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EMPIRICAL RESEARCH QUALITATIVE

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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

## 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.

**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.

## 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 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 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.

**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?

### 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 GPDR 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, 28 years, 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, 28 years, 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, 38 years, 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, 28 years, 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) |

**TABLE 3** Sexual dysfunction scores.

| 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.

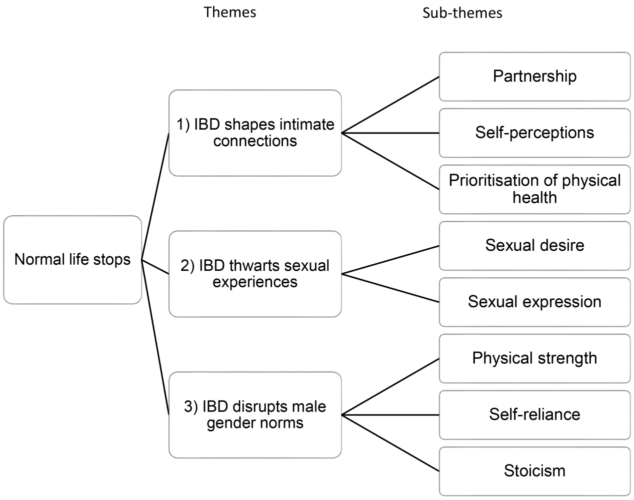

**FIGURE 1** Coding tree.

> 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 then 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 import 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 interpretated 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 recieved.

> (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 be 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 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 subthemes; *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 (Oliffe 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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