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An Interpretative Phenomenological Study Exploring the Intimacy and Sexuality Experiences of People Living with Inflammatory Bowel Disease

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King’s College London

Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care

An Interpretative Phenomenological Study Exploring the Intimacy and Sexuality Experiences of People Living with Inflammatory Bowel Disease

Ana-Simona Fourie

Thesis incorporating publications submitted for the degree of Doctor of Philosophy

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Abstract

Background

Inflammatory bowel disease is a chronic remitting-relapsing condition comprising mainly two different illnesses: Crohn’s disease and ulcerative colitis. Symptoms include abdominal pain, bloody diarrhoea, faecal urgency and /or incontinence, fatigue, and several extra intestinal manifestations, such as eye and joint inflammation. Over 40% of those with severe Crohn’s disease develop perianal disease, with anal fistulae. There is no cure for inflammatory bowel disease, and treatment remains mainly symptomatic and aims at maintaining remission. Surgery is needed in 80% of those with ulcerative colitis, and 25% of those with Crohn’s disease, leading in some cases to temporary or permanent stoma formation. Due to the unpredictability of the condition, the nature of the symptoms and stigma attached to it, patients have an array of worries and concerns.

Literature review

For a better understanding of care needs, a qualitative review of the qualitative studies reporting on the illness experiences of people with Inflammatory bowel disease was performed, with the aim of identifying what areas lacked evidence, t were under-researched and required further investigation.

A review of qualitative studies synthesised the evidence from 24 studies and 850 patients that met the inclusion criteria. The published review concluded that patients live in social isolation and with restrictions. Pain, fatigue, incontinence, body image and an uncertain future dominated their experiences. The need to address the psycho-emotional and social aspects of the condition was identified. Furthermore, issues related to intimacy and sexuality were not directly addressed in the literature, and inferred findings from the review suggested that these may

be present. Young women aged 16-24 were the group with the poorest representation in the study, followed by ethnic minorities living with IBD.

Aim of the thesis

No qualitative studies explored patient experiences behind these findings. Given the complexity of the components of sexual function, this is a gap in knowledge on this topic. Based on the findings from the literature review, aims of this study were formulated:

- To explore the lived experiences of intimacy and sexuality of people living with inflammatory bowel disease
- To explore the lived experiences of discussing intimacy and sexuality with healthcare professionals, and the need for these discussions.

Methodology

An interpretive phenomenological design guided by van Manen's framework was used. Data were collected from 43 participants via face-to-face and telephone interviews, as well as anonymous narratives collected via Google Forms.

Thematic analysis based on reflection on four existential domains (body, relationships, time and space) was used for interpreting the data.

Results

The results were presented in two parts reflecting the data analysis of each research aim.

- **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* that were found to be qualities of the experiences, with variations of each quality reflected in subthemes. Each theme covered an existential domain, as they were defined as a result of reflecting on the four existential domains. In lived **body** the theme captured the challenges of the sex life when the ill body no longer functions as before the disease and becomes a separate entity in the eyes of the participants. **Relationships** domain is thrown into chaos, and pressure strained some relationships. **Time** domain was suggestive of lost opportunities, inability to experience the desired intimacy and impact on choice of partners, and family planning. The last existential domain, **space**, was experienced as restricted space, not just physical but emotional space as well, where participants were unable to disclose their condition to potential partners. The four domains were difficult to separate and a close inter-relationship between each domain was acknowledged.

- **'These discussions aren't happening'** was the overarching theme for the experiences of discussing intimacy and sexuality with healthcare professionals in clinical setting. Barriers in discussing concerns, proposed ways to move forward and achieve holistic care, calls to break the silence and taboos surrounding these discussions as well as experiences of such conversations that reinforced the feelings that sex was not taken seriously, were all the findings presented in four themes: *I can't imagine talking about my sex life, I'm a person not my IBD, We need to talk about sex* and *Those who talked about sex, talked badly*. The findings concerning the discussions with healthcare professionals were published in a second paper included in the thesis.

Conclusion

Intimacy and sexuality are important and integral aspects of quality of life and those living with inflammatory bowel disease are severely affected by the condition. Sexual well-being is largely not addressed in clinical practice and the study provided evidence that healthcare professionals have a less holistic approach to care. Healthcare professionals should routinely ask about intimacy and sexuality issues in the clinical settings. Existing variations in the quality of care should be addressed, to promote better access to sexual well-being information. Recommendations for further research are to explore the views of healthcare professionals on discussing sexuality in clinical settings, training needs of healthcare professionals to enable effective communication, and development of a tool to assess sexual well-being.

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I am grateful to all those who volunteered to take part in my study, and I am humbled by their resilience and their outlook on life, in spite of the challenges that IBD added to their lives. I thank them for their willingness to expose their experiences, especially in the light of the sensitive topic that was studied.

Finally, I will be forever grateful to my husband and daughters, who were most patient and understanding during these years, and who have been my greatest supporters.

CHAPTER 1. Introduction

1.1. Overview of the chapter

This chapter provides an introduction to inflammatory bowel disease (IBD) classification, aetiology, symptoms, treatment and some of the extra-intestinal manifestations to illustrate how these have the potential to impact on one's intimacy and sexuality. A brief description of the evidence on quality of life and aspects of it, such as sexuality and sexual function precedes presentation of the aim and objectives of the thesis.

1.2. IBD: Classification, aetiology and incidence

Inflammatory bowel disease is a chronic condition broadly represented by two different illnesses, Crohn's disease (CD) and ulcerative colitis (UC). Both are inflammatory conditions of different parts of the digestive tract. UC affects the colon, the mucosal inflammation extending proximally from the rectum (Feuerstein and Cheifetz, 2014). CD can involve any segment of the gut from mouth to anus with around 50% of patients presenting terminal ileum inflammation extended to the colon, and around 25% of CD patients having perianal disease (Cheifetz, 2013). Around 5% of patients have a form that presents as an overlap between CD and UC, known as IBD unclassified (IBD-U) or indeterminate colitis (Tremaine, 2012).

The two conditions differ through the distribution of sites and the morphologic expression of the sites, and also have different endoscopic presentation (Fig. 1)

