



Grieving multiple losses: Experiences of intimacy and sexuality of people living with inflammatory bowel disease. A phenomenological study

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Abstract

Aim: To explore patient experiences of intimacy and sexuality in those living with inflammatory bowel disease.

Design: An interpretative phenomenological study guided by van Manen's framework. Thematic analysis was conducted through interpretation and reflection on four existential domains: body, relationships, time and space.

Methods: Data were collected during 2019–2021 from 43 participants via face-to-face or telephone interviews, as well as anonymous collection of narratives submitted via Google Forms.

Results: Four themes were identified: *Sexuality as lived incompleteness* was the overarching theme representing the essence of the experiences of intimacy and sexuality. This theme covered the four main themes: *Otherness of the body*, *Interrupted connectedness*, *Missing out on life fullness* and *Fragmented openness* and each corresponded to an existential domain. Intimacy and sexuality are negatively affected by inflammatory bowel disease, with impact on quality of life. Patients experienced grieving multiple losses, from body image and control, to choice of partners and future opportunities. The four domains were difficult to separate and a close inter-relationship between each domain was acknowledged.

Conclusions: A model was developed to draw new theoretical insights to understanding the relationship between sexual well-being and psycho-emotional distress similar to grief.

Impact:

- First qualitative study to explore intimacy and sexuality experiences of those living with inflammatory bowel disease.
- Illness impact on sexuality has negative psycho-emotional implications as a result of losing the old self and capacity to have the desired relationships/sex life.
- A theoretical model was developed in an attempt to illustrate the close relationship of intimacy, sexuality and psycho-emotional well-being.

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Patient or Public Contribution: Patients were involved in the study design.

KEYWORDS

advanced practice, chronic illness, gastroenterology, holistic care, nurse, patient perspectives, phenomenology, quality of life, sexuality

1 | INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic remitting–relapsing condition comprising mainly two different illnesses: Crohn's disease and ulcerative colitis (Nee & Feuerstein, 2015). Symptoms include abdominal pain, bloody diarrhoea, faecal urgency and / or incontinence, fatigue and several extra intestinal manifestations, such as eye and joint inflammation (Harbord et al., 2016). Between 25% and 80% of people living with IBD have major surgery and some more than once (Selinger et al., 2014). Over 40% of those with severe Crohn's disease develop perianal disease, with anal fistulae (Schwartz et al., 2001). There is no cure for IBD, and treatment remains mainly symptomatic and aims at maintaining remission. Most patients are diagnosed between the ages of 15 to 35 years (Loftus, 2004).

1.1 | Background

The impact of the disease on intimacy, sexuality and sexual relationships in IBD is under researched. The sexuality definition given by World Health Organization (2006) reveals the complexity of the concept and its multifactorial component and situates it as central to human existence. Sexuality covers sex, gender, intimacy, sexual orientation and is expressed in many ways, including practices, beliefs and relationships. There are many reasons why IBD might have a negative impact on sexuality: symptoms, perianal disease, body image, surgery and medication side effects. Furthermore, the high prevalence of depression and anxiety in this group can add burden to the already existing symptoms, and antidepressant medication is known to also have side effects affecting sexual function (Jing & Straw-Wilson, 2016). Sexuality is an important aspect of quality of life (O'Toole et al., 2018), and sexual well-being (intimacy and sexuality) of those living with IBD warrants assessment as part of quality-of-life evaluation. It is known already that sexual function scores (tools measuring body response to different stages of the sexual act cycle) are low in IBD (Marín et al., 2013; Timmer et al., 2007), but little is known about the factors involved in the low scores. A review on sexuality in the context of chronic illness reported that sexual well-being is influenced by disease severity, disease progress, psychological adjustment to illness and medication (Verschuren et al., 2010). Previous studies exploring the experiences of sexuality in the context of illness and discussing such concerns with healthcare professionals were conducted in oncology, cardiovascular diseases and rheumatology (Helland et al., 2017; Traa et al., 2014; Traumer et al., 2019). In spite of the evidence, healthcare professionals fail

to ask the right questions to fully assess the real impact of a condition on quality of life (Lönnfors et al., 2014) and to address patients' needs in a holistic manner. In the past two decades, there has been a shift towards exploring patients' lived experiences, where previously a bio-scientific perspective was predominant, and exploring experience can add a dimension to the existing quantitative data. A review of qualitative evidence in IBD highlighted a gap in research on aspects of intimacy and sexuality, although some studies inferred findings on these aspects of life (Fourie, 2022; Fourie et al., 2018).

2 | THE STUDY

2.1 | Aim

This study aimed to explore patient experience of intimacy and sexuality in the context of IBD and to explore the experiences of discussing these topics with healthcare professionals. This was a two-part study from a PhD research project, and the results reporting experiences of discussing sexual well-being with healthcare professionals were published earlier (Fourie et al., 2021). The results presented here report the findings from patient experiences of intimacy and sexuality in the context of living with IBD.

