understanding that just because a man demonstrates typical masculine characteristics in one domain of his life (for example, in employment) he will not necessarily concurrently hold masculine characteristics in another domain (for example, in sexual relationships). The idea that masculinity may be operated as a 'currency' across biographical domains (De Visser, Smith and McDonnell, 2009) or self-constructed into a 'mosaic' (Coles, 2008) may be an important consideration in supporting men to positively express masculinity if desired. De Visser, Smith and McDonnell (2009) provide an example of gay athletes whose sexuality may be considered 'non-masculine' but their physical athleticism provides them with 'masculine capital'. Some men within qualitative study 1 also conveyed this idea of being able to express their masculinities differently across social domains or self-construct a masculine identity within their own boundaries. For example, David described not being able to father children but being able to demonstrate the associated masculine qualities of fathering in other areas of his life, such as participating in cricket coaching.

Interestingly, in integrating age into his model, Griffith (2012) discusses that masculine norms may change throughout the life course; a phenomenon evident in the narratives of men in qualitative study 1. For example, age was frequently reported to be an important factor in what men expected from their physical bodies. However, Griffith (2012) attributes more 'positive' masculine norms to middle and older adulthood - a pattern not observed within the

current study. Participants across all ages exhibited positive masculine norms in varying ways, for example the desire to contribute to society was not only exhibited in the older men in the study. However, the possibility that masculine norms and characteristics change throughout the life course may be worthy of further investigation in future research. It is possible that a beneficial nursing strategy would be to seek an understanding of what masculine norms and ideals are important to individual men at varying intersections of their life and disease course. Interventions could then be targeted to support positive 'net-masculine' in biographical domains that are achievable for them whether that be work, health, or partnership.

There are two final observations of the model presented by Griffith (2012) relevant to the data reported in this thesis. Firstly, the model draws a link between gender and physiological response, and yet as discussed in the prior section (6.2) consideration of psychosocial response is equally important. For example, in qualitative study 1, sexual desire (psychological) was more widely discussed than erectile function (physiological). Some responses were also interlinked, for example the loss of muscle mass (physiological response to disease) was strongly linked with body image concerns (psychological response). Griffith (2012) notes that socially gendered norms may cause psychological strain, so it is somewhat surprising that it has not been made explicit within the model. Secondly, while the model (usefully) draws attention to the ways in which gender may induce disparities in health outcomes, it does not clearly illuminate the way in which gender can be positively harnessed to achieve health equity. In qualitative study 1, there were observed positive by-products of masculine norms, for example the desire to achieve physical strength could be a driver to undertaking physical activity. If the prior suggestion of supporting men in achieving masculine goals is to be made workable, it is important to clearly set out ways in which masculinity might also lead to positive health behaviours. An example of a way in which this could be achieved is the utilisation of 'strength-based' interventions where the focus is on positive individual features or aspects of life that make it meaningful rather than areas of fragility or illness (Englar-Carlson and Kiselica, 2013; Hammer and Good, 2010; Seligman and Csikszentmihalyi,

2000). The Positive Psychology/Positive Masculinity Model (Kiselica and Englar-Carlson, 2010) gender-sensitises the strength-based approach by encouraging men (and their counsellors) to identify and utilise positive aspects of their own masculinities which may include humour, courage, and problem-solving (Englar-Carlson and Kiselica, 2013). Although developed for counselling, this approach is likely to be compatible with nursing practice that also seeks to care for physical and psychological needs in tandem.

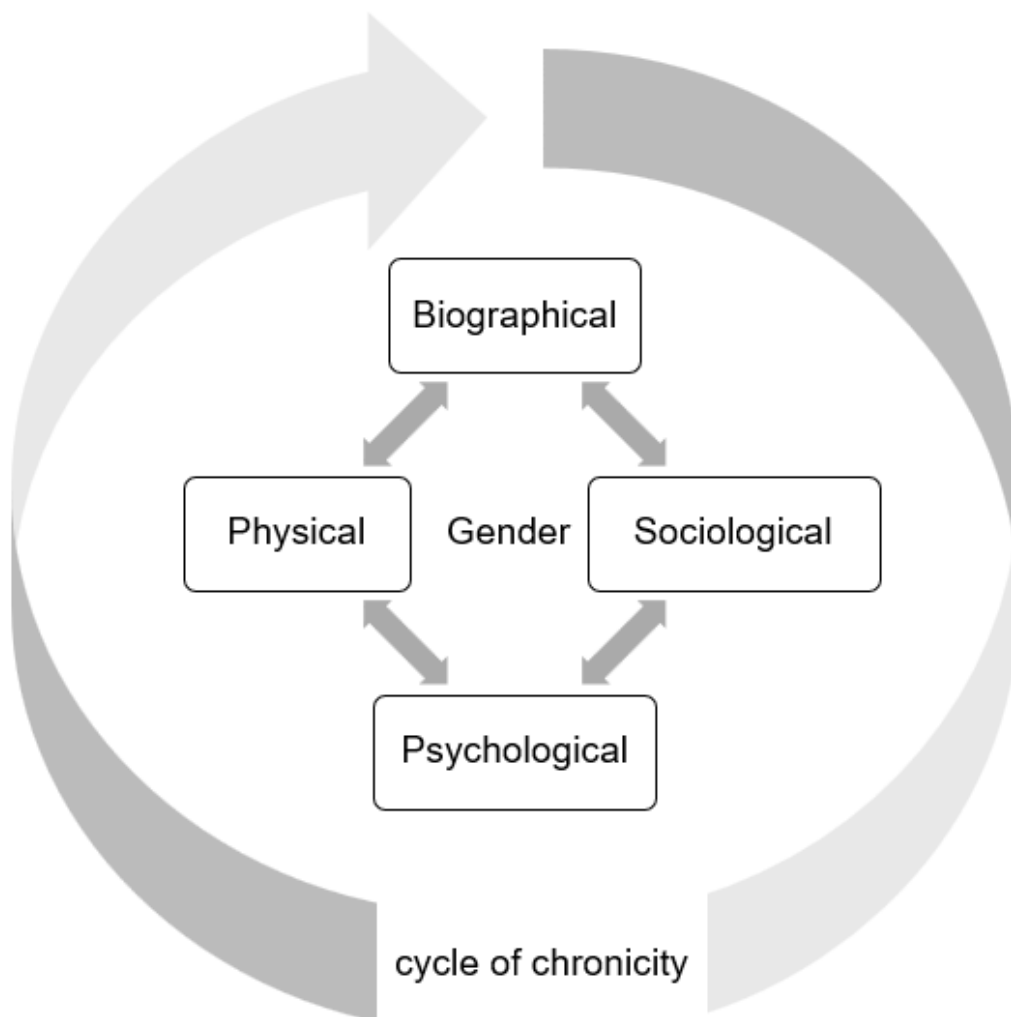
6.3.3 The role of biography in the sexual health of men with chronic health conditions

As highlighted in Section 6.2, a key finding and consideration of this work was the impact of the chronicity of IBD on men's lives and their sexual health. Biographical disruption (Bury, 1982) provides a useful and highly relevant theoretical background upon which the intersectionality of gender, disease, and sexual health may be developed. As with the 'Chronic Illness Trajectory Model' (Corbin and Strauss, 1991), the cornerstones of Bury's work remain relevant in contemporary health research. The narratives collected in qualitative study 1 reflected the disruption to daily activities, work, social interactions, self-perception, and societal roles that biographical disruption entails. Bury's work is based upon rheumatoid arthritis, a condition that in many ways closely overlaps with IBD due to the systemic, inflammatory nature of the diseases. However, Bury's seminal study only had a minority male sample (17%) (Bury, 1982). So while biographical disruption provides a confirmatory account of the sociological experience of living with chronic disease, it has been noted that the specific role of gender as a dimension of biographical disruption has been under-played (Williams, 2000). Recently, researchers have used biographical disruption to further explore gendered experiences of chronic illness (Wedgwood et al., 2020; Cayless et al., 2010) and sexuality in cancer (Hammond et al., 2024). When applied to this work, one of the most pertinent considerations for nursing is within the domain of 'resource mobilisation'. While Bury (1982) draws attention to the stigma of chronic illness as a barrier to mobilising resources, healthcare practitioners in qualitative study 2 viewed gender norms as a barrier to men accessing support. The likely compounding and negative effects of men's gender and

chronic illness in accessing sexual healthcare further supports a need to ensure that interventions are tailored to their specific needs.

Earlier the limitations of the Katz-Dizon (1996) model were highlighted in relation to the weighting given to the physiological domain, and similar observations have been made about Bury's work (Kelly and Field, 1996). A seminal finding of the two qualitative studies presented in this thesis is that the sexual health of men with IBD was not exclusively a physiological experience. This finding calls for the consideration of sociological perspectives that support the interpretive authority of the findings. However, there is an important adjunct to this point that is pertinent to nursing practice; sexual health in IBD is a biographical, physical, and psychological experience that is affected by gender (in this case masculinities) and the course of the disease. It would therefore be prudent to consider all these aspects when formulating care plans for sexual health needs in men with IBD in order to be comprehensive, holistic, and effective.

Figure 6.1: Fundamental domains of men's sexual health in IBD.



6.4 Providing sexual healthcare to men with IBD; *“we’re not addressing this with patients at all”*

The findings of the scoping review and two qualitative studies presented in this thesis indicated that the assessment and care of sexual health in men with IBD is currently limited. Implicated in this lack of healthcare provision were male gender norms and a perceived lack of clinician understanding; both of which may propagate internalised and externalised stigmatisation of the disease. In particular, the narratives of men from sexual minorities highlighted possible misconceptions about how gay and bisexual men engage in sexual

relationships and a lack of specialised support for them and their partners. In this section, exploring concepts of sexual stigma (Herek, 2007) and minority stress (Meyer, 2003) has facilitated the consideration of barriers faced by men with IBD and possible strategies for overcoming them.

Herek (2007) describes three possible layers of stigma experienced by non-heterosexual groups; enacted, felt, and internalised. Enacted-stigma refers to overt discrimination, felt-stigma is an internalised fear or expectation of enacted-stigma, while internalised- or self-stigma is where an individual believes or accepts the negative attitude towards them (Herek, 2007). The findings of qualitative study 1 correspond with Herek's (2007) conceptualisation of stigma. For example, one participant provided an example of enacted stigma where a potential sexual partner disengaged from sexual activity after learning of his disease. Enacted stigmatisation is likely to be particularly traumatic and, as Meyer (2003) highlights, a person's community (in this case other non-heterosexual people) usually acts as a buffer to minority stresses. In the example above, the trauma is compounded by the fact that the stigma is not only enacted but also from a member of the person's own community.

Minority stress is defined by Meyer (2003) as stigmatisation that minority status groups experience (defined as sexuality, race, and gender in the framework) and which are additional to the social stresses experienced by people. IBD itself is a stigmatised condition due to being a hidden disease associated with a taboo bodily function (defecation) and historical notions of the disease being psychosomatic in origin (Taft and Keefer, 2016). It is therefore arguable that IBD could also be considered a 'stigmatised social category' alongside gender and sexuality. The intersection of disease and gender therefore means that heterosexual men with IBD may experience a form of minority stress. Consequently, Meyer's framework is applicable across all men with IBD and draws attention to the possibility that sexual minorities may experience higher levels of stress due to the compounding effect of having more than one minority status.

Mayer (2003) suggests that expecting rejection and concealment are two minority-group stress processes. Understanding stress processes is important to clinical care as it provides a possible explanation for the likely reluctance of patients to come forward with sexual health concerns and emphasises the need for clinicians to initiate discussions. This concept is supported by existing research that has demonstrated patients are generally willing to answer routine questions about their sexual orientation (Bjarnadottir, Bockting and Dowding, 2017) and want practitioners to initiate conversations about sexuality (Fuzzell et al., 2016). Dibley, Norton and Schaub (2013) reported that gay men with IBD were hesitant to discuss their sexuality with practitioners due to fear that the disease would be attributed to their sexual practices. The possibility of an association between RAI and luminal inflammation is unknown. It is conceivable that physical disruption and the use of certain lubricants may irritate and exacerbate inflammation in the anal canal. In a recent letter published in *Gut*, authors reported an increased prevalence of IBD in men who have sex with men (MSM) as compared to men who have sex with women, surmising that sexual practices might affect the gut microbiome (Mansoor et al., 2023). The possible association between sexual practices and disruption to the gut microbiome or risk of disease needs further exploration so that people can be made aware of potential risks and the ways to mitigate them. However, it is also important to consider alternative explanations for this observed difference; for example, it is possible that MSM are more likely to identify and report rectal and anal changes leading to better identification of IBD. If a link between RAI and IBD is substantiated in the future, it is vitally important that men who engage in RAI are not stigmatised or subjected to blame or shame. Blame and shame may lead to concealment and further impede delivery of effective care. Whether or not a link between RAI and IBD is verified, the possible hesitancy of gay men to discuss their sexual practices with healthcare practitioners further supports the importance of tailored sexual health assessment and guidance that speaks to varying gender and sexual identities.

Herek (2007) claims that internalised stigma is a negative manifestation of self-identity. In Herek's work this is specifically homophobia; in the current

study it is also the negative perception of living with disease. This internalised stigmatisation reduces positive feelings towards oneself (Meyer, 2003) which in this work was interpreted to disrupt sexual health. Kinship stigma, defined as lack of acknowledgement of the disease and disease symptoms by family, has been identified within IBD (Dibley et al., 2019). Kindship stigma is likely to lead to felt- and internalised-stigma (Herek, 2007) and increase concealment or expectations of rejection as described by Meyer (2003). Evidence from the current study suggests that the involvement of partners in IBD clinics may help mitigate this. However, some men in this study demonstrated internalised-stigma even when they acknowledged that family members had been supportive. The negative internalised responses to the disease may be amenable to specialist psychological support such as Acceptance and Commitment Therapy, which has been demonstrated to reduce stress in IBD (Wynne et al., 2019).

6.5 Summary of discussion

The discussion in this chapter has revealed that there is no single current theoretical framework that fully characterises the interplay between (male) gender, chronic disease, and sexual health that was revealed within the findings of this research. As discussed in Section 6.2, while the Verschuren et al. (2010) framework portrays the physical and psychological components of sexual health in chronic disease, the role of cultural and social factors is absent. Social and cultural factors were found to be important considerations particularly within this gendered-approach of this work and they underpin the concept of intersectionality which was discussed in Section 6.3. The findings of this work draw attention to the possibility that men with IBD may face disparities in regard to sexual health experiences and healthcare. Additionally, the social identities (such as gender, sexuality, and disability) that may influence the sexual health experiences of men with IBD, parallel those originally described by the principles of intersectionality that was originally developed by considering the experiences of black women (Crenshaw, 1989). Griffith (2024) has also observed similar parallels between seminal theories of intersectionality while considering black men's health. Griffith's (2024)

analysis of black men's health under the pillars of structural intersectionality (where health and well-being are shaped by negative stereotypes), political intersectionality (where men's health is invisible in policy) and representation (where men are represented and understood in relation of hegemonic masculinity) echoes the discussion of findings within this work on men's sexual health in IBD. Overall, it is apparent that, while intersectionality has described the inequalities faced by women, it may also be used to frame men's experiences which can also be understood through multiple social axes such as social class, race, ethnicity, sexual orientation, gender, and disability. Importantly, while 'disability' (which under the Equality Act (2010) includes long-term conditions) is frequently described as an intersectional axis it has not been explored to the same depth as race and gender. This thesis, therefore, supports and extends existing theories of intersectionality by confirming the importance of long-term health conditions within people's experiences of their identities and social experiences. Subsequently, the findings of this thesis add to the theoretical conceptualisation of intersectionality which may usefully inform the development of recommendations for gender-specific sexual health care in men and further research in this field.

Overall, this chapter has drawn attention to how the findings of qualitative studies 1 (Chapter 4) and 2 (Chapter 5) have demonstrated the need to consider the sexual health of men with IBD in relation to the chronicity of the disease and masculine norms, aspects that were absent from the existing literature in the scoping review (Chapter 2). Importantly, these factors not only shape men's experiences but also their interactions with healthcare services and in many cases this can lead to needs going unmet. Research and clinical care therefore needs to work towards mitigating the possible health disparities brought about by gender and chronic disease. One possible way in which to do this, is to seek ways to work within and adapt care to specific stages of chronicity and harness the positive attributes of gender. This approach is described in the following chapter that presents the recommendations of the thesis.

CHAPTER 7: PROJECT REVIEW, RECOMMENDATIONS AND OUTCOMES

This chapter reviews the strengths and limitations of the work presented in this thesis as a whole (Section 7.1), summarises the salient recommendations arising from the findings (Section 7.2) and finally, offers suggestions for next steps (Section 7.3).

7.1 Critique of the thesis

The original contribution of this work to the current evidence-base is grounded in the adoption of a qualitative approach, which has led to the generation of novel insights into the ways in which men with IBD experience their sexual health. To date, research that has sought to better understand the impact of IBD on sexual health has typically been situated within a medical model and has focused on the assessment of erectile function. In depth knowledge into the human experience required by nurses to provide individualised and holistic nursing care of men's sexual health in IBD was absent in the pre-existing research; demonstrated in the scoping review (Chapter 2). The subsequent qualitative studies did not constrain exploration of male sexual health by employing a framework of sexual health or imposing ideas about what defines sexual well-being or male gender. Instead, through collecting personal narratives this work has identified what may be relevant to men's sexual health in IBD.

Adopting a gendered lens alongside a theoretical sampling strategy has enabled the collection of diverse and rich narratives of under-represented groups that have not been collected to date; including accounts provided by a man with HIV, a bisexual man whose rectum had been removed, a man on long-term parenteral nutrition, and a transsexual man. Subsequently, this work has shined a spotlight on the diverse needs of men that have been underexplored within the existing research.

The exploration of HCP perspectives in the second study (reported in Chapter 5) has not only provided further depth and context to the thesis but highlighted

the disciplinary relevance and contextual awareness needed to produce knowledge that is relevant to nursing practice. The inclusion of varying professional disciplines provided breadth of knowledge and reflects contemporary nursing practice that operates in a collaborative environment while learning and adopting practice from other disciplines.

The use of interpretive description (Thorne, 2016) as the overarching methodological approach to this work, supported the generation of knowledge useful to nursing. This approach enabled a selection of methods most suitable to the aims and objectives of the thesis. The application of thematic analysis (Braun and Clark, 2006) facilitated the organisation of the data into units of meaning that were either common across the narratives or deemed by the nurse-researcher as pertinent to driving forward nursing care in the field. The nurse-researcher as a co-producer of the data is supported within the constructivist paradigm adopted. This included the utilisation of expert knowledge when conducting interviews and interpreting the data. The nursing perspective applied to this work provides further originality.

There are also some limitations that should be addressed. Firstly, CD and UC are distinct phenotypes of IBD but have not been distinguished within the study data. Although the themes identified in qualitative study 1 (Chapter 4) transversed both disease presentations, the attention drawn to perianal disease (which is mostly a presentation of CD) and stomas (which are more common in UC) suggests that future research may benefit from exploring specific IBD phenotypes to understand the particular needs within these conditions. A strength of the studies was diversity within the samples and continuing data collection until saturation, supporting theoretical transferability of the findings. However, a possible limitation was the potential lack of depth of understanding in specific groups of men with IBD. For example, there were some groups of patients there were not included in the sample, including men with ileo-anal pouches, which have been demonstrated to be a risk factor for sexual dysfunction (Bengtsson et al. 2011). While the broad themes identified in this work may be applicable and transferrable to these groups of men, there may be specific needs that have not been unearthed in this work.

Demographic data on participants' country of origin and ethnicity were not collected. Pre-interview questions were restricted to reduce participant burden and ensure that only the most pertinent data was collected, which is a core principle of data management in research. Consideration of intersectionality theory in Chapter 6 highlights that ethnicity is an important area of consideration in regard to social contexts and in hindsight not collecting this data was a regrettable omission. The findings drew attention to the role of biographical and social factors in men's experiences. In particular, ethnicity and race are cited as important determinants of health disparities among men (Griffith, 2024; Griffith, 2012; Courtenay, 2000) and as critical aspects of theories of gender and masculinity (Kimmel, 2000; Connell, 2005). Due to the lack of data on ethnicity, this study cannot make any potentially useful insights into the intersections between ethnicity, gender, and sexual healthcare in IBD. The possible influence of ethnicity on sexual health experiences was not identified in this work. The lack of discussion around ethnicity may also have been due to a deficit in the interview guide and a lack of directive questioning. The possible effect of ethnicity on men's sexual health in IBD should be a consideration in further research.

A novelty of this work was the integration of photography as data. Photography strengthened the data by providing additional insights and supporting interpretative reasoning. For example, a number of photographs were submitted that demonstrated self-management of the disease through planning and organising supplies which reinforced the finding that being self-reliant was important to participants (Chapter 4, section 4.3.5.2). However, there was poor uptake by participants and the photography data subset was limited. No photographs were submitted that reflected partnership despite this being commonly discussed within the interviews. It is possible that submitting pictures of other people felt intrusive or inappropriate to participants, demonstrating the possible limitations of photo elicitation as a method within this research topic. Clearer information about auto-photography, including exemplars to make participants explicitly aware of the additional value of photographs to the researcher, may have improved uptake.

All interviews were conducted by a single female, nurse-researcher who was already known to some of the participants in both studies. The pre-existing relationship between the participant and interviewer may have influenced how candid some men and HCPs were in their accounts. The sensitivity of the research topic was managed by offering participants a choice of interview formats. Most interviews occurred online, which has been found to facilitate relaxed and open discussions when interviewing men about intimate relationships (Olliffe et al., 2021). However, there remains the possibility that some participants did not feel comfortable enough to disclose all aspects of their experiences. As discussed in Chapter 3, this is a recognised limitation of interviewing (see Section 3.4.2.1) and qualitative work (see Section 3.5.1) and can be mitigated through rapport building, sensitive questioning, and interviewing multiple participants. The researcher-participant relationship was managed by overtly delineating it from a clinical consultation and providing reassurances of confidentiality. Furthermore, as discussed in Section 4.4.3, interpretative credibility could have been improved with adding a second interview to allow for member checking.

Thorne (2013) claims that the quality of research guided by ID is also dependent upon integration of social justice and moral agency. This is pertinent to this thesis as one of the core justifications of undertaking this work was to address an apparent gap in men's sexual health research and healthcare provision in IBD, and subsequently to address gender disparities while propagating sexual autonomy (see Chapter 1, section 1.5.1 and Chapter 3, section 3.2.3 for further detail). Inherent to adopting a gendered approach is gender-equity. Although, it has not been possible to assess equity directly within this thesis nor consider the possible impact of these findings for women, the study methods and findings may pave the way for further research into the sexual health of other genders in IBD.

7.2 Recommendations for practice, research and theory

Currently the only guidelines for the management of sexual health in IBD are those on sexual dysfunction published by the Spanish Working Group on Crohn's disease and Ulcerative colitis (GETECCU) (Calvo Moya et al., 2024).

The clinical guidelines for sexual dysfunction within chronic disease produced by Basson et al. (2010) do not include IBD or similar inflammatory conditions, although the suggested assessment questions may provide a useful guide. Men in qualitative study 1 (Chapter 4) reported disruption to their sexual well-being and a lack of clinician-directed discussion around sexual matters, echoing the findings of existing work undertaken with men and women (Fourie et al., 2021). HCPs in qualitative study 2 (Chapter 5) confirmed a number of barriers to sexual healthcare in the context of men with IBD, including societal stigma, lack of training, an absence of clarity about who should be delivering care, and a shortage of practical support for HCPs and patients. The barriers identified highlight the need for the development of specific guidelines that consider a gendered approach to supporting the management of sexual health in IBD.

IBD-UK (2021) identified four priorities for overall IBD care: (1) improvements in diagnosis; (2) personalised care and support of self-management; (3) faster access to specialist advice; and, (4) effective multi-disciplinary working, which together provide a useful framework in which to situate the recommendations. In Section 7.2.1, a recommendation is made for normalising sexual health discussions in the IBD clinic in order to improve diagnosis of and support for sexual health related issues. In Section 7.2.2, a recommendation is made for gender-specific care, which for men is congruent to facilitating personalised, self-management strategies. In Section 7.2.3, the recommendation is centred around a fundamental need to provide specialist advice that bridges the domains of sexual health and IBD. Finally, in Section 7.2.4, it is argued that the findings presented throughout the thesis point toward the need for improved multidisciplinary collaboration and care.

7.2.1 Normalising the discussing of sexual health in the IBD clinic

Participants across both studies reported that healthcare in IBD was focused upon active disease. The development of nursing roles to include the assessment of organic disease and prescribing of medical therapies may also be a driver to a medical model being applied within specialist nursing in IBD.

The current study findings suggest that time could usefully be set aside to assess the psychosocial implications of living with chronic disease. In sexual health specifically, the precursor to achieving this is to first engage routinely in discussions of sexual well-being in a gender-equitable way (WHO, 2010).

Although stigma was a commonly cited barrier and healthcare practitioners are not immune to “the social forces that create and reinforce negative stereotypes” (Hayter, 1996, p665). IBD clinicians are accustomed to working with a disease that is associated with social taboos and are therefore well placed to dispel the embarrassment associated with sexual health, and acknowledge it as an important domain of health and well-being. Discussions of sensitive topics does however require culturally sensitive management (Douglas et al., 2014). While nurses are cognisant that sexuality is an important aspect of health and hold the interpersonal and communication skills for such consultation, they require further information on how to address the issue (Hayter et al., 2012). Prior research has shown that when family members normalise disease symptoms people experience feelings of dismissal (Dibley, Williams and Young, 2019). Findings from the current studies suggest the focus should be on normalising discussions of sexual health and well-being, rather than normalising the disease impacts. The findings of qualitative study 2 (Chapter 5) suggest that healthcare practitioners require additional training and support so that they can feel comfortable initiating conversations of sexual health in a sensitive way. The narratives qualitative study 1 (Chapter 4) demonstrated that partnership is central to men’s sexual health, and partners have a role in disease management, acceptance and overall well-being. The inclusion of partners in IBD healthcare provision may be an important way to improve patient-centred care and has also been suggested by other researchers working in this field (Dibley et al., 2019; Dibley et al., 2014; Basson et al., 2010; Moody, 1998; Salter, 1992).

7.2.2 Gender-specific care and support

The onus should be on healthcare providers to reach men (Gough, 2006) and to do this, care must be tailored to their specific needs. This work has shown that accessible, clear, and accurate information on sexual health and well-

being may be beneficial for men. Importantly, the findings of this thesis suggests that this information should include the psychosocial domains of sexual function, as well as erectile function. The possibility of permanent impotence induced by surgery was a common fear for participants who were awaiting or had undergone surgery, and for some men it influenced treatment decisions. Therefore, while erectile function was not the central concern of men within this study, it was nevertheless still an important concern where clear and accurate information may have helped to moderate unnecessary fears and enable patients to make more informed treatment decisions.

In Chapter 6 it was discussed that sexual health experiences intersected both gender and disease chronicity, these may therefore be important points of consideration in healthcare. To date, the role of disease chronicity has not been well captured within theories of gender and health, and therefore needs further exploration. In Section 6.2, it was suggested that personalised care and self-management support may benefit from being tailored to the specific stage of the disease trajectory. Additionally, implementing self-management programmes that are congruent with masculine ideals such as self-sufficiency and autonomy may be more acceptable to men. There is also evidence that suggests interventions should be gender-sensitised, an example for men would be action-orientated as opposed to passive programmes (Galdas et al., 2014). The findings of this work favour this approach with men describing that they liked to practically manage their disease. One possible action-orientated approach to supporting men with IBD would therefore be to find practical ways for men to regain a sense of control of their disease and self-reliance through problem solving. Some men inherently displayed this in qualitative study 1, for example preparing a “*shit-kit*” (Oliver) for leaving the house. Finally, psychological support, which already is known to improve overall quality of life in IBD (Gracie et al., 2017) is likely to take a central role in a strategy like this and include working towards sexual adjustment (Enzlin, 2014) rather than working to achieve a pre-disease state. The idea of redefining sexual expectations rather than aspiring to ideals of ‘normal’ sexual engagement is supported by Tepper (1999) who, in his auto-ethnographic account,

recognises that “the recall of pre-disability performance is highly subjective and still clouded by the fantasy model” (p45).

7.2.3 Specialist advice

Insights garnered from the current study indicate that IBD brings about a specific, unique set of symptoms and complications that can affect men’s sexual health and wellbeing. As well as needing care that is accessible both to men and their partners, which is gender-specific and tailored to the disease trajectory, it must also be disease-specific. In particular, certain disease presentations and minority groups are poorly served in IBD care, yet such groups often experience the most significant complications. In this study, these groups included those with peri-anal disease, those diagnosed with severe disease presentations during childhood and adolescence, and those who engage in receptive anal intercourse (RAI). Common to these groups of men was a fear of exacerbating the disease and embarrassment of symptoms. For two of the three men who engaged in RAI it had led to withdrawal from this sexual activity, potentially highlighting an urgent need to further understand how this might be mitigated or conducted safely to enable men to express their sexuality. Anal sphincter tightness, lack of lubrication, and angle of the rectum have all been attributed to anodyspareunia in RAI specifically (Dickstein et al., 2023). Evidence from the current study suggests that education on these factors and how they may be managed to best protect continence and reduce disease relapse may be required to improve the sexual health care of men from sexual minority groups. Common to all men’s experiences regardless of sexuality and RAI was the disease inducing ‘feeling dirty’. A better understanding of, and clinical advice on, how to safely maintain anal hygiene needs addressing.

Overall, qualitative study 1 (Chapter 4) has provided compelling evidence of the willingness of men with IBD, including those with varying sexual orientations, to speak openly and candidly about their sexual health experience when it is researched in a sensitive and professional manner. Researchers can build upon this by considering additional ways to focus on research that specifically explores sexual behaviours across men of various

sexual identities. Further work is particularly required to improve our understanding of what information needs and service provision are required to meet the needs of under-represented groups; enabling men burdened by poor sexual health to access the healthcare they require. Specialist clinicians who are familiar with the disease and treatments, are likely to be well placed to design and deliver specialist care. Qualitative study 2 (Chapter 5) found that HCPs can feel ill-equipped to have conversations with patients about sexual health and faced organisational and systemic barriers such as insufficient time, education, and training. While men with IBD are the focus of this work, an important outcome is the identified need for HCPs working in IBD healthcare to be supported with training, access to resources, and care pathways that facilitate the psychosocial support of men with IBD.

7.2.4 Multidisciplinary care

The findings of both the scoping review (Chapter 2) and qualitative study 1 (Chapter 4) draw attention to the multifactorial nature of sexual health in men. Disease symptoms, surgery, body shape changes, and self-perceptions were all found to have a role in men's sexual health, signalling an opportunity for input from current members of the multi-disciplinary team including gastroenterologists, nurses, surgeons, dietitians, physiotherapists and clinical psychologists. Importantly, qualitative study 2 (Chapter 5) highlights that health workers are unsure which professional groups should be leading the assessment and care of sexual health. Clear pathways and guidance may encourage cohesive interdisciplinary care. Khan et al. (2024) recommend the involvement of a sexual health therapist within the IBD multidisciplinary team. While the work within this thesis supports this addition, HCPs also noted the current strain on services within the NHS. It may be beneficial to draw upon the expertise of sexual health therapists to develop guidelines and provide IBD-specific training across the multi-disciplinary team rather than employ sex therapists at individual sites until the possible value of doing this is fully evaluated.

7.3 Next steps

The scoping review presented in Chapter 2 identified the assessment of erectile function as the mainstay of sexual health research in men with IBD to date. The findings presented in this thesis have drawn attention to the ways in which the disease affects men's sexual health beyond erectile dysfunction. Partnerships, body image, and gender roles were all found to be important factors in men's experiences of sexual relationship. Healthcare practitioners recognised the importance of sexual health in IBD but reported finding it difficult to discuss sex with male patients due to societal, interpersonal, and service barriers.

Recommendations arising from these findings have focused on: (1) normalising sexual health discussions in the IBD clinic; (2) the provision of accessible gender- and disease-specific information and care; (3) greater interdisciplinary delivery of care. A key priority is further gender-specific research exploring chronic health conditions and sexual healthcare provision. Although a strength of this work has been the focus on IBD as an under-investigated condition, exploration of other conditions is also likely to support theoretical understanding of the intersectionality between gender and health, and the development of sexual health guidelines for men. An additional research priority is to better understand the healthcare needs of men from under-represented groups, in particular across diverse sexualities. The scoping review demonstrated a deficit in research in this area while the findings of both qualitative studies 1 and 2, revealed gay and bisexual men faced specific barriers and challenges which are not currently supported in clinical practice.

A key ambition of this work was to act as a catalyst for further research in this field and the development of interventions that may improve care for men with IBD and their partners. Future research could usefully be directed to more comprehensive assessments of the care preferences of men with IBD, the current state of NHS provision, and finally what type of interventions are likely to be effective and acceptable in improving sexual health assessment and care of men with IBD. Following a successful application to the National

Institute for Health and Care Research, Research for Patient Benefit programme, this will be achieved through a mixed methods study. The study will involve three national UK surveys including: (1) men with IBD; (2) IBD CNSs (3) IBD services. These surveys will explore how sexual health is provided for across the NHS and seek to verify the findings of this study. Using interview and focus groups, in-depth exploration of appropriate and acceptable ways in which to provide sexual healthcare, will be gathered. Finally, co-production workshops will seek to create an intervention to improve the assessment and care of men with IBD. The feasibility and efficacy of the prototype intervention created through this proceeding work will need to be evaluated in a further study, either through a trial or service improvement project.

APPENDICES

Appendix 1: Publication: Ma et al. (2020) The impact of inflammatory bowel disease on sexual health in men: A scoping review



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REVIEW

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The impact of inflammatory bowel disease on sexual health in men: A scoping review

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Abstract

Aims and objectives: To review the literature on the impact of inflammatory bowel disease on the sexual health of men and make recommendations for nursing practice and research.

Background: Inflammatory bowel disease is a chronic condition of the gastrointestinal tract, causing symptoms that may impact upon sexual health. Specialist nurses are well positioned to assess and manage sexual health, but there is a lack of clinical guidance, especially in relation to men.

Design: A systematic scoping review following the Arksey and O'Malley (*International Journal of Social Research Methodology*, 8, 2005, 19) framework reported in line with the PRISMA-ScR checklist (Tricco et al., *Annals of Internal Medicine*, 169, 2018, 467).

Methods: OVID MEDLINE ALL [R], OVID EMBASE [R], OVID PsychINFO, EBSCO CINAHL Complete, The Cochrane Library and ProQuest were searched. Inclusion and exclusion criteria were applied independently by two reviewers. Data were extracted, charted and summarised from eligible studies.

Results: Thirty-one studies met the inclusion criteria. These were synthesised under three categories: mediators, moderators and descriptors of sexual health. Depression, disease activity and surgery were the most commonly cited disease-related factors to affect sexual health in men. The most commonly used assessment tool was The International Index of Erectile Function. Descriptors of function included frequency of intercourse, libido and the ability to maintain a desired sexual role.

Conclusions: The effect of inflammatory bowel disease on sexual health in men involves a complex interaction of physical and psychosocial factors. Researchers must explore areas outside of erectile function to understand how the disease impacts sexuality, sexual well-being and masculinity. This can be achieved through qualitative exploration of patient, partner and health professional experiences.

Relevance to clinical practice: A holistic nursing assessment of men with inflammatory bowel disease should include sexual health. Developing understanding of how

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the disease influences sexual interaction and expression will facilitate support that is relevant, accessible and of value to men living with the disease.

KEYWORDS

body image and sexuality, erectile dysfunction, literature review, men's health, sexual health, ulcerative colitis scoping review

1 | INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic, relapsing and remitting condition of the gastrointestinal tract. Prevalence ranges from 0.21%–0.44% in Western Europe and North America (Büsch et al., 2014). Peak onset of the disease is between the ages of 15 to 30 years (Meier, 2019). IBD is associated with distressing and embarrassing physical symptoms such as faecal urgency, incontinence, bloody diarrhoea, abdominal pain, fatigue and malnutrition. Extra-intestinal presentations can affect the joints, liver, skin and eyes. The disease can cause a psychological burden from attempting to live a normal life while living in fear of symptoms (Kemp, Griffiths, & Lovell, 2012).

Sexual health is an important adjunct of personal health and well-being. The World Health Organization (2006) defines sexual health as not "merely the absence of disease, dysfunction or infirmity... [but also] the possibility of having pleasurable and safe experiences." Sexual engagement and enjoyment may be disrupted by the symptoms and chronicity of IBD, particularly as peak onset is during early adulthood when people are developing their sexual and personal identities (Casati, Toner, De Rooy, Drossman, & Maunder, 2000).

Both men and women have an increased risk of sexual dysfunction in IBD (Zhao et al., 2019). Previous literature reviews have identified that disease activity, medications, surgery and poor perception of body image all lead to a negative impact upon sexual health (Giese & Terrell, 1996; Jedel, Hood, & Keshavarzian, 2015; Mantzouranis, Faffiora, Glantzounis, Christodoulou, & Katsanos, 2015). Variations in anatomy, biology and psychology mean men and women are likely to experience sexual health in IBD differently. To date, the literature on sexual health in IBD has predominantly focused on women (Bharadwaj, Philpott, Barber, Graff, & Shen, 2014; Bonthala & Kane, 2018; Johnson & McLeod, 2006; Moleski & Choudhary, 2011; Moody, Probert, Srivastava, Rhodes, & Mayberry, 1992; Rosenblatt & Kane, 2015; Sanders, Gawron, & Friedman, 2016; Timmer, Bauer, Kemptner, Furst, & Rogler, 2007; Trachter, Rogers, & Leiblum, 2002) and men's sexual health needs have been largely overlooked (Allocca et al., 2018).

Men are also reported to have poorer health-seeking behaviours than their female counterparts, particularly for psychological matters (Möller-Leimkühler, 2002). This is pertinent in the context of IBD, as depression could be at least twice as high as that of the general population (Graff, Walker, & Bernstein, 2009). Depression can lead to low interest, self-esteem, irritability and poor communication all of which can impair intimate relationships (Basson, Rees, Wang, Montejo, & Incrocci, 2010). We know from previous work that men with long-term conditions may benefit from models of service delivery that are tailored to their specific needs and preferences (Galdas et al., 2014).

What does this paper contribute to the wider global clinical community?

- Male sexual health in inflammatory bowel disease can be interpreted by identifying mediators, moderators and descriptors.
- Depression, disease activity and surgery are the most commonly cited inflammatory bowel disease-related factors to affect sexual health in men.
- Further exploration of male sexuality, sexual well-being and masculinity is required to inform holistic nursing assessment and care of men with inflammatory bowel disease.

Prior literature reviews have begun to map the literature on sexual health in men with IBD (Allocca et al., 2018; Feagins & Kane, 2009; O'Toole, Winter, & Friedman, 2014; Shin & Okada, 2016) but have either taken a reproductive or medical focus to sexual health. There is limited literature on sexual health that explores well-being and sexuality that is applicable to nursing practice. The European Crohns and Colitis Organisation recommends that nurses support patients in regard to sexual function (Kemp et al., 2018) but there is no consensus or best-practice guidance on how nurses can detect, assess and provide care for sexual health and well-being in men with IBD (White, 2013). To address this gap, we conducted a scoping review of the literature on the sexual health of men with IBD, with the aim of informing nursing practice and identifying future research priorities in his area.

2 | AIMS

To systematically identify and summarise peer-reviewed, published literature reporting the impact of IBD on the sexual health of men.

3 | METHODS

We undertook a scoping review following the five-stage framework described by Arksey and O'Malley (2005). We have reported our findings in line with the PRISMA extension for scoping reviews (PRISMA-ScR) (Tricco et al., 2018); the checklist can be found in Appendix S1.

3.1 | Identifying the research questions

This review was guided by the research question: What is known about the impact of IBD on sexual health in men? We defined "men" as people identifying as male, aged 18 years or over. We were guided by the WHO (2006) definition of sexual health: "a state of physical, emotional, mental and social well-being in relation to sexuality" (WHO, 2006). We sought to identify physical, psychological and societal factors associated with IBD that may influence male sexual well-being and clarify how effects are described, interpreted and defined. We did not explore fertility issues or sexually transmitted diseases. To ensure an exploratory approach, we considered personal experiences as well as measured effects.

3.2 | Identifying relevant studies

Search terms were purposely broad and related to the key concepts in the research question: "inflammatory bowel disease" and "sexual health." We chose not to employ sex/gender search terms to ensure we identified mixed-sex studies of potential relevance to the review (i.e. those which reported outcomes/findings disaggregated by sex/gender—see Table 1). The search strategy was reviewed by an information scientist and amended to suit MeSH headings and exploded terms across the databases searched: OVID MEDLINE ALL [R], OVID EMBASE [R], OVID PsychINFO, EBSCO CINAHL Complete, The Cochrane library and ProQuest. Reference lists of included and pertinent studies were reviewed to aid verification of the search strategy. No date restrictions were applied but searches were limited to publication in the English language. The searches were conducted between 6–8 February 2019 (see Appendix S2).