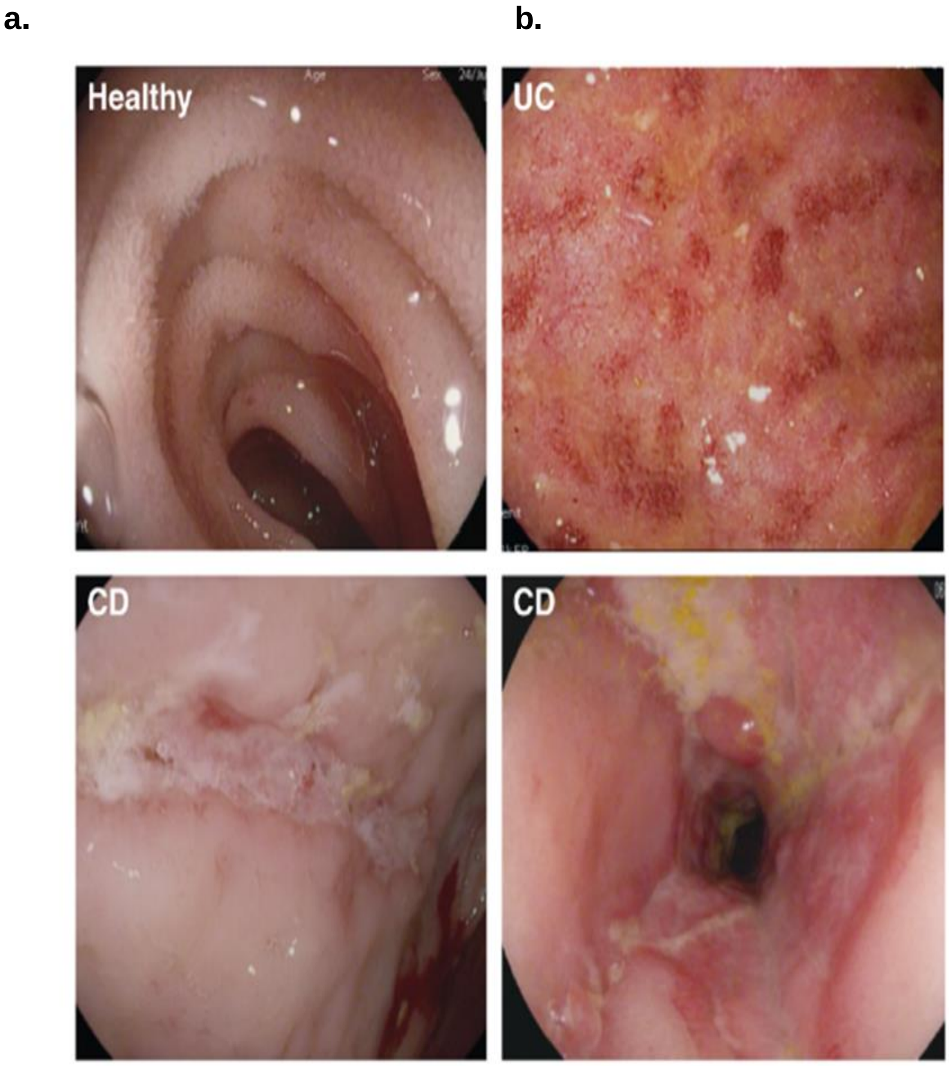

Figure 1.Endoscopic view of IBD.

- **a.** Inflammation in CD (left) has a segmented pattern and frequently affects the terminal ileum; in contrast, inflammation in UC (right) usually affects the rectum and sometimes the entire colon.
- **b.** **b**. Endoscopic features of CD (bottom row) and UC (top right) versus those of unaffected intestine (top left): erosions and bleeding (top right), large ulcers (bottom left) and ulcers with stenosis (bottom right) are visible (Neurath, 2019) pg.971)[1]

The exact cause of the disease is still unknown and IBD has no current cure. It is accepted that a combination of individual genetic factors, environment and gut microbiome alterations contribute to developing the condition (Ponder and Long, 2013). It is suggested that children treated with antibiotics for other conditions during their childhood have a seven-fold chance of developing CD later in their

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life (Hviid, Svanström and Frisch, 2011). It appears that smoking could precipitate the onset of CD in Caucasians (Higuchi *et al.*, 2012). Genetic studies have found that NOD2 mutations have a role in developing CD, but a mutation alone is not sufficient to cause the onset, therefore additional environmental factors are suspected to contribute to this (Eckmann and Karin, 2005). Epithelial response to gut bacteria has a considerable weight in the risk factors, and the recent discovery of a new goblet cell present in UC could explain one mechanism of dysregulated response, by secreting a mucus which allows epithelial penetration of some bacteria (Parikh *et al.*, 2019).

The incidence of IBD around the world varies and is increasing, Europe has the highest rates of IBD with UC cases 505:100/000, and CD 322:100/000. North America has around 249:100/000 UC patients and 319:100/000 with Crohn’s, whilst Asia and Middle East reported around 5:100/000 Crohn’s and 6:100/000 UC patients (Molodecky *et al.*, 2012). Up to 30% of those living with IBD are diagnosed in childhood and adolescence (Hanauer, 2006), and the evidence suggests that this group has a more severe course of the illness (Heyman *et al.*, 2005;Van Limbergen *et al.*, 2008). Furthermore, those diagnosed during their developmental stage often experience delayed puberty and growth (Suris, Michaud and Viner, 2004). Most IBD patients are diagnosed between the ages of 15 to 35 years, men being more likely to be diagnosed later in their lives than women (Loftus, 2004) .

1.3. Symptoms

Patients living with IBD can experience abdominal pain, chronic fatigue, bloody diarrhoea, urgency and/or faecal incontinence, weight loss, and in some cases extra intestinal manifestations such as joint or eye problems (Day *et al.*, 2012). The most common extra intestinal manifestations are arthropathies (Harbord *et al.*, 2016). Symptoms are unpredictable and the condition is characterised by periods when symptoms are quiescent followed by acute flare ups (Whayman, Duncan and O’Connor, 2011).

Pain is a major symptom reported by the patients, negatively affecting health related quality of life, and is a major concern for those living with IBD, with serious associated negative psychological effects (Lindfred *et al.*, 2012; Farrell, McCarthy and Savage, 2016; Sweeney *et al.*, 2018). Fatigue, although poorly described in existing studies due to its multidimensional nature (Czuber-Dochan *et al.*, 2012) Is also commonly reported by those living with IBD, and is construed in various ways, from having a lack of energy to not reaching full potential in life (Casati *et al,* 2000; Van Langerberg and Gibson, 2010; Stjernman *et al*,2010). Up to two thirds of those living with IBD have reported fatigue and faecal incontinence as main symptoms (Czuber-Dochan *et al*, 2012; Nigam, 2019). Symptoms vary during remission and flares, however, for some symptoms are persistent regardless their disease activity. Fear of incontinence and searching for toilet access in unfamiliar places are important stressors in the lives of many patients with IBD (Dibley and Norton, 2013; Lonfors *et al*., 2014). Up to 85% of those living with IBD have malnutrition (Nguyen, Munsell and Harris, 2008) due partly to inflammation in the gut and malabsorption, and partly due to dietary restrictions implemented in an attempt to control symptoms (Prince *et al.*, 2011). Up to 25% of those with UC and up to 80% of those with CD will undergo surgery at some point, and sometimes more than once (Selinger *et al.*, 2014). Given the chronic nature of the symptoms and the severity of these, the condition has a significant impact on the patients’ lives.

1.4. Treatment

Treatment is complex and primarily addresses inflammation, aimed at inducing and maintaining disease remission for as long as possible (Mowat *et al.*, 2011). Other aspects of treatment include management of iron deficiency anaemia and metabolic bone disease, and colorectal cancer surveillance due to the high risk of developing colorectal cancer.

1.4.1. Medical treatment

Medication is used both to induce and maintain remission with some medication classes effective in remission only, whilst others have evidence for both remission and relapse phases. Various treatment algorithms have been developed and they are based on severity of the disease, location and type of disease as well as risk factors, drug immunogenicity and costs (Torres *et al.*, 2020). For example, proctitis will follow a different algorithm to extensive UC or pan-enteric CD.

During flare ups, **corticosteroids (e.g. prednisolone, budesonide)** are generally used as first line of treatment, as they reduce inflammation rapidly. Budesonide is poorly absorbed and therefore has a more favourable side effect profile. Prednisolone should be used for short periods (2-3 months) to reduce the incidence of side effects such as infection, bone disease and diabetes, weight and mood changes (Dubois-Camacho *et al.*, 2017). Generally, corticosteroids should not be used as maintenance therapy in IBD. In situations where the disease does not respond to corticosteroids, early escalation to biological therapies, see below, may be needed to induce remission.

Aminosalicylates (e.g. sulfasalazine, mesalazine) may be used for both induction and maintenance of remission in UC. Both oral and topical (enema, suppository) formulations are available and for more extensive UC, combined oral and topical preparations are more effective than either formulation alone (Ford *et al.*, 2012). They act through reducing local inflammation by reducing prostaglandin production. There is no evidence for aminosalicylates in the management of CD. Periodically whilst on treatment with aminosalicylates patients' renal function should be monitored as they may cause nephrotoxicity (Heap *et al.*, 2016).

Thiopurines (azathioprine, 6-mercaptopurine) are immunosuppressants and they are also used for maintenance therapy, in both UC and CD. They suppress white cell formation and have significant side effects and an increased risk of certain malignancies, including skin and cervical cancers, and lymphoma (Annese *et al.*, 2015). Active cervical cancer screening is needed for women during treatment (Mowat *et al.*, 2011). During treatment, blood tests should be monitored both, for white cell count but also liver function as there is the potential for liver damage.