2.2 | Design

This phenomenological study was guided by van Manen's (1990) framework. van Manen's phenomenology is an established methodology used in health sciences for interpreting lived experiences and follows six steps for data analysis: turning to the nature of experience, investigating experience as lived, phenomenological reflection on existential domains (body, relationships, time and space), phenomenological writing, maintain an oriented relation and balancing the research context by considering parts and whole. The methodology was selected due to its approach that allows researchers to explore how to act thoughtfully in practice, based on their understanding of the patient experience. van Manen's framework is more likely to promote the concept of holistic care that is consistent with holistic research (Patton, 2020) and aligns with nursing practice. The framework has the potential to facilitate the understanding of various aspects of life that individuals encounter during illness and, therefore, equips nurses to assist patients more effectively once they acquire this knowledge. Furthermore, other studies exploring experiences of sexuality in the context of illness have used a phenomenological approach (Fourie, 2022).

2.3 | Participants, setting and data collection

Forty-three participants were included in this study (see Table 1) all previously unknown to the researchers. Participants with a self-reported a diagnosis of IBD, aged 16 years old and over, of any sexual orientation, and English speaking were included as a result of them approaching the study team following an advertisement on the Crohn's and Colitis UK webpage.

Four participants disclosed as being part of sexual minorities: one was gay, one was a trans man, and two were bisexual. Most participants ($N=40$) were from the United Kingdom. The study took place between April 2019 and August 2021.

Participants were purposively selected, and data were collected subsequent to written or verbal consent, either as a single semi-structured interview via telephone or face-to-face, or from narrative accounts submitted anonymously via Google Forms (link to this was included in the Participant Information Sheet) as per participants' choice. The study was advertised on Crohn's and Colitis UK website and those interested contacted the researcher directly or completed an anonymous Google Form. Google Forms were used to encourage participation those who would have not otherwise taken part in a face-to-face/telephone interview. Information was also provided about the person interviewing, her gender and professional experience. A couple of face-to face interviews were held in university private rooms where access was restricted; and the rest were telephone interviews. Interviews lasted between 20 and 80 min and a guide of the interview questions is found in Table 2.

2.4 | Ethical considerations

The study received a favourable ethical review from University of Oxford ethics committee (R60900/RE001). Privacy and anonymity were maintained throughout the study. All participants consented for the publication of anonymized excerpts and were given pseudonyms for the purpose of the publication. Direct quotes are verbatim

TABLE 1 Study population demographic and clinical characteristics.

Male	11 ^a
Female	32
Age range	17–64
Partnered	34
Single	9
CD	31
UC	12
Interviews	23
Google forms	20
Surgery	12
Perianal disease	10

^aKey: 1 trans man.

TABLE 2 Interview guide.

How long have you had the condition for?
Are you in a relationship at the moment?
What do you understand by intimacy and sexuality?
Can you describe your experiences of intimacy and sexuality from your perspective of living with IBD?
Can you explain more about it?

Abbreviation: IBD, inflammatory bowel disease.

and presented in italics, giving the participants' pseudonym, age, sex and type of diagnosis (UC for ulcerative colitis or CD for Crohn's disease). Participants were informed about how to access the findings if they wished to.

2.5 | Sample size

The sample size for phenomenological studies using van Manen's methodology usually ranges from 6 to 10 participants. Interviewing small numbers can capture a wide array of issues that could provide an understanding of the topic of research. However, it may not provide sufficient data richness to understand those issues in depth (Hennink et al., 2017). Therefore, it was decided to aim for a larger sample size as Google forms responses also lacked data richness. As van Manen (2014) has argued that data saturation is not relevant for hermeneutic phenomenology, this was not an aim. However, the larger sample also aimed to achieve better heterogeneity of participants in order to cover a diverse range of experiences.

A careful approach was employed during interviews, by using probing, paraphrasing and open-ended questions, aimed at getting as much detail as possible. The unpredictable state of the participants' health determined the choice for single interviews. The interviews were audio recorded and transcribed verbatim. NVivo was used for dataset coding. All transcripts were coded by one researcher (SF), as double coding is incompatible with van Manen's framework (2014), and the generated codes and themes were discussed and agreed on with all researchers.

2.6 | Data analysis and rigour

The study findings were reported in accordance with Consolidated Criteria for Reporting Qualitative Research (COREQ) guidance (Tong et al., 2007).

The analysis process entailed familiarizing with the data at the collection and transcription stages, followed by a descriptive thematic analysis as first step of investigating the lived experience. The reflective stage within the existential domain was of particular importance as it moved the analysis from description to interpretation. The themes generated were organized under each existential domain and were the essence of the phenomenological text presenting the interpretation of the findings. The thematic analysis led

to identifying themes found in the data and defining the essences of the experiences with the variations found in each theme (sub-themes) (van Manen, 1990, 2016). The first author had to recognize own assumptions, opinions and theories existing at the time of starting this project, as it was important to see where it aligned with those presented by participants as well as challenging these during data analysis. Questions about what was not seen or what was not given thought, or what aspects of the experiences were given privilege over others, were all valuable (Crowther et al., 2017) in practising researcher reflexivity.