3.3 | Study selection

The database searches yielded 1,679 titles (OVID EMBASE [R] $n = 1,118$; OVID MEDLINE ALL [R] $n = 374$; EBSCO CINAHL Complete $n = 98$; the Cochrane Library $n = 56$; OVID PsychINFO $n = 17$; and ProQuest $n = 16$). A further 21 articles not detected

by the database search were identified through review of reference lists. After duplicates were removed, there were a total of 1,373 unique citations. A two-stage screening process was used to assess the eligibility of studies. Two reviewers (SM and PG) independently screened titles and abstracts against predefined inclusion and exclusion criteria (Table 1). Two hundred and thirty-six papers were identified as potentially relevant. The full text of these records was reviewed, which resulted in 31 texts being identified as eligible for inclusion in the review (Figure 1). Disagreements regarding the eligibility of studies were resolved through discussion to reach consensus on a final decision. The search results were disproportionately female focused with only eight of the included studies containing male-only cohorts. One relevant RCT was found (Lindsey, George, Kettlewell, & Mortensen, 2002) but was excluded as it did not disaggregate the findings of men with IBD and those with other gastrointestinal disorders.

3.4 | Charting the data

Data including study aim, population, sample size, measurement of sexual dysfunction and key findings were extracted and charted in Microsoft Excel spreadsheets.

Descriptors of sexual dysfunction, IBD-related impact factors and potential interventions were also extracted and used to graphically illustrate the themes identified in the included studies (Figure 2). Charted findings were thematically analysed and are summarised narratively in our results.

4 | RESULTS

Thirty-one studies were included in the review and involved a total of 35,990 men with IBD (Table 2). The studies originated from 16 countries: the USA (7), the UK (4), Denmark (3), Germany (2), The Netherlands (2), Sweden (2), Spain (2), Australia (1), Austria (1), Canada (1), Finland (1), France (1), Italy (1), Japan (1), Taiwan (1) and Turkey (1). Studies were largely single-centre ($n = 20$) and cross-sectional ($n = 26$). The most commonly used research method was

TABLE 1 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
1. Peer-reviewed	1. Included participants under the age of 18 years
2. Available in English	2. Data on sexual function on men are not disaggregated from female data
3. Included male participants; aged ≥ 18 years (or, in mixed-sex/gender studies, where findings are disaggregated by sex/gender) with a diagnosis of inflammatory bowel disease (Crohn's disease, ulcerative colitis, indeterminate colitis or collagenous colitis)	3. Data in relation to men with IBD are not disaggregated from data on other diseases
4. Presented primary research data (any study design)	4. Studies on fertility, sexually transmitted diseases, sperm or fecundity without investigation of sexual function
5. Included sexual function/dysfunction or engagement in sexual activity or erectile dysfunction or sexual behaviour or physical and/or emotional intimacy as a primary outcome measure or focus of the study	5. Vaginoplasty studies
	6. Surgical studies where sexual function is not a primary outcome, measured within a wider quality-of-life measure or has not been clearly defined within the study
	7. Does not present primary research data (commentary articles/protocols, etc.)
	8. Case studies

FIGURE 1 PRISMA diagram [Colour figure can be viewed at wileyonlinelibrary.com]

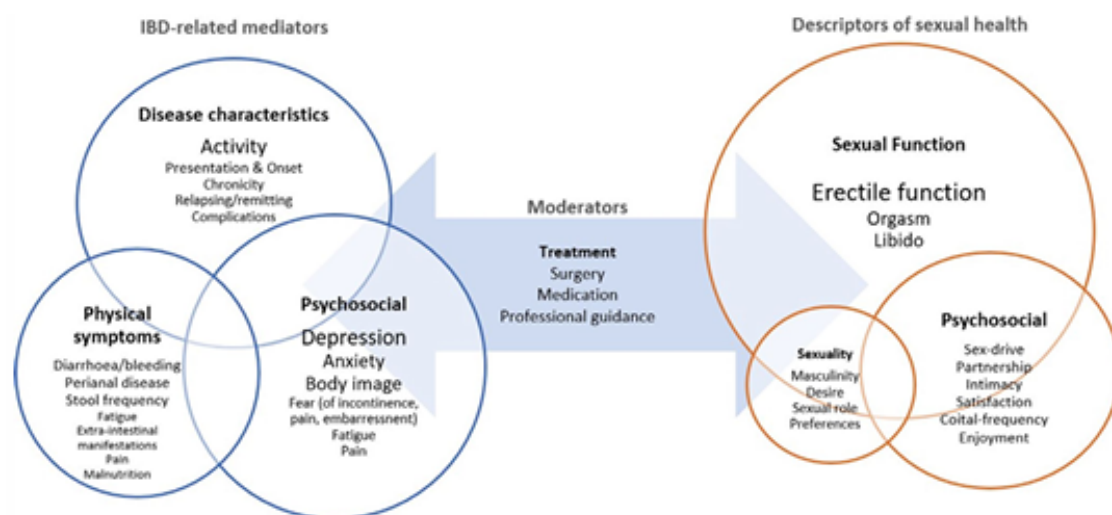
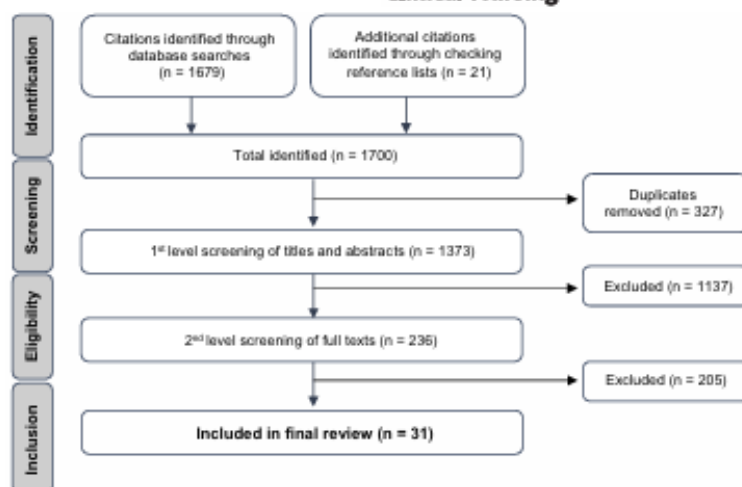


FIGURE 2 Mediators, moderators and descriptors of sexual health mapped out from the literature reviewed [Colour figure can be viewed at wileyonlinelibrary.com]

surveys ($n = 22$). Two studies used pre-existing patient databases to analyse relationships between the disease and sexual dysfunction. Two qualitative studies presenting patient narratives were identified. These were the only nurse-led studies in the review.

There were 15 surgical studies, of which 10 recruited exclusively ulcerative colitis (UC) participants. Of the 16 nonsurgical studies, 15 recruited participants with both UC and Crohn's disease (CD). Eleven nonsurgical studies used control groups, eight of which demonstrated a link between IBD and sexual dysfunction. One study included the partners of participants with IBD.

We were unable to determine the prevalence of sexual dysfunction in men as there was not a homogenous measure of sexual health and function across the papers reviewed. Erectile dysfunction was

the most commonly used measure across the studies. There was a reported erectile dysfunction incidence rate of 2.23 per 10,000 person-years (Kao et al., 2016).

Thematic analysis of the charted findings led to the identification of three categories:

- (i) Mediators of sexual health in men with IBD
- (ii) Moderators of sexual health in men with IBD
- (iii) Descriptors of sexual health men with IBD

Themes related to these categories are illustrated in Figure 2, which reflects the relative weight of evidence across the included studies.

TABLE 2 Aims of included papers

Authors	Year	Aim	Male patient sample size
Stahlgren & Ferguson	1959	Investigate changes in sexual function after abdominoperineal resection	25
Donovan & O'Hara	1960	Explore whether removal of the rectum causes sexual dysfunction	21
Fazio, Fletcher & Montague	1980	Evaluate the effect of conservative versus radical resection of the rectum on sexual function	9
Hendriksen & Binder	1980	Evaluate the social/emotional status in ulcerative colitis	52
de Bernardinis et al.	1981	Explore incidence of sexual dysfunction after colorectal resection	15
Leicester et al.	1984	Identify the incidence of sexual function after rectal excision	23
Salter, M.	1992	Identify body image problems for those undergoing a continent procedure versus stoma	4
Moody & Mayberry	1993	Assess evidence of sexual dysfunction among men and women with ulcerative colitis and men with Crohn's disease	100
Damgaard, Wettergren & Kirkegaard	1995	Assess quality of life with emphasis on social and sexual function in patients with a pelvic pouch	26
Tiainen, Matikainen & Hiltunen	1999	Document the kinds of change that take place in sexual functions and fertility after ileal pouch-anal anastomosis	44
Maunder et al.	1999	Evaluate differences between men and women regarding sexual performance and intimacy	147
Berndtsson, Oresland & Hulten	2004	Assess sexuality in UC patients pre- and post-ileal pouch-anal anastomosis	25
Timmer et al.	2007	Examine the nature and extent of sexual dysfunction.	153
Timmer et al.	2007	Assess physical and psychosocial determinants of sexual dysfunction	280
Muller et al.	2010	Explore perspectives of the impact of inflammatory bowel disease on relationships/body image/libido/sexual function/sexuality	74
Bengtsson et al.	2011	Compare sexual dysfunction in patients with functioning versus failing pouches.	13
Wang et al.	2011	Examine sexual function and quality of life before and after proctectomy	41
De Zeeuw et al.	2011	To pilot whether close rectal dissection is safe	6
Riss et al.	2013	Evaluate the impact of surgery for anal fistula on quality of life, sexual function and behaviour	22
Marin et al.	2013	Evaluate prevalence and predisposing factors of sexual dysfunction among inflammatory bowel disease patients	153
Yoshida et al.	2014	Evaluate sexual activity after restorative proctocolectomy with ileal j-pouch-anal anastomosis	30
Dibley et al.	2014	Explore the parallels between "coming out" and sexual identity and inflammatory bowel disease	33
Cohan et al.	2015	To examine relationship parameters in patients with ulcerative colitis and their partners	25
Bel et al.	2015	Evaluate the prevalence of sexual dysfunctions in men and women with inflammatory bowel disease	119
Kao et al.	2016	To determine whether inflammatory bowel disease is associated with increased risk of erectile dysfunction	1,845
Riviere et al.	2017	Determine the prevalence of sexual dysfunction	166
Valer et al.	2017	Secondary aim: evaluate impact of inflammatory bowel on sexual function	52
O'Toole et al.	2018	Determine disease-specific psychometric properties that can be used for assessment	175
Bulut & Toruner	2018	Evaluate anxiety, depression, quality of life and sexual dysfunction	69
Eluri et al.	2018	Evaluate interest and satisfaction with sex	745
Friedman et al.	2018	Examine the use of erectile dysfunction medications in men with inflammatory bowel disease	31,498

4.1 | Mediators of sexual health in men with IBD

We defined mediators as IBD-related factors that were reported as leading to, or associated with an impairment in men's sexual health and well-being. Five themes were identified:

4.1.1 | Disease onset or presentation

The literature on the impact of disease onset on sexual function in men is sparse. Three studies were identified that analysed a statistical relationship between duration of disease and sexual function (Muller, Prosser, Bampton, Mountfield, & Andrews, 2010; Timmer, Bauer, Dignass, & Rogler, 2007; Timmer, Bauer, Kemptner, et al., 2007; Yoshida et al., 2014). No statistically significant association between age of onset and sexual function was found, but a disease duration of ≥ 3 years was reported to have an adverse effect on libido (Muller et al., 2010), while an onset age ≥ 30 years was associated with poor sexual activity (Yoshida et al., 2014). Conversely, Timmer, Bauer, Kemptner, et al. (2007) found that longer disease durations were inversely associated with sexual function scores and inferred that coping strategies improved over the course of having the disease. No studies were identified that explored whether experiences varied with age of disease onset, or whether there is an impact on puberty and sexual development.

The two main presentations of IBD—CD and UC—were studied collectively in 19 of the 32 included papers. Men with either CD or UC were reported to have higher mean scores for erectile dysfunction than controls in one study, but this only reached statistical significance in CD ($p = .04$) (Bulut & Toruner, 2018). It is possible the study was underpowered or that erectile dysfunction is not sensitive enough to demonstrate an impact on sexual health in UC. Alternatively, CD may have a greater effect on sexual health as it is transmural and more commonly associated with extra-intestinal manifestations.

Perianal disease in CD can cause abscesses and fistulas that result in pain, discharge and bleeding. However, perianal disease was not associated with, or an independent risk factor for, erectile dysfunction (Marin et al., 2013; Riviere et al., 2017). No studies were identified that explored whether perianal disease impacts upon other aspects of sexual health, such as enjoyment.

4.1.2 | Disease activity

Active disease and symptoms are a key determinant of impaired sexual health and function in men with IBD. Tiredness, diarrhoea, fear of incontinence and abdominal pain were all reported to reduce frequency of sexual intercourse (Moody & Mayberry, 1993). Eight studies used a validated assessment tool to assess disease activity (Bel et al., 2015; Bulut & Toruner, 2018; Eluri et al., 2018; O'Toole et al., 2018; Riviere et al., 2017; Timmer, Bauer, Dignass, et al., 2007; Timmer, Bauer, Kemptner, et al., 2007; Valer et al., 2017). Patients with active disease

as measured by the Simple Clinical Colitis Activity Index or Harvey-Bradshaw Index had poorer sexual function than those in remission and controls (Bel et al., 2015). This finding has been replicated in self-reported disease activity scores (Eluri et al., 2018).

4.1.3 | Depression

There is strong evidence that depression is associated with sexual dysfunction in men with IBD in both univariate (Bel et al., 2015; Bulut & Toruner, 2018; Timmer, Bauer, Dignass, et al., 2007; Timmer, Bauer, Kemptner, et al., 2007) and multi-variate analyses (Marin et al., 2013; Riviere et al., 2017). Depression is also associated with decreased sexual interest and satisfaction scores (Eluri et al., 2018). In a mixed-sex study evaluating prevalence and predisposing factors of sexual dysfunction among IBD patients, men reported psychological factors such as depression as responsible for disrupting intimacy, whereas women were more likely to blame physical disease symptoms (Marin et al., 2013).

4.1.4 | Body image

People with IBD can have a distorted perception of their body image (Bel et al., 2015) and this could lower self-esteem and confidence, and in turn impact upon intimate relationships. Muller et al. (2010) found 51.4% ($n = 38$) of male patients had impaired body image. In this study, all those who had a stoma reported a negative impact on body image but there was no statistically significant difference between operated and nonoperated patients for body image overall.

4.1.5 | Non-IBD-related factors

Diabetes (Marin et al., 2013; Timmer, Bauer, Kemptner, et al., 2007), smoking (O'Toole et al., 2018; Riss et al., 2013), cardiac co-morbidities (O'Toole et al., 2018) and older age (Kao et al., 2016; Riviere et al., 2017) have all been shown to be significantly associated with some form of sexual dysfunction in IBD. The IBD specialist nurse will inherently focus on assessing and treating disease-related factors, but a broader awareness of other compounding issues is likely to lead to a more successful approach to care and appropriate referral to other services. Even when sexual ill health has not been caused by IBD, it may still affect a person's well-being and ability to cope and manage the disease, but this was not considered in any of the reviewed papers.

4.2 | Moderators of sexual health in men with IBD

Factors reported as mitigating or influencing the impact of IBD on men's sexual health are limited. The two moderators identified in the literature are medication and surgery.

4.2.1 | Medication

Inflammatory bowel disease may require management with complex medication regimens and potent drugs that can induce unpleasant side effects. Eluri et al. (2018) found prednisolone, which is commonly used for inducing remission, did not impact upon sexual satisfaction but the data for men in this study were not presented separately from women. Traditional maintenance therapies such as thiopurines and methotrexate were not found not to increase the risk of needing an erectile dysfunction prescription (Friedman et al., 2018).

The need for biological therapies was found to be an independent risk factor for sexual dysfunction (Marin et al., 2013) but this finding was not duplicated in a large cohort study (Friedman et al., 2018). It is possible that the need for biological therapy is a surrogate marker for disease severity rather than the drug causing a direct impact on sexual health.

4.2.2 | Surgery

Reports of postoperative erectile dysfunction ranged from 0% (de Bernardinis et al., 1981; De Zeeuw, Ahmed Ali, Van Der Kolk, & Van Laarhoven, 2011) to 48% ($n = 11$) (Leicester, Ritchie, Wadsworth, Thomson, & Hawley, 1984). All the surgical surveys had small sample sizes (<50 patient participants). Several large surgical studies were excluded from the review due to the inclusion of non-IBD diseases. The disparity in findings of postoperative erectile dysfunction may be due to the heterogeneity in population, measure of dysfunction, surgery and research methodology across included studies. The largest study that included 31,498 men with IBD but was not a surgical study found previous surgery in men with IBD increased the likelihood of needing an erectile dysfunction prescription (Friedman et al., 2018).

Inflammatory bowel disease surgery often necessitates the formation of a stoma. Timmer, Bauer, Kempner, et al. (2007) found no association between previous resecting surgery and sexual function or libido but the presence of an ostomy did have a negative impact. Conversely, an online survey by Eluri et al. (2018) found the presence of a stoma was not related to a reduction in sexual activity in men. Damgaard, Wettergren & Kirkgaard (1995) found men are more likely than women to continue having sex with a temporary stoma but as Berndtsson, Oresland, and Hultén (2004) highlight, measuring frequency does not afford insight into the quality of sexual function and relationships. An ileo pouch-anal anastomosis may offer patients a sense of normality and stoma reversal (Berndtsson et al., 2004; Salter, 1992) but pouches can become diseased or function inadequately. Anatomically, pouch formation frequently necessitates deep pelvic dissection and can therefore be more complex and detrimental than a laparoscopic resection or formation of ileostomy. Ileal pouches were found to be associated with sexual dysfunction (Bengtsson et al., 2011).

Two studies also reported that surgery can improve sexual function and quality of life (Cohan, Rhee, Finlayson, & Varma, 2015; Wang et al., 2011). This is possibly due to the positive impact on disease activity and ultimate resolution of symptoms.

4.3 | Descriptors of sexual health in men with IBD

Several physical and psychosocial descriptors of sexual health were identified (Figure 3).

4.3.1 | Erectile function

Erectile function was used in 22 studies as a descriptor (and measure) of sexual dysfunction. When compared to sex- and age-matched controls, men with IBD have a 1.64-fold higher risk of developing erectile dysfunction (Kao et al., 2016) and the crude hazard rate for needing an erectile dysfunction prescription in men with IBD is 1.22, 95% CI 1.18–1.27 (Friedman et al., 2018).

The International Index of Erectile Function (IIEF) was the most commonly used assessment tool, which evaluates erectile function, orgasm, sexual desire, sexual satisfaction and overall satisfaction. No significant difference between patients and healthy controls was found when observing the IIEF recognised cut-off of <42.0 for dysfunction (Bel et al., 2015; Marin et al., 2013; Riviere et al., 2017) but mean scores were significantly lower in the IBD group compared to healthy controls (Bel et al., 2015). The IIEF is based on sexual health impacts observed in other disease cohorts, and its validity in patients with IBD is uncertain. It is therefore possible that the given cut-off point for dysfunction is not sensitive enough in IBD or the tool itself does not reflect the challenges faced by men with IBD.

4.3.2 | Sexuality and sexual orientation

The impact of IBD on men's sexuality, as defined by orientation, pleasure, behaviours and relationship roles, has been largely limited to the measurement of satisfaction and desire within the IIEF. One study reported issues in relation to gay men, which included fear of judgement, lack of inclusion of same-sex partners in healthcare interactions, the absence of information on the safety of anal sex in active disease, concerns that sexual habits could trigger the disease and the possible change in sexual role due to the presence of disease (Dibley, Norton, & Schaub, 2013).

4.3.3 | Masculinity

Disability can have a negative impact on masculinity and the male social role (Tepper, 1999) but little was uncovered on this in the review. One survey assessed "feeling masculine" and found that this was reduced by disease activity (Timmer, Bauer, Kempner, et al., 2007).

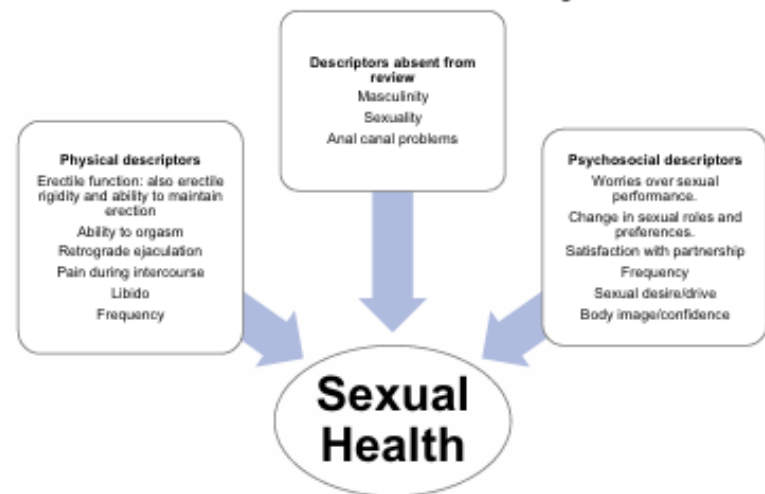


FIGURE 3 Descriptors of sexual dysfunction [Colour figure can be viewed at wileyonlinelibrary.com]

4.3.4 | Partnership

Partners can play a positive role in helping those with the disease to adapt (Salter, 1992), and partnership is a precursor to good sexual health. Seven papers explored this within their study but just one study included partners as study participants.

As much as 43.2% ($n = 32$) of male patients thought that IBD had affected their relationship (Muller et al., 2010), while a fifth were hesitant to start a new relationship because of their IBD (O'Toole et al., 2018). Bel et al. (2015) reported longer relationship duration was correlated to more sexual problems but this was the result of a combined male/female cohort sub-analysis. Conversely, in a study of UC patients, surgery did not negatively impact upon relationship status, perhaps reflecting the chronicity of the disease and preceding hardships which may have been overcome (Cohan et al., 2015).

No significant difference between duration of marriage or divorce rate between IBD patients and controls or general population data was described (Moody & Mayberry, 1993; Muller et al., 2010; Timmer, Bauer, Dignass, et al., 2007). The level to which IBD influences partnership and prohibits new sexual relations may be under-represented in the included studies due to a tendency for studies to recruit participants in established relationships.

4.3.5 | Sexual libido and frequency

Frequency of sexual activity and libido are a common focus across the literature. Maunder, Toner, De Rooy, and Moskovitz (1999) found that men ranked concerns regarding sexual desire and performance higher than women. In a case-controlled study, no statistically significant difference was observed between IBD patients and controls when sexual frequency was measured (Moody & Mayberry, 1993). However, a more recent study found a substantial number of men with IBD reported a negative impact on libido

(41.9%, $n = 31$) and reduction in frequency of sexual interaction (40.5%, $n = 30$) (Muller et al., 2010). Interestingly, higher levels of sexual activity have been observed in men with IBD compared to controls, despite having lower IIEF scores (Marin et al., 2013). There may be a relationship between libido and frequency, but these two factors can also be independently impaired and should therefore be measured separately.

4.4 | Assessment and clinical support

Four different sexual health assessment tools were used across the studies (Table 3). None of the tools have been validated in an IBD population and do not assess issues specifically related to IBD or consider wider sexual health domains such as sexuality, masculinity, partnership and sexual role. O'Toole et al. (2018) devised the IBD-Male Sexual Dysfunction Score (IBD-MSDS), which evaluates the impact of IBD-specific issues such as fatigue, abdominal pain, incontinence and bowel frequency. The IBD-MSDS may provide a useful tool for nurses but focuses upon sexual function, with no assessment of broader sexual health domains such as sexuality and gender identity. Further validation and evaluation of its effectiveness and applicability is required before it can be recommended in routine clinical practice.

We did not identify any studies that tested interventions for sexual dysfunction in IBD, though several have been proposed (Table 4). O'Toole et al. (2018) found that 23% ($n = 40$) of participants were taking erectile enhancing medications and 5% ($n = 9$) were using testosterone to improve sexual function. Timmer, Bauer, Dignass, et al. (2007) argued treatment should focus on inducing remission of the disease and psychological maladaptation rather than sex therapy. Psychosocial approaches that include treatment of depression or rebuilding intimate partnership such as couples counselling may develop resilience, coping and self-management, may also have a benefit to overall disease course. There is a need to defined treatment strategies that can be trialled and tested within this population.

TABLE 3 Assessment tools for sexual dysfunction used within included studies

Tool	Study(s)	Description	Pros	Cons	Common issues
International Index of Erectile Function (IIEF)	Timmer, Bauer, Dignass, et al. (2007), Timmer, Bauer, Kempthner, et al. (2007), Bengtsson et al. (2011), Wang et al. (2011), Marin et al. (2013), Riss et al. (2013), Bel et al. (2015), Riviere et al. (2017), Valer et al. (2017), O'Toole et al. (2018)	Questions in the domains of erectile function, orgasmic function, sexual desire, satisfaction and overall satisfaction	Validated in wider population Patient input used to develop measure Assesses some aspects of wider function such as desire and satisfaction Quick and easy to use	Does not account for other specific issues such as premature ejaculation	Not been validated in an IBD population Questions do not relate to specific IBD issues Do not consider wider sexual health domains such as sexuality, personal expression, masculinity, intimate partnership, sexual role
Sexual Function Questionnaire (SFQ)	Wang et al. (2011)	Seven domain questionnaire assessing desire, enjoyment, orgasm, sensation, arousal, pain, partner	Addresses aspects of the sexual response cycle	Developed and validated in women not men	
Arizona Sexual Experience Scale (ASEX)	Bulut and Toruner (2018)	Assesses desire, arousal, erection/lubrication, orgasm and satisfaction. Score is 5–30, higher indicating more dysfunction	Easy to use Designed to be self-administered Not dependent on user being in a current partnership	Based on domains most commonly impaired by psychotropic drugs not chronic disease. Not specifically designed for men	
Patient-Reported Outcome Measurement Information System Sexual Function and Satisfaction Scale (PROMISE SexFS)	Eluri et al. (2018)	Comprehensive assessment including sexual activities, interfering factors, therapeutic aids as well as satisfaction and erectile function	Derived from literature review, expert opinion, focus groups and qualitative data Considers anal discomfort	Originally, developed using cancer populations that may have differing experiences to IBD	

TABLE 4 Potential interventions for male sexual dysfunction in IBD

Interventions	Cited by
Physicians should be aware of risk and inform	Kao et al. (2016)
Reverse/treat the disease	Timmer, Bauer, Kemptner, et al. (2007)
Provide a safe environment for discussion	Dibley et al. (2013), Muller et al. (2010)
Treatment of depression as a first-line intervention	Timmer, Bauer, Dignass, et al. (2007)
Psychological assessment or clinical psychology	Bel et al. (2015); Moody and Mayberry (1993)
Referral to couples counselling	Moody and Mayberry (1993)
Involving partners in care	Dibley et al. (2013)
Nurse led coordination of rehabilitation and aiding acceptance of body	Salter (1992)
Sex therapeutic treatment	Bel et al. (2015)
Erectile enhancing medications and testosterone	O'Toole (2018)

5 | DISCUSSION

IBD can have a profound impact on an individual's sexual health and well-being. Nurses must be aware of the issues influencing sexual health when providing holistic care to patients living with the condition (Giese & Terrell, 1996). Information for nurses on sexual health in men with IBD is limited. This scoping review has mapped the current evidence on the sexual health needs of men with IBD.

This review has identified several physical and psychological disease-specific mediators and modifiers of sexual health that can help inform nursing assessment and intervention. Although the two main manifestations of IBD, CD and UC, have similar traits, they can vary in how they present and are treated. It is not possible to determine from the extant literature whether CD and UC equivalently affect sexual health in men with IBD. Understanding whether there is a substantial difference in how men with CD and UC experience sexual health is needed to identify whether assessment, treatment and support should be disease presentation-specific.

A history of surgical intervention was correlated to sexual dysfunction in several studies. Surgical studies spanned from 1959–2015 during which there was considerable advances in surgical technique, most notably the introduction of laparoscopic surgery which has reduced the need for deep pelvic dissection, reduced complication rates and improved postoperative hospital length of stay (Gagliardi, Davis, Bailey, & Cusick, 2019). It is also likely that the advances in the medical management of IBD including the introduction of biologic therapy have reduced or delayed the need for surgery (Olivera, Spinelli, Gower-Rousseau, Danese, & Peyrin-Biroulet, 2017). There is now the need to update the evidence base on the surgical effects on sexual function and expand this to cover psychosexual health implications. Future studies should

ensure that a distinction is made between the direct impact of surgery (e.g. possible impairment of erectile function due to nerve dissection), postoperative physical effects (e.g. wound healing, stomas, weight loss, fatigue), psychological impacts (e.g. body image impairment, embarrassment, sense of loss) and contextual implications (e.g. hospital stay, distance from partner). The effect of surgery will vary depending on a person's disease, surgical technique and type, stage of recovery and personal factors such as an ability to cope and social support network. This must be considered in future studies and when counselling patients. Notably, the effect of surgery on sexual function was not always reported as negative. Exploring this could be of major benefit to people who are unable to avoid surgical intervention and require practical support to optimise their sexual health in the postoperative period.

As with surgical care, medical management of IBD has advanced significantly in the last decade, with biological therapies becoming a widely available treatment option. The effect of medications on the sexual health and well-being of men with IBD remains under-explored. There has been no exploration of the influence of medication schedules and procedures on sexual well-being. We believe this is of interest in IBD as we presume the nocte rectal administration of medication could disrupt sexual interest and activity. Muller et al. (2010) indicate that medications may be omitted due to a perceived impact on libido and sexual activity. This needs to be investigated further so nurses can accurately inform patients and address concerns in order to overcome poor medication compliance.

There has been very little research into the effect of the disease on sexuality and sexual preferences, including the potential impact of the disease on receptive anal disease. This is something that should be considered in future research and may improve care and advice for those with perianal disease and anal ulceration.

Extra-intestinal symptoms and complications including joint and skin problems can impact on patient quality of life and possibly sexual health. Such issues were not raised in the studies, and yet, this is a key aspect of IBD nursing care. There may be insight to be gained from exploring the literature in hepatology, dermatology, rheumatology and related inflammatory disorders.

Moody and Mayberry (1993) reported no significant difference in rates of sexual activity between patient groups and controls, yet several IBD-related symptoms were attributed by men with the disease to sexual inactivity. It is possible that there is a mismatch between perceived and actual impact of the disease. When in remission, men with IBD were found to have better sexual functioning than healthy controls (Bel et al., 2015; Timmer, Bauer, Dignass, et al., 2007). This suggests that for some men, the disease may not produce a constant limiting factor on sexual health. Alternatively, it is possible that without an appropriate and validated assessment tool for sexual well-being in the IBD population, problems are not being detected by researchers and clinicians.

The IBD-MSDS could provide a much-needed aid to nurses wishing to assess sexual function. Muller et al. (2010) make an interesting observation that many studies attempt to quantify sexual dysfunction with objective measures. However, sexual health and function is

largely a subjective matter. It is possible that traditional assessment tools are not the most appropriate method of patient assessment. Research into the effectiveness, validity and applicability of sexual health assessment in IBD is required before they are recommended for nursing practice.

As well as promoting assessment, the potential for nurses to improve care by providing a safe sharing space and initiating conversation on this sensitive matter should also not be underestimated. Only 10% of patients in the O'Toole et al. (2018) study had been in a consultation with an IBD specialist about sex. Further exploration into the barriers to assessment and care of sexual dysfunction is required to inform approaches to overcome them. The appropriateness and acceptability of sexual health assessment in IBD clinics and by nurses needs assessing. Timmer, Bauer, Dignass, et al. (2007) stated that they would not necessarily recommend routine discussion of the matter because only 25% of male patients wanted to discuss sexual issues with a physician, suggesting that many men do not view sexual health as a medical matter. Recommendations against assessment of sexual health and well-being do not encourage the breaking down of taboos and normalisation of good sexual health and well-being. It is also worth noting that only 16% of controls in the same study wanted to discuss sexual issues with a doctor, demonstrating an increased need in the IBD population.

Overall, the current evidence suggests that sexual health should be sensitively assessed within the IBD clinic. 78% of patients reported they would be comfortable talking to a doctor about sex (O'Toole et al., 2018), and 52.1% of male participants expected to discuss sex with a physician (Riviere et al., 2017). Marin et al. (2013) reported 46% of men thought information about the impact of IBD on sex should be given at diagnosis and 44% believed the IBD specialist is an appropriate person to have this discussion with.

Only two qualitative studies presenting men's narratives were identified. Further qualitative research to capture the complexity of the disease and men's experiences is warranted to help inform the nursing assessment process and health service delivery. Ensuring that health systems are responsive to men's sexual and reproductive health needs has been identified as a key goal for improving the health and well-being of men by the World Health Organization (WHO, 2018). Men's under-use of healthcare services is consistent across many countries and is closely linked to masculine norms and ideals as well as to socio-economic factors (Galdas et al., 2014; WHO, 2018). Previous studies of men with a range of long-term conditions has shown that the accessibility and acceptability of services can be improved when the context, content and delivery style of interventions are tailored to be in alignment with valued aspects of their masculine identities (Galdas et al., 2014). However, we could not identify any studies that have explored men's experiences of IBD in this context. Only by illuminating the lived experience of people with this disease can health professionals interpret their needs and design relevant assessment and management strategies. This is particularly suited to nursing research as specialist nurses support and provide care for the biopsychosocial effects of the disease and aim to support these as an adjunct to medical consultant care in their nurse-led clinics.

5.1 | Limitations

As is common practice with scoping reviews, included studies were not critically appraised using a validated tool. Only papers available in English were reviewed but this led to the exclusion of just one paper.

6 | CONCLUSION

In this scoping review, we have sought to understand the potential impact of IBD on male sexual health and identify whether there is scope for nursing intervention and research. We have highlighted a paucity of studies investigating men's sexual health in IBD. Most of the current evidence concerns erectile dysfunction evaluated through small patient surveys. Of the methodologically robust studies, a comprehensive systematic review has recently been completed and demonstrated an a combined relative risk of 1.41, 95% CI (1.09–1.81) meaning men with IBD have a 41% higher risk of sexual dysfunction, mainly measured through erectile function, than their healthy counterparts (Zhao et al., 2019). This supports a case for further investigation but does not provide detailed insight into the concerns of men with IBD pertaining to sexual health and well-being.

The most notable gap in the literature is in the personal experiences of men with IBD and the broader concept of sexual well-being, particularly regarding sexuality, masculinity and psychosexual health. This review has demonstrated that men with IBD can suffer disruption to not only erectile function but also frequency of intercourse, sexual satisfaction and fulfilment of sexual preferences. The extent to which patients experience these remains poorly described. Disease activity, depression and surgery are the most reported IBD-related impact factors, but how these factors mediate the varying features of sexual health remains unclear. Further qualitative exploratory research into patient and professional experiences is required to provide a clinically useful understanding of male sexual dysfunction. This could help drive clinical practice that is based on patient need.

7 | RELEVANCE TO CLINICAL PRACTICE

Sexual health is a multifactorial and subjective feature of personal well-being shaped by biological, physical, psychological, social and cultural factors. Understanding how people perceive and experience their sexual function may deepen nursing assessment and guidance, including delivery of feasible and patient-acceptable self-management strategies. The ability to understand and empathise with a person's experience of disease is central to nursing practice and enables the nurse to be an effective and holistic source of support. It is important that nurses can confidently and sensitively discuss sex and intimate relationships to ensure sexual health problems are not left unaddressed. Judgement-free discussion of health is inherent to nursing practice and the development of a therapeutic relationship,

yet many nurses do not feel that they have the knowledge or competence to talk about sex. Perhaps the most important care nurses offer is "awareness of the sexual issues that often go unspoken" (Giese & Terrell, 1996) and further qualitative exploratory research could aid this. Exploration of the trilateral association between depression, disease activity and sexual health in IBD may assist the development of disease-specific support strategies. It is possible that an approach that blends treatment of physical symptoms and psychological effects will be beneficial. There is the opportunity for the development of training tools and clinical treatment pathways that specifically allow nurses to identify, facilitate, coordinate and manage appropriate care in this area.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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Appendix 2: Publication: Ma, Knapp and Galdas (2024) 'My sexual desires, everything, my normal life just stops'; A qualitative study of male sexual health in Inflammatory Bowel Disease

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'My sexual desires, everything, my normal life just stops'; a qualitative study of male sexual health in inflammatory bowel disease

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Abstract

Aim: To describe and interpret the sexual health experiences of men with IBD.

Design: Interpretive qualitative study.

Methods: In-depth, semi-structured interviews were conducted with 22 men with a diagnosis of Inflammatory Bowel Disease. Interviews were digitally audio-recorded and transcribed verbatim. Data were analysed using constant comparative, thematic analysis.

Results: Three themes were identified from interview data: (1) the disease shapes intimate connections, (2) the disease thwarts sexual experiences and (3) the disease disrupts male gender norms. Men reported that active disease lowered libido and could change pre-, inter- and post-coital sexual practices. All participants noted that health professionals did not initiate the discussion of sexual health and well-being needs in the outpatient hospital setting. Men who engaged in receptive anal sex reported a lack of disease-specific guidance and understanding from professionals.

Conclusion: Inflammatory bowel disease can negatively impact the sexual well-being, gender identity and activities of men. Further research is required to identify the care preferences of men with IBD and clarify the barriers and facilitators to sexual health assessment so that nurses may better support the health needs of this population.

Implications for the Profession and Patient Care: This study highlights the need for sexual health and well-being support that is specific to disease and gender in IBD. There is a paucity of information and guidance for men with peri-anal disease and proctitis who engage in receptive anal sex, which requires urgent attention.

Reporting Method: Reporting follows the COREQ checklist.

Patient or Public Contribution: A patient and public involvement group informed the development of the study design. The group reviewed public facing documents and interview guides. One member of the group provided comments on the identified themes.

KEYWORDS

body image and sexuality, chronic illness, masculinity, men's health, qualitative approaches, quality of life, sexual health, sexual wellbeing, stoma, ulcerative colitis

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1 | INTRODUCTION

Inflammatory Bowel Disease (IBD) is characterised by chronic intestinal inflammation which typically induces persistent diarrhoea, rectal bleeding and abdominal pain. Although a disease of the gastrointestinal tract, IBD can also induce several extra-intestinal manifestations which are most commonly experienced in the joints and skin. The unpredictable, relapsing–remitting nature of this multi-focal disease can lead to both physical and psychosocial ill-health, including within the domain of sexuality. Sexual well-being and sexuality are an important consideration in holistic healthcare. Sexual well-being is poorly understood in IBD and there is a paucity of research in this field, particularly in men (Ma et al., 2020). This qualitative study addresses the need for exploratory research to better understand the complex interactions between IBD and the psychosexual well-being of men.

2 | BACKGROUND

The two most common presentations of IBD are Crohn's Disease (CD) and Ulcerative Colitis (UC). There are less prevalent subtypes including microscopic colitis and IBD-unclassified, but all are characterised by chronic inflammation of the gastrointestinal tract. When severe the disease can require medications that suppress the immune system, lead to hospitalisation and in some cases, surgery. The mainstay of IBD treatment is inducing and maintaining disease remission while providing ongoing support. The disease is associated with a small increased risk of mortality as compared to age- and sex-matched controls, and colonic disease carries an increased risk of colonic cancer (King et al., 2020). Although the disease can affect any age group, it commonly affects working-age populations with the peak onset being ages 15 to 30, which coincides with the development of sexual maturity.

Sexual health is widely accepted as a basic human right and a component of overall well-being and quality of life. The World Health Organisation defines sexual health as the 'state of physical, emotional, mental and social well-being in relation to sexuality' (World Health Organization, 2006). While reproductive health and sexually transmitted diseases are established domains in healthcare, the idea of sexuality, sexual expression and sexual pleasure as a clinical matter is contentious (Lottes, 2013). With the focus of healthcare shifting from survival to quality of life, there is a strong case for sexual health research that aims to better understand sexual engagement, sexuality, and intimate relationships. The personally intrusive and embarrassing symptoms of IBD, such as rectal bleeding and diarrhoea may interfere with body image, self-confidence and sexual desire. Furthermore, perianal disease including fissures and fistulas, can lead to discomfort, pain and discharge in the anal region. This manifestation of IBD may also have a negative impact on sexual engagement, particularly receptive anal sex. A recent scoping review that sought to summarise the sexual health needs of people living with long-term conditions (Igerc & Schrems, 2023), located

What does this paper contribute to the wider global community?

- This study draws attention to the way in which living with a chronic illness, such as IBD, can affect men's physical and psychosocial experiences of sexual health and well-being.
- Study findings indicate that the sexual health and well-being of men is not adequately discussed during routine IBD consultations, with missed opportunities for assessment, information giving and support.
- Improving the delivery of patient-centred nursing care for men with IBD may necessitate disease and gender-specific sexual health information and education provided to both patients and clinicians.

only two articles that explicitly referenced nursing practice and only two studies that explored IBD.

Within the broader IBD research literature, the sexual health needs of men have been similarly overlooked (Allocca et al., 2018; Ma et al., 2020), with most studies focusing on women's health due to the impact of the disease on fertility and pregnancy. To date, sexual health research in men with IBD has mainly focused on the assessment of erectile dysfunction (ED), mostly in the context of surgery that carries a risk of pelvic nerve injury (Ma et al., 2020). While erectile function is an important component of sexual health for many men, the assessment of ED alone does not elicit a complete understanding of how the symptoms and complications of IBD may affect sexual well-being, including the wider aspects of engagement in sex and sexual expression. There is some evidence that for men with IBD, sexual health and well-being are more likely to be disrupted by psychological factors, such as depression (Marin et al., 2013). This is an important consideration as men are generally less likely than women to seek healthcare advice for psychosocial problems (Möller-Leimkühler, 2002). Evidence also suggests that men with long-term conditions may benefit from models of service delivery that are tailored to their specific physiological and psychological needs and preferences (Galdas et al., 2014). Examining the lived experiences of men with IBD is therefore critical to help inform the development of disease-specific guidance that is accessible and acceptable to men. This study addresses this gap in the evidence by asking: what are the sexual health experiences of men with IBD?