Over the past two decades, **biologics** have significantly changed the treatment for IBD. Initially introduced as a last option in the absence of response to other lines of treatment, nowadays biologics are increasingly used as first line treatment for severe cases of CD with co-existent perianal disease, steroid-dependent or steroid-refractory IBD, as well as for any patient whose previous treatment failed to achieve remission. The first biologic available for IBD was **infliximab**, part of the anti-tumour necrosis factor (anti TNF-α) drug class. The mechanism of action is by suppressing the production of the pro-inflammatory cytokine TNF–α. Some patients may develop loss of response over time (Billioud, Sandborn and Peyrin-Biroulet, 2011) with development of anti-drug antibodies. There is a risk of drug hypersensitivity, and it should be avoided in patients with active infection, or a history of demyelinating disease, certain malignancies, heart failure or tuberculosis (www.bnf.nice.org.uk). An alternative anti-TNF agent is **adalimumab** that is administered subcutaneously, as opposed to infliximab that is only administered intravenously. Others include **golimumab** and **certolizumab**. The choice of which anti-TNF agent to use requires discussion with the patient and knowledge of response to previous therapies. For instance, a patient who had lost response over time to infliximab might be considered for an alternative anti-TNF agent. Conversely, if a patient's disease never responded to infliximab, then an alternative anti-TNF agent is less likely to be effective. In these cases, consideration of an alternative drug class is advisable. Newer biologics in use include **vedolizumab** and **ustekinumab**. Vedolizumab inhibits alfa- 4-beta 7 (a molecule expressed in lymphocytes) and is used in the treatment of both UC and CD, through intravenous administration. It is fast acting with a response within 6 weeks with clinical trials demonstrating sustained remission over a year. Ustekinumab, which binds to the shared subunit of the cytokines IL-23 and IL-12, is also licensed for both CD and UC. **Tofacitinib**, a Janus Kinase inhibitor, is licensed for UC and is effective at both the induction and maintenance phases of treatment. With an increase in available treatments, the decision as to which drug to choose becomes more challenging and more nuanced.

Anti-TNF agents, particularly infliximab, are usually used in combination with thiopurines, or alternative immunomodulators such as methotrexate or mycophenolate mofetil. With increased immunosuppression there is an increased risk of infection.

Vaccinations are important for patients with IBD and knowledge of vaccination history is advisable prior to commencing advanced therapies. Vaccinations should be kept up-to-date, including annual influenza vaccines

(Mowat *et al.*, 2011) but live vaccines are usually contraindicated. There is no evidence that medication affects fertility in women, but active CD seems to negatively impact fertility (van der Woude *et al.*, 2015). As a result of surgical treatment (ileal pouch anal anastomosis) up to half women were found to have reduced fertility (Crowe *et al.*, 2017), but in men the effect of surgery on fertility was not studied yet (van der Woude *et al.*, 2015).

Treatment non adherence is common in IBD and is associated with poorer outcomes for patients and increased risk of relapses (Kane, 2007; Eindor-Abarbanel *et al.*, 2018). There is evidence that psycho emotional state of patients can also predict medication adherence (Sajadinejad *et al.*, 2012). Non-adherence is less common in patients receiving medication as intravenous infusions (17%) than those on subcutaneous regimens (30%) (Lopez *et al.*, 2013).

1.4.2. Surgical treatment

Surgery is necessary for various reasons, and can sometimes lead to permanent stoma formation. Up to 25% of those with UC and up to 80% of those with CD will undergo surgery at some point, ileocolonic resections were reported to have up to 47% recurrence within 5 years (Rutgeerts. *et al.*, 1990). Stoma formation presents emotional challenges, and although it is lifesaving, it adds to the disease burden related distress, stoma leakage, noises and odours contributing to stigma experienced by this group (Dibley and Burch, 2019). A study exploring young male experiences of living with a stoma in the context of IBD found that this sub group of patients require psychological support from healthcare professionals just as much as physical support related to care for their stoma (Ayaz-Alkaya and Sultan Ayaz-Alkaya, 2019). In CD, stricturing has seen a significant decrease in need for surgery as a result of introducing biologics

(Sokol, 2014). However, stricturoplasty, a type of surgery that preserves the length of the small intestine in strictures under 10 cm, is regularly performed. Perianal CD often necessitates surgical treatment in most cases, although surgery combined with anti TNF medication are used for better healing response (Adegbola *et al.*, 2018). The use of fistula plugs in perianal disease has up to 50% healing success rate (O'Riordan *et al.*, 2012). About 25% of those with UC will develop acute severe ulcerative colitis (ASUC), which can be life threatening and the treatment will also include antibiotics (Seah and De Cruz, 2016). In the case of ASUC emergency colectomy is often necessary (Kornbluth and Sachar, 2010) and around 20% of those who present ASUC at first admission will undergo colectomy (Dinesen *et al.*, 2010). Pelvic nerve damage is a potential risk of surgery with potential negative consequences on sexual function (Öresland *et al.*, 1994; Lindsey *et al.*, 2001).

1.5. Extra-intestinal manifestations of IBD

Over a third of those who live with IBD develop extra intestinal manifestations (van Assche *et al*., 2010). Due to the IBD aetiology it is considered a systemic disease (Ott and Scholmerich, 2013) (Fig.2).

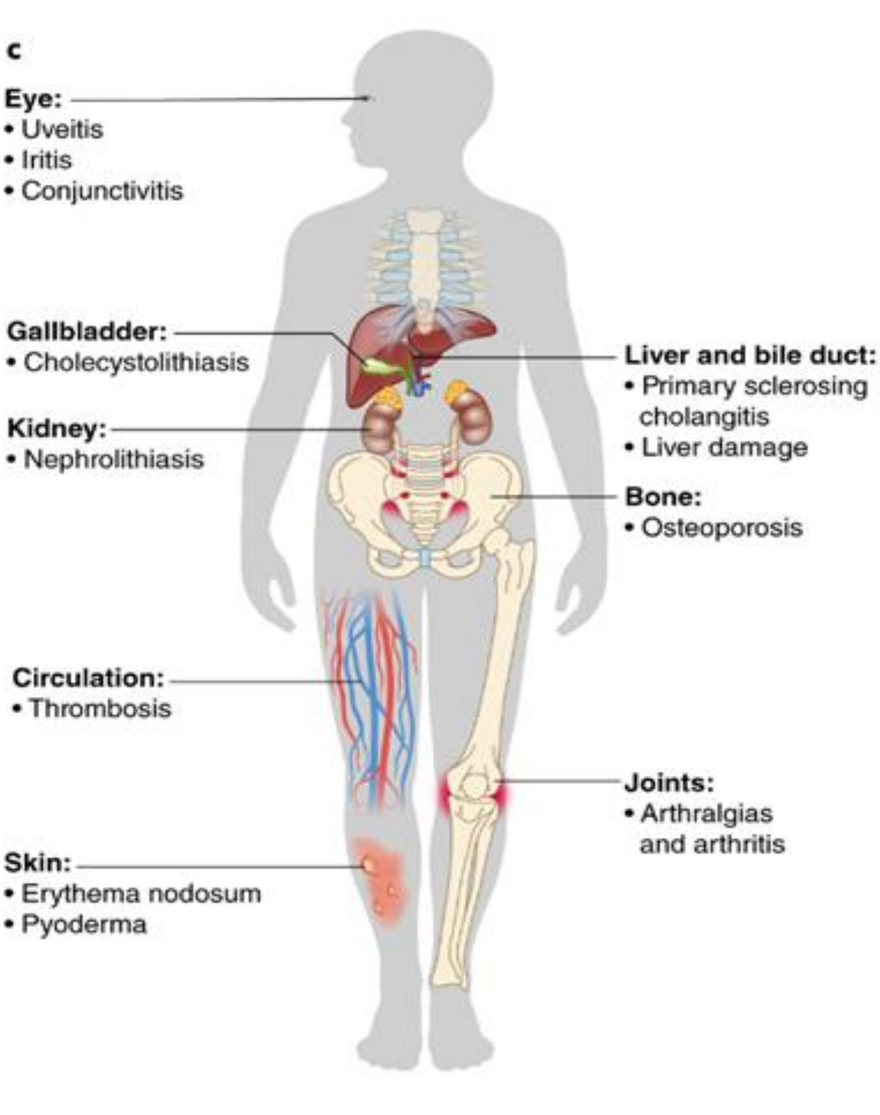

Figure 2. Extra-intestinal manifestations of IBD
(Neurath, 2019, pg.971).