A brief summary of the framework stages and steps undertaken by researchers to demonstrate adherence to the methodology is presented in Table 3.

The researchers decided to also use an appraisal of trustworthiness suggested by (De Witt & Ploeg, 2006), as this framework features characteristics suitable for van Manen's methodology, which are a balanced illustration of the findings and the research process undertaken. The proposed framework has five aspects that ensure quality of research for van Manen's methodology: balanced integration, openness, concreteness, resonance and actualization.

3 | FINDINGS

At the beginning of each interview and in the Google Forms, all participants were asked to describe their own understanding of intimacy and sexuality, in order to ensure there was shared understanding of the terms' meaning. Participants referred to a common understanding in the experiences explored in the study:

Intimacy to me means my relationship with my partner, when we are alone and spending time together,

expression of love. Sexuality is when we have sex or have fun together, we both express how much we feel for each other. (Sonia, 47, F, UC)

The themes and subthemes are presented in Table 4, indicating the essence of the intimacy and sexuality experiences in the context of IBD. These four main themes were essential themes and represent qualities of the experience, each one with variations of these qualities, illustrated in the subthemes. Each main theme corresponded to an existential domain and were interpreted from explanations of the issues as described by participants. Each subtheme is summarized below and illustrated excerpts from the participants' interviews.

3.1 | Reflection on body: Otherness of the sick body

The first theme was found through reflecting on the lived body and captures the transformation of the sex life when a body no longer functions as usual and becomes a separate entity in the eyes of the participants. Loss of control over bodily functions and altered body image hindered intimate relationships. The sick body was alien to participants, who widely reported a disembodiment from their own body and experienced feelings of being unattractive as a sexual partner.

3.1.1 | Unrecognized body

The discussions surrounding the sick body as a separate entity were covered by participants in numerous variations, most suggesting the struggle to live in a sick body:

TABLE 3 Adherence to van Manen's framework.

Framework steps	Procedures/activities
Turn to the nature of experience	<ul style="list-style-type: none"> Conduct a literature review to identify the experience of interest (published paper) Formulate research questions Identify researcher's assumptions and preconceptions related to the experience (diary)
Investigate the experience as lived	<ul style="list-style-type: none"> Gathering data (interviews, Google Forms) Exploring phenomenological literature Reading experiential descriptions in literature-developing linguistic skills and addressing researcher assumptions(diary)
Reflect on essential themes	<ul style="list-style-type: none"> Thematic analysis of data (selective coding with focus on intimacy and sexuality experiences, gathering codes in units of meaning, identified qualities of each experience-subthemes and collate them into structures of meaning-themes) Experiential domains used for reflection (reflect on lived body, lived relationships, lived time and lived space) and organized identified themes around each domain Name the overarching theme-essence of the experience Establish incidental and essential themes
Write the phenomenological text, maintain an oriented relation & balance the research context by considering parts and whole	<ul style="list-style-type: none"> Hermeneutic phenomenological writing (returning to the text with new layers of enquiry) Address the linguistic components (silence and unspoken words, metaphors and other figures of speech) Integrate artistic material with potential contribution to understanding the experience Orient the interpretation to the professional audience Maintain the balance between the researchers' voice and that of participants Write a rich text as a resource of professional knowledge

TABLE 4 Themes and subthemes.

Sexuality as lived incompleteness
Body-Otherness of the sick body
<ul style="list-style-type: none"> • Unrecognised body • Being unattractive
Relationships-Interrupted connectedness
<ul style="list-style-type: none"> • Silent relationships • Not being a suitable partner • Broken-down relationship
Time-Missing out on life fullness
<ul style="list-style-type: none"> • Sex is important • Sex is difficult • Embarrassing symptoms shame me during sex • Striving for normality
Space-Fragmented openness
<ul style="list-style-type: none"> • Reticent disclosure • Aloneness

the way you view your body is this sick kind of unwieldy thing that's almost an obstacle, and it's just a constant challenge. (Martha, 38, F, CD)

The inability to control their body functions and fear of bowel incontinence episodes during intimate moments were a concern and this was whether or not participants have experienced such episodes in the past or not:

I would be worried during sex that I would have an accident and be really paranoid about it but that has never happened before. (Corine, 23, F, UC)

The loss of body control was received not only with fear and avoidance of new relationships, but a general sense of disappointment with their own body:

I really feel like I was dealt a very defective body: I'm faecally incontinent of the night-time anyway, so I wake up every day covered in faeces out of varying holes and now some days [partner name] has to pull me up out of bed because I physically can't get up. It makes, it makes me very disappointed in my body. (Sara, 46, F, CD)

One participant felt that repeated intimate physical examinations undertaken as a result of the condition had 'medicalized' her body. The relationship that the participant had with their own body changed, as they lost the privacy of their intimate body parts, that become public during medical examination, with later consequences for their sex life:

The first time anyone ever touched me anywhere intimate, it was horrific, shaming medical examinations. That really, really fu...s you up. I was scared I wouldn't

want a partner to touch me. You can't escape your body being medicalised. (Matilda, 40, F, CD)