2.1 | Aims

The study aimed to (i) describe and interpret the sexual health experiences and activities of men with IBD; and (ii) generate clinically relevant knowledge to help guide nursing education and practice.

3 | METHODS

3.1 | Study design

Interpretive description (Thorne, 2016) provided the methodological framework for the study and enabled an adaptable but rigorous approach to qualitatively examine individual experience. Adoption of a constructivist epistemological position allowed the researchers to exploit specialist nursing knowledge during the research process in order to support the translation of findings into clinically relevant knowledge. A qualitative approach was selected for its appropriateness in examining the lived experience. The consolidated criteria for reporting qualitative research (COREQ) guidelines have been followed (Tong et al., 2007).

3.2 | Study setting and recruitment

The study was advertised in three NHS hospitals in England using a paper leaflet, and online via the Crohn's and Colitis UK website and social media channels. Potential participants could express an interest in the study by responding to the advert via telephone, email or completing an online form, and were then contacted by a member of the research team. Participants were aged 18 years or older, identified as male, had a diagnosis of Crohn's Disease, Ulcerative Colitis or IBD-U, spoke English, were able to provide informed consent and deemed themselves medically well enough to participate. A flexible and cyclical theoretical sampling approach was adopted, as described by Thorne (2016). Initial purposive sampling allowed rich and detailed accounts to be collected. Ongoing sampling decisions were informed by the themes derived from concurrent data collection and analysis which enabled the testing and refining of observations. Recruitment ceased when no new themes were identifiable within the interview transcripts (i.e. saturation).

3.3 | Data collection

Individual, semi-structured interviews were conducted between 1 July 2022 and 1 February 2023 by a female researcher (SM) who was an IBD Specialist Nurse and had undergone research training as part of a clinical doctorate programme. Face-to-face interviews were conducted in a private room within an NHS hospital. Interviews that took place via video call or telephone required participants to self-select a private location. Prior to interview, participants were asked to complete a short clinical and demographic questionnaire along with the International Index of Erectile Function (Rosen et al., 1997) and the IBD-Male Sexual Dysfunction Score (O'Toole et al., 2018) to provide contextual background. Interviews followed a topic guide based on key themes identified in published research and the input of a public and patient involvement (PPI) group. The guide included suggested questions, keywords and a list of prompts on areas for exploration (Box 1). Only the researcher and participant were present

BOX 1 Interview guide excerpt Interview guide

Topics in interview guide:

- Inflammatory bowel disease, general health and care.
- Social.
- Being a man and masculinity.
- Relationships.
- Sex.
- Support with sexual well-being.

Example of interview guide format:

Topic: Sex.

Questions:

- Do you feel that IBD and the way you have sex are connected, if so how?
- Has your UC/Crohn's impacted upon your relationships, intimacy, or sex life?
- Keywords; erectile function, sexually satisfied.
- Prompts; how does your partner feel about that? Does your IBD make that better/worse?

at the interview. At the start of each interview, the reasons for the research and the role of the researcher were clarified. The interviews ranged from 24 to 118 min, were digitally audio recorded and transcribed verbatim.

3.4 | Data analysis

The clinical and demographic questionnaires were imported into Microsoft Excel 360 (version 2410). Descriptive statistics were calculated to better understand the participant demographic data, including means, standard deviations, medians and interquartile-ranges. Interview transcripts were imported into NVIVO QSR International Release 1.7 and the data were subjected to constant-comparative thematic analysis (Charmaz, 2014; Thorne, 2016). Initial codes were derived by interrogating the data line by line, they were then reviewed for similarities and differences, amended, and grouped into themes. All codes, sub-themes and themes were logged in a spreadsheet. The development of themes and sub-themes was supported with diagramming and memoing to elicit patterns and new concepts. Themes were reviewed by all authors and a patient representative.

3.5 | Ethical considerations

Favourable ethical opinion was received from the Health Research Authority, North East-York Research Ethics Committee (REC 22/NE/0070, IRAS Number 279955) and the University of York, Health Sciences Research Governance Committee (HSRGC/2022/488/B). All participants provided written, informed consent prior to

TABLE 1 Participant demographics, listed in order of interview.

Pseudonym	Age	Disease	Years since diagnosis	Sexuality	Partnership status	Occupational status
Alex	28	UC	1	Heterosexual	Cohabiting	Working
Andy	28	CD	19	Bisexual	Cohabiting	Working
Arthur	47	CD	0	Heterosexual	Married	Working
Benjamin	20	UC	5	Heterosexual	Cohabiting	Student
Dara	24	CD	0	Heterosexual	Single	Working
David	66	IBD-U	53	Heterosexual	Married	Retired
Ethan	28	CD	12	Heterosexual	Cohabiting	Working
Ewan	34	CD	2	Heterosexual	Married	Working
Frank	31	CD	4	Bisexual	Cohabiting	Working
Freddie	64	CD	16	Homosexual	Single	Working
George	37	CD	21	Heterosexual	Married	Working
Guy	58	UC	7	Bisexual	Divorced	Unable to work
Hugo	24	CD	7	Heterosexual	Cohabiting	Working
Noah	38	CD	22	Heterosexual	Dating	Working
Oliver	52	UC	0	Heterosexual	Married	Working
Peter	26	UC	10	Homosexual	Single	Working
Raphael	43	CD	22	Heterosexual	Married	Working
Sam	28	CD	4	Heterosexual	Cohabiting	Working
Steven	31	CD	16	Heterosexual	Cohabiting	Working
Tim	46	CD	1	Heterosexual	Non-cohabiting	Working
Toby	34	UC	3	Heterosexual	Married	Working
Tom	28	CD	4	Heterosexual	Cohabiting	Working

participation. Confidentiality and anonymity were protected throughout the study including removal of identifiable information in interview transcripts and replacement of names with pseudonyms. Data were collected and managed in line with the Data Protection Act (2018) and GDPR regulations (2016). All participants were provided with a participant support leaflet that directed them to free online and telephone resources, if required.

3.6 | Trustworthiness

The interview guide was developed in collaboration with patient representatives and informed by a scoping review that identified gaps in current research (Ma et al., 2020). The interviewer had a professional clinical interest in the subject matter and was known in a professional capacity to five of the participants prior to interview. Analytical notes and a written journal were utilised to support reflexivity and identify pre-existing assumptions throughout the research process. A patient representative reviewed the themes and sub-codes. Transcripts were not returned to participants in order to reduce participation burden. A comprehensive audit trail, including verbatim transcripts, reflections, coding and data analysis was maintained throughout.

4 | FINDINGS

4.1 | Participant characteristics

Twenty-two men participated in the study with no withdrawals. Ten participants were recruited by a clinician during an NHS consultation and 12 via responses to an online advert. An additional 24 people requested the study information sheet but did not participate thereafter.

Participants were aged 20–66 years at the time of interview. The median time since diagnosis was 6 years (IQR 2–16) with a range of 0–53 years. Participant age, relationship status and sexual orientation are detailed in Table 1. Twenty-one participants were born male, and one participant identified as male and had undergone gender-affirming surgery.

Individual interviews were conducted by video call ($n=18$), telephone ($n=3$) or in-person ($n=3$). All participants spoke English and lived in the UK at time of interview, but English was not the native language of three participants. Participants reported a diagnosis of Crohn's disease ($n=15$), ulcerative colitis ($n=6$) or IBD-U ($n=1$). Additional disease characteristics are reported in Table 2.

International Index of Erectile Function (IIEF) and IBD-Male Sexual Dysfunction Scores (IBD-MSDS) are provided in Table 3.

Analysis of the interview data resulted in the development of three core inter-related themes (Figure 1). The themes demonstrate that IBD can shift men's emplacement within their personal, social and sexual relationships which can change the way that they engage in sexual activities and their sexual identity. Theme 1: *IBD shapes intimate connections*, describes how IBD shaped engagement in personal partnerships. Theme 2: *IBD thwarts sexual experiences*, conveys the negative impact on sexual desire and engagement which could limit the expression of sexuality. Theme 3: *IBD can disrupt conventional male gender norms*, draws together the complexity evident in men's narratives relating to the effect of IBD on expressions of masculinity and male identity.

4.2 | Theme one: IBD shapes intimate connections

This theme relates to the interactions and feelings that occurred between men and their intimate partners outside of coitus that could influence engagement in sexual relationships and overall sexual health and well-being.

4.2.1 | Partnership

Brought us closer together, but at the same time it separates you.

Alex, 28years, heterosexual, cohabiting.

An understanding and trusted partner was described as a key component of good sexual health and well-being for many participants, often described as facilitating a level of ease that could enable successful and fulfilling sexual engagement. For some men, casual relationships were consciously avoided for this reason.

I tried casual sex a couple of times and just never gelled with it really. And I think in part that's, I have to feel really comfortable with someone to be that intimate with them.

Andy, 28years, bisexual, cohabiting.

Many men referred to the challenge of communicating to their intimate partners the severity of hidden symptoms and the unpredictability of the disease. Men revealed that it could be difficult to decide when to seek new relationships or disclose their diagnosis to a new partner. A fear of rejection, not being able to meet expectations, and burdening others were raised.

It's a fear but they'll find it quite disgusting, maybe think of me as a lesser person and be completely turned off.

Noah, 38years, heterosexual, dating.

Men described receiving practical support with the disease from their partners but expressed guilt and embarrassment when discussing their need for partner-support.

I felt so guilty that she was having to take on that role for me and that definitely impacted, not just at the time, but you know for quite a while.

Andy, 28years, bisexual, cohabiting.

Some participants attributed relationship breakdowns to difficulties in communication about the disease, while others reflected on how being open about their condition had strengthened their partnerships and therefore sexual engagement. Meeting the sexual and emotional needs of their partners was important to many men in the study. For some men, sexually satisfying their partner took precedence over their own sexual satisfaction. It was felt that sexual engagement could reaffirm and strengthen relationships.

TABLE 2 Participant disease characteristics.

Category	Sub-category	Number (%)	Category	Sub-category	Number (%)
Disease	Crohn's disease	15 (68.2)	Participant rated disease severity	Mild	16 (72.7)
	Ulcerative colitis	6 (27.3)		Moderate	5 (22.7)
	IBD-Unclassified	1 (4.5)		Severe	1 (4.5)
Extra-intestinal manifestations	Perianal disease	8 (36.4)	Co-morbidities	Hypertension	2 (9.1)
	Ankylosing spondylitis	1 (4.5)		HIV	1 (4.5)
	Inflammatory arthritis	1 (4.5)		Eczema	6 (27.3)
	Oral crohns	1 (4.5)		Psoriasis	2 (9.1)
	Uveitis	1 (4.5)		Non-IBD arthritis	5 (22.7)
	Erythema nodosum	2 (9.1)		Depression	4 (18.2)
Disease complications	History of surgery	12 (54.5)	Stoma	Prior stoma	1 (4.5)
	Drug induced pancreatitis	1 (4.5)		Current stoma	3 (13.6)

Category	Sub-category	Total possible score	Mean (SD)
IIEF	Total	75	53.37 (16.2)
	Erectile function	30	23.36 (7.8) ^a
	Orgasmic function	10	8.05 (2.9)
	Sexual desire	10	6.73 (2.1)
	Intercourse satisfaction	15	7.68 (4.4)
	Overall satisfaction	10	6.77 (3.1)
IBD-MSDS	Total score	40	11.09 (5.9)

^a"Freddie's" data has been removed from the erectile function scores due to being aphallic. His data remains in the overall IIEF data as he was able to answer questions from the remaining categories.

TABLE 3 Sexual dysfunction scores.

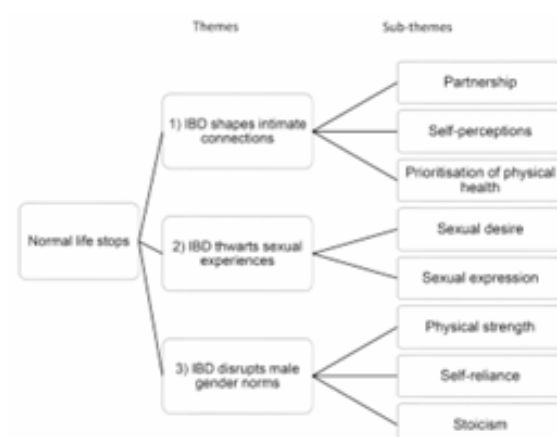


FIGURE 1 Coding tree.

If you don't engage in sexual acts with your partner for long enough, you can emotionally and mentally start to diverge.

Arthur, 47 years, heterosexual, married.

When considering the broader aspects of partnership, parenthood was commonly discussed. Some men required medications to treat the disease which had side-effects of reduced sperm count or infertility. David reported that this had been a contributory factor in his decision not to have children. Noah revealed that he had not yet discussed the possible fertility complications with his new partner, revealing the potential difficulties faced by men when navigating new relationships. Participants with young children mentioned that it could be difficult to engage with parenting duties when unwell, which could place a strain on their relationships or make them feel guilty.

Men often stated that their partners were engaged in their overall IBD care and supported them with the disease, but this did not always translate into having a direct involvement with the healthcare team. Some participants felt this was an omission in the healthcare provided to them and Noah called upon healthcare practitioners to invite partners to be involved when appropriate.

4.2.2 | Self-perceptions

You don't feel attractive yourself, then you know it's going to be a complete non-starter and it's a very easy condition to feel like that because you know the symptoms are what they are.

Raphael, 43 years, heterosexual, married.

Most men talked about changes in their body shape and appearance including weight and muscle mass fluctuations. Alterations to body image and self-esteem were described as reducing confidence and sexual desire. Men whose partners had taken on caring responsibilities such as dressing wounds and administering rectal therapies worried about how this could change their partner's perception of them.

I just didn't feel like sex, cause I just felt really self-conscious about it and her having to see me that way. I just felt small you know, I didn't think that she'd be able to see me as a sexual person, after seeing me like go through that and then like physicality's of wound care and stuff. I guess, I just thought like how on earth is she ever going to see me that way again?

Andy, 28 years, bisexual, cohabiting.

For many men, negative self-perception was transient and occurred with disease relapses or during short-term treatment episodes. However, some men, particularly those with permanent stomas and non-healing fistulas, grappled with the ongoing alteration to their body which could lead to feelings of frustration and a poor self-image. Partners had an important role in supporting acceptance of these body changes.

She was absolutely fine with it (the stoma), like probably couldn't be more supportive, was just like I'm not bothered if that's part of you.

Ethan, 28 years, heterosexual, cohabiting.

Men commonly reflected on feeling unclean because of gastrointestinal symptoms. Cleaning rituals and covering the body were

common practices used to overcome sexual apprehension and poor self-confidence. However, these practices also reduced sexual spontaneity and impulsiveness. A few men were unable to overcome the change in body image or their feelings of uncleanliness. For Freddie, the effect of peri-anal symptoms had led to complete disengagement in sexual activities with other people.

Just no way could I have coped with anybody down there and then I lost my nerve.

Freddie, 64 years homosexual, single.

4.2.3 | Prioritisation of physical health

I never really thought about things like dating, going out, being with anyone until probably after the line (for parenteral feeding) was fitted, it wasn't really a priority, it was more just figuring out my health.

George, 37 years, heterosexual, married.

Although overall sexual health and well-being were important to participants, the resolution of disease symptoms and improving physical health were often considered the priority. Many men valued sexual engagement but were also able to consider alternative activities that could lead to a good quality of life, such as engaging in social activities and work.

It was common amongst young, single men with more severe forms of the disease to completely abstain from seeking intimate relationships during relapse and recovery phases.

When I had the stoma...it was only a period of 6 months, I don't think from memory I was interested in anything romantic at all. I think because again, I was dealing with this thing.

Peter, 26 years, homosexual, single.

Some men in relationships were either upset or frustrated that prioritising themselves had left their partners feeling rejected.

They think I am not into them, or I'm losing interest when the reality is I'm so preoccupied by my illness, unfortunately, having to be a little bit selfish and prioritising myself and they are coming second.

Noah, 38 years, heterosexual, dating.

Balancing the need to prioritise physical health with a desire for children was a difficult challenge for some men. The desire for children or having young children could affect treatment choices. Some men believed the disease would be a barrier to parenting, influencing decisions about when to have children.

I need to be healthy to be able to look after a child or two and already I'm at a disadvantage because of

fatigue, because of pain, because of illness if I go to hospital, I can't work.

Noah, 38 years, heterosexual, dating.

Sam mentioned his reluctance to progress to a proctectomy for fear of impotence, which he feared would influence his fertility. Ethan wanted to proceed with a stoma reversal but had delayed this option due to concerns around destabilising his health while his son was young and needed care. Frank and his partner had considered child adoption prior to him being diagnosed with IBD. However, following multiple surgeries they had not revisited the idea and he joked that they had become dog owners instead.

4.3 | Theme two: IBD thwarts sexual experiences

All participants spoke about the negative impact of IBD on their sexual experiences, albeit to varying degrees. As with self-perceptions, for some men disruption was not permanent and was largely dependent upon symptoms, treatments, or social factors such as relationship status. The most discussed impact was a lack of desire, which was mostly a result of gastro-intestinal symptoms and fatigue. Some participants mentioned intermittent problems with erectile function, which they mostly attributed to fatigue or the psychological impacts of living with IBD.

4.3.1 | Sexual desire

A reduction in both desire and frequency of sex during disease relapses was a common experience.

My sexual desires, everything, my normal life just kind of stops.

Arthur, 47 years, heterosexual, married.

Bowel sensations inhibited feeling sexual and fatigue was frequently linked to a reduction in libido.

One doesn't feel sexy when one feels bloated or like you need the toilet and it's a sensually, it's a distracting feeling to have. So that had a big impact, that and being tired and low energy also impacted things, so even if I could get and maintain an erection doesn't mean that I was particularly kind of energetic or in the mood.

Ewan, 34 years, heterosexual, married.

Some men reported challenges in conveying their reduced desire and they expressed concerns that it could be misinterpreted as lack of attraction to their partner.

You don't want to come across as sort of not wanting to be with your partner, it's getting it across in the right way. I think sometimes it can come across in the wrong way.

Benjamin, 20 years, heterosexual, co-habiting.

Men also felt that medications, particularly rectal therapies, reduced sexual desire. Oliver spoke about needing to 'mentally prepare himself' to insert rectal therapies and would stay up late to wait for his partner to be asleep to ensure privacy. In turn this had reduced sexual interaction as his wife had always fallen asleep by the time he went to bed. Men's libido did not always return quickly following resolution of symptoms or cessation of treatment.

It's trying to find that spark again.

Oliver, 52 years, Heterosexual, Married.

4.3.2 | Sexual expression

Men's narratives portrayed varying ways in which the disease could constrain, change, or limit sexual activities. Men frequently spoke of sexual apprehension which could lead to a reduction in sexual engagement, and this was particularly an issue for those wanting to engage in receptive anal intercourse (RAI).

Pain is never too much of a limiting factor it's completely psychological. I'm afraid of doing damage I guess and making it worse.

Andy, 28 years, bisexual, cohabiting.

There was a reported lack of information and guidance in regards to RAI and participants explained that RAI was not discussed in the IBD clinic. For some men with peri-anal disease, pain and discomfort could lead to abstinence from sex, even upon resolution of symptoms.

Bisexual and homosexual participants alluded to a lack of understanding from healthcare professionals, the public and potential sexual partners about how they might express their sexuality.

He was like; I mean with your condition why are you like this and I'm just simply like; I like what I like and I have to make it work.

Peter, 26 years, homosexual, single.

Erectile function was noted to be an important part of sexual expression. Men who described occasional erectile problems could not always clearly identify the cause, although fatigue, lack of desire and medications were the issues most often discussed.

Fatigue was awful, I remember that really clearly. I couldn't walk down the road without feeling

absolutely dead on my feet. I could watch porn but I couldn't get an erection at all.

Dara, 24 years, heterosexual, single.

Some men had tried PDE5-inhibitor medications but these could reduce the spontaneity of sex and none of the men had opted to use them regularly. For men who may potentially need or had already undergone surgery, the risk of impotence was often discussed with concern. Frank, who was in a relationship with a man, had undergone a proctocolectomy. He explained that as the 'active' participant in his relationship, the post-operative risk of erectile dysfunction was more of a concern prior to surgery than the removal of his rectum. Although he explained that the removal of his rectum had reduced his sexual choices, he did not feel that the surgery had affected him as it may affect other men who engage in RAI.

Fear of colonic secretions, leaking fistulas or stomas and poor body confidence led to ritual cleaning practices, covering of bodies or avoidance of intimacy. The need to clean prior to sex also removed spontaneity and could lead to anxiety.

We've had a nice evening, are we likely to have sex tonight, I need to have a shower beforehand and prepare myself there's so many things I am trying to prepare, mentally prepare for all possible options in my head which is very taxing.

Noah, 38 years, heterosexual, dating.

Partner reassurance and support was noted to be an important trigger to regaining confidence and minimising cleaning practices. Sam explained how he covered his body after having a stoma but his partner had supported him in developing his confidence to remove clothing.

She did have the conversation with me eventually; 'you do realize I wouldn't be here if it bothered me', so I did then start taking my top off. I will still have my belt on, but that's so it doesn't get in the way. Right from there I would then say that I started to rebuild my confidence.

Sam, 28 years, heterosexual, cohabiting.

4.4 | Theme three: IBD disrupts male gender norms

Participants had varying thoughts and feelings on whether IBD impacted upon their masculinity. Many men discussed not feeling that their personal perspectives aligned with traditional masculine ideals. However, participants consistently referred to impacts of the disease on things that typically align with male gender, such as being physically fit, self-reliant and resilient.

4.4.1 | Physical strength

Being physically strong and fit was a commonly described aspiration which was interpreted to be an important attribute of masculinity. Men commonly stated that they had stopped engaging in their preferred physical activities including football, running, cycling and going to the gym. Group activities were particularly burdensome, especially due to the unpredictability of the disease. A few participants described adapting to their situation, for example by taking up refereeing instead of playing competitive sport or switching to alternative forms of exercise, such as yoga.

I haven't felt well enough to run for a couple of years now, because it just wipes me out, which is really sad because I love running...I've got weights, so I've been trying to keep my muscles up and I try and eat enough protein.

Freddie, 64 years homosexual, single.

Two men described how their diagnosis had led them to have a greater focus on their physical health, prompting them to take up or continue physical activity when in remission. Some men wanted to be physically strong to be involved in parenting and set an example to their children. The inability to maintain the pre-disease or aspired level of fitness featured throughout men's narratives on physical health and could impact upon their confidence and body image;

I used to be in decent shape before it happened. I had decent muscle on me and would be happy to walk around with my top off...we went on holiday and I had a lot of anxiety about walking around with my top off.

Sam, 28 years, heterosexual, cohabiting.

4.4.2 | Self-reliance

I need to get control of this, because I am not in control at the moment, I am so reliant on them being, you know, them managing this for me

Ethan, 28 years, heterosexual, cohabiting.

Participants described a lack of control and independence when living with IBD while concurrently demonstrating personal perseverance and determination. The variability and unpredictability of symptoms and constraints in treatment regimens often led to men describing feelings of a lack of control. Almost all participants expressed a desire to be in control and remain self-reliant. Men often found ways to achieve this by being practical and organised, for example Oliver referred to packing a 'shit-kit', which was a rucksack with cleaning wipes and fresh underwear.

For many participants, medications were an aspect of the disease they could self-manage, which afforded them a sense of self-reliance. However, IBD medications and treatments could also remove choice and autonomy owing to administration methods and side-effects that reduced self-sufficiency. For example, Alex needed his partner to help administer his rectal therapies, while George needed to be at home at certain times to carry out a parenteral nutrition regime. Lack of access to medications and treatments was a common frustration. Participants described annoyance with the lack of co-ordination between healthcare providers, inefficiencies in the healthcare system and a sense of feeling at the mercy of healthcare providers. Disease relapses or having to engage with healthcare providers could jeopardise feelings of control.

When I get ill and especially if I have to go into hospital, I really hate the kind of patient me that turns up. So even having this MRI tomorrow, I know as soon as I set off from home, I'm gonna go into this kind of patient mode, which is much more vulnerable and feels helpless and not in control, because you know, I put a lot of effort into being in control of my life.

Freddie, 64 years homosexual, single.

The desire to be self-reliant did not always align with recommendations from health professionals, and could contribute to men not disclosing problems to partners and disengaging from health services or ignoring medical advice. For example, Tim had returned to weight training against the surgeon's advice. However, for most men the aspiration to regain control and remain independent resulted in them seeking contact with healthcare professionals and a need to understand their treatments in great detail.

Many men sought information from the internet, including Reddit and other social media platforms. Online information was not always helpful or relevant and could heighten concerns and anxieties. Indeed, most men perceived there to be insufficient support overall or a lack of the 'right type' of information available. Employment was cited as an important aspect in many participants' lives and a way to retain self-reliance. Being unwell could threaten men's employment status which could have financial implications. There was a common desire to work even when unwell, to ensure financial stability. Some men had pursued alternative career paths and trajectories because of employment stresses or barriers. Occupations or employers that supported working from home and provided fair sickness pay, were reported to be key factors in alleviating occupational stress.

Men commonly expressed not wanting to be a burden and the desire to be financially stable or provide for loved ones was expressed in several interviews. The desire to contribute infiltrated into several aspects beyond work and was portrayed as important to intimate partnerships, the wider family, and in broader society. The ability to contribute was interpreted as critical to men's self-worth and this could be disrupted by illness.

When you're feeling really unwell and you're not able to do much, you just think, what am I bringing to this relationship really like she's having to do all this work, yeah look after me and do more around the house.

Andy, 28 years, bisexual, cohabiting.

Many participants expressed a desire to give back to society, with several participants engaging in volunteering or philanthropy. For David who had experienced multiple personal consequences of IBD including effects on childhood, career choices, partnerships and fatherhood, the ability to undertake activities that benefitted others or contributed to society had greatly enhanced a sense of self-worth and life-satisfaction.

I've actually achieved, although I have had all these things going on in my life, because I've kept myself busy or occupied in other ways, I suppose in a way that has fulfilled me, not in a sexual way, but in other ways.

David, 66 years, heterosexual, married.

4.4.3 | Stoicism

Living with IBD was described as physically and emotionally challenging. Almost all participants demonstrated emotional resilience, determination and stoicism even if they did not overtly recognise or report it. The need to be resilient and stoical was interpreted as a normative masculine ideal.

I think being a man is just, get on with it.

Alex, 28 years, heterosexual, co-habiting.

The concern for, and culpability of the emotional toll on loved ones was a driver to persevere and overcome the challenges presented by the disease.

I didn't think I would make it to be honest with you, but I just had to do it because my mom was next to me. I didn't want to see her sad, had to push myself a bit and my partner as well who would come every day and see me.

Frank, 31 years, bisexual, cohabiting.

For some men stoicism and acceptance increased with time since diagnosis. For other men the burden of the disease had increased over time. This varied according to the disease course and treatment received.

[It] chips away slowly in the background and the more flares you have the worst it will, the more of your identity becomes intertwined with living with IBD

and you know I think it does just kind of chip away at that part of yourself, as it does it with the physical nature of Crohn's disease.

Andy, 28 years, bisexual, cohabiting.

The severity of the disease could lead to a profound understanding of the fragility of life and mortality. This was particularly the case for participants who had undergone emergency surgery, been critically unwell, had rare presentations of the disease or were on advanced medical therapies. Men who understood the improbability of cure, exhibited a desire to live their lives as they wanted to, remain physically strong, be self-reliant and make a contribution. For some, this could be achieved through resolution of symptoms, while for others, particularly those with unstable and advanced disease, finding ways to adapt to the condition was more important.

5 | DISCUSSION

This study reports novel insights into how IBD can modify men's emplacement within relationships, highlighting how the condition can alter sexual health and wellbeing across a range of sexualities and sexual identities that have hitherto been under-represented in the empirical literature. The most frequently mentioned symptoms and complications of IBD that influenced men's sexual health were the presence of diarrhoea, fatigue, fear of incontinence, rectal pain, body shape changes, fistulising disease, stomas and the rectal administration of medications. The three primary areas of men's sexual well-being disrupted by these symptoms were relationships, sexual activities and gender identity. These findings can be mapped against biopsychosocial models of sexual health in chronic disease (Enzlin, 2014; Schover, 1988) that have informed arguments emphasising the importance of considering sexual well-being, pleasure and justice in the provision of sexual healthcare to ensure it is holistic and progressive (Ford et al., 2019; Gruskin et al., 2019; Mitchell et al., 2021).

Erectile function is an important physiological process that has been the predominant focus of sexual health research in men with IBD (Ma et al., 2020). The current study demonstrates that erectile function may be transiently altered by the malaise induced by IBD and that it should be carefully considered by healthcare practitioners. However, findings suggest that erectile dysfunction (ED) and penetrative sex are unlikely to be the primary sexual health concerns of many men with IBD. The mean scores for the IIEF domains within this study sample are comparable to the control group in the original IIEF validation study by Rosen et al. (1997). This suggests that the rate of ED in the current study sample is comparable to the general population. However, the mean IBD-MSDS score is higher than the original validation study for this assessment tool (O'Toole et al., 2018) indicating disease-specific sexual dysfunction in the current study sample. Although these findings highlight that the IIEF may be useful for detecting ED, as it is in the general population, the current study suggests that employing this tool in isolation may

result in important sexual health needs going undetected. The IBD-MSDS tool (O'Toole et al., 2018), which is disease-specific and includes broader aspects of sexual well-being, may be a better option for clinicians wanting to initiate sexual health conversations with men, and it offers a more comprehensive basis to facilitate in-depth assessment.

The possibility of permanent impotence was a common fear for participants who were awaiting or had undergone surgery. For some, this concern influenced treatment decisions. Evident across men's accounts were inaccurate understandings of the risk of ED post-surgery and the procedures associated with this outcome; a potential reflection of inadequate information provision to men with IBD about possible surgical complications. Accessing up-to-date clinical data on the risk of post-operative ED can be challenging due to advancements in surgical techniques. For example, impotence following rectum removal has been reported to occur in 15%–79% of cancer patients and 0%–20% of those with benign disease, with the variation in rates being attributed to factors such as patient age, pathology, surgical procedure and techniques. Reassuringly, the risk of post-operative impotence in rectal excision in IBD, particularly in patients aged under 50, is likely to be very low (Keating, 2004). IBD health-professionals need to better understand and convey the individual risk of post-surgical ED, so that patients can make informed decisions about their care, and can moderate any unnecessary fears and concerns.

A key finding of the study was that although erectile function was not the main concern of men with IBD, the impact of IBD on intimate relationships was important. A negative effect on relationships has also been reported in prior surveys of men and women with IBD (Argyriou et al., 2017; Muller et al., 2010) but this study provides new insights into how and why relationship status might be affected. Interestingly, these effects overlap with the experiences and perceptions of dermatology patients who also describe difficulties explaining their disease, not wanting to initiate relationships due to fear of rejection or having low confidence (Bhatti et al., 2014). Men within the current study also reported that they felt a need to prioritise their own physical health which could place a strain on existing relationships. In chronic disease, long-term partnerships have been associated with improved health, while relationship stress can exacerbate poor health outcomes (Gray et al., 2017). With this in mind, healthcare practitioners could usefully consider relational care and the role of partners in men's overall health, as part of their wider care plan.

Previous studies have identified that IBD can impede positive body image (Jedel et al., 2015; McDermott et al., 2015; Ruan et al., 2020) and this was replicated within the study across the sub-themes; self-perceptions, sexual engagement and physical strength. While body image dissatisfaction was once considered to predominantly affect females, it is now widely accepted that men can also be affected by body image concerns (Murray & Touyz, 2012). Muscularity in particular is recognised as a symbol of masculine norms (Murray & Touyz, 2012) that has been associated with sexual satisfaction (Daniel & Bridges, 2013). Participants in the study

often discussed the loss of muscle-mass and weight changes brought about by the disease or because of the barriers they faced in engaging in physical activity. These findings signal an opportunity for inter-disciplinary collaboration between gastroenterology medics, nurses, dietitians, physiotherapists and psychologists, all of whom may be able to support assessment and interventions to overcome this IBD complication.

A further interesting finding that has not been previously reported within the IBD literature was men's experiences of sexual apprehension. Related themes have been identified in patients with cardiovascular disease, who can experience fear that sex may trigger disease symptoms (Kazemi-Saleh et al., 2007), and in chronic renal failure, where sexual avoidance as a result of body shape changes has been reported to be a specific issue in male patients (Keskin et al., 2019). Our findings reinforce the need for better awareness of the association between disease symptoms, sexual apprehension and sexual engagement, particularly in those with borborygmi, faecal leakage/incontinence or peri-anal disease, so that fears can be discussed and possibly mediated.

Of key relevance to nursing practice was some men's lack of awareness around receptive anal intercourse within IBD. This is somewhat surprising considering that IBD is known to affect the anal canal and rectum. A prior study reported that rectal pain was significantly worse in people who engaged in RAI but only two men took part in that study (Groome et al., 2017). In a recent letter published in *Gut*, authors reported an increased prevalence of IBD in men who have sex with men (MSM) as compared to men who have sex with women, surmising that the sexual practice might affect the gut microbiome (Mansoor et al., 2023). This possible association needs further exploration to identify whether certain sexual practices may cause disruptions to the microbiome or trigger flares of IBD, so that MSM can be made aware of potential risks and the ways to mitigate them. However, it is also important to consider alternative explanations for this observed difference; for example, it is possible that MSM are more likely to identify and report rectal and anal changes leading to better identification of IBD. One participant in the study identified how the practice of douching prior to RAI sex could trigger minor relapses, demonstrating the need for a more thorough understanding of MSM practices outside of RAI. Another participant who was in a relationship with a man, highlighted that their sexual life rarely involved the rectum, demonstrating that anal sex is not always participated by MSM. If a link between RAI and IBD is substantiated in the future, it is vitally important that men who engage in RAI are not stigmatised or subjected to blame or shame, as this will only prohibit effective care. This study has demonstrated the willingness of men with IBD with varying sexual orientations and gender identities to come forward and discuss the issues faced when it is researched in a sensitive and professional manner. Researchers should consider ways to develop and expand this work and focus on research that specifically explores sexual behaviours across various sexualities. Further work is required to understand what service provision is required to meet the needs of under-represented groups.

Irrespective of sexuality, the men who participated in this study unanimously confirmed an absence of disease-specific information and clinician-directed discussion around sexual health and well-being, echoing the findings of existing work in this field undertaken with men and women (Fourie et al., 2021). Sex is a sensitive topic that can be uncomfortable for patients to discuss. There is a lack of training and guidance for IBD clinicians on how to create safe spaces for discussions on this private topic and how to incorporate the assessment and care of sexual well-being in their practice. Furthermore, this study highlights that sexual health disruption in IBD is often psychosocially driven. We already know that psychological support for people with IBD is beneficial to quality of life (Gracie et al., 2017) but the provision of specialist mental health support in IBD has been called a 'Cinderella service' that is scarce and under-resourced (Mikocka-Walus et al., 2020). Interdisciplinary working forms the backbone of IBD care, and this study draws attention to the need for greater provision of IBD-specialist mental health professionals working to better support the needs of this patient group.

5.1 | Limitations

This was a qualitative study and so the results do not indicate the prevalence of the issues raised, and the findings may not be generalizable to the wider population of men with IBD. As half of the study sample self-selected to participate by responding to an online advert, it is possible that the experiences collected in this study are examples of the most afflicted cases, the severity of which may not reflect the general IBD population. Participants recruited through online advertising also self-reported a diagnosis of IBD and the clinical data they provided was not verified by a clinician or clinical notes. 53% of participants with CD reported perianal disease, which is a higher rate than the general CD population, in which it is reported to be 19% (Tsai et al., 2022). This possibly reflects the severity of the perianal phenotype of CD and its impact on sexual health, but the difference must be considered when interpreting the results.

All interviews were conducted by a female researcher, which may have influenced how candid men were in their accounts. The sensitivity of the research topic was managed by offering participants a choice of interview formats, and most interviews occurred online, which has been found to facilitate relaxed and open discussions when interviewing men about intimate relationships (Olliffe et al., 2021). However, for some people who are less accustomed to online interaction, interviews online may reduce disclosure or rapport.

6 | CONCLUSIONS

This is the first male-specific study to explore the personal experiences of sexual health in IBD. To date, erectile function has

been the predominant focus of sexual health research in men with IBD, while broader sexual health implications have largely been overlooked. The narratives presented in this study bring to light the disease-specific issues faced by men and the urgent need for improved understanding, assessment and care of the wider sexual health and well-being issues faced by men with IBD, beyond erectile function. Further research that carefully considers the psychosocial sexual well-being needs of men and their healthcare preferences is needed so that clinicians may be educated to overcome the possible barriers to assessment and care within a busy IBD clinic. Certain disease presentations and minority groups who are poorly served in IBD care but who experience the greatest rates of complications include those with peri-anal disease, those diagnosed with severe disease presentations during childhood and adolescence, and those who engage in receptive anal intercourse. These groups require urgent consideration to improve equity in care and enable men burdened by poor sexual health to access the healthcare they currently lack.

7 | RELEVANCE TO CLINICAL PRACTICE

The findings of this study illuminate how IBD may disrupt the sexual health of men, and they demonstrate the necessity of a sexual health assessment within IBD consultations. There is a need for both clinician- and patient-focussed information that will improve the awareness of the issues faced, identification and assessment of sexual ill-health and access to relevant and disease-considerate healthcare. Nurses require additional training on how to facilitate and be confident in conversations that are open and non-judgmental in this often-taboo topic.

AUTHOR CONTRIBUTIONS

Sara Ma: Study conception, study design, acquisition of data, data analysis, data interpretation, drafting of article. Peter Knapp: Study design, data interpretation, revision of article critically for important intellectual content. Paul Galdas: Study conception, study design, data interpretation, drafting of article, revision of article critically for important intellectual content.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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Appendix 3: Qualitative study 1 protocol



PROTOCOL: Version 1.2 (19/05/2022)

An exploratory qualitative study of male sexual health, identity, and activity in inflammatory bowel disease.

**Short title: Male sexual health in inflammatory bowel disease
(MaSH-IBD Study)**

IRAS Number: 279955

SPONSORS Number: RE22_005_279955

This protocol has regard for the HRA (2017) guidance

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, (unless otherwise stated in this document) the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor.

I also confirm that I will make the findings of the study available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature: 

Date:
24/06/2022

.....

.....

Name (please print): Michael Barber

.....


.....

Position: Sponsor representative

.....

.....

Chief Investigator:

Signature: 

Date:
24/06/2022

.....

.....

Name: (please print): Sara Ma

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.....

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Committees	Thesis Advisory Panel – role is to inform and guide the progress of the study. Public involvement group – role is to feedback on design and public facing documentation for study. Ethics Committee: for review by University of York and NHS Ethics.

ABBREVIATIONS

CI:	Chief Investigator
CNS:	Clinical Nurse Specialist
CRF:	Case Report Form
HADS:	Hospital anxiety and depression score
IBD:	Inflammatory bowel disease
IBD-MSDS:	Inflammatory bowel disease Male Sexual Dysfunction Score
IIEF:	International Index of Erectile Function
NHS:	National Health Service
NVivo:	A qualitative data analysis software package
PI:	Principal investigator
PPI:	Public and patient involvement
PIS:	Participant information sheet
QoL:	Quality of life
RCN:	Royal College of Nurses
REC:	Research ethics committee
SD:	Sexual dysfunction
TAP:	Thesis advisory panel

STUDY SUMMARY

Study Title	An exploratory qualitative study of male sexual health, identity, and activity in Inflammatory bowel disease.
Short Title	MaSH – IBD (Male sexual health in inflammatory bowel disease)
Study Design	A qualitative study following Interpretive Description (Thorne, 2016).
Research Question	What can be learned from the sexual health experiences and activities of men living with IBD?
Research aim	To describe and interpret the sexual health experiences and activities of men with Inflammatory Bowel Disease, to inform recommendations for nursing practice, education and research.
Study Participants	Men ≥ 18 years with a medical diagnosis of inflammatory bowel disease.
Sample size	Until thematic saturation of the data. Estimated to be approximately 25 patient participants.
Study Period	36 months, commencing June 2022. A further 12 months for writing.
Data sources	Semi-structured interviews. Participant provided data including written, pictorial and audio accounts. Demographic-disease questionnaire. International Index of Erectile Function (IIEF). IBD-Male Sexual Dysfunction Score (IBD-MSDS). Lead researcher/interviewer reflexive accounts and diaries.
Analysis	Constant comparative thematic analysis. Thematic coding, memos and diagrams will enable interpretive analysis.

FUNDING AND SUPPORT IN KIND

In summary this is a non-funded academic project. However, the following financial and non-financial support has been received by the lead researcher Sara Ma.

Institution	FINANCIAL AND NON FINANCIALSUPPORT GIVEN
York and Scarborough Teaching Hospitals, NHS Foundation Trust	Support in kind; use of facilities for interviewing, participant identification. Financial; provision of stipend for Clinical Doctoral Fellowship.
The University of York	Support in kind; waiving of Clinical Doctoral Fellow university fees, use of university facilities, research advice
NIHR	£500 towards the development of a Public Involvement Group for the study. Funds spend on travel costs, refreshments and a amazon gift voucher for public involvement group members.