These are part of two main groups: reactive manifestations, related to the inflammatory activity from digestive system, and autoimmune diseases independent from IBD (Danese *et al*., 2005). The human leukocyte antigen (HLA) system (a group of cell surface proteins responsible for regulating the immune system) is commonly associated with extra intestinal manifestations of both CD and UC. HLA mutations significantly increase the risk of primary sclerosing cholangitis, ocular manifestations and ankylosing spondylitis. Up to 47% of those with HLA mutations will develop certain extra intestinal manifestations, and around half of them will have more than one (Vavricka *et al.*, 2015). Some of these are noticed after increased severity of luminal disease (Rothfuss, Stange and Herrlinger, 2006) others, such ankylosing spondylitis and uveitis are independent of the intestinal disease activity (Vavricka *et al.,* 2015). Eye manifestations are common for both CD and UC and untreated could lead to visual impairment (Vavricka *et al.,* 2015). Those with primary sclerosing cholangitis (PSC) can develop liver cirrhosis (Joo *et al.*, 2009).

In CD, the most frequently occurring extra-intestinal manifestation is perianal disease. These are fistulas arising from the intestine and opening in the vagina, bladder, perianal skin and rarely, vulva Perianal disease (PAD) is used as one of the diagnostic criteria for CD, although a case control study found that 5% of those diagnosed with UC developed PAD, which warranted extensive work to rule out CD in the group, and about a third of the initially diagnosed with UC had their diagnosis changed as a result of PAD (Zabana *et al.*, 2011). PAD has significant negative physical and emotional impact on patients, affecting their intimate and social interactions (Adegbola *et al.*, 2020).

1.5.1. Perianal disease in Crohn’s

More severe forms of CD are associated with a 43% incidence of PAD, which often leads to multiple surgical procedures in this patient group (Schwartz, Pemberton and Sandborn, 2001).

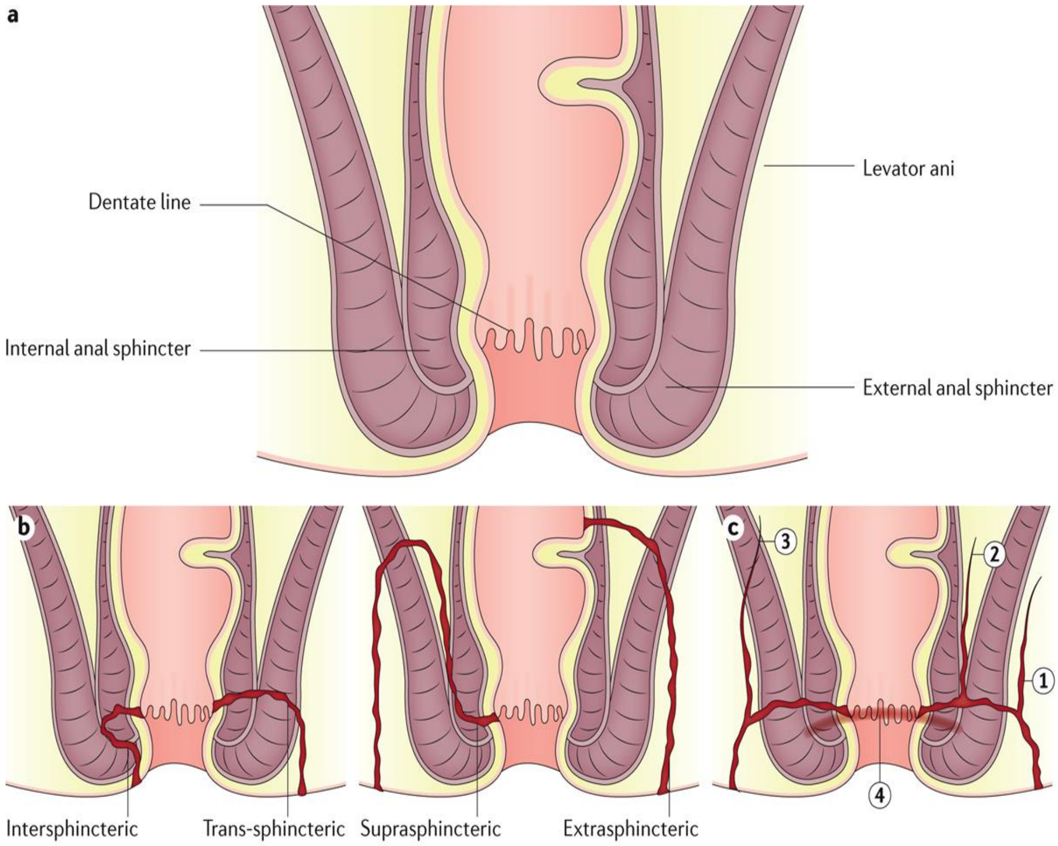

Figure 3. Classification of perianal fistulas.

a. The anatomic structures essential for fistula classification. **b |** Illustrations of the Parks classification of perianal fistula in a coronal plane. **c |** Illustrations of fistula extensions: extension into roof of ischioanal fossa (infraelevatoric) (1); supraelevatoric extension from apex of trans-sphincteric fistula (2); supraelevatoric extension from trans-sphincteric fistula (3); and horseshoe extension (4). (Panés and Rimola, 2017, pg.104).

It presents as simple or complex fistulas, and in women could increase the risk of complications when the recto-vaginal wall is involved (Hatch *et al.*, 2014). Some fistulas affect the anal sphincter, which can affect the bowel control especially if fistula repair surgery is involved. Pain, perianal swelling, and a purulent, bloody or faecal discharge from the perineum or vagina are the main symptoms (Sandborn *et al.*, 2003). Treatment could be medical or surgical, addressing symptoms, increasing the quality of life and preventing faecal incontinence (Singh *et al.*, 2004). Antibiotic treatment option has a success rate of around 50% for fistula healing, however, there is a high risk of relapse on withdrawal of antibiotic (Brandt *et al.*, 1982; Hvas *et al.*, 2011). Thiopurines and anti TNF medication studies have shown that the healing rate in recto vaginal fistulas was poor for those on Infliximab, but better for perianal fistulas (Sandborn, 2003). The surgical treatment aims at draining the collection of sepsis and a seton (a surgical thread) that may be placed in the fistula tract in an attempt to manage perianal sepsis (Safar and Sands, 2007; Kelley, Kaur and Tsikitis, 2017; Williams *et al.*, 2018). The setons prevent closure of tract and relapse in collection formation, and they could preserve the anal sphincter function (Buchanan, 2004; Malian *et al.*, 2020). Setons can be placed loose, to facilitate drainage of collection and healing of fistula tract, or tight-a cutting seton- to separate the sphincter muscles in the case of complex fistulas, and preserve the sphincter during surgical repair (Williams *et al.*, 2018). Once all signs of collection are eliminated, but no less than 6 weeks, the next step is a fistulotomy in most cases, although only performed in simple fistulas, with a healing rate of around 80%. In complex cases formation of permanent stoma may be needed (Bell, 2003). In others, where there is no healing of fistula tract, a seton is kept in situ long term, for palliation of symptoms (Williams *et al.,* 2018).