A wide range of issues that led to perceptions of not having the same body as before being diagnosed with IBD stemmed from perceived poor body image, which was one of the most frequently discussed topics with all participants, regardless of age, sexual characteristics, sexual orientation or disease type:

My labia was swelling up really bad and then all of a sudden my labia was hanging, and then the Crohn's starts eating in to that, so then there were like parts of it missing, like a caterpillar eating the leaf, really just crazy.... All these things will make you feel like you're not worthy, you're not right, you're not all there, there's bits and pieces of me missing. (Catriona, 43, F, CD)

Although discussed more in depth by younger women, men had also reported body image issues:

I was very comfortable before, having my shirt off. I had, I wouldn't say a good figure, I could have my shirt off and not be embarrassed by it prior to the surgery. Now, I will take my shirt off if I'm in the garden or something, I haven't taken my shirt off in public. And then, if me and my girlfriend are together and intimately, I just keep my [stoma] support belt on. (Adrian, 26, M, UC)

Low self-esteem and loss of confidence were perceived to be caused by changes in participants' body image:

[the surgical scar] It took my confidence away for a long time. (Lisa, 47, F, CD)

Surgical scars and especially having a stoma bag were the most frequently mentioned reasons leading to a poor body image perception, that had affected their intimacy and sexuality:

Since my [stoma] operation I have struggled for years with my body and how it felt afterwards. (Sonia, 47, F, UC)

Notably, a stoma was not a negative experience for all:

Since the infected bowel has been removed and got my bag, I feel like a completely different woman. I have my sex drive back, I think about sex all the time and my partner feels like he's got a new woman! (Adele, 30, F, CD)

Many participants described that they felt unconformable to be seen naked, or even to have their abdomen touched, as a result of their condition.

3.1.2 | Being unattractive

The physically visible aspects of IBD were the main reason for participants reporting a poor body image and feeling unattractive but also triggered negative feelings and low self-esteem. Worries and concerns arose from abdominal scars, fear of incontinence, stoma bags, perianal disease or, in men, erectile dysfunction following abdominal surgery. All of these had a negative impact on participants' sexual life experience:

When I've experienced abdominal pain, abdominal cramps and also when I'm having difficulty with the bags, the stoma bags adhering to me, I didn't feel particularly loveable. I mean, my wife she says would love me whatever, and if I felt able to be intimate sexually, she would've been happy to be the same with me, but I just didn't feel comfortable, emotionally I didn't feel comfortable and physically, I didn't feel very loveable. (Frank, 56, M, CD)

Feeling unattractive was also attributed to a body that was not functioning well, and it intensified feelings of shame:

I felt too ashamed of my body after my surgery because it was a physical reminder of my body's personal inability to function properly. I have also struggled with fluctuating weight issues throughout my adolescence that was caused by the medication I have been given which also affect my personal body image. (Angela, 20, F, CD)

For young single participants feeling unattractive brought fears that they would not find someone to accept them with their body, especially after having an operation for a permanent stoma:

It was a big thing for me at the time. I remember sitting in the hospital bed thinking well, that's my love life over, because no one will accept it. (Adrian, 26, M, UC)

One participant had expressed her fear of getting a stoma following a previous incident she witnessed during a hospital stay, feeling strongly that a stoma would break her marriage:

Another one of my friends went through the same operation as me- and she woke up with a bag. And her husband said 'you're not my wife anymore, my wife died on that table.' And [at next operation] I literally screamed that room down. And the only thing that I was screaming was 'I'm a married woman, I can't have a bag.' Because I thought that having a bag would break my marriage. (Orla, 41, F, CD)

3.2 | Reflection on relationships: Interrupted connectedness

Reflecting on lived experiences, the theme describes the chaos thrown into intimate encounters, showing itself as an interruption in the connection that existed or was expected to exist between a couple. Everything suddenly needed a lot of planning and preparation, sometimes with no conversation about it, which only deepened the distress and frustration for participants, making them feel as if they were not being the partner they wanted to be. Because of these feelings, some relationships became strained, although a few were positive and reported that the difficulties brought them closer as a couple. The variations of this experience were displayed as *Silent relationships*, *Not being a suitable partner* and *Broken-down relationships*. The elements that constructed this theme are detailed under the subtheme headings.

3.2.1 | Silent relationships

The nature of symptoms and stigma attached to bowel function, adding potentially sensitive issues related to a couple's sexual life, made discussing these with partners difficult, especially for those in their early stages of their relationship:

It was difficult to explain that during a flare up I can feel unwell and bloated which makes sex uncomfortable. (Florence, 24, F, CD)

Participants shared that feeling unable to be the partners they desired to be added to the embarrassment of bringing up issues and they felt this only added to the stigma of their symptoms:

Well, it's kind of been the elephant in the room, we haven't really discussed it thoroughly in the sense of sat down and had an honest discussion. (Sandra, 62, F, CD)

Unable to openly discuss embarrassing symptoms with their partners and experiencing guilt for not being able to be a good partner were contributing to putting pressure on relationships, which in some cases broke down.