ROLE OF STUDY SPONSOR AND FUNDER

The University of York will act as Sponsor for the research project and will therefore have ultimate responsibility for the project.

ROLES AND RESPONSIBILITIES OF STUDY GROUPS

Thesis Advisory Panel

The Thesis Advisory Panel (TAP) is responsible for reviewing the proposed research topic and methodology to ensure appropriateness, achievability and research rigour.

Public Involvement Group

A public involvement group has been formed to help focus the over-arching PhD project towards person centred-care. The group have reviewed the protocol and study documents.

Contact details of study groups can be obtained by contacting the research team.

PROTOCOL CONTRIBUTORS

Sara Ma: study design, conduct, data analysis and reporting.

Professor Paul Galdas: study design, conduct, data analysis and reporting.

Dr Peter Knapp: study design, conduct, data analysis and reporting.

Professor Martin Veysey: study design.

Public involvement group: research question, study design, study documents.

The funder(s) do not control the final decision regarding the design, conduct, data analysis, interpretation or manuscript of this study.

KEY WORDS

Inflammatory bowel diseases, sexual dysfunction, nursing

STUDY FLOW CHART

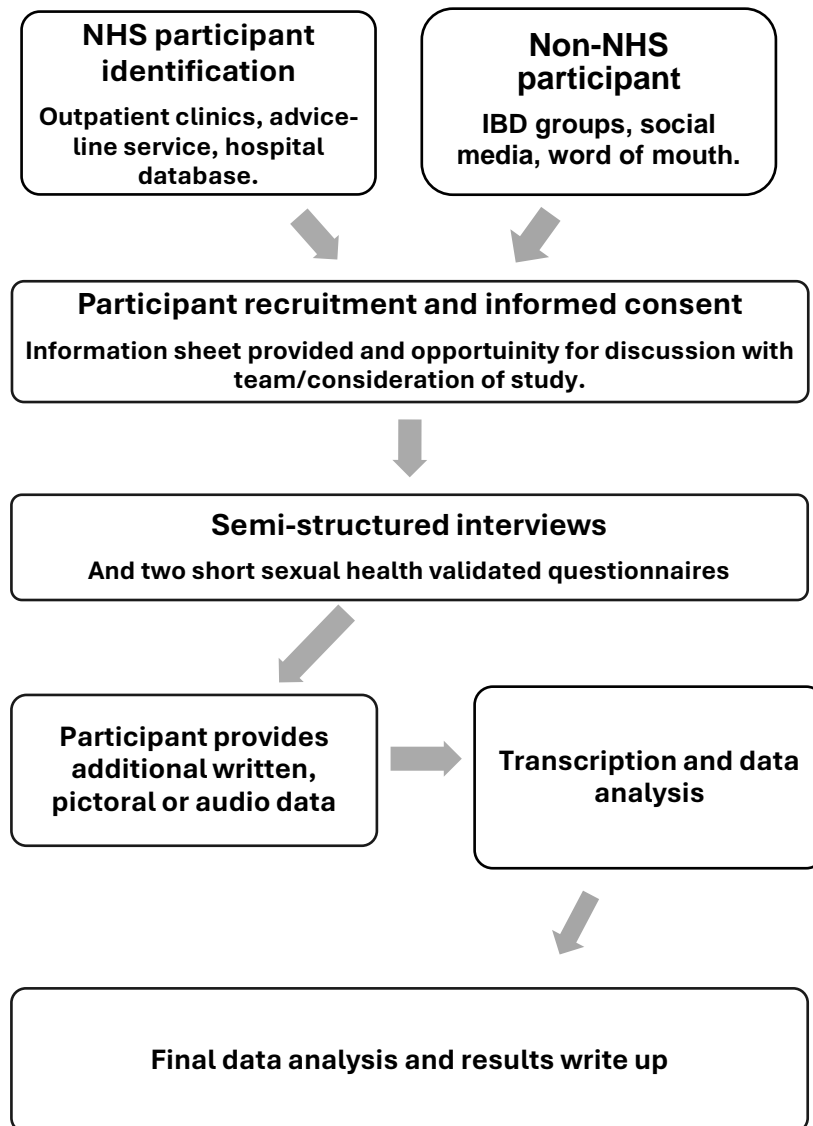


Figure 1: Study flow diagram

STUDY PROTOCOL

An exploratory qualitative study of male sexual health, identity, and activity in Inflammatory Bowel Disease.

1 BACKGROUND

Inflammatory bowel disease (IBD) is a long-term condition of the gastrointestinal tract that is relapsing and remitting in nature. Prevalence is 0.3% in western countries (Ng et al., 2017) with a peak incidence between the ages of 15 to 30 years (Sturm and White, 2019). IBD can cause debilitating symptoms including bloody diarrhoea, abdominal pain and fatigue, while also being associated with extra-intestinal manifestations in the joints, skin, liver and eyes. The course of the disease is unpredictable and when severe can lead to hospitalisation and surgery. A person's quality of life (QoL) can be greatly affected by the condition. The ability to engage in sex and a person's sexuality are recognised as an important aspect of QoL (Sainsbury and Heatley, 2005) which can be disrupted by IBD (Jedel, Hood and Keshavarzian, 2015; Rosenblatt and Kane, 2015).

People with IBD are primarily managed by hospital specialists in out-patient care. The IBD Specialist Nurse team at York and Scarborough Teaching Hospitals NHS Foundation Trust has innovatively evolved in the last decade. The hospital employs the UK's first RCN accredited Advanced Level Nurse in IBD and is hosting a Clinical Doctorate Fellowship in Nursing. Clinical Nurse Specialists (CNS) are the first point of specialist contact for approximately 3500 IBD patients in the region and review around 120 patients per week. This primarily occurs in nurse-led outpatient clinics and through a telephone advice line service. As nursing practice has developed, nurse-led clinics have broadened their scope to involve the initiation, prescribing and reviewing of new medical treatments and investigations. This allows timely and cost-effective medical care but should not be a replacement of the psychosocial support and self-management coaching conventionally provided by nursing teams. CNSs are well positioned to detect, assess and provide support for

sexual health and wellbeing but there is a lack of clarity and understanding of what exactly this should involve (White, 2013). There has been insufficient exploration of sexual health and wellbeing in IBD patients and consequently there is a deficit in contemporary, patient-centred information in this area.

This is a protocol for a qualitative study that will interpret the experiences of men with IBD to better understand their sexuality, sexual health, identity, activities and wellbeing in the context of inflammatory bowel disease. For this study we refer to the World Health Organisations working definitions of sexual health and sexuality;

“Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships. (...) Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.” (WHO, 2006, p5)

Improving understanding and awareness in this field will help inform recommendations for clinical practice, education and research. The methodological framework for the study is interpretive description (Thorne, 2016). Data will be primarily collected using individual, semi-structured interviews but may also be supported with written, pictorial and audio data supplied by participants and through searches made in the public domain. Findings from this study should support the development of recommendations for how nurses may assess and support male sexual wellbeing in IBD.

2 RATIONALE

Sexual activity is a healthy human behaviour and should be assessed as part of a holistic health review. It is conceivable that sexual interactions and therefore identities could become disrupted by the symptoms of IBD such as abdominal pain, bleeding and fatigue. It has been identified that sexual health and wellbeing in men with IBD is a neglected topic (Allocca et al., 2018) and there is a lack of exploratory, qualitative data in this typically taboo area.

Nurses are in an ideal position to assess the degree of impact IBD may have on a client's sexual health....perhaps the most important care nurses can offer is awareness of the sexual issues that often go unspoken.'

(Giese and Terrell, 1996)

Although sexual health research in IBD is limited across both genders, women's health has received more interest due to the potential impact on fertility, pregnancy and labour. There have been very few studies that have explored men's experiences of sexual health in IBD. In men sexual health and wellbeing is often measured by erectile function or frequency of intercourse. Erectile function can be enervated by pelvic nerve dissection during IBD-related surgical intervention or affected by other disease-related factors such as medical therapies, active disease, hypogonadism and secondary psychological factors. However, erectile function and frequency of intercourse are only one aspect of sexual health and sexuality and does not fully account for the complex interactions between disease, psychosexual well-being, sexual engagement and activity, as reflected in the WHO definition given on page 11.

One study that evaluated both men and women with IBD showed that while women thought physical symptoms of the disease disrupted their sexual function, men placed more emphasis on the role of psychological factors such as depression (Marin et al., 2013). This is particularly important in men, who are less likely than women to seek healthcare advice for psychosocial problems (Möller-Leimkühler, 2002). We also know that men with a long-term condition may benefit from models of service delivery that are tailored to their specific needs and preferences (Galdas et al., 2014). However, there is a paucity of interpretive research in IBD which has resulted in a limited

understanding of what aspects of sexuality in men can be disrupted by the disease. This makes it very difficult for nurses to provide the tailored healthcare that is required to engage men, potentially resulting in an unmet health need in this population. Studies that collect and interpret the lived experiences of men are required to ensure clinical practice is acceptable to men and relevant to their physical, psychological and social needs.

‘Clinicians glean crucial information from patient illness narratives’

(Greenhalgh, 2014)

3 RESEARCH QUESTION AND OBJECTIVES

3.1 Research question

What can be learned from the sexual health experiences and activities of men living with IBD?

3.2 Study aims and objectives

This study aims to describe and interpret the sexual health experiences and activities of men with Inflammatory Bowel Disease, to inform recommendations for nursing practice, education and research.

The study objectives are to:

explore how men with IBD identify, perceive and make sense of their sexual experiences.

describe the interaction between disease, sex life, sexuality and gender role.

identify whether men’s sexual experiences and activities tell us anything about their sexual health and welfare that may be amenable to nursing intervention and support.

3.3 Study outcome

An interpretive understanding of the participants’ sexual identities, activities and experiences that will inform clinical, educational and research recommendations that are appropriate, acceptable and accessible to men with IBD and their healthcare professionals.

4 STUDY DESIGN AND METHODS OF DATA COLLECTION AND DATA ANALYSIS

4.1 Study Design

This study demands a qualitative approach as it does not seek to identify statistical relationships but explore both the commonality and diversities of individual experiences in order to make a 'marginalized group visible, vibrant and multivocal within the research process' (Hall, 2013, p48). The researchers adopt a relativist ontological and constructivist epistemological position for which Interpretative Description (Thorne, 2016) is well aligned. Interpretative Description (ID) provides a flexible, yet rigorous qualitative methodological orientation for examining individual experience and translating findings into knowledge useful to nursing practice.

ID is grounded in nursing and unlike traditional qualitative methodologies such as descriptive phenomenology (Colaizzi, 1978) and grounded theory (Strauss and Corbin, 1997; Glaser and Strauss, 1967) does not prescribe the bracketing of researcher knowledge and biases. Instead, the researcher may exploit their clinical knowledge and experience during the research process to elicit clinically useful data. However, through adoption of a reflexive approach, the nurse-researcher's influence over the data is identified and constrained to remain faithful to the participant's narrative while also maintaining an ethical and professional responsibility to the participant. ID is also more suitable for this study than descriptive phenomenology and grounded theory as the aim is not to describe the essence of sexual behaviours in IBD or develop social theory. Instead, this research will illuminate lived experiences to expand awareness and knowledge so that healthcare practitioners may empathetically engage in difficult conversations and be responsive to their clients' potential needs.

ID allows researchers to select sampling, data collection and analysis methods that suit their research question. This study will adopt theoretical sampling and constant comparative thematic analysis as these are suited to exploratory studies and allow the researchers to investigate and scrutinise emergent findings.

4.2 Study Methods

4.2.1 Sampling

Valuable data in qualitative studies is derived from 'good informants' (Coyne, 1997) rather than large participant numbers. It is through individual and personal accounts that we may build a broader understanding about shared experiences in health and illness (Thorne, 2020).

The study will use theoretical sampling as described by Thorne (2016). The initial sample is a 'starting point to launch the data collection process' (Butler, Copnell and Hall, 2018, p562) and involves participants who have experience of the field. As the study progresses, ongoing sampling decisions can be informed by emergent themes from concurrent data analysis but participants must always meet the study inclusion criteria. This ensures good clinical practice and research ethical conduct while allowing the researchers to obtain deviant or analogous participant characteristics to scrutinise, test and refine their findings. This flexible and cyclical approach is inherent to qualitative research and means that recruitment continues within the constraints of the study period until there are no new emergent themes (saturation).

Initially, 3-5 participants who meet the inclusion criteria will be recruited. This is a form of purposive sampling of participants who may be able to provide a detailed and rich account of living with IBD and allows areas of interest to surface that will inform subsequent sampling decision. They may be patients who have regular contact with the clinical team and have previously discussed their sexual health with an IBD clinician.

The ongoing sampling process is then informed by the concurrent data analysis as illustrated in Figure 2. Participants must always meet the inclusion criteria but the interview guides may be amended in order to test emergent themes.

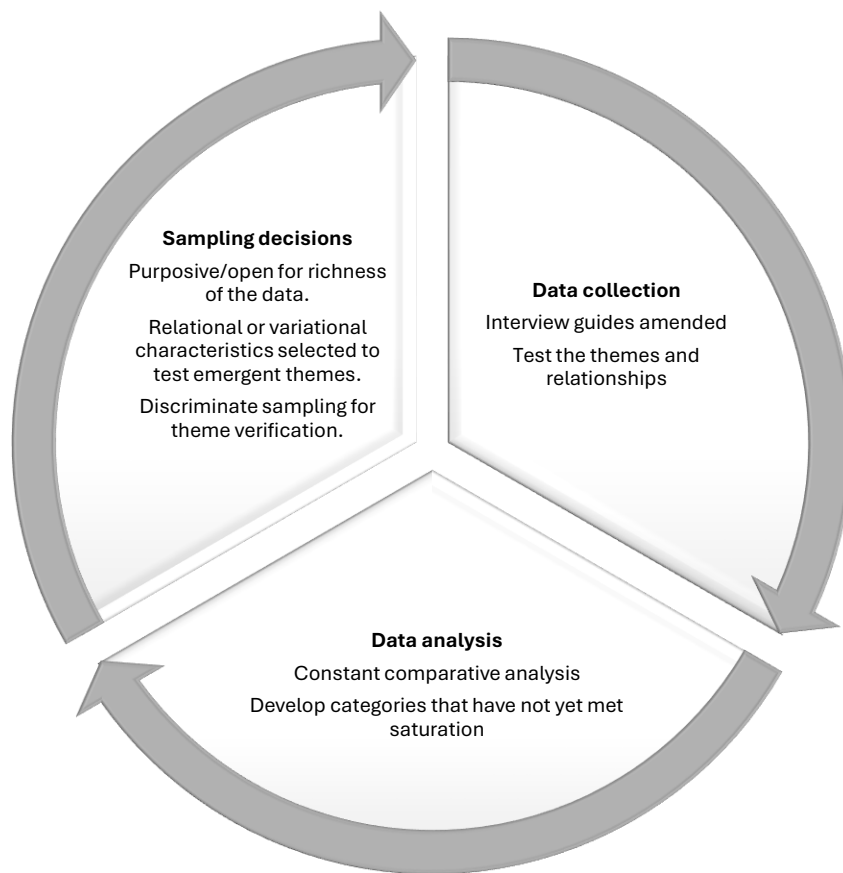


Figure 2: The sampling process

4.2.2 Eligibility criteria

Inclusion criteria:

A diagnosis of Crohn's Disease, Ulcerative Colitis, IBD-U or microscopic colitis.

≥ 18 years at time of enrolment.

Identify as male.

Able to give informed consent.

Exclusion criteria:

Does not speak English.

Not medically well enough to attend an interview.

4.2.3 Recruitment process

There will be two possible recruitment processes;

NHS site recruitment: eligible patients will be invited to participate at an appropriate point, this may be at the end of a clinical consultation. They will be provided with either the contact us leaflet or participant information sheet in person. If the contact is a teleconsultation then these documents will be provided either by email or post using an envelope marked private and confidential.

Non-NHS site recruitment: there will be a call for participants through social media platforms and word of mouth where the contact us leaflet or participant information sheet will be made publicly available.

The CI is based at York and Scarborough Teaching Hospitals, NHS Foundation Trust. This will be the lead NHS site for the project. Other NHS sites may also participate in patient identification activity and refer eligible participants to the research team using either the contact us leaflet or participant information sheet. Potential participants will be provided with at least 24 hours to consider the information, ask questions and discuss the project with others. A member of the research team will telephone or speak in person to potential participants. Informed consent will be obtained prior to the interview. Recruitment will follow good clinical practice guidelines (ICH, 2017) and the UK Policy Framework for Health and Social Care Research (HRA, 2017); it will be made explicit that participation is entirely voluntary and that non-participation will not change or affect current clinical care.

4.2.4 Data Collection

Demographic data and questionnaires

Some clinical details and demographic details (see appendix 8.1.5) will be obtained directly from the participant prior to the interview to construct a clinical and contextual background of the participants for the study results. Collection of this data also supports the researcher to remain sensitive to the participant's current situation and conduct an interview sensitively. This is an acceptable approach as we assume a constructivist stance and embrace data being co-constructed between the nurse-researcher and participant. This is inherent to ID, where nurse-researchers are not expected to surrender their professional role. Thorne (2016) does suggest dividing the research interview

in the event of any clinical discussion that is not relevant to the study. If this is to occur, any extraneous data will be removed from transcripts. If any clinical needs are identified during the interview, the researchers will advise participants to contact their responsible IBD or community clinician. No clinical care or advice can or will be provided during the interview.

The International Index of Erectile Function and IBD-Male Sexual Dysfunction Score will also be collected. The scoring systems may provide a route in to discussing this sensitive topic and prepare the participant for the interview. Collection of these data is not to try to quantitatively explore sexual dysfunction but including them may allow us to descriptively assess whether the participant's narrative around their sexual experiences aligns with the questionnaires.

Participant interviews

Semi-structured, individual interviews are suited to discussions of personal topics and enable the generation of rich data on individual experience. During a semi-structured interview the researcher will utilise an interview guide of suggested open questions to elicit personal, in-depth narratives. The researcher can also explore or delve deeper into relevant points raised by the participant. The premise of semi-structured interviews in this context is that the participant is given the space to provide stories of the lived experience in their own words with low interference from the researcher. The interviewer must therefore give space to the participant to speak freely, only speaking themselves to acknowledge or clarify what is being said, or maintain focus on the topic being investigated.

For participants that are local to the city of York, the interview can be conducted at York Teaching Hospital. All other interviews may be held and recorded either via a media platform such as zoom or Microsoft teams or over the telephone as it is not possible to fund travel for the study and travel is not desirable during the covid-19 pandemic. Interviews will be recorded and transcribed verbatim for analysis. An initial interview guide that has been reviewed for understandability, applicability and acceptability by the research team and public involvement group, will be used. In accordance with the

theoretical sampling strategy, the interview guide may be amended during the study to reflect emergent themes. Such changes will not be part of the amendment process as this is inherent to the qualitative and exploratory approach and themes will remain within the overarching research topic. The researcher will draw on her experiences and expertise to aid richness and detail of the collected data. This will be made transparent and considered during data analysis and the reporting of any findings to ensure validity. The researcher will regularly meet with the research team to discuss themes that arise from the interviews and review the simultaneous data collection and analysis process to ensure rigour.

The interviews will be conducted by a female nurse-researcher and it is recognised that gender, professional role and relationship may impact on what participants share. O'Toole et al. (2018) found that 72% of male participants had no preference for the gender of the healthcare professional when discussing sexual function. The nurse-researcher is also accustomed to discussing private and personal matters as part of her clinical practice.

For participants recruited through the NHS, the health professional and patient relationship can be complex, with an inappropriate distribution of power and authority. This could impact upon what is said by participants. However, public involvement members have highlighted that the relationship also brings an established trust and understanding of confidentiality and therefore may also be beneficial in the elicitation of frank and honest discourse. It is possible that the interviewer is already known in their professional capacity to the participant. This will be addressed prior to the interview, re-iterating that this is not a clinical consultation and any matters requiring medical treatment will be referred to the wider clinical team.

Participant written, audio or pictorial accounts

Sexual experience is a sensitive and private topic that some participants may find difficult to convey during the interview. The public involvement group felt that offering a 'private space' for participants to provide their accounts may be beneficial. Participants may bring photographs to the interview as an aid to telling their stories. Photos can capture details that may otherwise go unseen

or be difficult to describe verbally (Glaw et al., 2017). Photos can also help establish rapport and allow the participant to engage with the research and shape the content of the interview (Edmondson and Pini, 2019). Photos can be submitted to the interviewee for use in the study or retained by the participant and therefore not used directly in the data analysis.

At the end of the interview participants will be invited to submit any written, audio, or pictorial accounts that they feel are relevant; they will be asked to do this within three months of the interview. This means that should the participant reflect on the interview and feel that they have further points to contribute there is the opportunity to do so. Unless taken in a public space, photos will only be used in publications or made available if they have been anonymised and there is no copyright violation (for example if a participant brings a photograph they have not taken themselves). Anonymity can be maintained by blurring or pixilating any features that reveal identity (for example name badges or facial features). Section 2 of the consent form must be signed by any participants wanting to submit photographs for the team to keep on record. A participant may bring photographs to the interview but not submit them to the team to keep.

The participants can choose how to store their supplementary post-interview accounts but once submitted to the research team they will be anonymised and held securely following data protection principles and GDPR (2016) guidelines (see Section 6.6 for further detail).

4.3 Data Analysis

Data collection and analysis will occur concurrently. This means that after the interview the audio recording will be transcribed and analysed prior to the next interview which aligns with the theoretical sampling approach described above. A constant-comparison analytical approach informed by grounded theory principles will be used, where new data is compared to previously collected data to look for similarities and differences so that themes can be updated, validated and/or refined.

Data analysis will include 'initial coding', 'focused coding' and 'memoing' as described in the Charmaz (2014) constructivist approach to grounded theory.

Coding is a popular way to deconstruct data in qualitative studies; however, Thorne (2016) recommends that researchers do not become too fastidious or over-enthusiastic about the sequence of coding which can make it difficult to 'move beyond thematic analysis and into the more creative and interpretive realms of figuring out options for depicting patterns and meanings' (Thorne, 2016, p.169). Memoing and diagramming will therefore be just as valuable to the analytical process. To uphold rigour and trustworthiness of the findings, transparency is paramount so careful documentation of the steps undertaken will be made. A continuously reflective approach will be adopted and documented in a researcher diary.

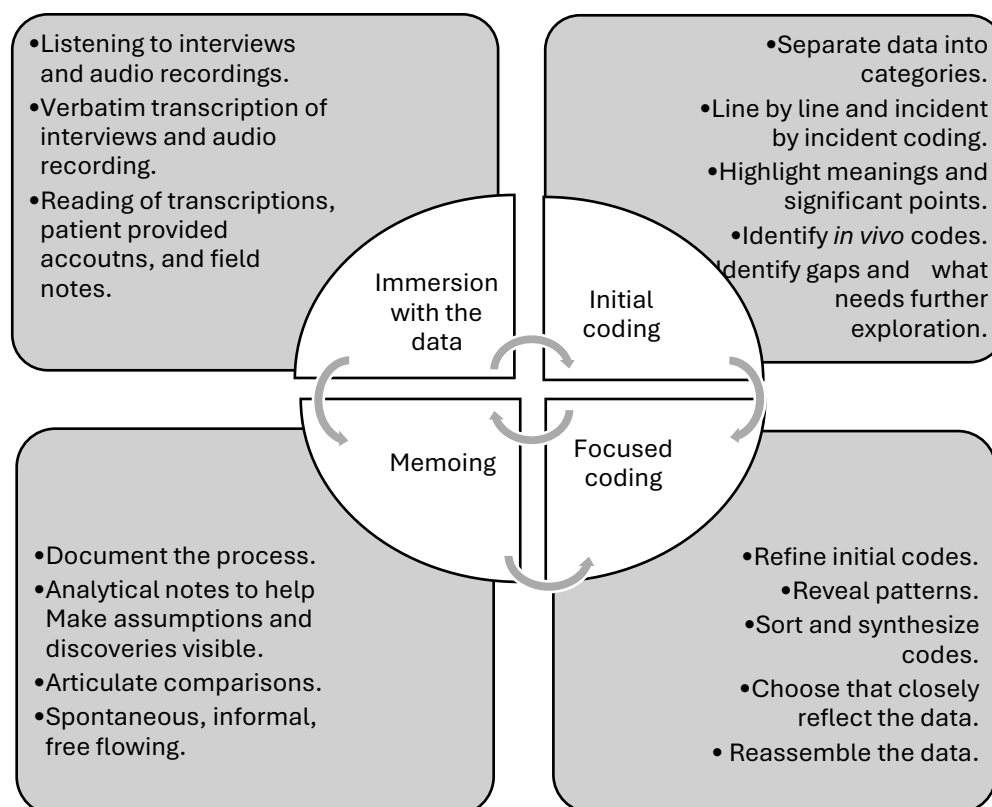


Figure 2: Data analysis process informed by Charmaz

Data analysis is not entirely linear and there may be some intersecting of the stages. During initial coding, the researcher will work through the data and code both line by line and segment-by-segment or incident by incident while also simultaneously comparing new code to previous codes. However, while

doing this they must also document their analytical journey (part of memoing) and identify any apparent relationships and patterns (part of focused coding). The whole process is also guided by Thorne's (2020) guidance on 'transforming data' which involves:

- Sorting data into what answers the question and what is circumstantial.
- Expanding and testing relationships.
- Identifying personal biases and assessing whether interpretations are true to the narratives.
- Considering the outliers and what else there is to learn.
- Uncovering any heuristic findings.
- Processing and conceptualising ideas.

NVivo 9.0 QSR NUD.IST will be used to aid indexing and charting of interview transcripts and steering group minutes. The supervisory team will review this process to ensure reliability and validity of the outcomes.

4.4 Methodological limitations

This is a qualitative study that will improve insight into sexual experiences and may identify commonalities, but generalisability of the results must be carefully considered.

Internal validity will be limited by the participants' ability to articulate their experiences and the researcher's proficiency at eliciting and interpreting the experience. This is mediated by observing a validated qualitative methodology, researcher reflexivity throughout the research process and academic supervision of the lead researcher.

5 ETHICAL AND REGULATORY CONSIDERATIONS

5.1 Assessment and management of risk

Risk to participants: This is a low risk study as no clinical intervention is being performed. There is no expected risk to participants, but the interviews may elicit an emotive response. Participants will be made aware that they do not need to answer any question and may take a break or withdraw at any time. The interviewer is a registered nurse and can respond to any emotional distress and escalate accordingly. Interviews will be terminated if it is felt that they are negatively impacting on a participant. All participants will be offered

the Participant Support Leaflet which will provide a list of helpful resources and sign post access to support for depression, anxiety and stress.

If any safeguarding issues or illegal activity are disclosed during the interviews they will be escalated via the appropriate channels.

There may be some inconvenience to participants regarding the time taken to participate. Participants will be offered a range of possible dates and times.

All government guidance in place at the time of the study running regarding the covid-19 pandemic will be followed. Additionally, the interviewer will perform a lateral flow test prior to any face-to-face interviews and wear a face mask for the entirety of the interview. Face to face interviews will be postponed should either the interviewer or interviewee have any symptoms of covid-19. The interviewer will be fully up to date on all offered vaccinations for covid-19.

Risk to researchers: The study setting carries very little risk to the interviewer. The interviewer is an experienced nurse and accustomed to asking difficult and personal questions. Debriefs will be held with the Gastroenterology Psychologist or academic supervisors as appropriate.

Informed consent: The process for obtaining informed consent will be in accordance with Good Clinical Practice (GCP). Potential participants will be given suitable time to consider the written information provided to them and discuss any queries with the research team or others. If they indicate they are willing to participate, eligibility will be reconfirmed. Participants will be given the opportunity to ask any questions and have any queries answered. To ensure informed consent, the researcher will review the information leaflet and the study procedures with the participant. The researcher taking the consent has attended a research consent training course and a GCP course and will be able to assess the participant for capacity to give consent. The study consent form must be signed and dated by both the participant and researcher before any data is collected.

For participants undertaking a video or telephone interview, the researcher will have a telephone call or video call with the potential participant to discuss

the project and undertake the consent process. The participant will then send the consent form to the researcher and once the form has been received the researcher will countersign the consent form. It is preferable to have the original consent form but due to the covid-19 pandemic, the potential locality of patients and as this is a low risk study, we will accept consent forms electronically scanned or photographed and emailed to the research team.

Enrolment log: this (alongside the consent forms) will be the only location of written personal information that is not anonymised. It is necessary for the purpose of contacting participants and quality assurance of the research. It will be password protected and kept on the secure digital network of the host institution. It will only be accessible to those signed on the delegation log.

Audio and video recordings: these are required for audio-transcription of the text. These must be immediately downloaded onto the secure network drive at the end of the interview and deleted from the original recording device or one-drive if video conferencing. Audio and video recordings may be identifiable so for additional security these files should be password protected and deleted at the end of the study.

Recruitment: No coercion or undue influence to take part will be used. Participants will be made aware that participation is voluntary, declining to take part will not affect their clinical care and they are free to withdraw at any point without giving a reason.

Deception: No misleading information will be given and no intentional deception used.

5.2 Research Ethics Committee (REC) and other Regulatory review & reports

The protocol will be submitted to a University and NHS ethics review board as it involves human subjects. The study will not commence until a favourable opinion from the University of York, Health Sciences Department Research Governance Committee and HRA NHS REC have been received.

All correspondence with the REC will be kept within the study site file.

Amendments will be reviewed by the Sponsor to assess whether they are substantial or non-substantial. Substantial amendments will be submitted to the REC for consideration. York and Scarborough Teaching Hospitals, NHS Foundation Trust R&D and any other NHS participating sites will be notified of all amendments. An amendment history will be kept within the study site file.

5.3 Peer review

This protocol was initially developed by Sara Ma. Professor Veysey (clinical expert in IBD), Professor Galdas (academic expert in qualitative research methods and nursing research) and Dr Knapp (academic expert in applied health research) have also contributed to the study design as part of the PhD supervisory team of Sara Ma. The Thesis Advisory Panel has also reviewed the protocol. The protocol will also be reviewed by a research governance committee at The University of York and through the HRA ethics process.

5.4 Patient & Public Involvement

A patient and public involvement group has been formed. This was initially supported by a NIHR RDS Public Involvement Fund. This group was identified through the Hospital's R&D public advisory panel and IBD patients known to the investigatory team. They have been consulted on the acceptability of the research concept and design. They have reviewed the protocol and study documents. They have advised on the acceptability of the screening and recruitment strategy and interview guides. The group will meet at least annually, and meeting minutes will be kept within the site file. The group may also be asked to feedback on themes identified and theories generated from the analysis of the interviews to help improve validity and rigour. No patient identifiable information will be made available to the group.

5.5 Protocol compliance

The research team will take the upmost care to adhere to the protocol throughout the study. Accidental protocol deviations can happen and should be documented and reported to the Chief Investigator and Sponsor straight away. Any deviations that recur will require immediate investigation and could be classified as a serious breach.

5.6 Data protection and patient confidentiality

Data management will comply with the Data Protection Act (2018), GDPR regulations (2016) and the University of York Research Data Management Policy.

It is important that the participant feels able to disclose intimate information and the researcher will inform participants that this information is handled sensitivity and confidentially. The subject of the interviews may result in the discussion of a participant's current or former partners and other family and friends. All names will be changed to pseudonyms. Qualitative research may produce unexpected data and therefore the researcher will be fully trained in research ethics to ensure a continued ethical approach to the data collection analysis.

A study number and pseudonym will be assigned to each participant. The study number will be allocated by the research team and used on the study documents including the CRF and transcripts. A pseudonym will be used within the interviews and transcriptions and will be selected randomly from a pre-defined list. A separate document will provide a list of study numbers and participant names. As this document will contain identifiable information it will only be accessible by appropriate study members signed on the site delegation log for the purposes of conducting the research and auditing. This will include the CI and York Teaching Hospital Quality Assurance Lead. The document will be stored separately from the site file and trial data using password protected on the University of York systems network. Patient confidentiality may be broken in the event of a disclosure of harm or potential harm that needs to be investigated. This will be escalated by the research teams through the appropriate safeguarding and legal channels.

Any paper documents will be kept within a locked cupboard in a locked room at The University of York or York and Scarborough NHS Foundation Trust. Electronic documents can only be stored on The University of York or York and Scarborough NHS Foundation Trust networks which is secure and backed by up IT services. Files will be stored in the CI's personal file store (drive) which is regularly backed by IT services and at the end of the study

deleted permanently after archiving has taken place. The CI may use a VPN to connect to her personal filestore when working away from the institutions but must only access the data when in a private setting and ensure only people signed on the delegation log may co-incidentally see the data.

In the case of face to face interviews, audio files will be stored as MP3 files and downloaded onto the University or NHS Foundation Trust network as soon as is reasonably possible after the interview. In most cases it is envisaged that this will occur on the same day of the interview. The original digital file on the Dictaphone will be deleted immediately after downloading. Audio and video files from virtual interviews will be stored as MP4s and transcribed into an Office Word file. A York University approved external transcription service may be used and will be bound by a confidentiality agreement. A SOP will be created for the storage and transfer of audio files in the case of external transcription. Audio and video files will be deleted at the end of the study. Written transcripts will be reviewed by the research team so that any identifiable information removed, these will be stored with the study data for 5 years after the completion of the study.

At the end of the study data will be archived for 10 years. If a participant decides to withdraw from the study, all data collected to the point of withdrawal will be kept as above and may be used within the study.

During publication the researcher's institution may reveal something about the participants, including location of habitation. Participants must not be identifiable and therefore any data for publication will be reviewed by the academic supervisory team to ensure this is the case.

Access to data will be limited to relevant individuals of the research team and Paul Galdas will act as the data custodian.

The University of York will be the owner of the copyrights and associated intellectual rights of the data.

5.7 Indemnity

The University of York will act as Sponsor for the project and provided legal liability insurance. Further cover is also provided by the NHS in regards to

NHS recruited participants as the CI is an employee of York Teaching Hospital NHS Foundation Trust.

6 DISSEMINATION

6.1 Dissemination policy

Data arising from the study will be owned by the Sponsor, The University of York. On completion of the study, the data will be analysed and presented as part of a PhD thesis, which will be made available via the University of York Library.

A short report of the findings will be prepared and provided to the R&D Department at York and Scarborough Teaching Hospitals, NHS Foundation Trust, the Public Involvement Group and any participants who request notification of the results. The results may also be published in the York and Scarborough Teaching Hospitals, NHS Foundation Trust IBD newsletter and at appropriate internal and external conferences, meetings and training days.

The researchers will aim to publish a research article in a peer-reviewed academic journal. If funding is sourced to contribute to the open publication of this, then acknowledgement of the funders will be made.

Findings will also be presented at relevant medical conferences.

6.2 Authorship eligibility guidelines and any intended use of professional writers

Authorship will be granted to Sara Ma, Professor Galdas and Dr Knapp. If any further investigators join the team that make a substantial contribution to the collection or analysis of data or writing of the final study report they will also be granted authorship.

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8 APPENDICIES

8.1 Appendix 1- Required documentation

8.1.1 Participant information sheet

8.1.2 Contact us leaflet

8.1.3 Patient Consent

8.1.4 Interview guide

8.1.5 Case Report Form (CRF)

8.1.5a IIEF participant form

8.1.5b IBD-MSDS participant form

8.1.6 Data management plan

8.1.7 Sara Ma (CV)

8.1.8 Paul Galdas (CV)

8.1.9 Peter Knapp (CV)

8.2 Appendix 2 – Schedule of Procedures

Procedure	Screening	Prior to interview	Interview	Within 3 months of
PIS provided	X			
Informed consent		X		
Demographic and medical data collected		X		
IIEF, IBD-MSDS		X		
Reconfirmation of consent			X	
Audio recorded, semi-structured interview			X	
Transcription of interviews				X
Participant provided written, audio and/or pictorial accounts				X

8.3 Appendix 3 – Amendment History

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made

Appendix 4: Qualitative study 1 ethical approval letter



Mrs Sara Ma
York Teaching Hospital NHS Foundation Trust
Wigginton Road
York
YO31 8HEN/A

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

30 May 2022

Dear Mrs Ma

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	An exploratory qualitative study of male sexual health, identity and activity in inflammatory bowel disease.
IRAS project ID:	279955
REC reference:	22/NE/0070
Sponsor	University of York

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "[After Ethical Review – guidance for sponsors and investigators](#)", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **279955**. Please quote this on all correspondence.

Yours sincerely,

Alex Martin

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Mr Michael Barber*

Are you interested in participating in a research study?

This study aims to find out more about **men's sexual health in IBD** so that we can improve care.

The study is being run by The University of York as part of a PhD project. The lead researcher is an Inflammatory Bowel Disease Specialist Nurse at York and Scarborough Teaching Hospital, NHS Foundation Trust.

The study has full ethical approval and confidentiality will be maintained.

We would like to hear from you if;

- You are male
- Over 18 years old
- Have a diagnosis of inflammatory bowel disease
- Are willing to participate in a web-based or telephone interview



Sara.ma2@nhs.net



01904 72 6154



<https://sites.google.com/york.ac.uk/mash>



UNIVERSITY
of York

Appendix 6: Qualitative study 1 participant information leaflet



Male sexual health in inflammatory bowel disease (MaSH-IBD) Participant information sheet

Introduction

We would like to invite you to take part in a research study. Before you decide whether you would like to participate, we would like you to understand why the research is being done and what it would involve for you. Please take time to decide if you would like to take part and ask for clarification if there is anything that is not clear or if you would like more information. Our contact details are on the final page of this information sheet.

Who is running this study?

The research is being conducted by the University of York and York and Scarborough Teaching Hospital NHS Foundation Trust. The research is being led by an inflammatory bowel disease Specialist Nurse at York and Scarborough Teaching Hospitals, NHS Foundation Trust. This study is part of a doctoral degree in Health Sciences at The University of York. This study is being sponsored by The University of York.

What is the purpose of the study?

Inflammatory bowel disease (IBD) is a life-long condition that can cause urgency to go to the toilet, bleeding from the back passage, abdominal pain, fatigue and malnutrition.

It is also possible that IBD impacts on a person's view of themselves and even their desire and ability to have sex. Sexual health, identity, and well-being are an important part of life, however, there has been very little research in this area. Whilst some research has focused on IBD in pregnancy and fertility in women, the male perspective is currently under-represented. This study aims to look at how IBD impacts on men's personal lives. We would like to talk to adult men with IBD and find out whether their disease has had any impact on their personal and sexual lives. By doing this we hope to improve understanding and awareness of this sensitive topic so that nurses and other healthcare professionals can develop IBD services to offer appropriate support to patients.

What is involved?

This study involves you:

- signing a consent form;
- completing a short questionnaire;
- attending a virtual interview (in some cases this may be face to face if appropriate and preferred);
- if you choose to, writing a journal, making an audio diary, drawing a picture or taking photographs to share any experiences or thoughts you may not have discussed during the interview.

Before interview we would like to collect some information about your IBD. This will include information like what form of IBD you have, how long you have had it, your age and any other health conditions you may have. This data will be anonymised so no one outside of the research team will be able to identify you from it. This information will be used during the analysis of the interviews to help provide some background to your story. We will also ask you to complete two questionnaires about your sexual health that will take no longer than 15 minutes. These are well established questionnaires that are used in clinical consultations to assess a person's sexual function.

The interview will be approximately 60 minutes long but no longer than 90 minutes. The interview can be held either over the telephone or via a video platform so you would need to have a quiet and private space. If you select a video interview, you will need access to a smart phone or computer with a microphone and camera. If you live locally to York and would prefer a face to face interview this can be arranged at the hospital. We will record the interview to make it easier for the research team to analyse the information afterwards. The interview recording will be deleted at the end of the study. During the interview we will discuss what it has been like living with IBD, what it is like being in intimate relationships when you have the disease and what support might be valuable. We are interested to hear stories or descriptions about your life and whether you feel IBD changes your sexual well-being.

Sometimes talking about photos can help recall experiences and feelings. If you would like to bring photographs of your life to the interviews or submit them to us afterwards this would be welcomed but is entirely optional. Photographs could be of anything that is important in your life from your

family or partner, your hobbies, things you enjoy or pictures at different time points of your life. Having a photograph can often help tell your story to the interviewer. If you are willing for us to use these photographs as part of our study data, we will ask you to sign part 2 of the consent form and send us an electronic or scanned copy of the photograph. Photographs that reveal your identity will not be used in any publication to maintain anonymity and we would ask for your permission before using any photographs you provided.

Following the interview discussion, you may also wish to jot down any further thoughts or experiences that you feel may be of interest to around the topic of men's health in IBD. If you would prefer to use an alternative method to record your thoughts, we will discuss these options with you during the interview. If you would like to do this, we would ask you to confidentially send us these after three months. These will be identified only by the unique code we would assign you so that no one outside of the research team would know these notes came from you.

[Why have I been invited to take part in this study?](#)

We are inviting you to take part in this study because you have a diagnosis of inflammatory bowel disease and identify as being male.

[Do I have to take part?](#)

You are under no obligation to take part in this study. If you decide that you would like to take part, we will ask you to sign a consent form. You are free to withdraw from the study at any time and without giving a reason.

[How long will I be involved?](#)

The study will last for up to 3 years but your involvement will be only for one interview and for up to three months following your interview if you decide you would like to send us any further accounts in the form of diary entries, audio recordings or photographs.

[What are the benefits to taking part in the study?](#)

It is unlikely that you will directly benefit from this study. In the future, patients may benefit from any improvements to care that are the result of the information we find.