Rectovaginal fistulas are present in up to 10% of women diagnosed with CD, and the main symptoms are passing gas and/or faeces through vagina. Vaginitis is a common complication in patients with rectovaginal fistulas (Safar and Sands, 2007).

1.5.2. Vulvar Crohn’s

Although rare (Andreani *et al.*, 2010), vulvar Crohn’s (VCD) is a particular variation of perianal disease found in women with CD, and these vulvo-vaginal cutaneous lesions take various clinical presentations: vulvar oedema usually unilateral, ulcerations, hypertrophic lesions and chronic suppuration (Barret, De Parades, *et al.*, 2014). It can be particularly difficult to diagnose in the absence of intestinal involvement (symptoms of active intestinal CD) and often patients require extensive investigation eliminating sexually transmitted diseases (STDs), other skin conditions, and infections.

The first case study on VCD was published in 1965 (Parker *et al*, 1965) and evidence suggests that current medically diagnosed cases amount to just around 200 cases worldwide. Treatment is not well established (Abboud, 2017) and the disease course is unpredictable, from some genital lesions resolving spontaneously to others remaining unresponsive to medical or surgical treatment. A multidisciplinary approach is required and a course of oral antibiotics and surgical debridement is the most common approach (Wells and Cohen, 2018). A variant of genital Crohn’s can also be found in men (Saha *et al.*, 2009). IBD treatment for intestinal symptoms is continued alongside with the one for genital lesion.

1.6. Risk of cancer in IBD

Studies have demonstrated that interaction between colonic epithelial cells, host genome and microbiota could be of carcinogenetic nature (Repass *et al.*, 2018). Chronic inflammation in IBD was found to have similar mechanisms as those promoting colorectal cancer development (Francescone, Hou and Grivennikov, 2015). Thiopurines could lead to cancer development through various mechanisms, such as DNA alteration, impaired immune response to oncogenic viruses and activation of certain cancer genes (O'Donovan *et al.*, 2005). Although Thiopurines can increase the cancer risk by 7 fold, the effect is reversible if medication is stopped (Beaugerie *et al.*, 2013; Pasternak *et al.*, 2013).

1.7. Quality of life in IBD

Physical, psychological, and social concerns of those living with IBD are extensive given the chronic nature of the symptoms and the severity of these. People living with IBD have described both physical and psychological burden of symptoms in previous studies (Casati *et al*, 2000; Mussel *et al.*, 2004; Kemp *et al*., 2012). Farell *et al.* (2016) found that the most burdensome symptoms reported during relapses were bowel urgency, fatigue, and diarrhoea, whereas during remission periods fatigue is the most burdensome. In terms of psychological burden, anxiety (worrying) was reported by over 60% of patients during relapses, and almost 40% during remission periods (Nahon *et al.,* 2012; Farell *et al.*, 2016). Depression and anxiety rates in IBD patients are higher than in healthy population (Mikocka-Walus *et al.*, 2015) with around 20% of those living with IBD presenting lifetime risk of anxiety and 40% depressive symptoms (Neuendorf *et al.*, 2016). It is evident that the condition is affecting every aspect of the lives of IBD patients, and the evidence of the negative impact of the condition on the overall quality of life is now three decades old (Sorensen *et al.,* 1987; Drossman *et al.,* 1989; Norton *et al*., 2012; Floyd *et al*., 2015). Mental health support remains poorly addressed in spite of the evidence for the need (Taft and Keefer, 2016) and disease related concerns were reported to increase levels of psychological distress in IBD, therefore addressing these concerns is important (Yanartas *et al.*, 2016).

The condition has a significant impact on the patients' lives, and a negative effect on their quality of life (QoL). QoL concerns in IBD are the most common concerns reported (Keeton, Mikocka-Walus and Andrews, 2015) and some argue that it varies greatly and is closely related to symptom severity (Janke *et al.*, 2005; Knowles, Gass and Macrae, 2013) whilst others found that remission status did not increase QoL (Keeton, Mikocka-Walus and Andrews, 2015). Fatigue, anxiety and depression are responsible for lower QoL scores in IBD (Tribbick *et al.*, 2015). Perianal disease (PAD) is known to lower the QoL (Vollebregt *et al.*, 2018). Following surgery, QoL increases short and medium term for those who had undergone ileocecal resection (D'Ugo *et al.*, 2020; Horgan, Richards and Joy, 2020). However, patient reported outcomes do not always give an accurate reflection of their QoL as some might under report gravity of the symptoms due to complex factors, such as fear of surgery (Mitchell *et al.*, 2017) or fear of stoma formation (Drossman *et al.*, 1991).

Another aspect that may be influencing a low QoL score is the treatment burden. Treatment burden is a relatively new concept (May *et al.*, 2014) and relates to the chronically ill patient experience with regards to taking medication or participating in medical interventions and self-management (Sav *et al.*, 2015).The concept is not well defined yet, but Sav *et al.* (2015) identified in their review that a consequence of treatment burden is non-adherence to medication. Up to 50% of IBD patients were found not to adhere to their medication treatment (Chan *et al.*, 2017), and although there are no studies yet looking specifically at treatment burden in IBD, the high rates of non-adherence to medication reported by Chan *et al.* (2017) may indicate the presence of treatment burden for this group.

In spite of all the evidence, healthcare professionals fail to ask the right questions to fully assess the real impact of the condition on QoL (Lönnfors *et al.*, 2014), and to address patients' needs in a holistic manner. Aspects of QoL are only addressed by half of clinicians (Mitchell *et al.*, 2009). In the past two decades, there has been a shift towards exploring patient lived experiences, where previously a bio-scientific perspective was predominant. Data from qualitative research undertaken from 2000 to date highlights the main concerns, fears and disease burdens of adults diagnosed with IBD. Some of these are fatigue, loss of control, fear and isolation, body image, and lack of information from healthcare professionals. More recent studies have explored the experiences of ethnic minorities (Alexakis *et al.*, 2017) and experiences of gay and lesbian people living with the disease (Dibley, *et al.*, 2014)

There are many aspects that remain limited in terms of research into adults' experiences of living with IBD. One of them is the impact of the disease on their relationships, intimacy and sexuality, and their sexual wellbeing. It is evident that are many reasons why IBD might have a negative impact on sexuality: symptoms, body image, surgery, medication side effects, the psycho emotional aspects of anxiety and depression. Furthermore, with the high prevalence of depression and anxiety in this group, the biological symptoms of depression (Mathew, Largen and Claghorn, 1979) can add burden to the already existing symptoms, and antidepressant medication is known to also have side effects affecting sexual function (Jing and Straw-Wilson, 2016). Sexuality is an important aspect of QoL (O'Toole *et al.*, 2018), and sexual wellbeing of those living with IBD warrants assessment as part of quality of life evaluation.

1.8. Sexual wellbeing in IBD

Sexual wellbeing refers to '*the perceived quality of an individual sexuality, sex life and sexual relationships*' (Laumann *et al.*, 2006, p.146). It does not imply the absence of disease, and should not be confused with sexual health, which refers to preventing or treating sexual transmitted infections. The definition of sexual wellbeing remains controversial due to the complexity of the concept and difficulty of measuring it. Lorirmer *et al.* (2019) included capability in assessing sexual wellbeing, as they aimed at '*not only seek to know what people have and do, but what they are able to do and b*e' (pg.844). Hence, this is a term that should be used in assessing the perceived quality of sexuality, sexual activity and intimacy in people living with chronic conditions, as it poses the question: "Do patients have the capabilities to express their sexuality according to own wishes in the presence of their chronic illness?" Sexual wellbeing includes two concepts of key importance in assessing and discussing it: intimacy and sexuality.

1.8.1. Definition of terms

1.8.1.1. Intimacy

The Oxford English dictionary defines intimacy as '*close familiarity or friendship'*. Also, it can be used as a euphemism to define sexual behaviour (Butler *et al*, 1998). For the purposes of this thesis, intimacy is defined as physical sexual relationship.