Although a minority, there were participants who stated they had no issues of discussing intimacy related issues with their partners:

We've got quite an open relationship, we talk a lot about intimate, personal things, so it wasn't too bad to talk about it. (Ben, 62, M, CD)

3.2.2 | Not being a suitable partner

Most participants experienced feelings of guilt for not being able to be as intimate as they wanted to be:

With the stricture, that completely dried up any feeling of wanting to have intimacy... The pain was just phenomenal, I was very malnourished so there was no energy for self-care, let alone the sort of thought of intimacy. And then that kind of leads you to feeling like guilt, guilt for your partner. (Emily, 42, F, CD)

Irrespective of how understanding their partners were about their ability to be intimate, participants experienced feelings of guilt.

3.2.3 | Broken-down relationships

Those who were in a relationship aimed to continue to be intimately connected to their partners, but a few feared that not being able to be the partner they wanted to be as a result of less spontaneous intimate moments due to their condition, would jeopardize the relationship. Others had already experienced broken-down relationships in the past. This generated the final subtheme, highlighting the pressure sexual issues may put on relationships:

IBD impacted upon my desire to have sex. I'm in a fairly long-term relationship of six years, and I feel that maybe the relationship will end because my partner and I feel very differently about sex. (Denise, 36, F, CD)

For some, stability of a relationship was going beyond its psycho-emotional aspects, and they felt trapped:

I'm financially dependent on my partner in a way most women aren't these days, which means I have very little courage to do or say anything that might destabilise the relationship. (Matilda, 40, F, CD)

Notably, there were participants who suffered broken-down marriages or relationships, where the impact of IBD on their sexuality was seen as a contributing factor to the loss of the relationship:

I'm divorced, so I don't know if other people have said this. I think relationships do break down about this, around intimacy, and obviously this is only one side of the story. (Martha, 38, F, CD)

The importance of an understanding partner was not just about keeping the unity as a couple, but also, providing psycho-emotional support for the participants:

It's very comforting to know that she is there and is very supportive of me in terms of intimacy. So yeah, it's critical to have that support because otherwise you would just crumble. I think you need someone to be supportive of you in that aspect. (George, 27, M, CD)

By contrast, an unsupportive partner who made insensitive comments had a profound impact on the future of one participant's relationship, eventually leading to a breakup:

My husband's comment at the time was 'well, until they've fixed you I'm not going anywhere near you, because the waste disposal unit is too close to the pleasure zone'. (Lisa, 47, F, CD)

3.3 | Reflection on time: Missing out on life fullness

Lived time reflections were based on the past, present and future intimacy and sexuality experiences, and how the chronic bowel condition robbed participants of living life to its full potential. Intimacy and sexuality experiences were dominated by lost opportunities, whether these were related to the choice of partners, the loss of a couple's opportunity to experience the desired intimacy or even adjusting to a childless life for some. The main subthemes of this theme were found to be *Sex is important*, *Sex isn't easy*, *Embarrassing symptoms shame me during sex* and *Striving for normality*. In spite of trying to live as normal a life as possible, participants struggled to do so and felt that IBD robbed them of a healthy sex life, pointing to missing out on life's fullness:

I've never really been able to have proper intercourse, it's just it caused so many problems down there. 41 years of age and I've had problems all my life really, and then with Crohn's a lot of people they have fistulas, and stuff anyway in their rectum or around that area, you know, it's going to hurt. (Catriona, 43, F, CD)

Although it became evident that those with a more severe course of disease had been more affected, all participants had reported a loss of what they would have expected to be their sex life:

It stole a good 10 years of my marriage; it stole my sex life in what should have been my prime. (Orla, 47, F, CD)

3.3.1 | Sex is important

The statement 'sex is important' was directly used or inferred across several narratives and is directly indicating the participants' attempt to continue a life as normal as possible; therefore, sex was given its own place in their lives:

It's an important part but it isn't all consuming. It isn't THE most important part, but it has been an issue sometimes. (Ben, 62, M, CD)

This subtheme was found as an introduction the participants made prior to sharing experiences of intimacy and sexuality in several

interviews, and this is why it was the foundation of this theme. It was also suggestive of the relationship with time, as sex was important in life before illness and remained important in the context of IBD.