[What are the risks to taking part in the study?](#)

This is a low risk study as we are not making any changes to your treatment or care. Some people may find the interview covers topics that may be personal or sensitive but we will aim to make you feel at ease and you can ask for the interview to be stopped at any point should you decide you no longer wish to continue.

[Will I be paid for taking part?](#)

Unfortunately, there is no funding to pay you for your contribution to this project and this must be undertaken in a voluntary capacity only.

[Who is funding the study?](#)

The study is being financially supported by the University of York and York and Scarborough Teaching Hospitals, NHS Foundation Trust.

[Who has reviewed the study?](#)

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to help ensure this study protects your safety, rights, well-being and dignity. This research has been reviewed by the Health Research Authority.

[How have the public and patients been involved in this study?](#)

A public and patient group have been consulted on the idea and design of this study, and in reviewing this document.

[Is my information safe and confidential?](#)

Yes we will keep all information about you safe and secure. The research team follow ethical and legal practice and all your information will be handled confidentially.

How will we use information about you?

We will need to collect some information from you for this research study. To safeguard your rights, we will use the minimum personally identifiable information possible.

The information that we collect for the research will include;

- The information from your questionnaire which includes some medical details such as what type of inflammatory bowel disease you have and what medications you take.
- The information from the interview and additional text or pictures you supply to us.
- Your name and contact details.

We will use this information only to do the research. Other authorised individuals may view the records we collect to make sure the research is being done properly.

Your name and contact details will be kept separate from the other information that we obtain from you during this research. Your research records will contain a unique study number so you are not directly identifiable when we use your data in our research. A form will be created correlating your unique study code with your contact details and this will be stored separately from other information and will be accessible only to the research team.

What are your choices about how your information is used?

The University of York is a publicly funded organisation that conducts research to improve health and healthcare services. In legal terms, we are using your information for this research as part of 'a task in the public interest'. This means the ability to change the data that we have collected, however, is limited, as we need to manage your information in specific ways for the research to be reliable and accurate.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. This does not apply to any photographs you have taken and supplied to us. You can request for these to be returned to you and any copies permanently deleted.

Where can you find out more about how your information is used?

You can find out more about how we use your information;

- at <https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/>
- at <https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/research-participants/>
- by emailing the University of York's data protection officer on dataprotection@york.ac.uk.

How will my information be kept safe and confidential?

If you decide to take part in this study, what you tell us will be kept safe and confidential. Data collected for the study may be looked at by authorised persons who are organising the research or checking that the study is being carried out correctly. All have a duty of confidentiality to you as a research participant.

The only time we would break our duty of confidentiality is if we are worried that you – or someone else – was being or likely to be, harmed. If that happens, any concerns will be escalated through the appropriate safe-guarding channels which may involve disclosure of your name, contact details and audio recordings.

Your name, contact details and research records, including the interview recordings will be stored electronically on a secure network at the University of York and York and Scarborough Teaching Hospital, NHS Foundation Trust. Access to this information will be restricted to authorised persons only. We will store hard copies of any information in a locked filing cabinet in a locked room which is not accessible to the public and only accessible to the research team.

The research team will securely keep a record of your name and contact details for a period of 3 years after your interview. This information will only be used to contact you about your involvement in the study or to send you a summary of the results if you request this.

At the end of the study any audio or video recordings will be deleted and all other study documentation will be stored securely for 10 years as is normal practice for research data. After this time all data will be destroyed.

What will happen to the results of this study?

We hope to publish the results of the study in specialist nursing or medical journals. We may also present the study at professional conferences, meetings and to relevant staff and patient groups. It is possible that some short direct quotes may be given in the presentation. Every measure will be taken to ensure these are appropriate and respectful and we will ensure that these would not identify you.

If you would like to find out about the results of the study, please let us know and we will endeavour to send you a copy of the final study report or publication.

One way we can get the most benefit from this work is to make the study data available for secondary research purposes and in future research. The study data may be reused by the research team but will not be used or released in such a way that you could be identified.

What if there is a problem?

If you are unhappy about any aspect of this study or wish to make a complaint, please contact Professor Paul Galdas.

If you are unhappy with the way your personal data has been handled, please contact the University's Data Protection Officer at dataprotection@york.ac.uk. If you are not satisfied with our response, you have a right to complain to the Information Commissioner's Office. For information on reporting a concern to the Information Commissioner's Office, see www.ico.org.uk/concerns.

Thank you for reading this information sheet and considering whether to take part in this study.

Research team contact details:

Mrs Sara Ma	Professor Paul Galdas
Specialist Nurses Office	Department of Health Sciences
York Teaching Hospital	University of York
Wigginton Road	Heslington
YO31 8HE	YO10 5DD
Sara.ma2@nhs.net	Paul.galdas@york.ac.uk
01904 72 6154	01904 321647

Sources of further information

- Crohns & Colitis UK; the UK's leading charity in the battle against Crohn's Disease and Ulcerative Colitis which together are called IBD: www.crohnsandcolitis.org.uk
- British Society of Gastroenterology; an organisation focused on the promotion of gastroenterology within the UK. It has over three thousand members of physicians, surgeons, pathologists, radiologists, scientists, nurses, dietitians, and others interested in the field: <https://www.bsg.org.uk/>
- The Royal College of Nurses is a nursing union and professional body. They provide further information on IBD specialist nurses; <https://www.rcn.org.uk/professional-development/publications/pub-003194>

Expression of interest form

If you would like to find out more about this study we would really like to hear from you. You can return this form to us, call or email us. There is no obligation to take part.

Contact details:

Sara Ma

Specialist Nurses Office
3rd floor Admin Block
York University Teaching Hospital, NHS Foundation Trust
Wigginton Road
York
YO31 8HE

Email; sara.ma2@nhs.net
Tel; 01904 72 6154

I..... am interested in finding out more about the MaSH-IBD Study.

The best way to contact me is:

☐ Telephone:

☐ Email:.....

☐ Letter (address).....

.....
.....
.....
.....

Appendix 7: Qualitative study 1 case report form



MaSH-IBD Case Report Form

Participant identification number: Date of enrolment: //

Participant would like to be provided an emailed copy of the study report : Yes ☐ No ☐

Pages 1-3 to be completed by researcher in conjunction with participant. IIEF and IBD-MSDS may be completed together or independently by participant. If completed independently use participant form.

Disease

Year of diagnosis (can be approximate):

Disease: Crohns Disease: ☐ Ulcerative Colitis: ☐ IBD-U: ☐ Microscopic: ☐

Previous surgery: Year N/A: ☐

Current stoma: Yes ☐ No ☐

Previous stoma: Yes ☐ No ☐

Current or history of perianal disease: Yes ☐ No ☐

Current or history of fistulising disease: Yes ☐ No ☐

Medications

5-ASA oral: Never ☐ Intolerant ☐ PRN ☐ Regular ☐ Not currently ☐

5-ASA rectal: Never ☐ Intolerant ☐ PRN ☐ Regular ☐ Not currently ☐

Rectal steroids: Never ☐ Intolerant ☐ PRN ☐ Regular ☐ Not currently ☐

Oral steroids: Never ☐ Intolerant ☐ PRN ☐ Regular ☐ Not currently ☐

Immunosuppression: Never ☐ Intolerant ☐ PRN ☐ Regular ☐ Not currently ☐

Biologic therapy: Never ☐ Intolerant ☐ PRN ☐ Regular ☐ Not currently ☐

Researcher Signature:.....

Date:.....

Participant identification number::

Co-morbidities

Joints: Never ☐ Previous ☐ Current ☐

Medical therapy: No ☐ Yes.....

Diagnosis.....

Skin: Never ☐ Previous ☐ Current ☐

Medical therapy: No ☐ Yes.....

Diagnosis.....

Cardiac/Vascular: Never ☐ Previous ☐ Current ☐

Medical therapy: No ☐ Yes.....

Diagnosis.....

Depression: Never ☐ Previous ☐ Current ☐

Medical therapy: No ☐ Yes.....

Diagnosis.....

Diabetes: No ☐ Type 1 ☐ Type 2 ☐

Medical therapy: No ☐ Yes.....

Diagnosis.....

Others: (use additional pages if necessary)

..... Never ☐ Previous ☐ Current ☐

Medical therapy: No ☐ Yes.....

Diagnosis.....

Researcher Signature:.....

Date:.....

Participant identification number::

Participant rated disease score:

Mild:

Moderate:

Severe:

/ /

Sexual orientation;

Heterosexual:

Homosexual or gay:

Bisexual:

Would rather not say

Age;

Researcher Signature:.....

Date:.....

Participant identification number::

International Index of Erectile Function (IIEF)

May be completed with researcher or independently by participant using participant IIEF form

These questions ask about the effects that your erection problems have had on your sex life over the last four weeks. Please try to answer the questions as honestly and as clearly as you are able.

In answering the questions, the following definitions apply:

- **sexual activity** includes intercourse, caressing, foreplay & masturbation
- **sexual intercourse** is defined as sexual penetration of your partner
- **sexual stimulation** includes situation such as foreplay, erotic pictures etc.
- **ejaculation** is the ejection of semen from the penis (or the feeling of this)
- **orgasm** is the fulfilment or climax following sexual stimulation or intercourse

Over the last four weeks....

	Question	Answers (check only one box)	Given score
1	How often were you able to get an erection during sexual activity?	<input type="checkbox"/> 0 No sexual activity <input type="checkbox"/> 1 Almost never or never <input type="checkbox"/> 2 A few times (less than half the time) <input type="checkbox"/> 3 Sometimes (about half the time) <input type="checkbox"/> 4 Most times (more than half the time) <input type="checkbox"/> 5 Almost always or always	
2	When you had erections with sexual stimulation, how often were your erections hard enough for penetration?	<input type="checkbox"/> 0 No sexual activity <input type="checkbox"/> 1 Almost never or never <input type="checkbox"/> 2 A few times (less than half the time) <input type="checkbox"/> 3 Sometimes (about half the time) <input type="checkbox"/> 4 Most times (more than half the time) <input type="checkbox"/> 5 Almost always or always	
3	When you attempted intercourse, how often were you able to penetrate (enter) your partner?	<input type="checkbox"/> 0 Did not attempt intercourse <input type="checkbox"/> 1 Almost never or never <input type="checkbox"/> 2 A few times (less than half the time) <input type="checkbox"/> 3 Sometimes (about half the time) <input type="checkbox"/> 4 Most times (more than half the time) <input type="checkbox"/> 5 Almost always or always	
4	During sexual intercourse, how often were you able to maintain your erection after you had penetrated (entered) your partner?	<input type="checkbox"/> 0 Did not attempt intercourse <input type="checkbox"/> 1 Almost never or never <input type="checkbox"/> 2 A few times (less than half the time) <input type="checkbox"/> 3 Sometimes (about half the time) <input type="checkbox"/> 4 Most times (more than half the time) <input type="checkbox"/> 5 Almost always or always	

5	During sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?	<input type="checkbox"/> 0 Did not attempt intercourse <input type="checkbox"/> 1 Extremely difficult <input type="checkbox"/> 2 Very difficult <input type="checkbox"/> 3 Difficult <input type="checkbox"/> 4 Slightly difficult <input type="checkbox"/> 5 Not difficult	
6	How many times have you attempted sexual intercourse?	<input type="checkbox"/> 0 No attempts <input type="checkbox"/> 1 One to two attempts <input type="checkbox"/> 2 Three to four attempts <input type="checkbox"/> 3 Five to six attempts <input type="checkbox"/> 4 Seven to ten attempts <input type="checkbox"/> 5 Eleven or more attempts	
7	When you attempted sexual intercourse, how often was it satisfactory for you?	<input type="checkbox"/> 0 No attempts <input type="checkbox"/> 1 One to two attempts <input type="checkbox"/> 2 Three to four attempts <input type="checkbox"/> 3 Five to six attempts <input type="checkbox"/> 4 Seven to ten attempts <input type="checkbox"/> 5 Eleven or more attempts	
8	How much have you enjoyed sexual intercourse?	<input type="checkbox"/> 0 No intercourse <input type="checkbox"/> 1 No enjoyment at all <input type="checkbox"/> 2 Not very enjoyable <input type="checkbox"/> 3 Fairly enjoyable <input type="checkbox"/> 4 Highly enjoyable <input type="checkbox"/> 5 Very highly enjoyable	
9	When you had sexual stimulation or intercourse, how often did you ejaculate?	<input type="checkbox"/> 0 No sexual stimulation or intercourse <input type="checkbox"/> 1 Almost never or never <input type="checkbox"/> 2 A few times (less than half the time) <input type="checkbox"/> 3 Sometimes (about half the time) <input type="checkbox"/> 4 Most times (more than half the time) <input type="checkbox"/> 5 Almost always or always	
10	When you had sexual stimulation or intercourse, how often did you have the feeling of orgasm or climax?	<input type="checkbox"/> 1 Almost never or never <input type="checkbox"/> 2 A few times (less than half the time) <input type="checkbox"/> 3 Sometimes (about half the time) <input type="checkbox"/> 4 Most times (more than half the time) <input type="checkbox"/> 5 Almost always or always	
11	How often have you felt sexual desire?	<input type="checkbox"/> 1 Almost never or never <input type="checkbox"/> 2 A few times (less than half the time) <input type="checkbox"/> 3 Sometimes (about half the time) <input type="checkbox"/> 4 Most times (more than half the time) <input type="checkbox"/> 5 Almost always or always	
12	How would you rate your level of sexual desire?	<input type="checkbox"/> 1 Very low or none at all <input type="checkbox"/> 2 Low <input type="checkbox"/> 3 Moderate <input type="checkbox"/> 4 High <input type="checkbox"/> 5 Very high	
13	How satisfied have you been with your overall sex life?	<input type="checkbox"/> 1 Very dissatisfied <input type="checkbox"/> 2 Moderately dissatisfied <input type="checkbox"/> 3 Equally satisfied & dissatisfied <input type="checkbox"/> 4 Moderately satisfied <input type="checkbox"/> 5 Very satisfied	

14	How satisfied have you been with your sexual relationship with your partner?	<input type="checkbox"/> 1 Very dissatisfied <input type="checkbox"/> 2 Moderately dissatisfied <input type="checkbox"/> 3 Equally satisfied & dissatisfied <input type="checkbox"/> 4 Moderately satisfied <input type="checkbox"/> 5 Very satisfied	
15	How do you rate your confidence that you could get and keep an erection?	<input type="checkbox"/> 1 Very low <input type="checkbox"/> 2 Low <input type="checkbox"/> 3 Moderate <input type="checkbox"/> 4 High <input type="checkbox"/> 5 Very high	

Function domain	Max score	Participant score
Erectile Function (Q1,2,3,4,5,15)	30	
Orgasmic Function (Q9,10)	10	
Sexual Desire (Q11,12)	10	
Intercourse satisfaction (Q 6,7,8)	15	
Overall satisfaction (Q13,14)	10	

Researcher Signature:.....

Date:.....

Participant identification number:

IBD-MSDS

May be completed with researcher or independently by participant using participant IBD-MSDS form

	Never or rarely	A few times	About half the time	Most times	Always or almost always
In the last year how frequently has CD or UC affected your desire for sexual activity?	0	1	2	3	4
In the last year has having CD or UC prevented you from having sex?	0	1	2	3	4
In the last year has having CD or UC caused problems during sex?	0	1	2	3	4
In the last year has having CD or UC caused you to feel guilty about intimacy of intercourse?	0	1	2	3	4
In the last year to what extent has fatigue or lack of energy impacted on your sex life?	0	1	2	3	4
In the last year to what extent has abdominal or pelvic pain affected your sex life?	0	1	2	3	4
In the last year how much has increased bowel movement frequency affected your sex life?	0	1	2	3	4
In the last year how much has anal bleeding or discharge affected your satisfaction with your sex life?	0	1	2	3	4
In the last year how much has anal pain, discomfort or irritation affected your satisfaction with your sex life?	0	1	2	3	4
Are you ever afraid of participating in sexual activity due to your CD or UC?	0	1	2	3	4
Total score					

Researcher Signature:.....

Date:.....

Appendix 8: Qualitative study 1 interview guide



Male sexual health in inflammatory bowel disease Interview Guide

Research Question:
What can be learned from the sexual experiences and activities of men living with IBD?

Welcome and housekeeping

Location of toilets, fire escapes, re-introductions, breaks.

Reminder that interview will probably last 60 minutes but we can stop at any point.

Reminder the interview will be recorded.

Brief revisit of aims of the study. Re-confirm they are feeling well-enough and consent to participate. Explain that interviewer will attempt to not use their name and if possible they may want to refrain from using real names and place names but not to worry if they do as these can be removed during transcription.

General prompts and probes:

Can you describe your experience of that?

How did that make you feel?

What was that like for you?

Can you give me an example of that?

Tell me more about that.

What does that mean to you?

How does that compare to...?

Can we explore.....this in more detail?

INTRODUCTORY QUESTION – LIMIT TIME TO PREVENT INTERVIEW FATIGUE

Inflammatory Bowel Disease, general health, treatment and care

Tell me a bit about your journey with Inflammatory Bowel Disease? (or)

Can you help me understand what your life is like living with Inflammatory Bowel Disease? (or)

What has living with Inflammatory Bowel Disease been like for you?

Key Words: Onset, diagnosis, bowel symptoms, extra-intestinal symptoms, pain, fatigue, bleeding, body changes, complications, treatment, medications, relapses, surgery,

Prompts: How is your health at the moment? Are there any particular experiences that you would like to discuss? Is (symptom) a problem for you? What has it been like having (treatment)?

OR

Social

Can we talk a bit about what's important to you in your life and what you enjoy doing?

Can you tell me a bit about your day to day life, for example what do you enjoy doing?

Who is important to you, how have they dealt with you having this disease?

Key words; Partner, family/children, hobbies, employment, living arrangements, support network, challenges in life, big life events

Prompts; Did your disease ever influence (that)?, How does your disease fit into (this)?

Being a man & masculinity

Being a man or masculine means different things to different people.

What does being a man mean to you?

Does this disease change the way you feel about (your masculinity)?

Key words; Body image, physical strength, work/employment, wealth, control, being sensitive, independent, pride, self-sufficiency, diet, being stoic, fatherhood, relationships

Relationships

Would you be able to tell me about a significant relationship in your life, maybe one that has involved some level of intimacy?

Was/Is this relationship (or any of your relationships) affected by your disease?

Key words; partnership, love, sexuality, support, compassion, satisfaction,

Sex

I wonder if you could talk freely about sex and if your disease plays any role in that aspect of your life?

Do you feel that IBD and the way you have sex are connected and if so how?

Do you ever worry about having sex specifically and if so why?

Has your UC/Crohn's impacted upon your relationships, intimacy or sex life?

Did the way you had sex change after you started with your disease symptoms?

Key words; erectile function, rectal bleeding, sexually satisfied

Prompts; how does your partner feel about that? Have you ever had any issues when having sex? Does your IBD make that better/worse?

Support with sexual well-being

Is there anyone in your life that provides a listening ear or support in regards to your sexual well-being?

Is there anything that might help you or other people in your position with what we have discussed today?

Key words; communication, information, specialist nurses, doctors, counselling, assessment, support

Closing questions

Thank you for sharing your experiences with me, is there anything we've missed?

Is there anything else we should talk about regarding this issue?

Appendix 9: Qualitative study 1 data management plan

Data Management Plan (DMP) MaSH-IBD

Postgraduate researcher: Sara Ma
Project title: Male sexual health and well-being in inflammatory bowel disease
Project start/end: June 2022 -September 2024
Funder (where applicable):
Project context: This is a qualitative study of male sexual health, identity and activity in inflammatory bowel disease. One-off semi structured interviews with participants will be conducted and further participant accounts in the form of diaries, audio recordings or photos may be submitted following the interview.

Defining your data
<p>1a. What data will you produce? Case report form including participant completed surveys. Audio and video recordings of interviews (Videos will be recorded using the video conferencing software used and downloaded and transferred to be saved to the university drives. Audio recordings made on a Dictaphone will be immediately downloaded onto the university drives and deleted from the recorder and computer used to download the recordings immediately after the interview). Transcriptions of interviews. Participant photographs – to be stored electronically. Participant accounts – handwritten (to be scanned and stored electronically) and electronic formats including audio. Researcher reflexive accounts/diaries – to be scanned and scored electronically.</p>
<p>1b. What formats and what software will you use? Microsoft Office Word, NVIVO, MP3 – audio files, .doc – word files, .jpg – pictures, excel spreadsheets for personal data</p>
<p>1c. How much data do you expect to generate? 30 hrs worth of interviews plus participant submitted accounts and questionnaires.</p>
<p>1d. Who owns the data you will generate? The University of York. Copyrights of participant photographs are retained by the participant or photographer of the photograph.</p>

Looking after your data
<p>2a. Where will you store your data? The University of York secure network.</p>

The anonymisation key will also be stored in the University of York secure network but in a separate drive.

Hard copies of any trial documents will be locked in a filing cabinet in a locked room at the University of York or York and Scarborough Teaching Hospital if immediate transfer to the university is not viable. Original paper documents will be scanned to PDF file for archiving at the end of the study and then destroyed using the confidential waste system.

Data will be transferred using <https://dropoff.york.ac.uk>

2b. How will you back-up your data?

Centrally backed-up by IT services at the University of York.

2c. Who else has a right to see or use this data during the project?

R&D at York and Scarborough Teaching Hospitals for research auditing purposes.
PhD supervisory team.
Participants may have access to their photographs.

2d. How will you structure and name your folders?

Example of expected folder structure with example of

Site file documentation

- Protocol
 - o YYYYMMDDMASHIBD1Protocolv1.0.doc
- Regulatory approval documentation
- Delegation log
 - o YYYYMMDDMASHIBD1Delegationlogv1.0.doc
- Researcher CVS
- Recruitment log (password protected)
- Consent forms
- PIS
- Monitoring plan
- Data management plan
 - o YYYYMMDDMASHIBD1Datamanagementplanv1.0.doc
- File notes
- Correspondences
- Meeting logs
- Adverse events
- Amendments
- Contracts
- Study reports

Data


- Data collection
 - Participant Interview recordings
 - 20201204MASHIBDInterview1PIN01.mp3
(YYYYMMDDSTUDYDataParticipantIdentificationNumber)
 - 20201204MASHIBDInterview2PIN01.mp3
 - Participant Interview transcripts
 - 20210112MASHIBDInterview2PIN01.doc
 - Participant Photos
 - 20210604MASHIBDPhoto1PIN01.doc
 - 20210605MASHIBDPhoto1PIN02.doc
 - Participant Diaries
- Data analysis

<ul style="list-style-type: none"> - NVIVO files - Coding - Memoing - Reflexive accounts
<p>2e. How will you name your files?</p> <p>All files will start with the full year, month and date (in numerical format) they were created followed by IBDMASH, then the name of the file followed by the participant identification number for the participant in which the file pertains to if relevant and then a version.</p>
<p>2f. How will you manage different versions of your files?</p> <p>Documents are versioned (and date) controlled in the footer of the document. File names will also be labelled vX.Y at the end of the document.</p> <p>Minor versions are denoted with ordinal numbers after the decimal 1.1, 1.2, 1.3</p> <p>Major version changes are denoted 1.0, 2.0, 3.0.</p> <p>All versions must also be dated.</p>
<p>2g. What additional information will be required to understand your data?</p> <p>N/A</p>

<p>Archiving your data</p>
<p>3a. What data should be kept or destroyed after the end of your project?</p> <p>Data to be archived: Site Files, CRFs, Data documents that do not form part of the participants medical records, documents that demonstrated a clear audit trail of study processes.</p> <p>Scanned copies of consent forms and the document linking the participant name and unique identification number (the only documents that will contain patient identifiable information) will be archived for three years and all other study data for 10 years which is proportional for the study and common for non-CTIMP studies.</p> <p>All other data to be destroyed.</p>
<p>3b. For how long should data be kept after the end of your project?</p> <p>10 years</p>
<p>3c. Where will the data you keep be stored at the end of the project?</p> <p>As the University is the Sponsor, archiving will be carried out electronically as per the University of York local policy. Should archiving be required to be undertaken by York Trust then all research data will be collected and stored at ReStore commercial archiving facility as per York Trust policy. Access will be controlled by the archivist at each organisation depending on which institution is chosen. The study site (York Teaching Hospital) may retain a core set of study documents at site as per normal Trust policies.</p>
<p>3d. When will you archive your data?</p> <p>After 6 months but before 12 months following the end of study to ensure all queries are answered.</p>

Sharing your data at the end of the project
4a. What data should or shouldn't be shared openly and why? Participant identifiable information will not be shared to protect patient confidentiality.
4b. Who should have access to the final dataset(s) and under what conditions? The PhD supervisory team and examining body if required as part of the examination process. Peer reviewers that want to view anonymised aspects of the data set. Data can only be accessed for the defined purposes set out in the protocol and for what consent has been provided. Data cannot be shared outside of the EEA to comply with GDPR.
4c. How will you share your final dataset(s)? Extracts from the final data set will be used as part of the thesis, in publications and presentations on the topic.

Implementing your plan
5a. Who is responsible for making sure this plan is followed? Sara Ma (CI) and the PhD supervisory team at the University of York.
5b. How often will this plan be reviewed and updated? If any amendments are made to the research protocol.
5c. What actions have you identified from this plan? Identify any archiving costs. Create site file.
5d. What policies are relevant to your project? Data Protection Act 2018 EU General Data Protection Regulation 2018 Health Research Authority Guidance 2017 UK Clinical Trial Regulations International Conference of Harmonisation (ICH) of Good Clinical Practice

Signed: 	Version: 1.3
Date created: 08/12/2021	Date amended: 21 March 2022

Appendix 10: Qualitative study 1 consent form



Participant consent form Male sexual health in inflammatory bowel disease (MaSH-IBD)

Part 1

Please initial box

1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care or legal rights being affected. I understand that if I withdraw from the study, information collected about me until that point will be included in the study. ☐
3. I understand that sections of my study documents may be looked at by responsible individuals from the University of York or regulatory authorities or from York and Scarborough NHS Foundation Trust, where it is relevant to my taking part in research. I give permission for these individuals to have access to my study documents. ☐
4. I agree for the interviews to be audio or video recorded so they may be transcribed by a researcher or through a professional transcription service bound by a confidentiality agreement. Recordings will be deleted at the end of the study but transcripts (where identifiable information has been redacted) will be archived for 10 years. ☐
5. I understand that study data may be stored and used in relevant future research, including by researchers in other institutions, but the data will not be used or released in such a way that I could be identified. ☐
6. I understand that my contact information may be held and maintained by The University of York, to inform me of the study results and/or to invite me to participate in future research studies for a maximum of 3 years following the end of the study. ☐
7. I understand that anonymised data will be archived for 10 years following the end of the study. ☐
8. I understand that if the researcher thinks that I or someone else may be at risk of harm they may have to contact the relevant authorities. ☐
9. I understand that information I provide will be kept confidential and stored securely. Some of this information may be included in published documents but will be anonymised. ☐
10. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Name of Person confirming consent

Date

Signature

Participant consent form - optional
Male sexual health in inflammatory bowel disease

Part 2

I give permission for the photographs provided by myself to be used within the study. I have received permission of any photographs of people who are alive and have not been taken in a public space to be used for the purposes of this study. I understand that my permission will be sought prior to the use of any photographs for publication. I understand that unless otherwise requested, photographs will be archived electronically for 10 years and then destroyed. I understand that faces and identifying features will be pixilated or blurred if the researchers request to use a photograph in print.

Name of Participant_____
Date_____
Signature_____
Name of Person confirming consent_____
Date_____
Signature

When completed: 1 copy for participant; original for research file

Appendix 11: Qualitative study 1 patient support leaflet



HELPFUL RESOURCES

There are several ways to access support for depression, anxiety and stress. In the first instance we advise you speak to someone you trust and this could include you GP or IBD Specialist team at the hospital.

Support can also be accessed through charities, helplines, online resources, apps, talking therapies and for some people workplace benefits. We have also collated a list of some NHS approved resources.

Where to go when in a crisis?

Samaritans	Tel; 116 123 <i>Free phone line</i> <i>24hrs a day 7 days a week</i>	www.samaritans.org	Offering emotional support for anyone experiencing suicidal thoughts.
CALM (Campaign Against Living Miserably)	Tel; 0800 585858 <i>Free phone line from 5pm to midnight, 7 days a week</i>	www.thecalmzone.net	For people who are down, have hit a wall for any reason and needs to talk or find information and support.
Shout	Text 'Shout' to 85258	www.giveusashout.org	Text line for anyone experiencing a personal crisis and in need of support.
Papyrus	Tel; 0800 068 4141 <i>Free phone 9am to midnight, 7 days a week</i>	www.papyrus-uk.org	Provides support to people who are experiencing thoughts of suicide up to the age of 35 or anyone worried about a young person.

Talking therapy

Information on talking therapies and counselling can be found here:

<https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/>

<https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/counselling/>

Additional resources

NHS	www.nhs.co.uk/livewell		Advice, tips and tools for general wellbeing and mental health.
	www.nhs.co.uk/apps-library		List of available apps for mental health, sleep, etc.
Anxiety UK	03444 775 774	www.anxietyuk.org.uk	Offer a range of support services to help people with anxiety.
Crohns and Colitis UK	0300 222 5700	www.crohnsandcolitis.org.uk	Helpline for IBD specific topics including wellbeing.
Blue Ribbon Foundation	www.blueribbonfoundation.org.uk		Charity promoting mens health awareness issues. Provides a good list of resources for mens health information
LGBT Foundation	https://lgbt.foundation/		Offer a wide range of service to support lesbian, gay, bisexual and trans people
Mens Health Forum	www.menshealthforum.org.uk		Charity supporting men's health offering online resources and signposting.
Mind	0300 123 3393	www.mind.org.uk	Offers advice, support and information to people experiencing a mental health difficulty.
NSPCC	https://www.nspcc.org.uk/what-is-child-abuse/types-of-abuse/non-recent-abuse/#support		For support on non-recent childhood abuse.
Recovery College	www.recoverycollegeonline.co.uk		Online educational courses and recourses for mental health and well-being
Survivors UK	https://www.survivorsuk.org/		Online resources and signposting for men who are victims of sexual violence

Appendix 12: Qualitative study 1 coding Log exemplar interviews 1-3

Study 1 Coding Log Exemplar

1st Interview	2nd Interview	3rd Interview
being a father	being a father	being a father
being in a relationship	being comfortable within your masculinity	being comfortable within your masculinity
being intimate	being in a relationship	being hopeful
having a good sex life	being supported	being in a relationship
having sex less frequently	disease disrupting the relationship	being supported
being supported	having sex	disease disrupting the relationship
disease disrupting the relationship	anal play	fulfilling your obligations
continuing to work	casual sex	having sex
expressing hegemonic masculinity	frequency of bowels preventing sex	anal play
being in control	having a good sex life	casual sex
being physically strong	having sex less frequently	frequency of bowels preventing sex
being self-reliant	the disease as a barrier to sex experiences	having a good sex life
being the one to fix things	having to be cared for	having sex less frequently
being the provider	not being interested in a relationship	lack of desire
cracking on	someone having to care for you	pleasing partner above self
not wanting sympathy	the importance of trust	sex as a route to intimacy
being a burden	expressing hegemonic masculinity	the disease as a barrier to sex experiences
down playing symptoms	being in control	having to be cared for
not wanting to be seen as the disease	being physically strong	not being interested in a relationship
not wanting to have to ask for help	being self-reliant	someone having to care for you
the status of money	being the one to fix things	the importance of trust
the value of money vs health	being the provider	denial
living before the disease	continuing to work	expressing hegemonic masculinity
living with a covert disease	cracking on	being in control
it being a secret	down playing symptoms	being physically strong
learning to talking about it	earning your place	being self-reliant
not speaking about it	joking as a coping mechanism	being the one to fix things
other people not understanding	not wanting sympathy	being the provider
living with a disease that has developed	not wanting to be seen ill	being virile
disease becoming the new norm	not wanting to have to ask for help	continuing to work

falling apart	stoicism	cracking on
loss of previous self	the status of money	down playing symptoms
recognising you can take control yourself	living with a covert disease	earning your place
the disease changing life plans	it being a secret	joking as a coping mechanism
living with chronic disease	not talking about it	not wanting sympathy
being a 'sicknote'	living with a disease that has developed	not wanting to be seen ill
there not being a cure	disease becoming the new norm	not wanting to have to ask for help
wanting it to be fixed	falling apart	stoicism
Living with symptoms	living before the disease	the status of money
being incontinent	loss of previous self	living with a covert disease
being tired	recognising you can take control yourself	it being a secret
flactulance	reestablishing yourself	not talking about it
having joint pain	the disease changing life plans	living with a disease that has developed
increased stool frequency	living with chronic disease	disease becoming the new norm
loosing weight	accepting the disease is restrictive	falling apart
passing blood	being a 'sicknote'	living before the disease
masculinity as a nurtured trait	living with a disease that is difficult to control	loss of previous self
Navigating health care	not being able to do things	recognising you can take control yourself
fighting to get treatment	other people not understanding	reestablishing yourself
learning to manage the disease	relapsing remitting nature of the disease	the disease changing life plans
not knowing about the disease	still being able to do things	living with chronic disease
not seeking healthcare	there not being a cure	accepting the disease is restrictive
not trusting the treatment	wanting it to be fixed	being a 'sicknote'
not understanding the treatment	Living with symptoms	living with a disease that is difficult to control
problems with medications	being incontinent	living with it for life
people not caring	being tired	not being able to do things
Powerful quotes	flactulance	other people not understanding
reaching out for help	having joint pain	relapsing remitting nature of the disease
speculating how others are affected by IBD	increased stool frequency	still being able to do things
speculating the impact on others	loosing weight	there not being a cure
the emasculating effects of IBD	passing blood	wanting it to be fixed
being ill as feminine trait	perianal disease	Living with symptoms
feeling useless	masculinity as a nurtured trait	being incontinent

feeling violated	Navigating health care	being tired
treatment taking away feeling masculine	being treated as a person not a disease	flattulence
the emotional baggage carried	fighting to get treatment	having joint pain
being bitter	lack of available psychological support	increased stool frequency
being up and down	learning to manage the disease	losing weight
confidence being knocked	not being told information	passing blood
feeling envious of others	not knowing about the disease	perianal disease
feeling fatalistic	not seeking healthcare	masculinity as a nurtured trait
feeling frustrated	not taking medication	Navigating health care
feeling useless	not trusting the treatment	being treated as a person not a disease
struggling mentally	not understanding the treatment	fighting to get treatment
thinking money will fix things	problems with medications	lack of available psychological support
	professionals not really caring	learning to manage the disease
	speaking to the IBD nurse	not being told information
	talking to IBD team about sex	not knowing about the disease
	secondary effects of living with the disease	not seeking healthcare
	the effect of disease on education	not taking medication
	sexual identity	not trusting the treatment
	speculating the impact on others	not understanding the treatment
	strategies for coping	problems with medications
	acceptance	professionals not really caring
	being open with people about the disease	speaking to the IBD nurse
	gravitating to people who are understanding	talking to IBD team about sex
	feeling connected	not being very active
	other advocating for you	Powerful quotes
	reaching out for help	rejecting masculinity
	what is really important	relief of diagnosis
	the disease is part of ones self	secondary effects of living with the disease
	the emasculating effects of IBD	the effect of disease on education
	being ill as feminine trait	sexual identity
	feeling scared	speculating the impact on others
	feeling useless	strategies for coping
	feeling violated	acceptance
	the disease being in control	being open with people about the disease

	treatment taking away feeling masculine	gravitating to people who are understanding
	the emotional baggage carried	feeling connected
	being bitter	other advocating for you
	being different	reaching out for help
	being up and down	what is really important
	confidence being knocked	symptom control as a priority over sex
	fear of loss	the disease is part of ones self
	feeling embarrassed	the emasculating effects of IBD
	feeling envious of others	being ill as feminine trait
	feeling fatalistic	feeling scared
	feeling frustrated	feeling useless
	feeling guilty	feeling violated
	feeling useless	the disease being in control
	lack of self-esteem	treatment taking away feeling masculine
	struggling mentally	the emotional baggage carried
	the impact on sexuality	being bitter
	the role of age in understanding disease	being different
		being up and down
		confidence being knocked
		fear of loss
		feeling embarrassed
		feeling envious of others
		feeling fatalistic
		feeling frustrated
		feeling guilty
		feeling mardy
		feeling useless
		feeling weak
		lack of self-esteem
		struggling mentally
		the impact on sexuality
		the role of age in understanding disease

Appendix 13: Qualitative study 1 coding descriptors

MASH IBD Codebook Version 4

Theme 1; IBD shapes intimate connections with others

Code	Description	Code Development	Examples
Partnership	<p>Core to this code is the importance of an intimate partner being empathetic and clear communication of feelings. Many participants expressed the need to feel comfortable, supported and trusting of the person they were intimate with for successful sexual engagement and partnership. Poor communication and a lack of partner insight into men's experiences of illness could cause a breakdown in intimate interactions that men reported at times difficult to navigate. Men reported wanting to meet their partners needs but the illness can make this difficult and this could lead to guilt and a fear of unsuccessful relationships.</p> <p>I also interpreted mens experiences of supportive and open partnerships as being facilitators of coping and living with chronic illness.</p>	<p>An amalgamation of 'it is finding the right partner' and the language of intimacy' which were developed from 'casual sex', 'being supported', 'having someone to care for you', 'disease disrupting the relationship', 'confiding in others', 'the importance of trust' and 'it brought us closer together but at the same time separates you'.</p>	<p><i>"I tried casual sex a couple of times, and just never gelled with it really. And I think in part that's, I have to feel really comfortable with someone to be that intimate with them. And that could well be 'cause you know I mentioned that I wouldn't necessarily go into the gory detail of my crohns disease with someone I didn't know particularly, so, I guess subconsciously I'd be oh, you know like if I had this casual hookup or whatever and then I was unwell halfway through."</i> (Andy, 28yrs, Bisexual, Cohabiting)</p> <p><i>"she just understands and its more of a supportive kind of thing so if it's not sort of full on then you know still, okay, to just cuddle, hold hands whatever"</i> (George, 37yrs, heterosexual, married)</p> <p><i>"if I am upset about something, I can just tell her how I feel and she just always makes things better in how she talks to me."</i> (Ewan, 34yrs, heterosexual, married)</p> <p><i>"it's my problem, you don't have to worry about it, but I think generalizing maybe over sort of failed relationships over a number of years, actually maybe that approach hasn't been very good, because I'm not telling them everything and there I think there's an element that I don't open up"</i> (Noah, 38yrs, Heterosexual, dating at time of interview)</p> <p><i>"she was more like, she was just a fucking carer for a year"</i> (Alex, 28yrs, heterosexual, cohabiting)</p>

<p>Self-perception</p>	<p>The prominent concept is the illness and disease symptoms makes you feel less attractive sexually. This reflects the way in which the disease can impact mens body image, confidence, and self-esteem.</p> <p>How you perceive yourself can then impact upon how you believe others may view you, which can disrupt successful intimate and sexual engagement.</p> <p>There is the physicality and the way the disease can affect the body which was often described negatively especially around weight and muscle mass. There is also a psychological change in self-perception which can conflict with the hegemonic concept that being a sexual male is aligned with being healthy and strong. For some men this is reflected in the way in which they believe their partners might not view them as a sexual being. For some men this is transient as the disease relapses and remits, for others is it a permanent adjustment.</p>	<p>This code draws together 'Seeing me as a sexual person' and 'body image' which stemmed from earlier codes of 'having to be cared for', 'not wanting to be seen as being ill', 'how your partner perceives you', 'feeling embarrassed', 'the disease as a barrier to sex'.</p> <p>Although more general expressions of low confidence have not been coded here, this is an issue that frequently comes up in broader conversation about the disease.</p> <p>References from men who suffered from body image concerns but their relationships had surmounted that are also included to illuminate contrasting positions.</p>	<p><i>"know it sounds awful, men are just as bad, its physical attraction, how can my missus, at one point, you do think how is my missus attracted to me"</i> (Alex, 28yrs, heterosexual, cohabiting)</p> <p><i>"I guess maybe, perhaps a masculinity thing there, I just felt small, you know that, you know I didn't think that she'd be able to see me as a sexual person, after seeing me like go through that and then, like with the like physicality's of like wound care and stuff, I guess, I just thought like how on earth is she ever going to see me that way again?"</i> (Andy, 28yrs, bisexual, cohabiting)</p> <p><i>"I was dating a guy, really nice and stuff and you know we're going back to you know a place where we're gonna sleep together. On the way there, I told him about my condition and everything and then I feel like that may have changed the mood because when we got to the bedroom and stuff he kind of said he wasn't feeling it."</i> (Pete, 26yrs, homosexual, single)</p> <p><i>"I'm like right I've got this disadvantage of a crohns, but I can't afford to be looking rubbish, and to be overweight, and unfit, top of that, because you know I wouldn't find a partner, so there is a pressure back what I have to look good."</i> (Noah, 38yrs, heterosexual, dating at time of interview)</p> <p><i>"If you know you've got no energy, and you don't feel attractive yourself then you know anything is going to be a complete non-starter, and it's a very easy condition to feel like that about because it's, you know the symptoms are what they are"</i> (Raphael, 43yrs, heterosexual, married)</p>
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<p>Prioritisation of personal health</p>	<p>Men often discussed how getting on top of their IBD symptoms was more of a priority for them than their sexual health. This is an important concept when informing healthcare decisions. It was not that sex wasn't important but general health comes first which is also a reflection of the severity of the disease and the impact the symptoms can have on day-to-day life. For men who were single this meant not engaging in intimacy. For those in relationships it could lead to changes and sometimes difficulties in intimate relationships.</p>	<p>This code links to 'desire' which describes how sexual interest wanes as the disease flares, but this code specifically covers the idea that if you are preoccupied with illness it is very difficult to prioritise or have interest in intimacy and sex.</p> <p>Initial codes that fed into this was 'living with chronic disease', 'accepting the disease is restrictive', 're-establishing yourself', 'what is really important'.</p>	<p><i>George; I would say so from a personal standpoint, I never really thought about things like dating, going out, being with anyone until probably after the line was fitted.</i> <i>Interviewer; Okay. Okay.</i> <i>George; I think I, just so, I would have liked to but in my twenties it wasn't really a priority it was more just figuring out my health. (37yrs, heterosexual, married)</i></p> <p><i>"I've not really put myself out there since the hospital trip, I haven't at all. I've kind of wanted to but I've been very aware, I'm aware my farts are significant, I find my flatulence, and all these are things which are just not fun for anyone really, and I don't want to subject someone else to that, until I've got on top of it a lot more" (Dara, 24yrs, heterosexual, single)</i></p> <p><i>"I think we humans know this, if you don't engage in sexual acts with your partner for long enough, you, you can you emotionally, and you mentally start to to to diverge." (Arthur, 47yrs, heterosexual, married)</i></p> <p><i>"Yeah, perhaps, but I have to say, though, you know, at the point while I was flaring badly, I'm not sure any amount of chat about my sexual activity I would, I would have found that helpful, in fact if anything, I might have found that more stressful because it would have been going Oh, you're right, that's not working either. Yeah, so it's a tough one." (Oliver, 52yrs, heterosexual, married)</i></p> <p><i>"unfortunately, having to be a little bit selfish and prioritising myself and they are coming second, and I think, unfortunately, with crohns, I have to put myself first and as a result that's sort of miscommunication and lack of me opening up has always been an issue in the past" (Noah, 38yrs, heterosexual, dating at time of interview)</i></p> <p><i>"when I had the stoma was not really, it was only a period of 6 months, I don't think from memory I was interested in anything romantic at all, I think because again, I was dealing with this thing" (Peter, 26yrs, homosexual, single)</i></p>
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Theme 2; IBD vicissitudes mens experiences of sex