1.8.1.2. Sexuality

Sexuality remains a concept difficult to define (Gott, 2005; Parker and Aggleton, 2007), and in dictionaries is rather described than defined. Sexuality is part of the world we live in, and in the view of modern sexuality ideologies, is not a single essence, but a group with sub-categories, that are shared by humanity (Parker and Aggleton, 2007). In the last decades the assumptions held about sexuality are that it is a separate part of existence, pertaining to private life (Parker and Aggleton, 2007). Plummer (1992) defined sexuality as the gender one is expressing, the body and identity constructed around these, as well as the relationships that are chosen, although he admitted this is a limiting definition due to the complexity of the concept.

As no one definition is fully accepted, the term does not only refer to the sex act but to a much more complex factors that are encompassed under the notion (Webb, 1985). Hillman (2000) included specific emotions and behaviours in the previous attempts to define sexuality. According to her, it should include a vast amount of other aspects: body image, intercourse, love, relationship/marital satisfaction and desire (Hillman, 2000).

The current World Health Organisation (WHO) definition of sexuality is:

'*a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors*. '(WHO, 2006a).

Foucault (1978) stated that the term only appeared in the 19th century, and claimed that whilst sexuality is a secret deeply embedded in the private life, it is largely addressed in the public discourses. In nursing, due to the nature of the profession, sexuality is acknowledged as fundamental part of human experience, both in health and in illness (Hazel and White, 2002). Without another equally comprehensive definition, this thesis uses the WHO (2006) definition for defining sexuality in the context of IBD.

1.8.2. Sexual function and IBD

Sexual function in IBD can be affected by disease specific factors such as surgery, perianal disease and medication. Measuring sexual function has provided important data in evaluation of patient reported outcomes, as a way of assessing the efficacy of certain treatments or procedures, particularly for those who had undergone surgery for IBD. Most of the current evidence is quantitative and based on questionnaires assessing the sexual function, or sexual quality of life for those living with IBD. Sexual function can be directly and indirectly affected by IBD, more severe course disease and surgery being associated with lower QoL (Jedel, Hood and Keshavarzian, 2015). Increased depression levels associated with IBD was linked to lower scores of sexual function (Timmer *et al.*, 2007; Knowles *et al.*, 2013), and decreased levels of QoL (Timmer *et al.*, 2007; Marín *et al.*, 2013; Mikocka-Walus *et al.*, 2014). Psychological effects of depression had the strongest link to decreased sexual quality of life in IBD population reported compared to a healthy population (Roseira *et al.*, 2020).. Furthermore, sexual dysfunction, representing a variety of sexual concerns related to sexual function (Leyla J. Ghazi, Patil and Cross, 2015) was found in most newly diagnosed male patients (Shmidt *et al.*, 2019) and IBD was associated with significant risk of sexual dysfunction in people under 50 (Zhao *et al.*, 2019). The complexity of multiple factors involved in sexual dysfunction in IBD was discussed in a paper (Leyla J Ghazi, Patil and Cross, 2015) and encompasses disease activity, surgery, body image, treatment and pelvic floor disorders amongst the factors (Fig 4).

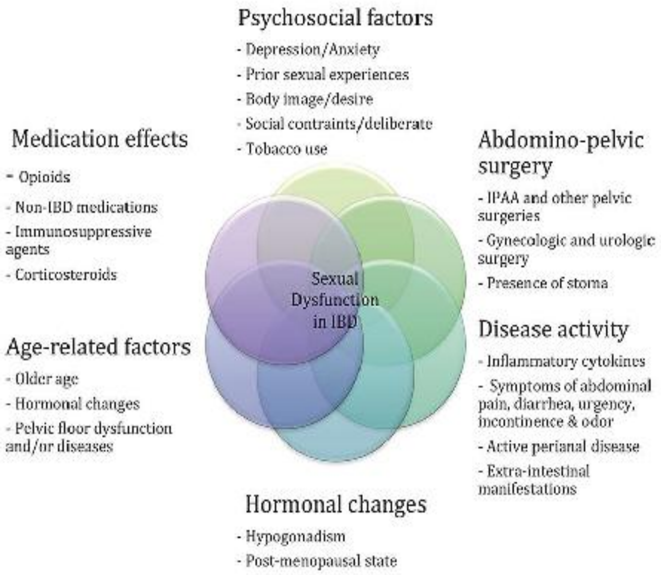

Figure 4. Multifactorial aetiology of sexual dysfunction.

(Leyla J. Ghazi, Patil and Cross, 2015)

Two reviews of the tools used to measure sexual quality of life in IBD found these lack important domains, have limited applicability to sexual preferences, and only a few had evident validity and reliability (Arrington, Cofrancesco and Wu, 2004; O'Toole, Winter and Friedman, 2014). Work done so far was aimed at quantifying sexual function, but other aspects pertaining to sexuality remain largely unaddressed. The existing quantitative evidence only reflects the extent of the sexual dysfunction and the level of sexual quality of life of those living with IBD, without exploring the patient experiences behind these. Given the complexity of sexual function components, sexual function as well as sexual health are essential aspects of QoL (George *et al.*, 2014).

1.9. Aim of the thesis and research questions

The aim of this thesis was to explore the patient experience related to the IBD impact on their romantic relationships, intimacy and sexuality. The aim was finalised following a comprehensive literature review (Chapter 2). Furthermore, the study had two research questions:

- What are the experiences of intimacy and sexuality of people living with IBD?
- What are the experiences of people living with IBD discussing intimacy and sexuality with healthcare professionals?

This thesis had the following objectives:

- Identify concerns of those living with Inflammatory Bowel Disease related to intimacy and sexuality.
- Explore how these aspects of their life should be discussed with the healthcare professionals.
- Relate the findings to other work in the field and make recommendations for future clinical practice

CHAPTER 2. Literature review

2.1. Overview of the chapter

This chapter presents a published paper integrated into the chapter and a literature review update undertaken after the publication.

2.2. Rationale for the literature review

Understanding experiences of living with IBD could help healthcare professionals to offer better support to those living with the condition. In order to establish areas with limited evidence, a comprehensive literature review of the evidence was necessary to identify a gap in current knowledge and outline a research question for the thesis. This review is a synthesis of the qualitative evidence and contains studies about patient experience used to answer the research question: '*what are the illness experiences of living with IBD*?' Meta-synthesis of qualitative research aims to support the researcher in how best to approach the phenomena of interest, and build a basis for what features of it should be the object of research (Thorne, 2017). Therefore, the researcher has used search terms that would provide wider understanding of living with IBD as a way of capturing aspects of the phenomena, with the prospect of refining a research questions to address the knowledge gap. The literature review was published and is included in this chapter. The authors of the publications are the previous supervisory team, as this was published prior to the PhD student transferring to King's College London.

The aim of the review was to explore the experiences of living with IBD and identify aspects of these experiences that are under researched. The review helped in formulating this thesis research question. A copy of the published paper is included in the Annex, therefore in the section 2.3 is the verbatim reproduction of the publication text. The references for this paper are included in the reference list.

2.3. Living with Inflammatory Bowel Disease. A review of qualitative research (published paper)

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Review

Living with Inflammatory Bowel Disease: A review of qualitative research studies

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Abstract: Background: Inflammatory Bowel Disease (IBD) is a chronic, untreatable condition represented by two illnesses, Crohn's Disease (CD) and Ulcerative Colitis (UC). Despite high incidence in the well-developed industrialised countries, and the significant impact of symptoms on patient's quality of life, little is known about living with IBD.

Aim: To explore the patients' experiences of living with IBD Design: A qualitative systematic review. Data sources: CINAHL, Medline, British Nursing Index, PsycINFO were searched which identified 23 qualitative and mixed methods studies published in English from 2000 to 2017.

Review method: thematic synthesis

Results: Data from 825 research participants identified that fatigue, incontinence and uncertainty about future, body image, and lack of information from healthcare professionals dominated the experiences of those living with IBD. Also, IBD

patients were reluctant to disclose their illness due to lack of public awareness and stigma surrounding symptoms. From these, an overarching theme has been identified: Living in isolation and exclusion.