3.3.2 | Sex is difficult

Symptoms like abdominal pain, pelvic pain, fatigue and faecal incontinence made sex difficult, but these were not the only factors complicating sex. The symptoms were present regardless of the temporality of their experiences. Those with perianal disease stressed how difficult sex could be for them. Having a seton was an issue for those with active perianal disease:

Sex isn't easy, if you think you've got strings in your vagina, and holes that leak faecal matter out of your vagina it makes sex very complicated. (Sara, 46, F, CD)

3.3.3 | Embarrassing symptoms shame me during sex

Negative feelings of shame and embarrassment caused by their symptoms and how these interfered with their sex life, were widely reported amongst the participants. Stigmatizing symptoms shamed participants during sex, and avoiding intimacy due to symptoms that may have occurred during sex, were experienced as missing out on sex life, therefore, missing out on the future aspects of the temporality domain, with a significant effect on their mental health, particularly during active periods of IBD:

I feel quite helpless, embarrassed, and disgusting at these times. I have feelings of anger at my condition. I feel embarrassed to share a bed with my spouse at these times. (Kate, 47, F, UC)

Anger and sadness were associated with experiencing shameful symptoms and embarrassing situations during intimate moments:

You just feel disgusting, it's embarrassing, it's shameful, and also it makes you feel quite sad, because you think, you know, this isn't something you've chosen to be like. (Emily, 42, F, CD)

3.3.4 | Striving for normality

Although this was indirectly related to intimacy and sexuality experiences, it was important to retain the status of a 'normal' person as a potential sexual partner and plan for family life. Lived time in this instance was about participants wanting to turn the time back, to

before the diagnosis. This last subtheme was particularly found in younger participants, some of whom were single. However, similar experiences were narrated by older participants diagnosed during their teenage years, both male and female, who recounted their experiences from younger years, and their wish at the time to be seen as 'normal', when they struggled to fit in:

I get quite low in a sense that it's that feeling abnormal, and not feeling like you fit in, and I miss the old me, and I don't think I could ever get back to that. So, it does make you feel very single, very alone, like there's not really anyone, and just very different, very outcast from everyone. (Jasmine, 17, F, CD)

Delayed puberty and not being as interested in sex as their peers were, led to experiences that they were not fitting in, and this affected their experiences of romantic relationships.

Apart from the sense of missing out on a fulfilling sex life, some discussions were on the effect of their condition on how they would have wanted to plan their family. Some participants decided on a childless life, or the condition itself imposed that on them.

I couldn't look after a child; I couldn't get up in the middle of the night or even try to feed myself, because I wouldn't have the energy to actually feed myself properly or cook something. You know, I was like no way, I couldn't look after a child. (Catriona, 43, F, CD)

Past medication, that's what I've been told would harm it for many years, has that done its final blow and means that I would never be able to father children at all? (James, 26, M, CD)

3.4 | Reflection on space: Fragmented openness

Reflecting on the lived space, including the emotional space, the fourth theme manifests as fragmented openness; and restrictions were experienced about disclosing their condition to potential romantic partners, and the deliberate or forced circumstances that led participants to be celibate. Struggles to disclose their condition to potential romantic partners for fear of being rejected constructed the subtheme *Reticent disclosure*. The avoidance behaviour was employed in different manners, for some avoiding relationships, while for those in a relationship, avoiding intimate moments and was captured in the subtheme *Aloneness*.

3.4.1 | Reticent disclosure

Disclosing their condition to potential partners was a common topic, suggesting its importance to the participants. In almost every

interview the topic of dating was raised, without a consensus on what is the best course to follow. A few confessed that they have withheld their condition from their prospective partners for the first few dates:

I think it took about 10 dates for me to be able to break it to her. And the way I went about it was again, didn't have confidence around it, I sent her a text. I don't even think I told her that I had any stomach issues. But I had to tell her for us to be able to progress with that relationship. (Adrian, 26, M, UC)

The unease of discussing stigmatizing symptoms, fear of rejection and being judged weighed heavily when disclosing their condition:

I feel like I'm going to be judged sort of thing. So obviously, when you're introducing that to anyone, there is always that sort of daunting feeling of like 'oh, how are they going to react' and that's always affected me, and I feel like it would affect others as well. (Klara, 19, F, CD)

3.4.2 | Aloneness

A few took a more extreme decision and gave up becoming romantically involved. The fear of failing in a relationship by not being able to be the expected partner was frightening for some:

I am aware of what will be expected of me if I get married to him, and I don't think I can raise to those expectations. I feel helpless and I can't let anyone in my life. (Gemma, 19, F, UC)

Similarly, other concerns related to IBD prevented participants from getting involved in new romantic relationships:

In recent months, I have tried dating new people, but have always felt weird around them and unable to become intimate with them because of how I feel about my body, and certain incontinence issues that have been caused as a direct result of my Crohn's. (Angela, 20, F, CD)

Although a minority, some participants felt that removing themselves from any relationship would potentially protect them from disappointment and from disappointing others. After being rejected in a past relationship, for some, a new relationship was seen as impossible:

Nobody would ever want to go anywhere near me because I had Crohn's, and I had this fistula and that

was it, that nobody would ever want to go near me because of this. (Lisa, 47, F, CD)

The researchers perceived a deep sense of grief amongst the participants during the interviews. Regardless of how long the participants were diagnosed with the condition, when they recounted sexuality experiences, most presented themselves as being in an active grieving process, which is plausible due to the relapse/remission pattern of the disease.