Code	Description	Code Development	Examples
Sexual desire	<p>Core to this code is the described reduction in or lack of sexual desire, commonly reported during relapses of the disease.</p> <p>Even when personal sexual desire is low, men in established relationships expressed a continued desire to meet the needs of sexual partners. Satisfying your partners needs is an expression of masculinity. One participant mentions how it is easier to satisfy himself alone – possibly reflecting the challenge of meeting the expectations of others.</p>	<p>This code really brings together how mostly the fatigue but also other disease related issues reduce sexual desire.</p> <p>This code was originally named 'IBD; the buzz killer' and encompasses a common issue expressed across the interviews that when the disease is flaring there is little or no engagement in sexual activity at all, or a reduction in desire. The idea of navigating both the needs of partners and oneself underpins and connects this code to 'partnership'. 'Self-perception' and 'sexual desire' are also linked and articulated by Ewan in the example here.</p>	<p><i>"I would, my appetite would immediately drop off, obviously because I'm bloated my physical activity would drop completely off that would impact, see, my sexual desires everything, my normal life just kind of stops, you know. You start taking naps at 5 o'clock in the afternoon"</i> (Arthur, 47yrs, heterosexual, married)</p> <p><i>"I tell a partner not really feeling... discomfort, and they might convince me otherwise, I'm still not 100% convinced, but no, I don't wanna disappoint them"</i> (Noah, 38yrs, Heterosexual, dating at time of interview)</p> <p><i>"Fatigue was awful, I remember that really clearly, I couldn't walk down the road without feeling absolutely dead on my feet. I could watch porn but I couldn't get an erection at all"</i> (Dara, 24yrs, heterosexual, single)</p> <p><i>"a very uncomfortable feeling and it's not a sexy feeling erm, it's a very distracting feeling and its one that, you know one doesn't feel sexy when one feels you know bloated or like you need the toilet and it's a sensually, it's a distracting feeling to have, so that had a big impact, that and being tired and low energy erm also impacted things, so even if I could get and maintain an erection doesn't mean that I was particularly kind of energetic or in the mood erm so that's kind of how it impacted sexual health I would say"</i> (Ewan, 34yrs, heterosexual, married)</p> <p><i>"I think only in that that kind of mental thing that we talked about there, and and the only kind of other thing would be that the fatigue levels when you're tired, and you're weak and you're not strong, not physically active. It is that then it would have an impact I don't think perhaps directly, but certainly like crohns is, indirectly it affects everything."</i> (Raphael, 43yrs, heterosexual, married)</p> <p><i>"Yeah, I think probably the biggest impact was when I was first being diagnosed, and like was still having symptoms, I think, I I like didn't have sex during that time, like I don't think it probably even crossed my mind very often"</i> (Hugo, 24yrs, heterosexual, cohabiting)</p>

<p>Sexual engagement</p>	<p>This code is encompassed all the references participants made IBD stopping or changing the way in which they engaged in sex.</p>	<p>This code was originally called 'my IBD was like nope you can't have that'. Initial codes that fed into this one included 'the before vs the after', 'the disease as a barrier to sexual experiences,'</p> <p>The idea of being clean also underlines this code, feeling unclean can lead to withdrawing from intimacy. Many men reported needing to feel clean to engage with sex and maybe feel free of the disease.</p>	<p><i>"I guess, of peri-anal disease is, so we're quite adventurous with our sex life, and and always, always have been, we've kind of grown together in that regard and did quite enjoy, you know, anal play for her and me as well and probably coincidentally, but the abscess happened fairly soon after we'd been exploring, that, so, I know rationally that it's probably not a direct cause but in the back of your head, you just like, oh, like do I want to"</i> (Andy, 28yrs, bisexual, cohabiting)</p> <p><i>"I wouldn't go out on a night I've got, I'm feeling iffy, no I would literally stop in, because I didn't want to go and work myself up thinking, and then can't do it cause that's a disappointment for me"</i> (Guy, 58yrs, bisexual, divorced)</p> <p><i>" 'cause I got ill so quickly after my surgery, that, I just wasn't well enough to do anything like that for 2 years you know didn't even think about it. And then, when I did start to get some libido back again, I just couldn't cope with you know the seatons, the lack of bowel control, I mean just with penetrative sex just because things were still painful down there, just no way, you know was I going to have, could I have cope with anybody down there doing that, and I think I lost my nerve as well"</i> (Freddie, 64yrs, homosexual, single)</p> <p><i>"I don't feel I'm clean enough, you know, because with the ileostomy, I had a fistula, which would leak constantly, so, and obviously with the colonic secretions as well I don't know if I would be able to hold them so you know, this impacted me a lot psychologically. So while my partner really didn't kind of you know care when I had this problem so much, it was more me kind of stopping myself from you know starting you know any anything, you know I would find excuses just to avoid the kind of situation where we would get more intimate"</i> (Frank, 31yrs, bisexual, cohabiting)</p>
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<p>Sexual expression</p>	<p>This code describes how the disease can interplay with expressions of sexuality in all orientations. The overarching impression that the disease can constrain, change and limit expressions of sexuality. The lack of specific advice and guidance for men in progressive sexual relationships is evident.</p> <p>Anal play is a significant aspect within this code. Anal play is something that can be enjoyed in both heterosexual and homosexual relationships but significantly impacted by the disease, especially peri-anal disease. There is clearly a lack of guidance for men wanting to engage in this form of sexual expression.</p>	<p>The code 'erectile function' was amalgamated into this code as it is a key aspect of sexual expression for many men. However, it is important to note that although being able to have an erection is an important part of many men's sexuality and ability to engage in sexual acts is not the only way sexuality is expressed. Ewan articulates the need for the 'emotional-psychological' side as well as the physical ability to perform sexual acts and so again this highlights a thread that runs through the codes that the physical and psychological are of equal importance in this field. Sexuality is also expressed by bringing about partner satisfaction and the desire to meet the needs of sexual partners and that was expressed by many participants.</p>	<p><i>Interviewer; Okay, and in terms of anal play. Is that something that you engaged in and did, having the disease change that as well?</i></p> <p><i>Frank; I didn't much no, no no previously I didn't much, so having the disease just took the options from me but you know, but you know I didn't really, basically I don't have the option anymore but obviously I didn't do much previously so it kind of affected me minimally, you know somehow but not much. (31yrs, bisexual, cohabiting)</i></p> <p><i>"I say I'd say, personally, I'm more like more of a receiver, although I have done both. So so he was like of like why didn't, I mean with your condition why are you like this? and I'm just simply like, I like what I like and I have to make it work. I mean I wish I didn't have these desires, I mean, I wish I could enjoy being, I wish I could be, you know, more active, like I could enjoy that more, but I just don't, it would have been great for me but it's not so I have to like really prepare and stuff. If I am going to have intercourse of something I really have to make sure as much as I can, like bowels clean so I go to the toilet as much as I can. Maybe take my suppository like that morning, or being, you know, a good time beforehand. And just hope it works out and hope it's not too painful and use a lot of lubricant to be frank" (Peter, 26yrs, homosexual, single)</i></p> <p><i>"it kind of focused on you know ability to get and maintain an erection and ejaculate as being the kind of definition of sexual health but it didn't erm it didn't touch on the kind of mood or emotional or psychological side of it which is you know I think a very important, it's not just the physical side of it but the emotional-psychological side of it is very important as well" (Ewan, 34yrs, heterosexual, married)</i></p> <p><i>Well, to be honest with you when you, when you are looking at it from my point of view, it's probably worth that risk. For the sake of your health and not dying for the sake of not getting an erection, there more about life than just that (Tom, 28yrs, heterosexual, cohabiting)</i></p> <p><i>"you've let your partner down and you want to fulfil or satisfy her in every way, and that at times is really very frustrating". (David, 66yrs, heterosexual, married)</i></p>
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Theme 3; IBD disrupts male gender norms

Code	Description	Code development	Examples
Physical Strength	Being physically strong and fit was a common aspiration that the disease was reported to impact. Many men changed the way in which they engaged in physical activity because of their illness, many attributed the disease to a lack of ability to maintain fitness. Being strong was perceived as sign of being healthy, which I interpreted as an attribute of masculinity. Arthur says "if anything, it's prompted me to try and be a bit more physical" presenting an alternative perspective; for him becoming unwell motivated him to improve his level of fitness.	This code developed out of 'being physically strong', 'not being able to do things' and then also reviewing all the other codes and seeing that it underlies a number of symptoms and codes such as 'participating in hobbies', 'feeling weak', and also 'body image'. Most recently this code was called 'recreation' but most activities were physical activities and discussions of how the disease prevents or changes the way men can engage with this and therefore it organically evolved into this code.	<p><i>"I suppose you know I'd seen myself as being a generally healthy person, a generally fit and healthy person, and I suppose it has made me feel, you know even though I'm generally fit and health now, if I am kind of thinking of my body and my health, even when I am not symptomatic, I am aware that is something I have" (Ewan, 34yr, heterosexual, married)</i></p> <p><i>"sometimes I felt like I you know, wasn't physically able to keep up with my counterparts at my age, and stuff like that. I don't, I didn't like being the sick boy really, I just wanted to live my life without problems, as we all do" (Peter, 26trs homosexual, single)</i></p> <p><i>"I haven't felt well enough to run for a couple of years now, because it just wipes me out. Which is really sad, because I love running" (Freddie, 64yrs, homosexual, single)</i></p> <p><i>"You know I took up going to the gym and subsequently kind of power lifting as a sport, sort of got stuck into that. It's the first time really that I've done anything physically active. You know, I was, cause I suppose when I was younger I couldn't really take part in sports or anything like that because I was, I was ill. So I really, really enjoyed that."(Andy, 28yrs, bisexual, cohabiting)</i></p> <p><i>"but I think it's just I've, I've accepted like you know I can't play football, I wouldn't be able to play football forever, but I can do something else like yoga and swimming which is fine" (Noah, 38yrs, heterosexual, dating at time of interview)</i></p>

<p>Self-reliance</p>	<p>Participants described wanting to have independence and control over their lives and health but the disease could disrupt this. This can feed into self-perception and also their role and position in intimate partnerships.</p>	<p>'Being self-reliant' was one of my very first codes developed after the first interview. It evolved into other codes but now replaces 'independence; control, practical and persevering' and 'dependence; vulnerability and weakness' as I no longer felt I needed two separate codes to represent this hegemonic masculine ideal and its counterpart. I separated them in the process of sorting the data and to assist in analysis. Many participants presented experiences of both. This is one of the largest sections and demonstrates a possible foundation of sexuality that feeds into codes given in the first two themes.</p> <p>Work is often cited as an important aspect of life but also how men position themselves within society. Varying ideals of the importance of work/study and experiences of the impact the disease has on this. The value of a supportive employer and good sick pay and policies is evident. Hugo presents a different perspective – one where he is comfortable with the idea his partner will provide for him if he is unwell.</p>	<p><i>'think that was clicking moment of being like actually I need to get control of this, because I am not in control at the moment, I am so reliant on them being, you know, them managing this for me, (Ethan, 28yrs, heterosexual, cohabiting)</i></p> <p><i>"because when, when I get ill, and especially if I have to go into hospital, I really hate the kind of patient me that turns up so you're even having this MRI tomorrow, I know as soon as I set off from home I'm gonna go into this kind of patient mode, which is much more vulnerable and feels helpless and not in control, because you know, I put a lot of effort into being in control of my life." (Freddie, 64yrs homosexual, single)</i></p> <p><i>"You know, so I said to myself from the start, I am going to be authentically me, I'm gonna do it, I'm gonna do it my way. It's not gonna be someone else's way, it's not gonna be me, it's gonna be my style" (Dara, 24yrs, heterosexual, single)</i></p> <p><i>"I think so they those concerns have never like come into my mind, I've never worried that like if I like, if I had a flare up tomorrow, and I couldn't go to work for like next month, I know that my girlfriend would just like help look after me and that doesn't bother me at all" (Hugo, 24yrs, heterosexual, cohabiting)</i></p>
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Emotional Resilience	Being emotionally resilient and battling through the challenges was an under current that ran through many interviews even if not always overtly apparent on first review of the transcripts. Have strong emotional resilience is a hegemonic trait which at times was demonstrated through response to the illness and at other times could be fractured by the condition.	Early codes that fed into this included 'stoicism', 'reestablishing yourself', 'struggling mentally' and 'carrying on'.	<p><i>"I think I was very willing to accept it, like I didn't want to be poorly anymore, this is what you have to do to not be sick and it's like therefore I will do it. It's like I didn't ever see it as a choice and I don't think and it was part of my upbringing, I just didn't see it as a choice. It's like I will do with this and it will be fine."</i> (Hugo, 24yrs, heterosexual, cohabiting)</p> <p><i>"I remember sitting on my bedroom floor just crying to myself thinking I don't want to be here anymore"</i> (Alex, 28yrs, heterosexual, cohabiting)</p> <p><i>"I think being a man is just, get on with it"</i> (Alex, 28yrs, heterosexual, cohabiting)</p> <p><i>"Oh, I think there was sort of a level of vulnerability, you know sort of, I think on most days you just sort of accept it, but if you sort of sit down and think you know"</i> (George, 37yrs, heterosexual, married)</p>
Contribution	Although there is a strong overlap with self-reliance, this code include what one can give and bring to their relationships and also other aspects of their lives. Initially we can think of financial contributions but in reality it is more than that and encompasses what one might contribute to the relationship and is directly related to self-worth.	'Continuing to work', 'earning your place', 'relying on others'	<p><i>"I'm just a body lying here that's not contributing"</i> (Alex, 28yrs, heterosexual, cohabiting)</p> <p><i>"being the provider that's quite a big thing for me"</i> (Ethan, 28yrs, heterosexual, cohabiting)</p> <p><i>"I think as a man, you don't not want to go to work do you, I don't know. I never understand me why people don't want to go to work. Go to work, do your bit and go home and enjoy your life"</i> (Alex, 28yrs, heterosexual, cohabiting x)</p> <p><i>"I wanted to keep doing the same, you know, paying the same bills, you know, paying for food. So I didn't rely on (partner) only from partners wage. So I kept paying what was due and I think my bank went to 0, so my bank account went completely flat"</i> (Frank, 31yrs, bisexual, cohabiting)</p>

Appendix 14: Qualitative study 1 photo analysis exemplars

Associated excerpts

"My rucksack which always contains a spare change of clothes and a toilet roll. I have to take this bag with me everywhere."

"A lot of anxiety came with it, er like everywhere I go, everything I do".

"I think it, it mostly affects sort of like being able to do things so like we do make an effort to go out and try and do stuff and things, but we probably don't do as much as, much things because I can't go places, like this places she wants to go."

Analysis

The majority of photographs did not really directly reflect sexual health and this was expected considered due to the sensitive and private nature of the topic. They do illuminate the way in which men live with the disease. The photo's submitted closely paralleled his story; the anxiety going out, having to be prepared and organised, the disease being part of his every day life and very much a part of his identity.



Associated excerpts

"I've attempted to show what I normally carry in my pockets every day. Left side shows toilet roll, change for public toilets which might charge, and Imodium instants. Right side shows 'urgent cants wait' Crohn's and Colitis card, tofacitinib alert card, steroid alert card, and disabled toilet key".

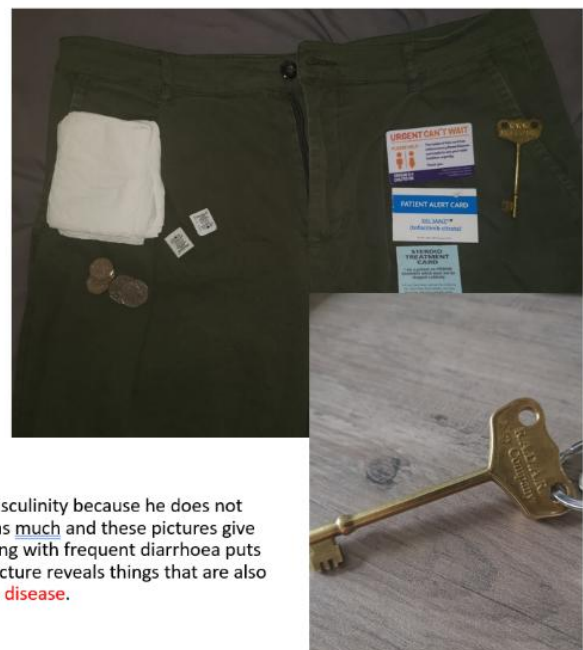
"Shows the RADAR key for disabled toilets that I have to keep on my keys for emergencies."

*"so it does **stop me from doing things** quite regularly, sort of going out and things like that"*

*"I don't think its necessarily the masculinity side because I don't view it as something that I've ever had really, erm I view it more like, it just makes me feel like I can do less and I do feel a bit upset about the fact I can't do these things, I'd be able to, **I've missed out on things**, it makes me feel a bit lesser, than some people maybe"*

Analysis

He mentions that he doesn't feel that the disease impacts his masculinity because he does not see himself as 'masculine'. However, he does report he can't do as much and these pictures give some insight into the limitations on his everyday life and how living with frequent diarrhoea puts constraints on normal activities. What is interesting is that this picture reveals things that are also hidden day to day, once again reflecting the **hidden nature of the disease**.



Associated exerts

"Shows my 'urgent cant wait' Crohn's and Colitis card in my wallet."

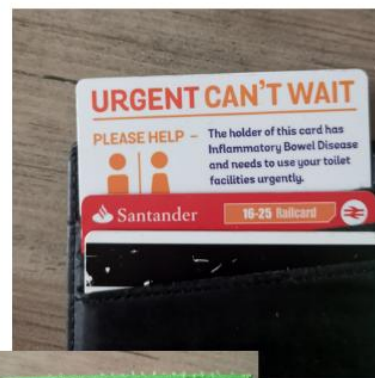
"Section of my wallet where I have to keep my alert cards for tofacitinib and steroids".

"We do talk about it because I do you feel bad about it, and like she is understanding and stuff. And sometimes she will bring it up and be like we need to do more stuff and sort of push me out of my comfort zone, because it used to, because sometimes can get comfortable in not doing things. So she'll make me go do something which is good, especially because you know she knows how like how anxious I feel about it"

"its hard to explain things, and when people thing, cause, for somebody who doesn't know anything, they view it as sort of, a bit of a joke, 'ok, well just hold it', 'we're all tired' sort of thing, it's just people not understanding can make you feel a bit like invalidated, and a bit small, embarrassment. I suppose there is a little bit of it, but not lots of shame".

Analysis

I interpret the cards in the wallet as symbolic of how the disease is part of his identity and its importance in the every day, yet once again hidden. The 'can't wait' card helps him make his disease overt when needed and gives it validation – which is why I aligned it to the quote from his transcript on feeling invalidated.



Associate exerts

Shows the draw that I have to keep all my colitis medication in, all of this is medication I take daily just for colitis, excluding the shingles medication in the top right which I was given for emergencies.

"it got better when I came here because and I have access to more drugs, so (location) I couldn't get vedolizumab or tofacitinib, they don't fund them and my mum had a lot issues with the medical teams and stuff, it was really bad, I was hospitalised three times, maybe 4"

"even if this drug did work realistically it won't work forever and it's not great to be on it, a drug that has all these negative side effects from such a young age, because like the steroids have started to effect my bones and stuff my bone density is really low, so, being on all these different drugs, doesn't really give me any positive"



Analysis

His experience of healthcare has been challenging, with limited access to the right medications ultimately leading him to have his bowel removed leaving him with a stoma. The medications, and prior lack of medications has shaped his experience of the disease. Going for surgery has become the way for him to regain control and in the [interview](#) he looks forward to that and he believe it will better his relationship and improve his [day to day](#) life.

Associate exerts

"Shows vedolizumab injection in fridge (it is out of the box here for the purpose of the picture and the fact I need to get rid of it)."

"Shows sharps bin that is filled with used injections"

Analysis

I find it interesting that he still has his vedolizumab even though he no longer requires it. When he participated in the study he was going through a transitional period. The vedolizumab is there to protect his bowel but the bowel is going to be removed – he needs to get rid of both. **Letting go** and move forwards can be a process for people living with chronic disease and I believe he knows this himself, acknowledging the need to dispose of the medications in his description. The irony of these medications needing to be refrigerated is that many people with this condition often can only tolerate very limited and bland diets. Looking into the fridge and seeing the medications and food together is a powerful image to those who understand the disease. We can also see healthy foods, reflecting that he is invested in his overall health.



Associate exerts

"Thought this might also be useful. In addition, I also have an Infliximab Infusion every two months at my local Hospital. Some of the creams and sprays etc are only used as required, but I'm now feeling ill just looking at them all."

*"well it was a joint decision, because of both of our **health**s really, the sulphasalazine thing is incidental if we had intended on having children anyway, erm but you know I know, if we had decided to go ahead, then that you know could have potentially stopped us anyway, because of the sperm count being low".*

"But I suppose, I had always had slight difficulties maintaining an erection and so on and you know, I have often wondered is this because of the drugs, or is it you know perhaps because as I get older it is probably more difficult, is it just age, am I becoming impotent".

Analysis

He does not like the idea of having to use medication, I wonder whether the daily routine of taking them is a reminder of his health issues. In clinic many people do not like the idea of being on long-term medications, it is a reminder that the condition is **on-going** and they are dependent on something else to keep them well. In his interview he alludes to the side effects of medications including infertility and impotence. This is a common juxtaposition patients struggle with – taking something to improve your health in one way but then compromises something else. The decision to take medications a choice made according to personal priorities, bringing me back to the code **'sex wasn't a priority'**.



Associate exerts

"I would always try and go out on the bike as often as I could, but where I live is up a fairly steep hill, which was great going down hill to work on the bike, but then up hill on the way back wasn't quite so good, so in the end, I just found it too tiring, and one of the problems with IBD is the fatigue, it really is a problem, and that probably indirectly has a bearing on you know my sexual",

"So during the lockdown I realised they were having problems trying to supply bikes, so I promptly advertised mine locally and quickly got £60 or £70 pounds for it, it was a 20 year old bike, it was in good condition to be fair, I looked after it, I've actually achieved, although I have had all these things going on in my life, because I've kept myself busy or occupied in other ways, I suppose in a way, that is, that has fulfilled me in other ways, not in a sexual way, erm but in other ways".



Analysis

This is a further representation of **letting go**, and I do not find it surprising to make this association through photography as we often photograph things that we must relinquish, are proud of or that we know will change.

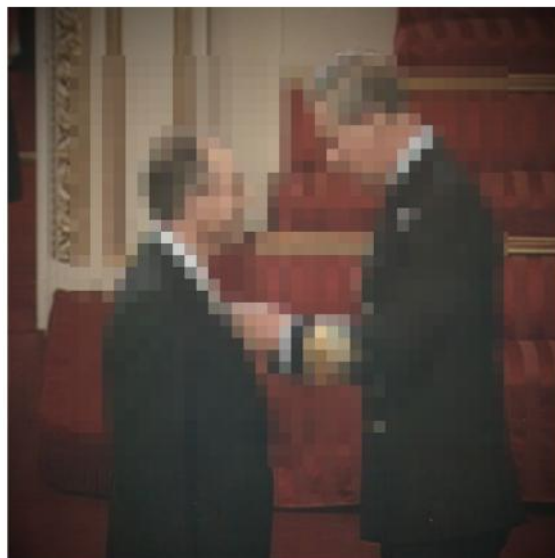
The combination of his disease and other factors puts a stop to cycling and once again we are reminded how the disease can stop people from living their lives. **Physical activity** is a common theme and in the associated quote related the fatigue to both reduced physical activity and sexual engagement and this is important due fatigue being an IBD symptom that is often poorly managed.

Associate exerts

"I've actually achieved, although I have had all these things going on in my life, because I've kept myself busy or occupied in other ways".

Analysis

Being able to achieve in other ways outside of sexual health was an important part of his story. Although he expressed concern that he could not always meet his wives sexual needs he is proud of other aspects of his life (including their love for one another). I have pixelated this picture to protect anonymity but we are still able to see that he is being presented with an award by the then Prince of Wales, now King Charles. I interpret the fact that he chooses to submit this photo, as a reflection of what men may value in their lives and how they may feel rewarded.



Associate exerts

"I was thinking to make something that would bring a smile to people's face."

"So, you know, trying to be more active, you know, going up, going out for walks with my dog every day. So that that would that impacted obviously, because I couldn't really go out much, especially because my dog is a quite you know, medium big size generally quite pully. And you need quite a lot of energy to like to to keep her at bay."

"And then we have a dog now". (When asked about whether he may reconsider having children now he is better)

Analysis

His dog is an important companion who has helped him through the course of his disease – reflected in the quote he attaches to his picture. He talks about how he thought of having children but after becoming unwell he decided against this path, him and his partner instead now have a dog. This is a significant change partly induced by the complexity of his disease course, yet He is accepting and rewarded by the relationship with his furry companion. I interviewed him very shortly after major surgery so only time will tell how he feels after a full recovery.

Again we are reminded of how the disease impacts **physical activity** with him not being able to walk his dog while he was unwell.



Associated exerts

"I've attached a short video, showing the amount of PN & ancillaries I have to take when I travel abroad"

"I had to leave the job and that's when, when they did the first line. I was in hospital for 5 weeks, and I think that's what really hit me a bit, because I was sort of starting again from square one, you know there's, it, it wasn't a great career, the pay wasn't amazing, but it was almost like I could see myself in the games industry",

"it is just, it's it's a waiting game pure and simple. You know I know there's no cure for the Crohn's, I know the Hickman line still there, I'm one, infection, actually, you know one bad connection away from sepsis, you know, so it's like an incredibly vulnerable position to be in",

"there's quite a few accounts for people talk about their stoma bag, but it's very rare, you see any accounts, especially men with hickman lines you know",

"it was only after the line got put in 2012. I think it's probably more of a case of my general health has improved and you know, some of the desire came back",

"yeah spontaneous things are very, very difficult. If I want to go abroad, f I want to go even a weekend away or anything, everything needs to be planned",

"with the fatherhood side of things I think with my son I've always connected, disconnected with him around to the point where I think he just thinks it's normal, you know".

Analysis

TPN has saved his life but at a cost. He has adapted to the limitations it has put on his life but must live with the knowledge he is "one bad connection away from sepsis". The weight of this burden is reflected in the amount of equipment and supplies he uses. Although the TPN line can interfere with sex, he also acknowledges that his sex drive returned after it was fitted and he was better.



Associate experts

"Not sure if this picture is suitable. I have no problem with my image, and even my name is shown. But if you need to, then crop this to a suitable size. Showing the Campaigning and Treatment Advocacy that I have been involved in."

Interviewer: And so do you feel like you've ever needed advice, around your kind of sexual life and in terms of Ulcerative Colitis?
Participant: No, because I engage with everyone, all my conditions, even my optician, actually on Monday, I've got to go into, I've got to go and see an eye specialist, because I might have glaucoma because one of my eyes is really, really, but you know it's only the one, but it could be, that scared me a bit when think about losing sight. But that went, that passed, you know, you know first shock, and then you deal with it. But not really, at that side, I didn't talk about the sexual life, I mean most people I didn't talk you know, none of the things I talked about. Yes, we talked about within the in support groups and everything else about Hep C, HIV, HIV, they did that. Hep C was different. Hep C there was the people who were you called the undetectables, Invincibles that I called them they would live with the HIV Positive, but they were on, on medication, they were, they were, you know, undetectable so they couldn't transmit but you mentioned Hep C and I got blocked out of whatapp groups and, and, and meetings and everything else, they basically just stigmatized me further. And that got me angry, because basically it could be any of us. So that you know that, that's why I started doing this, you know the campaigning and stuff I've done.

"part of the actual volunteering stuff, the social groups we do is basically all we share in talking questions amongst ourselves. We're not medical, but we can... the lived experience is really important."

Analysis

He gives us insight into living with IBD alongside a sexual health disease. His narrative has similarities and differences to others; firstly he occasionally uses a stick to make his illness 'overt' this diverges from others who often conceal their disease or do not consider themselves 'disabled'. As with the badges on his jacket – he wares his disease with overtly and unashamedly. Like others, he reports similar feelings of being marginalised. Having multiple conditions has led him to be engaged with healthcare and a strong sense of wanting to campaign and improve the experiences of others.

PHOTO REDACTED TO PROTECT ANONOMYNITY

Associate experts

"please see below a photo of a small metal tin that is in the bottom of my backpack. I always have it in the bottom of the backpack (which I take to work, out with friends, travelling, everywhere) and kinda nickname it in my head a 'pharmacy tin' it has various tablets in it but also other bits that have ended up in it. I have had some form of this tin in the bottom of my backpack ever since I was diagnosed, although back then it used to have stronger painkillers in it".

"I was quite focused on trying to get myself better, and I think the thought of trying to build a relationship with kind of like new people at that, time was, yeah, I wasn't even really sure what was going on with myself and so I kind of like trying to build a deep connection with someone else was just not, not kind of on the cards, and I think in terms of casual sex, like I was always been a bit wary of that just cause again, especially like when I was first being diagnosed and kind of like first year of uni and and I'm still having those like pains, the thought of like, maybe being overnight somewhere else, at someone else's house, and like all of a sudden being like 'Oh, God, like I feel awful' was just like, I just wouldn't have put myself in that situation, I would rather be at my own uni house, with kind of like my flatmates who I knew I can speak to if I needed to. And yeah, where I knew there was like kind of like painkillers, and like the bathroom and that kind of stuff. So I think it probably, it just it made me like yeah more hesitant like during those early years of diagnosis. But since being in remission, I think the impacts been like yeah, basically none."

Analysis

The tin shows tablets but also interestingly a condom and toothpick. He reports being wary of casual sex but carries these items on him – they could have been left there from before his disease or are they there because he's now back in remission? It is enlightening to have both the picture and account together. The picture is a good representation of how the disease and sexual health are both notable aspects in his life.



Associate exerts

"I've attached a photo of my work laptop bag with my "secret" compartment open showing the change of underwear I carry around with me. I hope that's not inappropriate!"

"A little bit is kind of planning things and eating and drinking, and then all also where access to toilets and that sort of thing. I carry around a change of underwear, just discretely in the side pocket on one of my bag you know my work bag has that, just in case you know, that should happen. And and so it that's it's always I think you kind of understand, realize your own life, but find it fitting those types of things in around is your own, and I certainly have got a lot better at that"

"it's difficult to see that and understand that and know that sometimes I'm gonna be limited in what I can do, and it it's not all the time, and I'm still you know I can still go and play football with him, and we can still do the things we do"

Analysis

This photograph corresponds with other participants stories. It supports the impact on every day life and the hidden nature of this disease. I was interested in the comment that he hopes it was not inappropriate, showing the inherent clandestine nature of matters of the bowel and defecation. Even though he knows I am a nurse he worries that his underwear is inappropriate, such barriers must be brought down if we are to have open conversations about sexual health and well-being.



Associate exerts

"I used to be in decent shape when I was like, back in the States so around 2018 like just before it happened. I had decent muscle on me would be happy to walk around with my top off, I would say that I was very confident"

"So yeah, my job prior to and I was just being a football coach. So then, as soon as I was diagnosed and obviously read into things more and thought of the risks, and what might be, if I have to take a long period of time off, or can't be active as such then the risk of my income suddenly increase a lot hence why I then went into accounting because it's all can be behind a desk if I need to."

Interviewer; And how did that make you feel? Is that something that you were naturally able to transition to?

I struggled being behind a desk to begin with but that's probably explained by the ADHD that I had no idea about at the time. But then at the same time my degree is in sport, all I've wanted to do is sport, and then suddenly feel as though that's being taken away it's a massive knock."

Analysis

So much of his story involves the significant changes brought about by his disease. Football was an important aspect of his life, and there is some grief in what has been lost. Again I do not know if these pictures are pre or post surgery. The composition of the photographs being taken from behind I interpreted as a reflection of his reported loss of confidence or something that is difficult for him to look back on.



Associated exert

"we went on holiday in September, and I had a lot of anxiety about walking around with my top off "

Analysis

I am not sure whether this picture is of the holiday the participant discusses in his interview. However, the fact that he submits a picture where his body is submerged under water and not visible mirrors the story. The picture presents a dichotomy, on the surface is beautiful setting, someone enjoying their holidays and living life to the full. Under the surface of the water is a hidden body, which is representative of the hidden disease. The fact that he presents this picture also shows his unwillingness to share pictures of his body.



Appendix 15: Qualitative study 1 examples of reflexivity in the analytical process

Reflective focus	Reflective diary extract	Explanation of researcher position and impact on data collection and analysis
Methodological: interview technique	We came to this point where I realised that whole background story had a significant part to play. This is a good learning point and in the future I need to allow some time for background and not assume that it's going to be irrelevant.	Allowing the participant to lead and have space to explore the wider context was ensured their lived experience was captured and help to position the interviewer as an observer. The contextual background was essential to disease narratives disease informed the development of the theme on male gender norms and helped interpretations of how and why men responded to their disease in varying ways.
Ethical and methodological: interview technique	At times I felt like we were stepping into a counselling session especially when I asked about how things made him feel, In the future I will try and ask more 'tell me about your experience' – it's a subtle difference but an important one. Feedback from participant included in reflective diary; <i>'I just wish we had this conversation years ago. It could well have changed my life and would have left me feeling more fulfilled in every way'.</i>	Negotiating the role as a nurse-researcher was an important part of the research process. The benefit of nursing experience was the ability to elicit personal life experiences around health but the purpose was not therapeutic intervention. <i>'Good data' often reflects deeply felt and rarely articulated material, and as our study participants come closer to such revelations, our moral obligations toward ongoing negotiation of informed consent is intensified' (Thorne 2016, p124).</i>
Methodological; constant comparative analysis	A contrasting story in that the participant had suffered with the disease since childhood so there was no 'before' and 'after' as with the first interview one. Much more aggressive disease and yet in some ways less emotional about it – possibly because he has had so much time to sit and reflect on it	Reflecting after each interview aided the constant comparative approach and helped to draw parallels and variations between the narratives. This helped identification of gaps which was need to inform the sampling strategy. In this example, the observation led to collecting further accounts from men with variable ages at diagnosis and years since diagnosis.
Analytical	As with interview 1, this participant thought his partner wouldn't be able to view him in the same light after she had seen him unwell – is this an inherently male fear – being seen as sick, being seen in a way you haven't chosen to be?	This reflection demonstrates the process of refining ideas and trying to understand patterns. Noting questions aided the testing of interpretations and articulation of how data has been interrogated. This case shows development of thinking around self and partner perception.
Analytical: uncovering heuristic findings	He doesn't really seem to portray a lived experience where the disease has had a big impact and he is very much a 'just get on with it' kind of person. When you delve in deeper to the story you can see things have been different – he doesn't stay in the swimming pool for very long, he referees instead of playing football, he stays close to people.	To really get to the essence of the human experience it was important to be able pull apart the deeper meanings that lie beneath what was verbally said. To do these initial impressions were noted, then further reflection following audio emersion with the data.

Analytical: uncovering heuristic findings	Being in control is very important to him and that is entwined in also being independent. He wasn't able to do things for himself. Unlike 002, he was able to engage in one night stands, but like 002 trust and being drawn to people who will not judge is very important to him.	This example demonstrates moving from descriptive to interpretive analysis. The descriptive analysis is some men with IBD are not able to engage in one-night stands. The interpretation is the disease can impact on body control and so intimate relations but be with someone who can be empathetic. For some men this need may prohibit engagement in casual intimate relationships where there is an unknown, lack of control or emotional security.
Analytical; remaining close to the data	When coding I initially created many de novo codes to try and keep them close to the data but as more files are added to the data set suddenly the number of codes is becoming unmanageable. As I group codes some of the subtle differences in meaning are lost and I am finding it increasingly difficult to remember all the things I found enlightening that led me to the initial coding. Although the approach is systematic, the subjective and idiosyncratic nature of the data that is so context dependant creates the possibility of varying interpretation.	The process and associated challenges of fracturing and reassembling the data is reflected upon here. It was important to recognise that there are alternative interpretations. Verbalising this process allowed the essence of the human experience to be understood while maintaining closeness to the data. Concerns over losing subtlety in meaning was important in the process of ensuring interpretations and codes remained true to the individual account.
Analytical: personal biases, researcher position	Who am I to describe someone I have only met for an hour...it is to humanise them, note down initial impressions and describe what I feel as I engage with them. Is it even important to the analysis I ask myself? I am not sure but this additional layer of context is not always portrayed through the transcripts, it is felt in the interaction and can be sometimes heard when listening to the interviews. Understanding the underlying personality traits helps contextualise the lived experience and the way the individual has responded to and perceives their condition.	Embracing subjective description of the data is welcomed within an ID approach allowed articulation of interpretations in a transparent way. The descriptions of the people themselves was circumstantial, but understanding the personal response of the researcher to the participant was an important part of the reflective process.
Identifying personal assumptions, managing outliers or opposing cases	Before the interview I knew he was with a male partner, and I wanted to explore how having his rectum removed may have changed the way he experiences sex but was interested to discover that for him although previously he had engaged in anal play this was not important to him so in fact the surgery had not had the impact I thought it may have. Still there was mention of removal of choice – and I feel like although I had not really identified it as a theme, thinking back over the other interviews it most definitely could be.	Identification of subconscious biases or stereotypes was important in the analytical process. This participant was sampled due to his very specific disease presentation and subsequent intervention and his account challenged researcher presumption that the removal of his rectum would be sexually inhibitive. However, his account still presented a common underlying threat of lack of choice thus connecting his experiences to that of other participants.



PROTOCOL: Version 1 (12/01/23)

A qualitative study exploring IBD health professional experiences and understanding of the sexual health and associated care needs in men with inflammatory bowel disease

Short title: Health Professional perspectives on Mens Sexual Health in Inflammatory Bowel Disease (HP-MeSH-IBD Study)

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Committees	<p>Thesis Advisory Panel – role is to inform and guide the progress of the study.</p> <p>Ethics Committee: for review by University of York</p>

ABBREVIATIONS

CI:	Chief Investigator
CNS:	Clinical Nurse Specialist
GMC:	General Medical Council
HPC:	Health and Care Professions Council
IBD:	Inflammatory Bowel Disease
NMC:	Nursing and Midwifery Council
NHS:	National Health Service
NVivo:	A qualitative data analysis software package
PI:	Principal Investigator
PPI:	Public and Patient Involvement
PIS:	Participant Information Sheet
RCN:	Royal College of Nurses
REC:	Research Ethics Committee
SD:	Sexual Dysfunction
SOP:	Standard Operating Procedures
TAP:	Thesis Advisory Panel

STUDY SUMMARY

Study Title	A qualitative study exploring IBD health professional experiences and understanding of the sexual health and associated care needs in men with inflammatory bowel disease
Short Title	Health Professional perspectives of Men's Sexual Health in Inflammatory Bowel Disease (HP- MeSH – IBD)
Study Design	Qualitative interpretive description study.
Research Question	What are health professionals' experiences and perceptions of the sexual health and care needs of men with Inflammatory Bowel Disease?
Research aim	To describe and interpret health professional experiences and understanding of male sexual health and care needs in Inflammatory Bowel Disease, to inform recommendations for clinical practice, education, and research.
Study Participants	Health professionals who have undertaken clinical consultations with men with inflammatory bowel disease including IBD specialist nurses, stoma nurses, Gastroenterologists, surgeons, specialist doctors, GPs, clinical psychologists, dietitians.
Sample size	12-20
Study Period	12 months, commencing April 2023
Data sources	Semi-structure interviews. Research reflective accounts.
Analysis	Inductive thematic analysis as described by Braun and Clarke (2006).