Conclusion IBD patients face a variety of problems, often their priorities and those of healthcare professionals (HCP) differing greatly. HCP have little evidence needed to provide adequate, holistic care to this group. With a rise in the IBD population in newly industrialised countries it is estimated that IBD is turning into a global disease, potentially making long term care unsustainable. More evidence is needed to understand what is important to this group as the world faces an increase of IBD morbidity in a population with higher life expectancy.

There is a wealth of quantitative studies which measure quality of life, the concerns and worries of those living with IBD, or the impact of symptoms on daily living, with the majority suggesting a negative impact of the condition on the health related quality of life. However, these studies do not give an insight on the patient experience. Studies drawing on qualitative data can provide rich detail about the lived experience of patients with IBD, attributing broader meanings and enhancing understanding.

Contribution of the paper

What is already known about the topic?

- There is little qualitative evidence on patient experiences of living with Inflammatory Bowel Disease (IBD)
- Understanding their needs and concerns helps nurses to deliver holistic patient centred care

What this paper adds

- People living with IBD have a wide array of concerns with significant impact on their physiological and emotional wellbeing
- The impact of the condition on their daily life leads to an existence in isolation and exclusion
- Further research should be done on adolescents/young adults living with the condition as a significant gap was found in the literature

2.3.1. Introduction and background

Inflammatory Bowel Disease (IBD) is a chronic condition broadly represented by 2 different illnesses, Crohn's Disease (CD) and Ulcerative Colitis (UC). The exact cause is still unknown and IBD remains untreatable for some patients. Patients can experience abdominal pain, diarrhoea, weight loss, chronic fatigue and in some cases extra intestinal manifestations such as joint or eye problems (Day *et al.*, 2012). Symptoms are unpredictable and the condition is characterised by periods when symptoms are quiescent and acute flare ups (Whayman *et al.,* 2011). Between 25% and 75% of IBD patients will experience at some stage episodes of faecal incontinence due to the illness (Norton *et al.*, 2012). Complications as a result of IBD can include bowel strictures resulting in surgery and stoma formation, weakened immune system and increased risk of bowel cancer. The incidence around the world places Europe as having the highest rates of IBD with UC cases 505:100 000 population, and CD 322 :100 000.

North America has around 249:100 000 UC patients and 319:100 000 with Crohn's, whilst Asia and Middle East reported around 5:100000 Crohn's and 6:100000 UC patients (Molodecky *et al.,* 2012). Given the chronic nature of the symptoms and the severity of these, the condition has a significant impact on the patients' life, not to mention costs to the health services. As an example the lifelong costs for the care of an IBD patient are comparable to the costs for some cancer patients (Mowatt *et al.*, 2011). There is a wealth of quantitative studies which measure quality of life, the concerns and worries of those living with IBD, or the symptoms impact on daily living, majority suggesting the negative impact of the condition on the health related quality of life. However, these studies do not give an insight on the patient experience. Studies drawing on qualitative data can provide rich detail about the lived experience of patients with IBD attributing broader meanings and enhancing understanding.

2.3.2. Aim

In this literature review we sought to identify and synthesise the existing evidence which provided a qualitative in-depth account of the experiences of those living with IBD, in order to understand their concerns and impact of the illness on daily life.

Research question: What are the experiences of those living with IBD?

2.3.3. Design

Thomas and Harden's (2008) thematic synthesis approach was used for this review and ENTREQ guidelines for reporting systematic qualitative reviews (Tong et al, 2012).

2.3.3.1. Search methods

A systematic literature search was run on several electronic databases: CINAHL, British Nursing Index Database, Medline and PsycINFO. The following search terms were used: IBD OR inflammatory bowel disease OR Crohn's disease OR ulcerative colitis AND Experiences OR perceptions OR attitudes OR views. Searches were limited to ‘English language’ and ‘human’ from 2000 to 2017 (December). A further hand search was performed through the reference lists of the articles identified as answering the research question, with one thesis being identified and retained for review. We read all the abstracts in first instance as a study screening method.

Table 1. Inclusion and exclusion criteria

Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Primary research	Research looking solely at experiences following surgery in Inflammatory Bowel Disease (i.e. stoma)
No age restrictions	Experiences related to treatment and the provision of care.
Inflammatory Bowel Disease diagnostic	Studies where Inflammatory Bowel Disease and other chronic illness were analysed together
Experience of living with Inflammatory Bowel Disease	Quantitative research
English language	
Published 2000–2017	

2.3.3.2. Search outcome

A total of 705 studies were retrieved, and after removing the duplicates 663 papers were retained. From these, all the quantitative studies were discarded, leaving 36 full texts that were read after the abstracts were matched to the inclusion/exclusion criteria and were confirmed as primary research of a qualitative nature. Studies where IBD was not the main focus were removed due to the difficulties in correctly assessing what statements belonged to our group of interest if other long term conditions were compared to IBD. Similarly, those who did not represent patients’ perspectives were excluded. As a result, 23 studies were included in the review, of which 5 are theses and dissertations (see Fig.5).

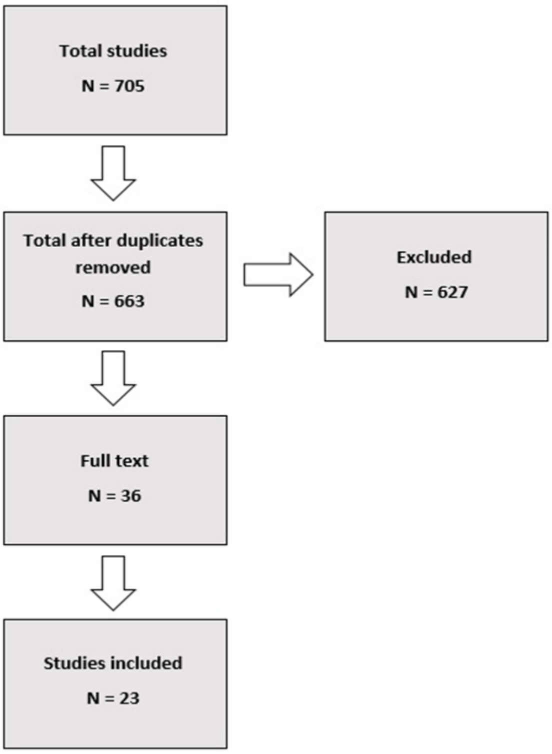

Figure 5: PRISMA diagram

2.3.3.3. Quality appraisal

All the studies included were subject to critical appraisal guided by the Critical Appraisal Skills Practice tool (2017) for appraising qualitative research. It was concluded that all used appropriate methods for their aims, and was noted that newer studies had a more detailed methodology than older publications. Although several papers lacked detail regarding ethical issues, the decision to include them was taken based on the fact that reporting and publishing standards have changed significantly in the past 17 years, therefore at the time of their publishing these papers have met the criteria existing at that time. Some difficulty was encountered in evaluating the auto ethnographic research, but the decision to include them in the review was taken as they provide valuable insight to the lived experience of this group, evoking a believable and possible experience (Ellis and Buchner, 2000). The autoethnographic studies included in this review were appraised following Richardson’s (2000) criteria for autoethnography reviews. Autoethnography should be appraised based on credibility, accountability and dependability (Medford, 2006) and ultimately on the judgement of an experienced researcher (Le Roux, 2016).

2.3.3.4. Data abstraction

Thomas and Harden (2008) framework was used for analysis as data originated from a range of studies that were relevant to the research question. The concerns and perspectives described by those living with the condition were identified in the studies, annotated and assigned to a code (Aveyard, 2016). Concerns of IBD population identified in previous literature (Casati *et al.,* 2000; Stjernman *et al.,* 2010) were used at first for coding using framework analysis. Following line-by-line coding of all data in the studies included, more codes were identified and used to define the descriptive subthemes.