4 | DISCUSSION

To the researchers' knowledge, this is the first qualitative study to explore the experiences of intimacy and sexuality of those living with IBD. The overall message that is captured when individual or composite data is analysed is that participants experienced *Sexuality as lived incompleteness*. The essence of their experiences was found by reflecting on the four existential domains, although it is not possible to isolate each domain. Participants responded to their ill body through disembodiment, and their connection in relationships was interrupted. Although sex was important to them, most experienced missing out on sex life, and their space became constricted and fragmented, for some leading to loneliness. The findings are important as they highlight the multiple losses that may be experienced by those living with IBD and explain the negative impact of sexual well-being concerns on their psycho-emotional well-being and ultimately, their overall quality of life.

Participants lived with a constant reminder of their lost self, their lost opportunities, lost freedom and self-worth. Therefore, a theoretical model was developed, describing the inter-relationship of the main existential domains, losses experienced in each domain, and main themes, in an attempt to illustrate the close relationship of sexual well-being and psycho-emotional well-being (Figure 1). The loss of privacy was experienced through a new body that was the result of the IBD, and which behaved as an intruder in participants' bedroom. The loss of spontaneity affected the relationships, intimacy was no longer spontaneous, as the loss of body control sometimes meant extensive preparation for intimate moments. Loss of future prospects, such as the choice of a partner, was closely linked to the loss of freedom. The impact of a stoma or a seton had led to the loss of personal space and as a result, loss of freedom to be intimate as desired. All these losses added to the researchers' perception of participants grieving multiple losses.

Grief is an expression of being in the world and defines our relationship with love, and we only experience grief when something that was loved is lost. Certain psychological distress is associated with grieving; therefore, it is often referred to as a negative emotion (Brinkmann, 2018). This model was developed as the existing models of grief are referring to the loss of a loved one, bereavement and coping, whereas this model refers to the loss of self.

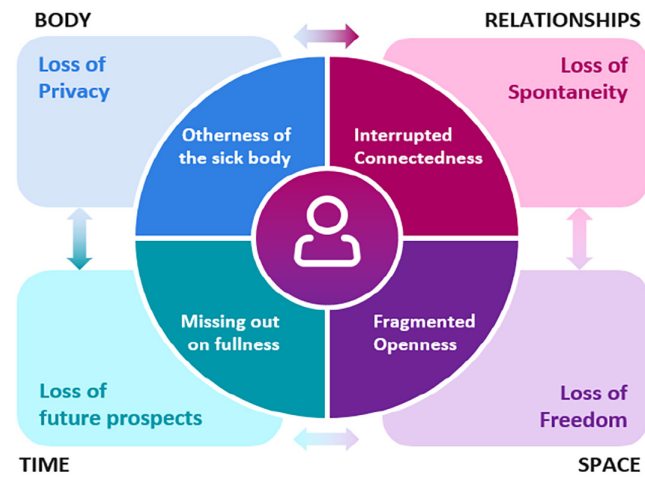


FIGURE 1 Theoretical model of grieving multiple losses in intimacy and sexuality due to inflammatory bowel disease.

It was apparent that most of those living with IBD were caught in a struggle to maintain normality. This entails keeping two identities, of which one is presented to the society, friends and sometimes even family, which all act as an audience, through performing, attempting to appear to the others as being the 'normal' self (Goffman, 1959). As in day-to-day life, performance is also employed in romantic relationships, and considering the effort needed in maintaining an image that is not matching with the reality, it is likely that these performances take their toll on mental health, especially in a population where energy levels are low. The negative effect of anxiety and depression on sexual function is already known in IBD (Marín et al., 2013; O'Toole et al., 2018; Timmer et al., 2007); however, there is little understanding about poor sexual well-being and its effect on anxiety and depression, in general, not just for those living with inflammatory bowel disease. These findings are supported by our Grieving multiple losses model, that could suggest the intricate role of sexual well-being concerns in developing anxiety and depression.

Sexual function is closely linked to quality of life which implies that in the absence of satisfactory sexual function, the overall sexual well-being is disrupted. Previous studies have been quantitative and documented sexual dysfunction, and this is the first qualitative study to date that specifically explores how IBD impacts on peoples' intimacy and sexuality. An earlier quantitative study found that the main reason for reporting lower sexual function in women with the condition was fatigue, followed by abdominal symptoms (Marín et al., 2013). Compared to healthy controls, women with IBD have an impaired sexual function regardless of disease activity (Timmer et al., 2007). A review concluded that sexual function is important and often impaired in women living with inflammatory bowel disease (Mantzouranis et al., 2015). Women who had surgery for this condition are more likely to have sexuality concerns but around 80% of them said they would not discuss this with their healthcare professionals (Rosenblatt & Kane, 2015). It has been recommended that adolescent girls should receive adequate advice on all aspects of women's

health, particularly on those aspects of IBD that have an impact on quality of life, such as body image (Nee & Feuerstein, 2015). Findings from this study suggested that a poor body image and function within the intimacy/sexuality domain (suggestive of low sexual well-being) were subsequently provoking negative feelings, such as anxiety, low self-esteem, embarrassment and shame. These findings further support our grieving model, particularly the losses experienced through body, and the loss-of-future prospects.