FUNDING AND SUPPORT IN KIND

FUNDER(S)	FINANCIAL AND NON FINANCIAL SUPPORT GIVEN
The University of York	Support in kind; waiving of Clinical Doctoral Fellow university fees, use of university facilities, research advice

ROLE OF STUDY SPONSOR AND FUNDER

The University of York will act as Sponsor for the research project and will therefore have ultimate responsibility of the project.

ROLES AND RESPONSIBILITIES OF STUDY GROUPS

Thesis Advisory Panel

The Thesis Advisory Panel (TAP) are responsible for reviewing the proposed research topic and methodology to ensure appropriateness, achievability, and research rigour.

PROTOCOL CONTRIBUTORS

Sara Ma: study design, conduct, data analysis and reporting.

Professor Paul Galdas: study design, conduct, data analysis and reporting.

Dr Peter Knapp: study design, conduct, data analysis and reporting.

The funder(s) do not control the final decision regarding the design, conduct, data analysis, interpretation, or manuscript of this study.

KEY WORDS

Inflammatory bowel diseases, sexual dysfunction, men, nursing

STUDY FLOW CHART

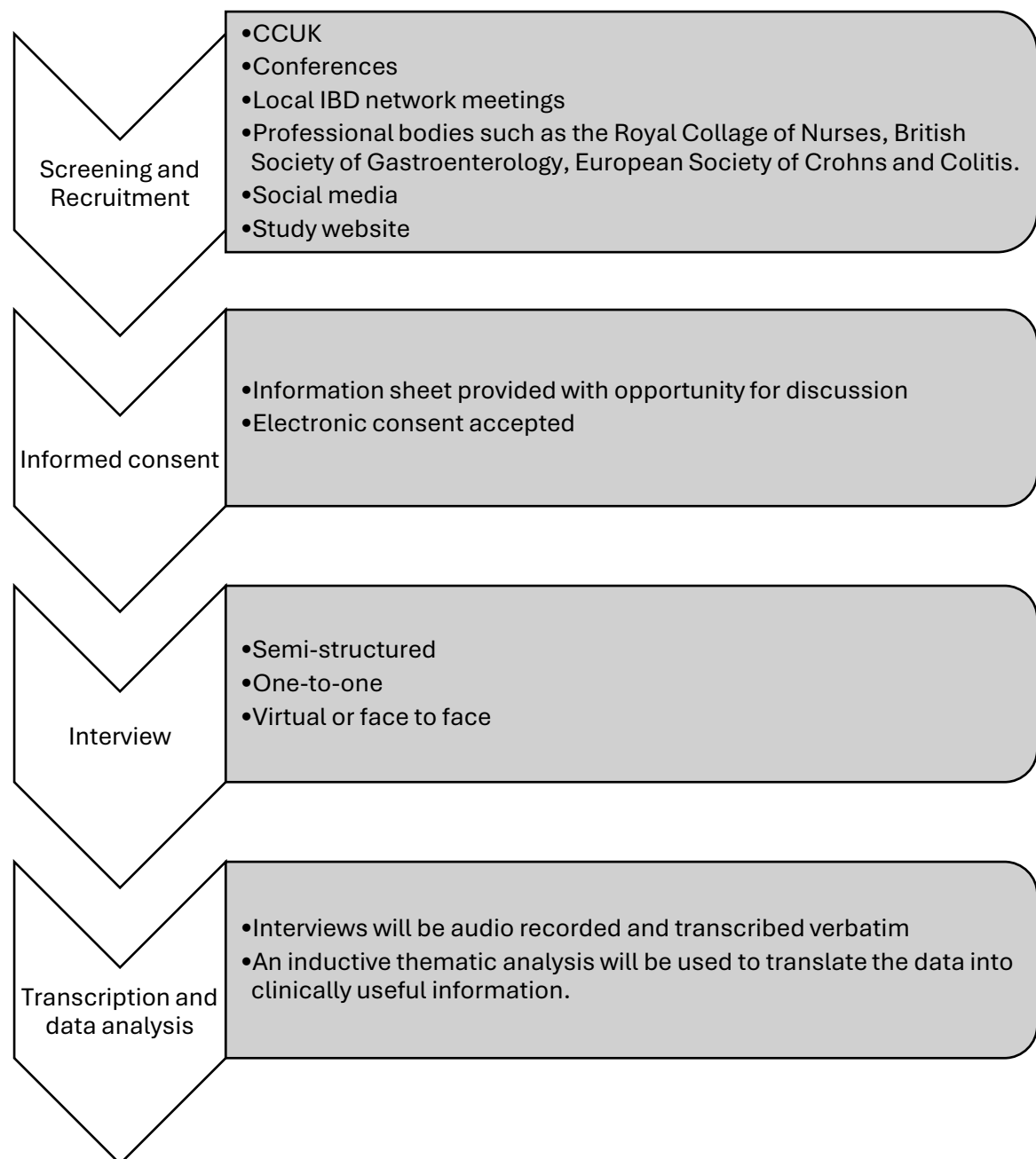


Figure 1; Study Flow Chart

STUDY PROTOCOL

A qualitative study exploring IBD health professional experiences and understanding of the sexual health and associated care needs of men with inflammatory bowel disease

1 Background

Inflammatory Bowel Disease (IBD) is a chronic condition of the gastrointestinal tract that is relapsing and remitting in nature and has a peak incidence between 15 to 30 years (Sturm and White, 2019). Symptoms include bloody diarrhoea, abdominal pain and fatigue, while also being associated with extra-intestinal manifestations in the joints, skin, liver and eyes. The course of the disease is unpredictable and when severe can lead to hospitalisation and surgery.

The diagnosis, assessment and treatment of people with IBD occurs in consultation with General Practitioners, Gastroenterologists, Surgeons, Dietitians and Clinical Nurse Specialists. (CNS's) It is further supported by those working in radiology, endoscopy, pharmacy, infusion units, home care teams, acute hospital wards and in the event of extra-intestinal symptoms other departments such as dermatology, rheumatology and ophthalmology. IBD Clinical Nurse Specialists are often the first point of contact for those with the disease once a diagnosis has been made and are responsible for co-ordinating the patient care pathway. As nursing practice has developed, the clinical specialist nurse-led clinics have broadened their scope of practice to include the initiation, prescribing and reviewing of new medical treatments and investigations. This permits timely and cost-effective medical care but should not replace the psychosocial support and self-management coaching conventionally provided by the nursing team. As clinical pressures have increased over the last few years, personal experience tells us that much of the care provided by CNS's is medically driven. This means that the psycho-social aspects of living with a chronic disease may go unsupported, particularly private matters such as sexual health. Sexual health can greatly influence a person's health and well-being yet there is a paucity of clinical guidance that is IBD specific, particularly in men.

In our exploratory study, Male Sexual Health in Inflammatory Bowel Study (MaSH-IBD, sponsor number; RE22_005_279955, IRAS; 279955), we investigated the sexual health, identity and activity of men with IBD through semi-structured interviews. Men reported the disease disrupted their sex lives and negatively impacted on their intimate relationships. Active bowel symptoms were correlated to a fear of incontinence, feeling unclean, fatigue, a lack of desire, a lack of self-esteem and low confidence. The chronicity and unpredictability of the disease induced feelings of frustration, bitterness and being “lesser” than others. Men in relationships were concerned the disease would make their partners see them differently and whether they would be a burden. Interviews with men who identified as gay and bisexual highlighted the need for better understanding and information on homosexual relationships and receptive anal sex. It was also regularly noted that discussions regarding sexual well-being were not raised in the IBD clinic and there was a perceived lack of understanding of the sexual challenges faced by men with IBD by health professionals.

This is a protocol for a qualitative study that will further expand and develop the findings of the MaSH-IBD study. This is needed in order to develop clinical, educational and research recommendations that are both appropriate and accessible to men with IBD and their health practitioners but also practical and feasible within the clinical environment. Data will be collected using semi-structured interviews. Interpretive description (Thorne, 2016) is the selected methodological framework. Findings from this study will support the development of recommendations for how health professionals may support sexual health in men with IBD. This should lead to further research that validates measures of male sexual dysfunction in IBD, a nurse-led care pathway and the creation of a supportive tool-kit for patients and professionals.

2 Aims and objectives

2.1 Research questions

What are health professionals' experiences and perceptions of the sexual health and associated care needs of men with Inflammatory Bowel Disease?

2.2 Study aims and objectives

This study aims to describe and interpret the experiences and knowledge of health professionals of the sexual health and care needs in men with Inflammatory Bowel Disease to inform recommendations for clinical practice, education, and research.

The study objectives are to:

- I. explore current practice in relation to the assessment of sexual health needs in men with IBD and delivery of care.
- II. explore the perceived barriers and facilitators to engaging with men about their sexual health.
- III. explore professionals' recommendations for ways to improve care.

2.3 Study outcomes

An interpretive understanding of health professionals understanding and needs that will inform the development of an education package and pathway that will improve the clinical practice and care of men with IBD.

3 Study design and methods of data collection and analysis

3.1 Study design

A qualitative interpretive description design using individual semi-structured interviews. Interpretive Description (Thorne, 2016) has been selected as a methodological approach as it is grounded in nursing and suited for examining experience and translating that into clinically applicable information. Interpretive Description (ID) was successfully utilised in the precluding MaSH-IBD Study (IRAS; 279955, RE22_005_279955) as it permitted flexibility in the selection of sampling, data collection and analysis methods to suit the research question while prescribing a reflexive approach that allowed the clinical researcher to exploit and draw upon their

own knowledge and experience during data collection and analysis. This underlining methodological framework will be replicated in this study.

3.2 Study Methods

3.2.1 Sampling

The study population are registered health professionals who are regularly involved in the healthcare of men with IBD and routinely make up the IBD multi-disciplinary team.

Professional Group	Key informants	Registering body
Medical doctors	Gastroenterology Consultants and Registrars. Surgeons with a specialist interest in IBD. General Practitioners	General medical council (GMC)
Nurses	IBD and Gastroenterology Specialist Nurses Stoma Nurses Biologics/Infusion unit nurses Nurse endoscopists	Nursing and Midwifery Council (NMC)
Clinical Psychologists	Clinical psychologists working within gastroenterology departments or with a specialist interest in IBD.	Health and Care Professions Council (HCPC).
Dietitians	Hospital based dietitians working in gastroenterology departments.	Health and Care Professions Council (HCPC).

Table 1: Study population

Purposive sampling will be used as it allows the researchers to utilise their expertise to select potential participants on their ability to provide rich and informative data. In this study, our 'key informants' (Thorne, 2016) who are most likely to produce the most contextually relevant findings is experienced clinicians that regularly and directly provide health care to men with IBD in varying settings. We have included the four professional groups listed in Table 1 to promote sample diversity. The key informants list is not exhaustive but represents those who are most likely to have direct and regular contact with men with IBD and have involvement in the clinical assessment and management. Purposive sampling is also cost and time effective which is of essence in the context of a PhD.

A sample of 12-20 is argued to be a suitable sample size when looking for disconfirming evidence and trying to achieve maximum variation (Kuzel, 1992). This sample size should also allow us to recruit more than one participant from each of the professional groups identified above and also opportunity for variation in other factors identified to enhance representation, including;

- Geographical location, in order to capture professionals who care for varying populations and within varying clinical practices.
- Level of expertise and training, to represent the diversity of experience, training and expertise that occurs in the clinical environment

3.2.2 Eligibility criteria

Inclusion criteria;

- Adult, aged 18 years or above
- A health professional registered with the GMC, NMC or HCPC who's professional role is considered part of the IBD multidisciplinary team.
- Currently or previously employed in a role that directly provides care, support or advice to men with a diagnosis of IBD.
- Able to give informed consent

3.2.3 Recruitment process

Relevant professional organisations, committees and networks will be used to publicise the study and invite expressions of interest to become a participant. These specifically include the following;

- Crohns and Colitis UK
- The RCN IBD facebook group
- Local IBD specialist nurse networks
- NIHR Clinical Research Network

The study will also be advertised at any relevant conferences or meetings.

Participants who express an interest in taking part will be sent the information sheet and invited to ask any questions, prior to completing a consent form (see appendices). It will be made explicit that participation is voluntary and there is no financial reward.

3.2.4 Data collection

Interviews will be held mainly via video conference call but for any participants who would prefer a face to face interview and can attend the University of York without need for travel re-imbursement a face-to-face appointment can be held. Semi-structured interviews have been selected as they are able to To ensure they are provided with the opportunity to participate and to capture the views of varying

professional groups the option of an individual semi-structured interview will also be available. This will be conducted remotely either via telephone or video call.

3.2.5 Data Analysis

Thematic analysis as described by Braun and Clarke (2006) is suited for this research not only for its systematic approach at identifying, categorising and translating patterns of meaning most relevant to the research question but also effective at reporting collective and 'obvious' semantic meanings (Braun and Clarke, 2012). Furthermore, thematic analysis is suitable for the constructivist theoretical framework this study sits within, allowing the researcher to utilise their expertise and prior knowledge in the data collection to obtain clinically relevant information. As this area is poorly explored, an inductive approach will allow findings to emerge from the perspectives of the health professionals, however it must also be recognised that some elements of deductive analysis will also be used as the researchers draw upon their findings of the patient participant study MaSH-IBD. The six phases of analysis as described by Braun and Clarke (2006) as detailed in figure 2 will be applied.

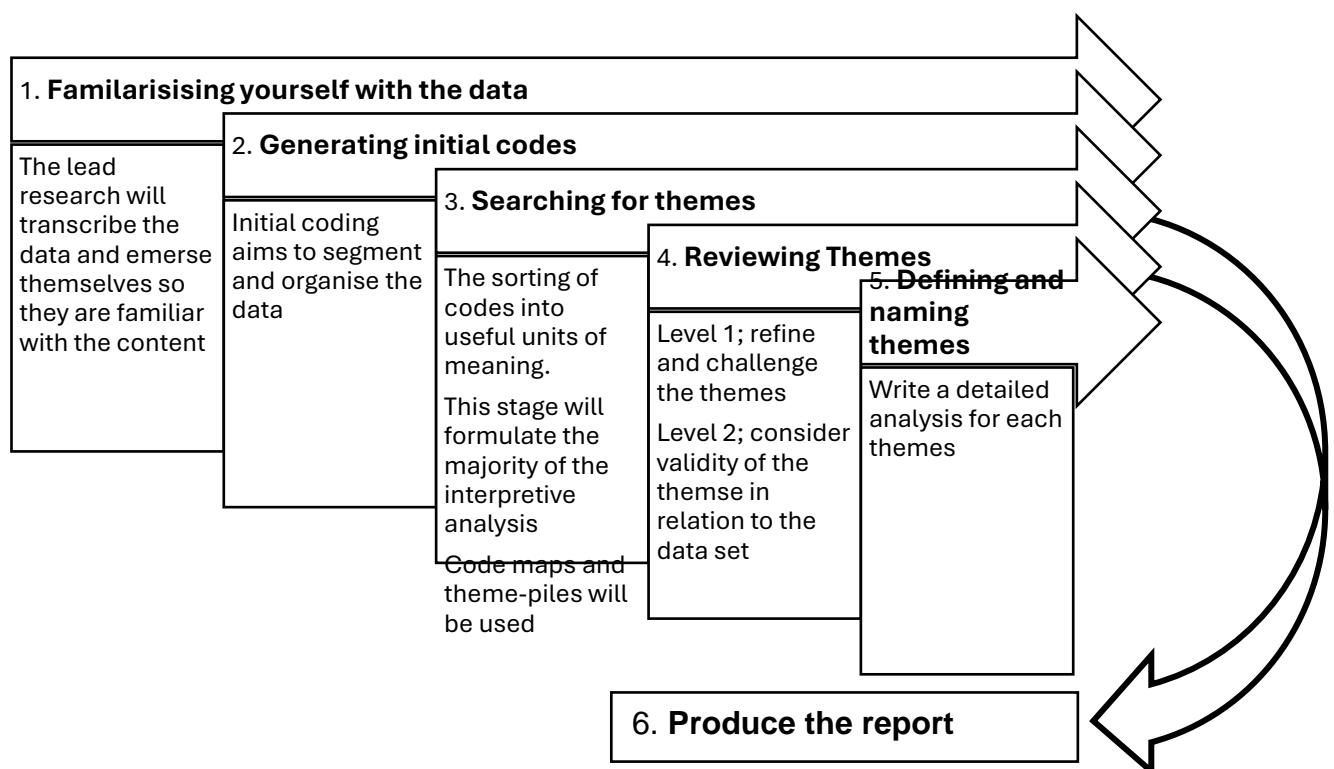


Figure 2; Thematic Analysis (Braun and Clarke, 2006)

3.2.6 Methodological limitations

This is a qualitative study designed to improve insight into health professional perspectives on the sexual health of men with IBD and what is needed by clinicians to improve practice. Generalisability of the results must be carefully considered.

With purposive sampling it is difficult to pre-determine the sample size as the range of variation in the sample cannot be fully known at the outside. An iterative and reflexive approach will ensure transparency of this process. It may not be possible to achieve maximum variation sampling, for example a male IBD specialist nurse may come forward for interview, so careful consideration of the generalisability of the data collected alongside identification of gaps for further exploration must be described within the findings.

4 Ethical and regulatory considerations

4.1 Assessment and management of risk

Risk to participants: This has been deemed a low-risk study as no intervention is being performed. This is not a clinical trial of a medicinal product. There is a small risk that the interviews may elicit upsetting feelings. Participants will be made aware that they do not need to answer any question and may withdraw at any time. The interviewer will be a registered nurse and can respond to this and escalate and issues raised accordingly. Participants are registered health professionals accustomed to discussing patient conditions, service delivery and clinical needs. There may be some inconvenience to participants regarding the time taken to participate.

Risk to researchers: The study carries very little risk to the interviewer. The interviewer is an experienced nurse and researcher accustomed to discussing clinical matters and patient care. Face to face interviews will only be conducted on the University grounds to reduce any risk to the researcher and mitigate lone working risk.

Informed consent: The process for obtaining informed consent will be in accordance with Good Clinical Practice (GCP). Due to the low-risk nature of the study consent forms may be electronically signed by the participants.

Enrolment log: this will be the only location of personal information that is not anonymised and kept only for the purpose of contacting participants and quality

assurance of the research. It will password protected and kept on the secure digital network of the host institution.

Recruitment: The researcher/interviewer may be known to participants. No coercion or undue influence to take part will be used. Participants will be made aware that this is voluntary, declining to take part will not affect their clinical care and they are free to withdraw at any point without giving a reason.

Deception: No misleading information will be given and no intentional deception used.

4.2 Research governance

The protocol will be submitted to a University of York research governance committee for ethical approval. The study will not commence until a favourable opinion has been received.

All correspondence with the committee will be kept within the study site file. The CI will notify the committee when the study has close and provide a final report within 12 months after the close of the study.

Amendments will be reviewed by the Sponsor to assess whether they are substantial or non-substantial. Substantial amendments will be submitted to the REC for consideration. An amendment history will be kept within the study site file.

4.3 Peer review

This protocol was initially developed by Sara Ma and has been reviewed by Professor Galdas and Dr Knapp through the PhD supervisory process. Two patient representatives have reviewed the protocol.

4.4 Protocol compliance

The research team will take the upmost care to adhere to the protocol throughout the study. Accidental protocol deviations can happen and should be documented and reported to the Chief Investigator and Sponsor straight away. Any deviations that recur will require immediate investigation and could be classified as a serious breach.

4.5 Data protection and patient confidentiality

Storage and access to the data will comply with Data Protection Act (2018) and GDPR regulations (2016) and the University of York Research Data Management policies. To ensure confidentiality of both professional participants and any discussions of patient interactions there will be an agreement at the start of each

interview patient confidentiality must be maintained during the study. Participant names will be redacted from transcripts and replaced with an allocated number. A separate document will provide a list of study numbers and participant names. As this document will contain identifiable information it will only be accessible by appropriate study members for the purposes of conducting the research and auditing. The document will be stored separately from the site file and trial data using password protected storage on the University of York. Electronic files will be stored only on The University of York secure network.

Audio files will be downloaded onto the University network and password protected as soon as is reasonably possible after the interview. In most cases, it is envisaged that this will occur on the same day. The original digital file on the Dictaphone will be deleted immediately after downloading. Audio files may be transcribed by an external transcription service. If this is the case, a confidentiality agreement will be used. A SOP will be created for the storage and transfer of audio files in the case of external transcription. Audio files will be deleted at the end of the study. Written transcripts will be reviewed by the research team so that any identifiable information can be removed, these will be stored with the study data for 5 years after the completion of the study.

At the end of the study, data will be archived as per the University SOPs. Data will be archived for 10 years. If a participant decides to withdraw from the study, all data collected to the point of withdrawal will be kept as above and may be used within the study.

Access to data will be limited to relevant individuals of the research team and the PI will act as the data custodian.

4.6 Indemnity

The University of York will act as Sponsor for the project and provided legal liability insurance..

5 Dissemination

5.1 Dissemination policy

Data arising from the study will be owned by the Sponsor, The University of York. On completion of the study, the data will be analysed and presented as part of a PhD thesis. The PhD thesis will be made available via the University of York Library.

A short report of the findings will be prepared and provided to the research governance committee and participants.

The researchers will aim to publish a research article in a peer reviewed academic journal. If funding is sourced to contribute to the open publication of this, then acknowledgement of the funders will be made. Findings will also be presented at relevant medical and academic conferences.

5.2 Authorship eligibility guidelines and any intended use of professional writers

Authorship will be granted to Sara Ma, Professor Galdas and Dr Knapp. If any further investigators join the team that make a substantial contribution to the collection or analysis of data or writing of the final study report they will also be granted authorship. All other contributors will be acknowledged.

8 References

Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), pp. 77-101. Available at: 10.1191/1478088706qp063oa [Accessed 20 October 2021].

Braun, V. and Clarke, V. (2012). Thematic analysis. *APA handbook of research methods in psychology*, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological. Washington, DC, US: American Psychological Association.

Kuzel, A. J. (1992). Sampling in qualitative inquiry. In Crabtree, B. & Miller, W. (eds.) *Doing qualitative research*. Newbury Park, CA: Sage Publications.

Sturm, A. and White, L. (2019). *Inflammatory Bowel Disease Nursing Manual*, Switzerland: Springer.

Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice*, New York: Routledge.

9 Appendices

Required documentation

- 9.1 Participant information sheet
- 9.2 Consent form
- 9.3 Contact us leaflet
- 9.4 Cover letter
- 9.5 Management plan
- 9.6 Interview guide

Amendment History

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made

Appendix 17: Qualitative study 2 ethical approval letter and application



Department of Health Sciences

c/o Department of Philosophy
Heslington
York YO10 5DD

Telephone (01904) 323253/1
E-mail
stephen.holland@york.ac.uk

Prof Stephen Holland
Chair, Health Sciences Research
Governance Committee

www.york.ac.uk/healthsciences

3 February 2023

Mrs S Ma
University of York
Department of Health Sciences
York
YO10 5DD

Dear Sara

HSRGC/2023/546/B: Health professional perspectives of Men's Sexual Health in Inflammatory Bowel Disease (HP- MeSH – IBD)

Thank you for submitting your project to the Health Sciences' Research Governance Committee for approval. The committee considered the application at its meeting on 30 January 2023.

I am pleased to confirm that the project was approved by the committee. I was asked to provide the following feedback to be taken up within the study team.

- The committee were a little unclear as to why there is a cover letter (Appendix 9.4) since the approach will be through the ContactUsLeaflet (Appendix 9.3). To be clear, the letter is fine, and if this is simply an alternative way of approaching prospective participants, that's fine too. But it doesn't tally with the recruitment method described in S.12 of the submission, so please raise this with your supervisors to check that the initial approach is appropriate.

If you have any queries regarding the decision, or make any substantial amendments to the study, please contact me. Finally, if you intend to include this decision letter in any assessed work that will be anonymously marked, please ensure that your name is not disclosed.

Yours sincerely

A handwritten signature in purple ink that reads 'S. Holland'.

UNIVERSITY *of York*
The Department of Health Sciences

RESEARCH GOVERNANCE COMMITTEE

SUBMISSION FORM

Please refer to the Guidance Notes at the end for help with filling in this form.

Please complete the following check-list before submitting the completed form:

I have completed all relevant sections of the Submission Form having read the 'Guidance Notes'.

I have signed my Submission Form.

[Student submissions only] My Supervisor(s) have read and signed my Submission Form

I have attached all supporting documents (information sheet, consent form, etc.) to my Submission Form.

I agree to inform the HSRGC of any major changes to my research.

GENERAL INFORMATION

1. Please give the full title of your study, and provide a short title for reference.

Full title	A qualitative study exploring IBD health professional experiences and understanding of the sexual health and care of me with inflammatory bowel disease
Short title	Health professional perspectives of Mens Sexual Health in Inflammatory Bowel Disease (HP- MeSH – IBD)

2. If you are an academic member of staff, please provide the following details about yourself.

Name and title	
Post	
Institution (including address if other than Health Sciences)	
Email and telephone number	

3. If you are a research student, please provide the following details.

Your name and title	Mrs Sara Ma
Name and level of course/degree	PhD Health Sciences
Institution (including address if other than Health Sciences)	University of York, Department of Health Sciences
Email and telephone number	Srm537@york.ac.uk, sara.ma2@nhs.net 07821 586796
Name and email address of supervisor(s)	Professor Paul Galdas, paul.galdas@york.ac.uk Dr Peter Knapp, peter.knapp@york.ac.uk

4. Please briefly describe the specific expertise, including experience and training, you and your research team will bring to the study.

Qualitative Research Methods module at MSc level (University of York)

Advanced qualitative methods course; Ethics of Methodology (White Rose Consortium)

Good clinical practice training (NIHR)

Academic Integrity Tutorial (University of York)

Experience; conducted 1st PhD study - Male Sexual Health in Inflammatory Bowel Disease

5. If the research is funded, please provide the following details.

Name of funding body	York and Scarborough Teaching Hospital NHS Foundation Trust
Duration of the grant	5 years
Describe any external influence the funding body has on the conduct or dissemination of the research	I am provided a stipend to support my studies but the data rights and study ownership remains with The University of York as the sponsor.

6. If the research is to be reviewed by an ethics committee other than HSRGC, please provide details.

N/A

THE PROJECT

7. Explain the aims, objectives and scientific justification of the research, in a maximum of 200 words, and in language comprehensible to a layperson.

Inflammatory Bowel Disease is a chronic condition of the gastrointestinal tract that can bring about distressing and life-inhibiting symptoms. When severe it can cause a threat to life and need hospital admission and surgical intervention. Sexual activity is a healthy human behaviour that should be assessed by clinicians as a part of a holistic health assessment. A literature review (Ma et al. 2020) has revealed a lack of information on male sexual health in inflammatory bowel disease and a potential unmet clinical need. We are currently conducting a

qualitative study to explore the lived sexual health experiences of men with IBD (MaSH-IBD, RE22_005_279955). This study aims to describe and interpret the experiences and knowledge of health professionals so that we can put forward recommendations for clinical practice and research that are appropriate and accessible to patients and their clinicians.

The study objectives are to:

- (1) explore current practice in relation to the assessment of sexual health needs in men with IBD and delivery of care.
- (2) explore the perceived barriers and facilitators to engaging with men about their sexual health.
- (3) explore professionals' recommendations for ways to improve care.

8. Please provide a brief summary of the research design/method, in a maximum of 200 words, and in language comprehensible to a layperson.

This qualitative study will involve semi-structure interviews with registered health professionals. Participants will include medical consultants, doctors, surgeons, endoscopists, nurses, clinical psychologists, and dietitians. They should have experience of working in a professional capacity to provide care, support, or advice to men with a diagnosis of IBD.

A purposive sampling strategy will be used. We will recruit 12-20 participants which is a recommended sample size for reaching variation in qualitative interviews (Kuzel, 1992, Guest et al. 2017, Gues Bunce and Johnson, 2006). It is our intention to recruit participants from a medical, nursing and allied-health professional backgrounds, working in different clinical settings and who serve varying populations across the UK. Interviews will be conducted either face to face or online using a video conferencing programme. Semi-structured interviews offer a valid research method for collecting and exploring experiences and personal opinions. Interviews will be audio recorded, transcribed and analysed using thematic analysis (Braun and Clarke, 2006). Informed, written consent will be obtained. Transcriptions will be immediately anonymised. At the end of the study the recordings will be deleted, and the anonymised transcripts archived.

If approvals are in place, recruitment we aim to start no later than April 2023 and finish by March 2024.

9. Please outline any patient and public involvement (PPI) in the study.

Two patient representatives have read and reviewed the study protocol and interview guide.

10. If the study requires statistical analysis, please explain your statistical methods.

N/A

11. For qualitative studies, please outline your method of analysis.

This study will use thematic analysis as described by Braun and Clarke (2006) as it uses a systematic approach for identifying, categorising, and translating patterns of meaning that are most relevant to the research question. The six phases include;

- 1) Familiarising yourself with the data
- 2) Generating initial codes
- 3) Searching for themes
- 4) Reviewing themes
- 5) Defining and naming themes
- 6) Writing the report

This will mainly be an inductive process that will lead to both description and interpretation of the data. Findings will be represented using code maps and appropriate illustrative measures.

As with many qualitative studies there is not a predetermined sample size. 12-20 participants has been argued to be an acceptable sample size when looking for disconfirming evidence and trying to achieve maximum variation (Kuzel, 1992). We are hoping to conduct interviews with male and females, representatives from each of the usual IBD multi-disciplinary team members (namely; consultants, doctors, surgeons, endoscopists, nurses, dietitians, clinical psychologists, we have not included radiologists as they have limited direct patient contact). We also aim to recruit health professionals from across the UK.

RECRUITING PARTICIPANTS

12. Please explain how research participants will be (a) identified (b) approached and (c) recruited.

Relevant professional organisations, committees and networks will be used to recruit health professionals that meet the criteria including but not limited to Crohns and Colitis UK, the Royal College of Nursing, NIHR Clinical Research Networks.

Potential participants will not be excluded in regard to gender, age, race/ethnicity, sexual preference, faith or disability.

Inclusion criteria;

- Adult, aged 18 years or above
- A health professional registered with the GMC, NMC or HCPC who's professional role is considered part of the IBD multidisciplinary team.
- Currently or previously employed in a role that directly provides care, support or advice to men with a diagnosis of IBD.
- Able to give informed consent

Invitation to participate will be made using the contact us leaflets that will be made available at professional conferences or meetings. Social media adverts will be created using the wording from these documents, for example a post on the RCN IBD Network Facebook group.

Permission from the appropriate owners/chairs/organisers if the professional networks will be sought before advertising takes place. Approaches to participants will not be made directly through NHS organisations and therefore HRA/IRAS will not be required for this project. As participants are not clinical patients but professionals and because we are not approaching professionals through their employing organisations a direct approach when suitable (for example the researcher handing out information sheets at a conference) is justified. No coercion will take place. The lead researcher is a clinician who previously worked as a research nurse and is trained and experienced in Good Clinical Practice and Informed Consent. Informed consent will occur after the participant has time to consider the participant information sheet (PIS). This should ideally be at least 24 hours, although less will be appropriate if the participant feels that they have had time to consider the study and any questions answered. This is considered acceptable as participants are registered health professionals who are accustomed to weighing up the potential benefits and risks of participation in research and reading research documentation. A copy of the signed consent will be provided to the participant.

The PIS and consent form makes explicit that the participant is free to withdraw at any time without giving any reason. This will also be verbally relayed during the consenting process. All data collected until the point of withdrawal will be used within the study and this is also made explicit in the PIS.

13. If participants are to receive incentives to take part in the study, or reimbursement of expenses, please give details and rationale.

There will be no incentives to participate.

14. If your study includes participants from vulnerable groups, please provide details and rationale.

N/A

15. Please explain any arrangements for participants who do not understand English well.

N/A

ETHICAL ISSUES

16. Please clarify and justify potential harms to participants.

There is no envisaged harm to participants.

17. If your study is likely to elicit information requiring disclosure – such as incidental medical findings, evidence of professional misconduct or neglect, or criminal behaviour – please explain how you will proceed.

This is very unlikely to occur.

In the event of a disclosure, it will be discussed with the supervisory team and reported to the professional governing body, employer and/or police will be made as appropriate.

18. Please explain and justify any deception of participants required by the study.

No deception required by study.

19. Please describe any potential benefits to participants.

Participants will have the opportunity to discuss, share and reflect upon clinical practice. In the future, there may be in indirect benefit of improvements to healthcare practice and education.

20. Please clarify and justify potential harms to researchers.

There is no envisage harm to the researcher.

21. Please provide details of any conflicts of interest created by the research and explain how they will be resolved.

There are no conflicts of interest.

22. Please provide details of any personal material benefits researchers will receive for undertaking this study, including personal payment over and above their normal salary.

I receive an annual stipend to support my PhD studies from York and Scarborough Teaching Hospital, NHS Foundation Trust.

23. Please describe any other ethical problems you think the proposed study raises, explaining what steps you will take to address them.

This study is a low-risk study and no clinical intervention is being performed. Participants are registered health professionals accustomed to discussing patient conditions, service delivery and clinical needs. It is recognised that these discussions can sometimes be upsetting or induce bad memories. The researcher is a registered nurse who can identify, respond, and escalate any psychological burden induced.

There is very little risk to the researcher as the participants are professional peers and the interviews will be held on campus or online. The interviews will be held professionally and with research integrity to maintain the researchers and the University of York's reputation as per the university research policies and codes of practice (<https://www.york.ac.uk/staff/research/governance/research-policies/>).

Data will be managed in accordance with relevant laws, regulations and policies as detailed in the following section.

The researcher may be known to the participants, but no coercion or undue influence will be used. Reflective supervision will be conducted by the supervisory team on the recruitment process.

The researcher is trained in Good Clinical Practice (GCP), has undertaken the departments Research and Academic Integrity courses, and is supervised by two senior University of York employees.

Participants will be asked to consent to upholding professional integrity and maintaining patient confidentiality during the study.

The researcher has recently conducted a study involving semi-structured interviews and undertaking the training as detailed in box 4.

No ethical issues were raised by the patient representatives.

DATA MANAGEMENT

24. Please explain what, where, and for how long data will be stored.

Please refer to the submitted data management plan for further detail.

Participant contact details, consent forms audio recordings of the interviews, researcher notes, transcriptions and analysis files will be stored at The University of York either electronically on the university server or in a locked cabinet if hard copy. Data will be archived at the end of the study. Participant contact details (name, email address and if preferred postal address) will only be collected for dissemination of results and be kept for 3 years, and all other data archived for 10 years after the end of the study.

25. Please explain the process by which data will be transferred.

Data will be directly downloaded onto the university server through the VPN connection or via <https://dropoff.york.ac.uk>.

26. Please set out how anonymity of data will be ensured; if data are not anonymised, explain why not and describe how data confidentiality will be maintained.

Transcriptions will be immediately anonymised.

Participants will be given a number along with a code to denote their professional occupation.

27. Please state who will have access to data generated by the study.

The PhD supervisory team and examining body if required as part of the examination process.

Anonymised data will be made available to peer reviewers should they request access to the data set.

The data set may be made available to other researchers if the correct approvals are obtained and it is within the defined purposes set out in the consent form and PIS.

28. Please state who will act as custodian of data generated by the study.

Professor Paul Galdas.

29. Please state whether the study requires a Data Protection Impact Assessment.

A DPIA is not required.

30. Please state whether your data has to be included in the Health Sciences data asset register and, if so, whether the asset register questionnaire has been completed and returned to the IT manager.

The asset register has been completed and returned to the IT manager.

DISSEMINATION

31. Please explain how you plan to disseminate your results.

We hope to publish the results of the study in specialist nursing or medical journals. We may also present the study at professional conferences, meetings and to relevant staff and patient groups.

The study will formulate part of a PhD thesis which will be made available on the University of York and White Rose repository.

32. If results will be made available to participants and the communities from which they are drawn, please explain how.

Participants will be asked if they would like to be provided a copy (either electronically or by post) of the final study report.

INDEMNITY

33. Please confirm the indemnity arrangements for your study.

Standard University of York indemnity arrangement	Yes
Other indemnity arrangement	

Your signature:  (12/01/2023)

Supervisor(s)' Signature:  (12/01/2023)



Are you a registered health professional who works with men with IBD?

Are you able to participate in an interview to help improve understanding and patient care?

This study aims to find out more about health professionals experiences and understanding of sexual health in men with IBD so that we can improve care.

The study is being run by The University of York as part of a PhD project.

The lead researcher is an Inflammatory Bowel Disease Specialist Nurse at York and Scarborough Teaching Hospital, NHS Foundation Trust.

The study has full ethical approval and confidentiality will be maintained.



Sara.ma2@nhs.net
Srm537@york.ac.uk



01904 72 6154



<https://sites.google.com/york.ac.uk/mash-ibdstudy/home>

Version 1.0 12/01/2023

Appendix 19: Qualitative study 2 participant information leaflet



Health Professional perceptions of Mens Sexual Health in Inflammatory Bowel Disease (HP-MeSH-IBD)

Participant information sheet

Introduction

We would like to invite you to take part in a research study. Before you decide whether you would like to participate, we would like you to understand why the research is being done and what it would involve for you. Please take time to decide if you would like to take part and ask for clarification if there is anything that is not clear. Our contact details are on the final page of this information sheet.

What is the purpose of the study?

As you will know, Inflammatory bowel disease (IBD) is a chronic, relapsing and remitting disease that can cause distressing and embarrassing symptoms that may include; urgency, rectal bleeding, abdominal pain, fatigue and malnutrition.

Sexual health and well-being are an important part of life. It is possible that IBD impacts on a person's desire and ability to have sex. However, as this is a 'taboo' subject and private matter, the research in this area is limited. IBD can affect pregnancy and fertility in women so there has been some research with female participants. However, the male perspective is under-represented.

I have been interviewing men with IBD to uncover the impacts on the disease on their sexual health and well-being. I now want to talk to healthcare professionals to gain further depth of understanding about this sensitive and hidden topic. This research will inform recommendations for further research and clinical intervention so that health professionals can develop IBD services to offer appropriate support to patients.

Who is running this study?

The research is being led by an IBD Specialist Nurse who is employed by York and Scarborough Teaching Hospitals, NHS Foundation Trust. This study is part of a doctoral degree in Health Sciences at The University of York. This study is being sponsored by The University of York.

Why have I been invited to take part in this study?

I am inviting you to take part in this study because you are a registered health professional with experience of working with men with Inflammatory Bowel Disease.

Do I have to take part?

You are under no obligation to take part in this study. If you decide that you would like to take part, we will ask you to sign a consent form.

Can I withdraw from the study at any time?

You are free to withdraw from the study at any time and without giving a reason. Please contact the researchers using the contact information on the final page of this information sheet or notify them during the interview if you would like to withdraw. All information collected until the point of withdrawal will be retained.

What is involved?

This study involves you:

- consenting to take part in the study by signing a consent form;
- participating in a semi-structured interview.

The interview will be approximately 60 minutes long. It will either be held via a video conference platform such as zoom or face to face at the University of York if you prefer. The interviews will be recorded and transcribed. Any information that can identify you, such as your name will be removed from the written version. The recording will be deleted at the end of the study.

The study will last for 12 months but your involvement will be only for the duration of the interview. The data obtained during this will be anonymised and kept for 10 years after the end of the study.

What are the benefits to taking part in the study?

You may benefit from meeting other health professionals working in IBD and discussing clinical practice. In the future, health professionals and patients may benefit from any improvements to care that are the result of the information we find.

What are the disadvantages or risks to taking part in the study?

We cannot offer you payment or funding for the time you give to participate and it must be undertaken in a voluntary capacity. We do not envisage any risks to you of taking part.

Who is funding the study?

The study is financially supported by the University of York. York and Scarborough Teaching Hospital, NHS Foundation Trust provide me with a stipend for the 2 days a week I dedicate to my studies.

Who has reviewed the study?

The study has been reviewed by my PhD supervisory team and the University of York's Health and Sciences Research Governance Committee.

How will the information and personal data I give be handled?

You can find out more about how we use your information;

- at <https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/>
- at <https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/research-participants/>
- by emailing the University of York's data protection officer on dataprotection@york.ac.uk

If you decide to take part in this study, what you tell us will be kept safe and confidential. Data collected for the study may be looked at by authorised persons who are organising the research or checking that the study is being carried out correctly. All have a duty of confidentiality to you as a research participant.

The only time we would break our duty of confidentiality is if we are worried that you – or someone else – was being or likely to be, harmed. If that happens, any concerns will be escalated through the appropriate safe-guarding channels which may involve disclosure of your name, contact details and audio recordings.

To safeguard your rights, we will use the minimum personally identifiable information possible. The information that we collect include your name, contact details, profession and what you say during the interview. The University of York is a publicly funded organisation that conducts research to improve health and healthcare services. In legal terms, we are using your information for this research as part of 'a task in the public interest'. This means the ability to change the data that we have collected, however, is limited, as we need to manage your information in specific ways for the research to be reliable and accurate.

Your name, contact details and interview recordings will be stored electronically on a secure network at the University of York. Access to this information will be restricted to authorised persons only. We will store hard copies of consents in a locked filing cabinet in a locked room which is not accessible to the public and only accessible to the research team.

The research team will securely keep a record of your name and contact details for a period of 3 years after your interview. This information will only be used to contact you about your involvement in the study or to send you a summary of the results if you request this.