Grieving over lost health and declined confidence, altered body image, as well as feelings of shame, are all illness-related problems (Kleinman, 1988). People living with IBD grieve mostly the loss of self, but also, they grieve the loss of their relationships, the loss of prospects and the loss of their space in society, as this disease remains seen as a stigmatizing condition, and sex issues are taboo. Despite the losses they suffer, it is evident that society and healthcare professionals are not responding to their grief, resulting in disenfranchised loss. Disenfranchised loss is a form of grieving that is not socially accepted, and one of the reasons for this is that the loss is not recognized by the society (Doka, 1999). As long as the losses experienced by those living with IBD are silent to the wider society, they will not be recognized, accepted and acted on, by giving appropriate support. This is particularly important as new evidence shows that a quarter of people living with the condition experience post-traumatic stress symptoms caused by their illness experiences (Taft et al., 2022). Understanding the implication of unaddressed sexual well-being issues on the mental health of those living with IBD should support healthcare professionals to improve illness experience and decrease the risk of developing post-traumatic stress symptoms.

5 | STRENGTHS AND LIMITATIONS

The study had relatively large sample size for a phenomenological study, and included a varied population, with a representation of sexual minorities. By offering participants the option to take part in an anonymous way an opportunity to voice sexuality concerns was given to those who otherwise would have not joined, as well as to those who could not have been interviewed for various reasons, offering an inclusive approach to exploring the topic.

In terms of the methodology used, van Manen's framework strengths are situated in the approach to analysis. Another strength is that phenomenological studies give a voice to participants, the essence of their experiences is based on their recounting of such experiences and are not driven by researcher in a prescriptive way, and the results show the facets of the experiences that are lived, without the claim that all experiences are similar to those presented.

In terms of limitations, it is acknowledged that those who responded to the study advert may be people who had more significant issues than most of this population. Participants were mainly from the United Kingdom, and English speaking, and experiences in other cultures are unknown. Although sexual minorities were represented in the study, ethnicity of the participants was not recorded,

TABLE 5 Recommendations for clinical practice and research.

Recommendations for practice

- Initiate routine conversations about sexual well-being/relationship issues without the expectation that there must be a solution for patient concerns. Involve partners wherever this is agreed with patients
- Assess the level of concern about sexual well-being, especially for those with perianal disease and/or undergoing surgery
- Recognize the impact of illness on relationships if sexual dysfunction is identified and consider the role of psychological interventions for those who report high levels of anxiety and depression
- Recognize the negative impact on sexual well-being especially in those with severe forms of perianal disease.
- Recognize and address HCP knowledge gaps on illness impact on sexuality

Recommendation for research

- Tool development for sexual well-being assessment
- Further explore intimacy and sexuality in the context of IBD in different cultural and clinical settings
- Further research to develop theoretical models around sexual well-being in long-term conditions
- Explore the impact of IBD on intimacy and sexuality from the perspective of partners
- Explore the barriers and facilitators encountered in practice by HCPs for initiating discussions on sexual well-being
- Expand the research question to other health conditions such as colorectal cancer and pelvic floor disorders
- Explore the need for specific services that could support patients with sexual well-being concerns

Abbreviations: HCP, healthcare professional; IBD, inflammatory bowel disease.

and authors recognize the potential for cultural impact on the experiences.

6 | CONCLUSION

People living with IBD experience intimacy and sexuality in a variety of forms, with negative impact on their psycho-emotional well-being, as they experience grieving multiple loses. This is important when depression and anxiety are identified in people living with this condition, as unaddressed sexual well-being concerns of this group could contribute to increased anxiety and depression.

The findings from this study are relevant for nursing practice as it highlights the need for understanding the illness impact on sexual well-being and to be included in education programmes to better prepare nurses for initiating such conversations. Several recommendations relevant for nursing practice and research are made in Table 5. Further recommendations for how to discuss sexual well-being concerns were made in a previous publication (Fourie et al., 2021). The transferability of the findings from this study is assumed to potentially extend to other long-term conditions, particularly pelvic floor disorders, as well as to those undergoing major gastrointestinal surgery; however, further research is needed to test these assumptions.

AUTHOR CONTRIBUTIONS

Simona Fourie involved in design of the study, data acquisition and analysis. Simona Fourie, Christine Norton, Debra Jackson and Wladyslawa Czuber-Dochan involved in data interpretation, drafting the article and final approval of version submitted.

ACKNOWLEDGEMENTS

We acknowledge Crohn's and Colitis UK for their support to reach their members, by advertising our study on their research page. We are grateful to all participants who took part in the study.

CONFLICT OF INTEREST STATEMENT

None.

PEER REVIEW

The peer review history for this article is available at <https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jan.15879>.

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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How to cite this article: Fourie, S., Norton, C., Jackson, D., & Czuber-Dochan, W. (2024). Grieving multiple losses: Experiences of intimacy and sexuality of people living with inflammatory bowel disease. A phenomenological study. *Journal of Advanced Nursing*, 80, 1030–1042. <https://doi.org/10.1111/jan.15879>

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