At the end of the study any audio or video recordings will be deleted and all other study documentation will be stored securely for 10 years as is normal practice for research data. After this time all data will be destroyed.

[What will happen to the results of this study?](#)

We hope to publish the results of the study in specialist nursing or medical journals. We may also present the study at professional conferences, meetings and to relevant staff and patient groups. It is possible that some short direct quotes may be given in the presentation. Every measure will be taken to ensure these are appropriate and respectful and we will ensure that these would not identify you.

If you would like to find out about the results of the study, please let us know and we will endeavour to send you a copy of the final study report or publication.

One way we can get the most benefit from this work is to make the study data available for secondary research purposes and in future research. The study data may be reused by the research team but will not be used or released in such a way that you could be identified.

What if there is a problem?

If you are unhappy about any aspect of this study or wish to make a complaint, please contact Professor Paul Galdas.

If you are unhappy with the way your personal data has been handled, please contact the University's Data Protection Officer at dataprotection@york.ac.uk. If you are not satisfied with our response, you have a right to complain to the Information Commissioner's Office. For information on reporting a concern to the Information Commissioner's Office, see www.ico.org.uk/concerns.

Thank you for reading this information sheet and considering whether to take part in this study.

Research Team Contact Details

Mrs Sara Ma	Professor Paul Galdas	Dr Peter Knapp
Specialist Nurses Office	Department of Health Sciences	Department of Health Sciences
York Teaching Hospital	University of York	University of York
Wigginton Road	Heslington	Heslington
YO31 8HE	YO10 5DD	YO10 5DD
Sara.ma2@nhs.net	Paul.galdas@york.ac.uk	Peter.Knapp@york.ac.uk
01904 72 6154	01904 321647	

If you would like to make a complaint about this study please contact;

Professor Kate Flemming
Head of Department
Department of Health Sciences
Room 232
University of York
Heslington
York
YO10 5DD

Appendix 20: Qualitative study 2 Interview guide



Health professional perspectives on Mens sexual health in inflammatory bowel disease

Research Question:

What are health professionals' experiences and perceptions of the sexual health and care needs of men with IBD?

Welcome and housekeeping

Reminder that interview will last approximately 60min and will be recorded.

Brief revisit of aims of the study.

Reminder to maintain patient confidentiality.

- (1) Could you please give a very brief overview of your job role and experience of working with IBD patients?**
- (2) Have you been approached by a male patient to discuss their sexual health?**
 - a. If so can you describe your experience of these encounters? What did you find challenging?**
 - b. If not why do you think that is?**
- (3) What you think might be the difficulties and challenges men with IBD might face regarding their sexual health?**

Prompt; The World Health Organisation defines sexual health as;

"Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships. (World Health Organization, 2006; p5)

- (4) When I interviewed men with IBD they told me health professionals didn't ask them about their sexual health in clinic. Do you agree with this? Why?
- (5) Do you feel discussions about sexual health are appropriate in the IBD clinic? Why?
- (6) Do you assess the sexual health and function of men with IBD? If yes, how?
- (7) In what ways do you think healthcare professionals working in IBD are or can provide sexual healthcare and support to men with IBD?
- (8) What do you think are the barriers to discussing male sexual health in the IBD clinic?
- (9) What do you think might help facilitate health care professionals in engaging with men about their sexual health?
- (10) Have you ever received any training in sexual health in general or in IBD specifically?
- (11) Do you have any recommendations for improvements that could be made in sexual healthcare provision for men with IBD?

If attempting to stimulate more in-depth discussion;

When I interviewed men with IBD they told me things like;

- When I am flaring I have no sexual desire.
- My partner doesn't believe me when I say I am too tired/in pain/feel unwell.
- I never feel like I can get clean and that stops me wanting to have sex.
- My partner administers my rectal medication/dresses my peri-anal wounds/cares for me and this makes me feel less of a man.
- I worry my partner will see me differently.
- I have low confidence because my body has changed.

Have you every heard similar things? Could you describe these stories to me. Were you able to provide any support to patients? Is there anything on reflection you feel could have been done better?

Thank you for sharing your experiences with me, is there anything we've missed?

Appendix 21: Qualitative study 2 data management



Data Management Plan (DMP) HP-MeSH-IBD

Postgraduate researcher: Sara Ma
Project title: Health professional perspectives of mens sexual health in inflammatory bowel disease
Project start/end: June 2023 -May 2024
Funder (where applicable):
Project context: This is a qualitative study of health professional experiences of mens sexual health in inflammatory bowel disease. Semi-structured interviews will be conducted.

Defining your data
<p>1a. What data will you produce? Audio recordings of the interviews (recorded using the online conferencing software, downloaded, and transferred to be saved to the university drives or via a Dictaphone then immediately downloaded onto the university drives and deleted from the recorder). Transcriptions of the interviews. Researcher reflexive accounts/diaries – to be scanned and scored electronically.</p>
<p>1b. What formats and what software will you use? Microsoft Office Word, NVIVO, MP3 – audio files, .doc – word files, excel spreadsheets for personal data</p>
<p>1c. How much data do you expect to generate? 12 to 20 hours of interview data.</p>
<p>1d. Who owns the data you will generate? The University of York</p>

Looking after your data
<p>2a. Where will you store your data? The University of York secure network. Hard copies of any trial documents will be locked in a filing cabinet in a locked room at the University of York if immediate transfer to the university is not viable. Original paper documents will be scanned to PDF file for archiving at the end of the study and then destroyed using the confidential waste system. Data will be transferred using https://dropoff.york.ac.uk</p>
<p>2b. How will you back-up your data?</p>

Centrally backed-up by IT services at the University of York.
<p>2c. Who else has a right to see or use this data during the project? PhD supervisory team.</p>
<p>2d. How will you structure and name your folders? Example of expected folder structure with example of</p> <p>Site file documentation</p> <ul style="list-style-type: none"> - Protocol <ul style="list-style-type: none"> o YYYYMMDDHPMeSHIBDProtocolv1.0.doc - Regulatory approval documentation - Researcher CVS - Participant contact details (password protected) - Consent forms - PIS <p>Data management plan</p> <ul style="list-style-type: none"> o YYYYMMDDHPMeSHIBDDatamanagementplanv1.0.doc <ul style="list-style-type: none"> - File notes - Correspondences - Adverse events - Amendments - Contracts - Study reports <p>Data</p> <ul style="list-style-type: none"> - Data collection <ul style="list-style-type: none"> - Interview recordings YYYYMMDDHPMeSHIBDInterviewXRecording.mp3 - Interview transcriptions YYYYMMDDHPMeSHIBDInterviewXTranscription.doc - Participant Diaries - Data analysis <ul style="list-style-type: none"> - NVIVO files - Coding - Memoing - Reflexive accounts
<p>2e. How will you name your files? All files will start with the full year, month and date (in numerical format) they were created followed by IBDMASH, then the name of the file followed by the participant identification number for the participant in which the file pertains to if relevant and then a version.</p>
<p>2f. How will you manage different versions of your files? Documents are versioned (and date) controlled in the footer of the document. File names will also be labelled vX.Y at the end of the document. Minor versions are denoted with ordinal numbers after the decimal 1.1, 1.2, 1.3</p>

Major version changes are denoted 1.0, 2.0, 3.0. All versions must also be dated.
2g. What additional information will be required to understand your data? N/A

Archiving your data
3a. What data should be kept or destroyed after the end of your project? Data to be archived: Site Files, scanned copies of consent forms, interview transcripts, data analysis files, research reflections All other data to be destroyed.
3b. For how long should data be kept after the end of your project? 10 years
3c. Where will the data you keep be stored at the end of the project? As the University is the Sponsor, archiving will be carried out electronically as per the University of York local policy.
3d. When will you archive your data? After 6 months but before 12 months following the end of study to ensure all queries are answered.

Sharing your data at the end of the project
4a. What data should or shouldn't be shared openly and why? Participant identifiable information will not be shared.
4b. Who should have access to the final dataset(s) and under what conditions? The PhD supervisory team and examining body if required as part of the examination process. Peer reviewers that want to view anonymised aspects of the data set. Data can only be accessed for the defined purposes set out in the protocol and for what consent has been provided. Data cannot be shared outside of the EEA to comply with GDPR.
4c. How will you share your final dataset(s)? Extracts from the final data set will be used as part of the thesis, in publications and presentations on the topic.

Implementing your plan
5a. Who is responsible for making sure this plan is followed? Sara Ma (CI) and the PhD supervisory team at the University of York.

5b. How often will this plan be reviewed and updated? If any amendments are made to the research protocol.	
5c. What actions have you identified from this plan? Create site file.	
5d. What policies are relevant to your project? Data Protection Act 2018 EU General Data Protection Regulation 2018 Health Research Authority Guidance 2017 UK Clinical Trial Regulations International Conference of Harmonisation (ICH) of Good Clinical Practice	
Signed:	Version: 1.0
Date created: 12/01/2023	Date amended:

Appendix 22: Qualitative study 2 consent form

Participant consent form

Health Practitioner perspectives of Mens sexual health in Inflammatory Bowel Disease (HP-MeSH-IBD)

Please initial box

1. I confirm that I have read the information sheet dated 12/01/2023 (version 1.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected. I understand that if I withdraw anonymised information I have provided will still be included in the study. ☐
3. I understand that my contact information may be viewed by responsible individuals from the University of York for the purpose of contacting me during the study. ☐
4. I agree to the audio recording of the interview so it may be transcribed by a researcher or through a professional transcription service bound by a confidentiality agreement. Recordings will be deleted at the end of the study but transcripts (where identifiable information has been redacted) will be archived for 10 years. ☐
5. I understand that study data may be stored and used in relevant future research, including by researchers in other institutions, but the data will not be used or released in such a way that I could be identified. ☐
6. I understand that my contact information may be held and maintained by The University of York, to inform me of the study results and/or to invite me to participate in future research studies for a maximum of 3 years following the end of the study. ☐
7. I understand that anonymised data will be archived for 10 years following the end of the study. ☐
8. I agree to uphold professional integrity during the interview and ensure patient confidentiality is maintained. ☐
9. I understand that information I provide will be kept confidential and stored securely. Some of this information may be included in published documents but will be anonymised. ☐
10. I agree to take part in the above study. ☐

Name of participant

Date

X

Signature of participant

Name of person confirming consent

Date

X

Signature of person confirming consent

Research Team Contact Details

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If you would like to make a complaint about this study please contact;

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Appendix 23: Qualitative study 2 coding log exemplar

Study 2 Coding Book Exemplar		
Coding after 2nd interview	Coding after 10th interview	Coding after 16th interview
It's difficult to discuss	1) The multiple intersections of IBD and sexual health in men	1) Its difficult to discuss sex
Male-gender issues	I wouldn't normally label that sexual health	I wouldn't normally label that sexual health
Not being equipped to deal with it	Psychosocial aspects of sexual health	it's our professional responsibility
Sex is not a priority	Relationships	Professional roles
Time is a barrier	Sexual functions	Stigma
Transforming services	2) Its difficult to discuss sex	It's easier to talk to women
The stigma of sex	anal play	2) The health system as a barrier
Stomas and peri-anal disease	Being approached	Lack of capacity within the health system
Relationships can be disrupted	external factors	Not being equipped to give advice
Relationships can improve IBD management	Gay and bisexual	sex is not a priority
Psychosexual as a priority	It's easier to talk to women	3) Service transformation/HCP needs
More education is needed	patient-professional relationship	Better access & more options, inclusion
There is a lack of assessment guidance	Stigma	partners in the clinic
The needs of gay and bisexual men	3) Issues induced by healthcare systems	Broader awareness and break down the taboos
Anal issues	Lack of capacity within the health system	creating the right environment time and place
Concerns over erectile function	Not being equipped to give advice	More training & clearer pathways
System barriers	Professional roles	Assessing sexual health
	sex is not a priority	Key quotes
	4) Transforming services	Male gender issues
	Assessing sexual health	
	Better access & more options	
	Better support for men	
	Broader awareness and break down the taboos	
	More training & clearer pathways	
	partners in the clinic	
	Key quotes	
	Male gender issues	

Appendix 24: Qualitative study 2 coding descriptors

MeSH-HP IBD Codebook

In general, HCP's were able to identify the aspects of IBD (including bleeding, abdominal pain, fatigue, unwanted odour, body shape changes) that could negatively impact the sexual health and well-being of men. Furthermore, they were also able to identify how men might be affected including the impact on engagement in intimate relationships, negative body image and diminished erectile function.

Theme 1: It's difficult to discuss sex

All HCP recognised there were barriers to discussing sex in the IBD clinic and agreed that it was possible that sexual health issues were likely to be under-identified in this population. This theme brings together the personal, professional and societal factors given to why this might be the case.

'We talk a lot about holistic care, and we need to walk the walk, as you know as well' (CNS6)

Code	Description	Examples
'Disconnection of communication'	<p>It was almost universally recognised that discussing sex is embarrassing, and embarrassment could be experienced by the professional, patient or both.</p> <p>Most participants believed that the stigma associated with sex was cultural and many reference 'British Culture' specifically as being inhibited in matters of sex. One nurse considered religion as a factor. The ACP interviewed wondered whether there was possibly a professional-patient power imbalance that contributed to the difficulties in raising discussions about sex.</p> <p>There was a consensus that sexual health was not discussed in the IBD</p>	<p>'I think that's where maybe there's a there's a kind of disconnection of communication between us and the patient.' (GP2)</p> <p>'I think there is this two-way thing, where the patient is probably not comfortable asking or we don't encourage them to ask.' (R1)</p> <p>'We're not really asking that unless we see there is an immediate problem, or the patient has opened up to us that they would like to talk about it.' (CG1)</p> <p>'I think it does feel rather intrusive to us, asking somebody how it affects them.' (CG1)</p> <p>'Because from a medical perspective sexual health often sounds like genitourinary medicine and actually, you have sexually transmitted diseases and all that I don't know whether the patients think about it that way, and I mean, if it definitely goes down that route most IBD clinicians are completely out of our depths' (CG1)</p> <p>'I think, when patients come to us we should be able to give them decent advice. We shouldn't blush and brush the topic away.' (CG1)</p> <p>'I think there is that British embarrassment to do with sexual health.' (GP2)</p> <p>'I wouldn't bring it up because the patient's not brought it up.' (CNS1)</p> <p>'It probably does rely a lot on the patient saying that they've got a bit of a problem which for many young males will be very difficult to say.' (CNS1)</p>

	<p>clinic. Some HCPs felt that it was 'intrusive' to raise the topic or admitted they placed the onus on the patient to raise it. Many HCPs recognised they as HCPs should raise the topic and create a safe space for that to happen but did not know how to.</p> <p>A further important point raised by a couple of HCPs was the possible misunderstanding around what sexual health means and what discussions should be covered within a health assessment.</p>	<p>'I agree that it is that they don't get asked in clinic, but I don't agree that it shouldn't happen. I believe that we should ask it.' (CNS3)</p> <p>'Our responsibility as the as the professionals to start those conversations' (CNS4)</p> <p>'I think the barrier for me as a professional is, is that assumption that I should have let them come to me with the question, I suppose that might be a barrier.' (CNS7)</p> <p>'I think that's our responsibility as healthcare professionals. I feel to make that a non-issue, make our sex a non issue, we're professional. And if we start a conversation about sex, then that will help male, female either there's no back boundary to the conversations I've been able to have.' (CNS4)</p> <p>'As a nation, we're a bit prudish aren't we, don't like to talk about things like sex with people we don't know, and also there's the relationship of the health, professional in a more, I don't say powerful, but patients often look up to professionals that they and you don't want them to feel embarrassed talking about things.' (ACP1)</p> <p>'Even as a healthcare profession, professional, you're not immune to not feeling most comfortable.' (CNS6)</p> <p>'I mean, it's a societal thing isn't it, that we're little repressed.' (CNS6)</p> <p>'We're inhibited to talk about it because of cultural elements.' (CNS9)</p> <p>'I think patients have got a kind of preconception that they're going to be judged, that I think you know their sexuality is totally different from a disease or condition that they've got so they don't want to open up and discuss what they see as private things, for fear of being judged,' (CNS3)</p> <p>'I think another, issue could possibly be, be not for myself, but maybe like people say you know religion or beliefs, or how they've been brought up. You know that you don't talk about that,' (CNS3)</p> <p>'So whether it's me as a psychologist or somebody like yourself as a nurse is that you know, where does that ball start rolling.' (CP1)</p> <p>'It certainly is something that I speak about in other areas. It's just seemingly not come up in IBD as much as I've anticipated.' (CP2)</p> <p>'There is kind of it's not a stigma, is it, but there is kind of a level of discomfort, I think, about talking about sexual health just generally kind of within society, isn't there? It kind of feels like a bit of a bit of an uncomfortable thing to kind of go into. So when that is something that comes up with somebody, I think I do feel very kind of like there is an importance isn't it, of just kind of sitting with it and exploring it, and not trying to shut it down.' (CP2)</p> <p>'Yeah, I think it's just, well, it's the British stiff upper lip, isn't it? And the fact that we don't discuss that and it's hard enough getting people to discuss their bowel habits without actually discussing you sex life as well, isn't it?' (D1)</p>
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<p><i>Feeling 'ill-equipped'</i></p>	<p>All HCPs reported not receiving adequate training in sexual health and well-being which contributed to feeling of being ill-equipped to assess and support issues in the field. One of the Clinical Psychologists had some training which was reported co-incidental.</p> <p>As well as describing a lack of education there was also a reported lack of pathways or support in matters of sexual health. HCPs did not know of referral pathways or specialist services nor how to deal with any issues raised.</p>	<p>'We feel utterly ill equipped in actually giving quality advice thereafter.' (CG1)</p> <p>'I don't think I have any experience, or questions that I would routinely ask thinking about the area.' (GP1)</p> <p>'its not something I have had any formal recent training, suppose the last thing was my obs and gynae post which isn't particularly relevant for men' (GP2)</p> <p>'Especially in gastroenterology. No apart from if you read any articles or any guidelines as part of it which might make up a very small portion of them, there is no specific training in our training.' (R1)</p> <p>'We're not really training to ask about sexual health and just thinking about it as a colorectal surgeon or you know as a general surgeon, I just don't think we are made to think about this just whenever thinking about all the training we've had to talk about all the various risks and how to do things and things to watch out for afterwards. But it's very, very rare that we've ever been advised, you know, to ask about sexual herd and to think about this and specifically what that sexual health we need to ask. So in all honesty, you know, you pick up on things when you read, you pick up on things and patients mentioned them to you or when other colleagues discussed that they've come across such and search, but I've never really had any form of training or formal education on sexuality, on sexual health specifically in IBD patients.' (S1)</p> <p>'I can't remember any, particularly training all the years back about how to, approach this topic. So, yes, I think that I would say training, skills for an entrée is the biggest problem.' (CG2).</p> <p>'If someone's having sexual health issues, I'd have to really look into it. Maybe there's a sexual health clinic that they would be able to use but off the top of my head I wouldn't know whether that would be appropriate for them or not.' (CNS1)</p> <p>'I've got a problem with then know what to do with that information, because all of us can ask that question in clinic, but why would we ask if we don't know how to deal with the problem.' (CNS1)</p> <p>'I'm pretty sure that a lot of us always felt, you know, a little bit under educated.' (CNS6)</p> <p>'I just basically tell them kinda what I know from learning myself, so I've not had any formal training we've got no professional resources that give us advice.' (CNS3)</p> <p>'I think I've refined it over the years and definitely experience helps with that as well.(CP1)</p> <p>'I feel very confident talking about sex within the context of relationships within the context of somebody's identity and self esteem and yeah, kind of how they view themselves as kind of a sexual person. I don't feel as confident thinking about the specifics of sexual relationships. And I think that is possibly where more of the kind of sex therapy side of things would potentially kind of fit that remit.' (CP2)</p> <p>'I said, well, it's no point in interviewing me. I don't know anything about it. We never, we never get asked, but. That's the whole point, isn't it?' (D1)</p>
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<p><i>'Ask the IBD Nurses, they'll know'</i></p>	<p>In general, the HCP's interviewed believed sexual health was important and felt a professional responsibility to provide care. However, there was a lack of clarity over whether the responsibility lied with them or whether another professional group should initiate or co-ordinate sexual health care. Some suggested that the IBD nurses might be well suited to sexual health review, other felt it should be a collaborative effort.</p> <p>The clinical psychologists recognised they had more time and the ability to create a safe environment for patients to raise sexual health issues however both felt they were possibly not doing this adequately.</p> <p>A few nurses referred to the surgeons as being very open to discussing sexual health as part of the consenting process for surgery. Surgeons were portrayed as setting an example in honest and frank conversations without shame. Interestingly, the surgeon who was interviewed felt this was only done in a very 'superficial' way and did not explore in depth the wider aspects of sexual well-being outside of function.</p> <p>Both the GP's interviewed felt the IBD specialists would be better placed to assess and support sexual health needs that were specific to the condition. They also felt there was a role for primary</p>	<p>'I realize that patients open up with nurses a lot more.' (CG1)</p> <p>'The IBD nurse role, through necessity and through professional development wishes has in large aspects moved away from a supporter for all to either hybrid medical role or really a medical role.' (CG1)</p> <p>'I think it doesn't fall inside our remit' (GP1)</p> <p>'It kind of maybe goes back to that point of who's coordinated and taking responsibility for this area of their health. Who's leading it? If are we both looking over the fence at each other and saying, what you do about this kind of thing.' (GP1)</p> <p>'I will talk about it, to be honest, in very brief superficial terms.' (S1)</p> <p>'I do know that if the surgeons are quite, quite open at discussing.' (CNS5)</p> <p>'I think as nurses we have an innate ability to spot people in trouble, it is what we naturally do.' (CNS2)</p> <p>'Doctor such and such would you know would say, you know, oh, ask the IBD nurses they all know. I'm like oh, my God, right, Okay, I'm gonna look something up here because I don't actually know.' (CNS6)</p> <p>'In my experience surgeons that certainly the ones that I worked with were really very good at raising sexual health' (CNS6)</p> <p>'There's a couple of patients that have phoned in over the past few years, especially on the advice line asking to speak to a consultant. You know about, and they'll just say sexual health, but they'll not go into exactly what they want to say, and their consultant as a male consultant' (CNS3)</p> <p>'I wouldn't certainly wouldn't do anything specific or specialist, because it's not my role. So it would definitely be part of just a general assessment in terms of functioning you know.' (CP1)</p> <p>'I do think we definitely have a role and a remit and it's certainly something I'm kind of open to exploring with people to think about. Yeah, more of those kind of themes of sexual identity, sexual relationships and sexuality just more generally, and I think we can certainly do that within our role.' (CP2)</p>
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	care but could not clearly clarify what they through that role should be.	
<i>Men tend to 'bravado'</i>	<p>Many HCPs discussed the possibility that there were gender specific factors. Some wondered whether male patients were more likely to hold fears of being judged or find it more difficult to discuss intimate aspects of their likes. Two HCPs specifically mentioned the possibility of the male 'bravado' as a barrier.</p> <p>Many wondered whether gender and age differences between the professional and patient might contribute to embarrassment. The most cited concern was that men might struggle to discuss issues with young or older female HCPs. Although it was mentioned that men do not discuss sexual health in their friendships interestingly HCPs did not consider whether discussing sexual health with a male HCP could also be challenging for some. Interestingly, there were many references to the lack of male nurses however both male and female professionals reported that they felt it might be easier to discuss sexual health with women. Some of the reasons for this was that it was felt women might be more forthcoming in intimate issues or used to discussing sexual health issues.</p>	<p>'It could be difficult with men, you, fall into some sort of bravado very easily' (CG2)</p> <p>'If it comes to it, because that is kind of this life plan behind, it is more like choices in life rather than and I'm not asking in the moment, do you have sex? I'm more asking the woman. Would you consider having a baby? Whereas with men it really boils down to do you have sex?' (CG1)</p> <p>'It feels that it's more difficult for men to talk about the intimacies of life, so poo and toileting, and all of that kind of stuff is difficult in the first place, and then to then bring in sex into it is, you know, when there's idea, perhaps, of male virility in the whole, you know I'm a man.' (CNS4)</p> <p>'I think with male patients they are more difficult to raise, they don't want to appear like they don't know, and they don't want to ask the questions because they are frightened of the answer.' (CNS2)</p> <p>'I think it's quite difficult with men to get them to open up.' (CNS2)</p> <p>'I guess also a lot of your patients are quite young, so there's probably quite a lot of embarrassment type issues, with young men.' (CNS8)</p> <p>'I would feel easier speaking more comfortable, speaking to a woman.' (ACP1)</p> <p>'I wonder if it is more likely for women to kind of have that external expression of what's going on emotionally for them, then it is for a male.' (CP2)</p>

Theme 2: Service transformation is needed

"You look at what it is in in your living that makes you that makes the lights go on makes life worth living what's good about it and in that way you're finding these qualitative elements that's so important and we should be capturing those and then making sure our service supports these elements."

(CG2)

"The barriers are very real, aren't they? In healthcare time, you know, priority, urgency, but actually, when we really get down to what is it that matters to you?" (CP1)

"An IBD service has to constantly be reinventing itself, modernizing, re-establishing its roles, it's responsibilities within a health care setting to respond to the needs of patients" (CG2)

Code	Description	Examples
A 'fire-fighting' service	<p>Although HCPs agreed sexual health is an important aspect of overall well-being and needed consideration they also recognised that it was often not considered a clinical priority and there was a lack of capacity in the system to address this health need.</p> <p>HCPs were interpreted to operate in silos of care for example a surgical intervention, an nutritional assessment or dealing with an acute disease flare. Assessment and resolution of active disease was at the forefront of most clinicians' minds and central to their consultations. Possibly, more significantly, the barrier mentioned by almost all HCPs was time. Others included long waiting lists, lack of specialist services/referral pathways, a couple of people referred to lack of continuity of clinicians. Some did also mention the complexity of caseload experienced as well.</p>	<p>'I think we are still run a fire fighting type service, we're still about just keeping the plates spinning, and I think we, there is a huge amount of personal, interpersonal family, relationship difficulties that we just leave for people to work out for themselves.' (CG2)</p> <p>'Where do we send this patient to?' (CG2)</p> <p>'Time limiting factor and the fact that, you know, there are so many people on, on the waiting list to be seen.' (R1)</p> <p>'You're very much focused on assessing that formulating a treatment plan for that.' (CG1)</p> <p>'The consults remain targeted, if I can get the Crohn's disease usually or the ulcerative colitis better' (CG2)</p> <p>'When they see a doctor, they're more concerned about their symptoms, their physical symptoms.' (R1)</p> <p>'Perhaps 15 years ago and took on nurse specialists and, their role initially was to provide an additional quality of care that we felt was being missed. So, we and perhaps that's in developing that role perhaps that's perpetuated this lack of a connection, lack of thought around this subject so the consultant team largely retained a very mechanistic view about disease activity' (CG2)</p> <p>'I think probably the reason we get away with it is that most of our patients are young and young people are resilient, get better quickly if the disease is switched off and have a life to get on with and I suspect that's the difference, if we, if you look at the urology service and you see the size of the problem with, and you see the size of the problem with, male sexual health after, in, relating to prostate disease. It's, a huge, problem, so I think it's what we have the advantage of is the youth.' (CG2)</p>

		<p>'We're often quite practical and trying to deal with the immediate flare-up and so perhaps not had enough time to delve into other problems.' (CNS1)</p> <p>'I think that's why it's really important to talk about it.' (CNS3)</p> <p>'We talk about living with IBD, but you can't live with IBD if you don't talk about sexual health and relationship health.' (CNS4)</p> <p>'I mean, we think about overnight disturbance from the bowel point of view, but we don't necessarily think about what that's what that is doing to that relationship.' (CNS4)</p> <p>'Whether it's pre-op or after surgery, and I will see to them. It's probably the least important thing that's going on with you just now, but it is something that we can discuss in the future.' (CNS5)</p> <p>'Clinics are so short, and you tend to focus in on the physical things that you need to treat at that point. I think there is a huge risk with that, you know that you don't think beyond what's right in front of you.' (CNS6)</p> <p>'Time is a huge factor because if we had longer clinics or more staff to speak to more patients, you'd have time to bring up potential problems and to discuss these issues and even just an element of health and promotion. So speaking about problems before their problems, health prevention.' (CNS1)</p> <p>'that's the biggest issues is that there are time constraints and they worry if they open that can then they haven't got the time to deal with it' (CNS2)</p> <p>'And that you know you will you know intimately that we're in a in a challenging situation in the NHS at the moment because there's what we would like to be able to provide and what we're actually able to provide.' (CNS9)</p> <p>'You end up really dealing with the bits that absolutely need the priority.' (CP1)</p> <p>'I think sometimes it is about the wider system that you working in, isn't it? And I, meeting the nurses. I know that I will get the sense that everybody is kind of incredibly skilled about asking about this stuff, and that's the feedback I've been having from people have been seen I suppose it's just how do we, how do we as a service kind of prioritize that time to just check in with somebody's well-being.' (CP2)</p> <p>'To be perfectly honest, no, because I think you get to the point where you're so focused on the nutrition' (D1)</p> <p>'But they've got to build their relationship with you first and that comes back to what we were saying doesn't it? About this idea of time safety? And you know we're very lucky as psychologists that currently that we do have, that we have that time which is useful.' (CP1)</p> <p>'You have such a kind of complex and massive caseload of people to kind of help support that you don't have the time that we have. We have the luxury of being able to sit and explore it, and I</p>
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		<p>know you guys have the skills to do it absolutely it's more about having the time to be able to do it.' (CP2)</p> <p>'I think sometimes it is about the wider system that you working in, isn't it?' (CP2)</p>
Systemic change is needed: access, inclusion, clear pathways, patient-led.	<p>HCPs made several suggestions for how sexual health care provision within IBD could be improved. Although many were specific ideas targeted to their own profession principles or practices together they highlighted the fundamental need for services that are patient-centric with inclusive access to healthcare provision and well defined referral pathways alongside interdisciplinary collaboration.</p> <p>Although it was beyond the scope of this study to comprehensively define what needed to change and how change could be achieved, several preliminary ideas were put forward. For example, the mode of service delivery was often considered including utilisation of tele-clinics and mobile apps. It was often recognised that utilising new technologies may help improve accessibility and efficiency however this should not replace more traditional consultation methods with patient choice being key.</p>	<p>'You know, we have a women's health, women's health examination appointments where women come and have, you know, have double appointments, and full examination, and swabs taken as routine, whereas we don't have that that pathway of care for men.' (GP1)</p> <p>'There are gaps to do with the psychological support.' (GP2)</p> <p>'I don't think there are enough resources.' (S1)</p> <p>'This area of men's or sexual health is really important, and we need to start building a structured service beyond just the simple issues of a pharmacy, dietetics and a little bit of clinical psychology.' (CG2)</p> <p>'We have self-help, we have charities, we have Crohns and Colitis UK, so there may be the option to provide a different tier of support, in fact, I suspect the need for a different tier of support, which would be person-led, patient-led rather than driven from secondary care.' (CG2)</p> <p>'I think holding this together with an IBD nurse specialist service is probably the most sensible going forward. But it requires also this concept ...(of) being much more patient activated.' (CG2)</p> <p>'Men and women are suffering very similar in many aspects and we're not helping the men as much.' (CNS1)</p> <p>'Our service provision is not holistic' (CNS6)</p> <p>'Why we can't have integrated tools, why can't have kind of integrated pathways. Why, am I doing something different where I am to you?' (CNS4)</p> <p>'If they feel like they're having difficulty with their partners, making sure that they access all those things are available like couples counselling and things like that, because, you know, it's again we're not the experts like we can't be relationship counsellors, but we can certainly, you know, look at directing them to places.' (CNS4)</p> <p>'It's something that that I've thought about all the time is the use of digital tools like apps, so that you can pre-screen someone and talk about relationships, sexual health and all of the rest of it and they can answer those questions without actually having to answer you directly.' (CNS4)</p> <p>'It probably just needs to be higher up on the MDTs agenda, doesn't it?' (D1)</p>
Creating a safe environment	Underpinning the concept of improving access to and the mode of delivery of healthcare services was the idea of creating a safe space in which men might discuss their sexual	<p>'It's easy for us to ask the questions, because we can train ourselves to do that, I think for the patients, I think they need to have a relationship with you, to answer those questions.' (CNS2)</p> <p>'Encouraging, open and honest discussion.' (CNS4)</p>

	<p>healthcare needs. There were some practical considerations, for example the stoma nurse noted the benefit of being able to visit people at home which provided a physical safe and familiar environment in comparison to the surgeon, ACP and endoscopist whose working environments were not private. The need for changes in overarching attitudes towards sexual discussions was the most common theme. It was frequently recognised that professionals needed to find ways to have open and honest discussions with patients and make them feel emotionally safe and secure enough to do so. This leads into the following theme of improved training and education to enable this to happen. Inclusion of partners was often discussed. One HCP felt that having partners meant they would be less inclined to discuss sexual health matters whereas a number of participants wondered whether inviting partners into consultations would help open the door to discussions. For adolescent patients, having parents in the consultation was seen as prohibitive to having discussions of that nature.</p>	<p>'Just talking about it more even within the nursing teams that we're in. Just make it a kind of an open discussion to talk about' (CNS3) 'I think we just need to get the IBD nursing population to talk about it more.' (CNS9) 'A safe space to have those conversations and ask questions and you know, what do you do if they say this, or what do you say about that, try and build the nurses confidence levels up, because I think if the nurse is confident then the patient feels reassured, they are talking to somebody who knows what they are talking about' (CNS2) 'I think the key thing is getting the message out that it's okay to come forward.' (CG1) 'So whether they need a more friendly environment where, or dedicated sort of clinics where they can have that discussion in more open discussion.' (R1)</p> <p><i>CP1, CNS8 and CNS9 all discussed the importance of normalizing conversations around sexual health.</i></p>
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Appendix 25: Qualitative study 2 example of reflexivity in the analytical process

Reflective focus	Reflective diary extract	Explanation of researcher position and impact on data collection and analysis
Methodological: interview technique	We came to this point where I realised that whole background story had a significant part to play. This is a good learning point and in the future I need to allow some time for background and not assume that it's going to be irrelevant.	Allowing the participant to lead and have space to explore the wider context was ensured their lived experience was captured and help to position the interviewer as an observer. The contextual background was essential to disease narratives disease informed the development of the theme on male gender norms and helped interpretations of how and why men responded to their disease in varying ways.
Ethical and methodological: interview technique	At times I felt like we were stepping into a counselling session especially when I asked about how things made him feel, In the future I will try and ask more 'tell me about your experience' – it's a subtle difference but an important one. Feedback from participant included in reflective diary; <i>'I just wish we had this conversation years ago. It could well have changed my life and would have left me feeling more fulfilled in every way'.</i>	Negotiating the role as a nurse-researcher was an important part of the research process. The benefit of nursing experience was the ability to elicit personal life experiences around health but the purpose was not therapeutic intervention. <i>'Good data' often reflects deeply felt and rarely articulated material, and as our study participants come closer to such revelations, our moral obligations toward ongoing negotiation of informed consent is intensified' (Thorne 2016, p124).</i>
Methodological; constant comparative analysis	A contrasting story in that the participant had suffered with the disease since childhood so there was no 'before' and 'after' as with the first interview one. Much more aggressive disease and yet in some ways less emotional about it – possibly because he has had so much time to sit and reflect on it	Reflecting after each interview aided the constant comparative approach and helped to draw parallels and variations between the narratives. This helped identification of gaps which was need to inform the sampling strategy. In this example, the observation led to collecting further accounts from men with variable ages at diagnosis and years since diagnosis.
Analytical	As with interview 1, this participant thought his partner wouldn't be able to view him in the same light after she had seen him unwell – is this an inherently male fear – being seen as sick, being seen in a way you haven't chosen to be?	This reflection demonstrates the process of refining ideas and trying to understand patterns. Noting questions aided the testing of interpretations and articulation of how data has been interrogated. This case shows development of thinking around self and partner perception.
Analytical: uncovering heuristic findings	He doesn't really seem to portray a lived experience where the disease has had a big impact and he is very much a 'just get on with it' kind of person. When you delve in deeper to the story you can see things have been different – he doesn't stay in the swimming pool for very long, he referees instead of playing football, he stays close to people.	To really get to the essence of the human experience it was important to be able pull apart the deeper meanings that lie beneath what was verbally said. To do these initial impressions were noted, then further reflection following audio emersion with the data.

Analytical: uncovering heuristic findings	Being in control is very important to him and that is entwined in also being independent. He wasn't able to do things for himself. Unlike 002, he was able to engage in one night stands, but like 002 trust and being drawn to people who will not judge is very important to him.	This example demonstrates moving from descriptive to interpretive analysis. The descriptive analysis is some men with IBD are not able to engage in one-night stands. The interpretation is the disease can impact on body control and so intimate relations but be with someone who can be empathetic. For some men this need may prohibit engagement in casual intimate relationships where there is an unknown, lack of control or emotional security.
Analytical; remaining close to the data	When coding I initially created many de novo codes to try and keep them close to the data but as more files are added to the data set suddenly the number of codes is becoming unmanageable. As I group codes some of the subtle differences in meaning are lost and I am finding it increasingly difficult to remember all the things I found enlightening that led me to the initial coding. Although the approach is systematic, the subjective and idiosyncratic nature of the data that is so context dependant creates the possibility of varying interpretation.	The process and associated challenges of fracturing and reassembling the data is reflected upon here. It was important to recognise that there are alternative interpretations. Verbalising this process allowed the essence of the human experience to be understood while maintaining closeness to the data. Concerns over losing subtlety in meaning was important in the process of ensuring interpretations and codes remained true to the individual account.
Analytical: personal biases, researcher position	Who am I to describe someone I have only met for an hour...it is to humanise them, note down initial impressions and describe what I feel as I engage with them. Is it even important to the analysis I ask myself? I am not sure but this additional layer of context is not always portrayed through the transcripts, it is felt in the interaction and can be sometimes heard when listening to the interviews. Understanding the underlying personality traits helps contextualise the lived experience and the way the individual has responded to and perceives their condition.	Embracing subjective description of the data is welcomed within an ID approach allowed articulation of interpretations in a transparent way. The descriptions of the people themselves was circumstantial, but understanding the personal response of the researcher to the participant was an important part of the reflective process.
Identifying personal assumptions, managing outliers or opposing cases	Before the interview I knew he was with a male partner, and I wanted to explore how having his rectum removed may have changed the way he experiences sex but was interested to discover that for him although previously he had engaged in anal play this was not important to him so in fact the surgery had not had the impact I thought it may have. Still there was mention of removal of choice – and I feel like although I had not really identified it as a theme, thinking back over the other interviews it most definitely could be.	Identification of subconscious biases or stereotypes was important in the analytical process. This participant was sampled due to his very specific disease presentation and subsequent intervention and his account challenged researcher presumption that the removal of his rectum would be sexually inhibitive. However, his account still presented a common underlying threat of lack of choice thus connecting his experiences to that of other participants.

ABBREVIATIONS

BSG	British society of gastroenterologists
CCUK	Crohn's and Colitis UK
CD	Crohn's disease
CGT	Constructivist grounded theory
CNS	Clinical nurse specialist
DOH	Department of Health and Social Care
EIM	Extra intestinal manifestation
FSFI	Female sexual function index
GI	Gastrointestinal
HCP	Healthcare professional
IBD	Inflammatory bowel disease
IBD-MSDS	IBD-Specific male sexual function scale
IBDQ	Inflammatory bowel disease questionnaire
ID	Interpretive description
IIEF	International index of erectile function
MDT	Multi-disciplinary team
MSM	Men who have sex with men
NATSAL	National Survey of Sexual Attitudes and Lifestyles
N-ECCO	Nursing European Crohn's and Colitis organisation
NICE	National Institute for Health and Care Excellence
PICO	Population, Intervention, Comparator, Outcomes
PIC	Participant identification centre
PIS	Participant Information Sheet
PPI	Patient and public involvement
QoL	Quality of life
UC	Ulcerative colitis
RAI	Receptive anal sex
RDS	Research design service
SPICE	Setting, Perspective, Intervention, Comparison, Evaluation
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research Type
TA	Thematic analysis

TAP Thesis advisory panel

Researcher Initials;

SM Sara Ma, Lead Researcher and PhD Student

PG Professor Paul Galdas, Supervisor

PK Professor Peter Knapp, Supervisor

GLOSSARY

Anodyspareunia: rectal pain

Aphthous ulcers: painful ulcers within the mouth

Biological therapy: a disease treatment made from substances from living organisms

Crypt abscesses: accumulation of inflammatory cells within the glands found in the lining of the digestive tract

Goblet cells: cells that secrete mucus

Microscopic colitis: a form of IBD that can only be visualised under the microscope and leads to frequent, watery diarrhoea

Natsal: National Survey of Sexual Attitudes and Lifestyles

Perianal disease: inflammation around the anal cavity that can include fissures, fistulas, abscesses or stenosis leading to pain, discharge, discharge, bleeding and incontinence

Pouch: an internal reservoir created during surgery after the removal of the colon and rectum

Pseudopolyps: polyps caused by severe inflammation

Pudendal nerve: one of the nerves responsible for erectile function

Seton: a thread inserted through a fistula to aid drainage after an infection and healing

Stoma: an artificial opening, usually made on the abdominal wall through which a section of the intestine protrudes in order to allow the excretion of faeces

Strictures: a narrowing of the intestine caused by scar tissue

Thiopurines: medications used to modulate the immune system

Transmural: involvement of the full thickness of an anatomical wall, in IBD usually meaning the intestinal wall

5-Aminosalicylates: a medication used to treat inflammation of the gut wall, can be administered orally or rectally

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