2.3.3.5. Synthesis

From descriptive subthemes were generated analytical themes through inductive analysis; providing new interpretations to the data from the primary studies. After preliminary themes were identified by first author, all three authors audited the process, refined the themes and a consensus was made to final naming of themes. Once the analytical themes were named, a second assessment of each studies’ contribution to these themes was conducted (Dixon Woods, 2006).

2.3.4. Results

Data were collected from 18 studies, 4 theses and 1 dissertation that met the inclusion/exclusion criteria. Of these, 19 used qualitative methods and 4 mixed methods; however, only the qualitative data from these was used for our review.

The total sample was 825; geographical areas of the studies was mainly UK and Europe, followed by Canada, Australia, New Zealand and USA.

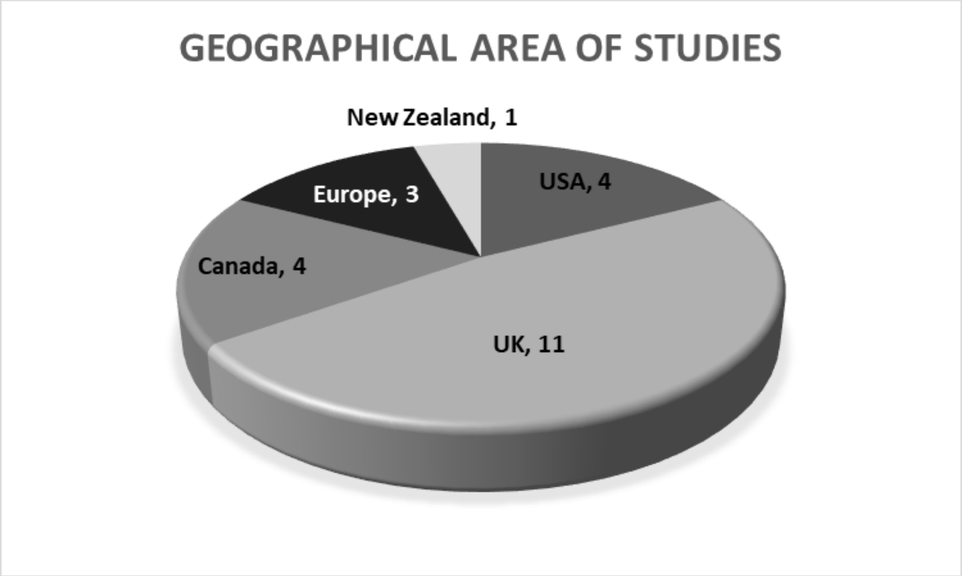

Figure 6.Geographical area of studies included

Little information was provided in terms of ethnic diversity, some studies giving limited details regarding the sample they have included, but most of the studies' limitations suggested that a predominantly white Caucasian population was included. In terms of the age groups studied, the majority of the population included in selected studies is adult. Analysis of the studies demonstrated the profound impact on the everyday life of those living with IBD. The main finding was the overarching theme Living in isolation and exclusion, as all the identified subordinate themes lead to isolation and exclusion. The following subordinate themes were identified: living in isolation and exclusion, living in secrecy, living with a flawed body, living with restriction and living in fear. Each theme is comprised of a number of subthemes (see figure 7).

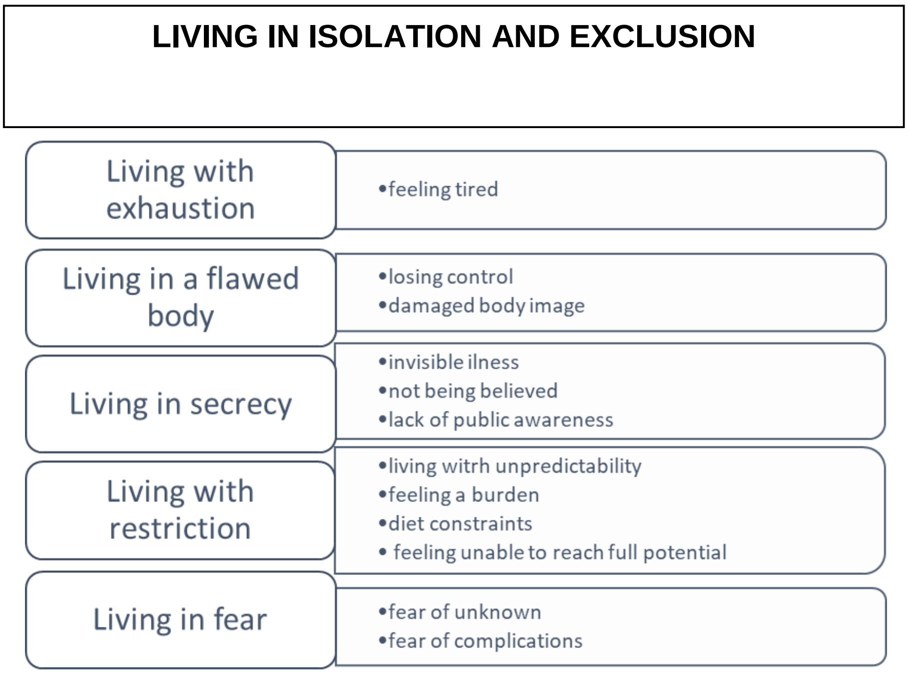

Figure 7. Themes and subthemes

The themes were found in almost every study with few exceptions in cases where the study was looking at specific aspects of IBD impact, such as fatigue or diet (see table 2).

Table 2. Theme occurrence.

Author	Living in secrecy	Living in a flawed body	Living with exhaustion	Living with restriction	Living with fear
Alexakis *et al*	✓	✓	✓	✓	✓
Burger, J	✓	✓	✓		
Barned, C. *et al.*	✓	✓	✓	✓	
Compton, I	✓		✓	✓	
Cooper *et al*	✓	✓	✓	✓	✓
Czuber-Dochan *et al*	✓	✓	✓	✓	
Daniel,J	✓	✓	✓	✓	✓

Defenbaugh ,N	✓	✓	✓	✓	✓
Devlen *et al*	✓		✓		
Dibley *et al*	✓	✓	✓	✓	✓
Dibley L	✓	✓	✓	✓	
Hall *et al*	✓	✓	✓	✓	
Lindfred *et al*		✓	✓	✓	
Lynch &Spence		✓	✓		✓
Matini & Ogden	✓		✓		✓
Moore, I	✓	✓	✓	✓	
Mukherjee *et al*	✓	✓	✓	✓	
Micallef-Konewo,E	✓	✓	✓	✓	
Nicholas D *et al*	✓	✓	✓	✓	
Palant *et al*	✓	✓	✓	✓	
Prince *et al*		✓	✓	✓	
Sammut *et al*	✓	✓	✓	✓	✓
Sykes et al	✓	✓	✓	✓	

2.3.4.1. Living with exhaustion

Fatigue has been given much attention over the years as being one of the most distressing consequences of the disease reported by patients. The lack of energy was expressed by participants in most of the studies from 2000 onwards (Cooper *et al*., 2010; Sykes *et al.,* 2015; Sammut *et al.*, 2015; Dibley *et al.,* 2014). There are various aspects of fatigue that were investigated such as causes, management, impact on daily life and support seeking for (Czuber-Dochan *et al*., 2012). However, the most inconvenient, from patients' perspective was the effect that fatigue had on the participants' life. The constant struggle to perform normal daily activities was highlighted in a few studies (Cooper *et al.*, 2010; Czuber-Dochan *et al.*, 2012; Burger, 2005; Moore, 2012; Sykes *et al.*, 2015).

‘*It’s not just the tiredness, it’s this feeling of not being able to bother with anything… just losing interest* (Czuber-Dochan *et al.*, 2012, pg.1991).

This is also illustrated by a statement showing the effect of fatigue depicted in an auto ethnographic study (Moore, 2012, pg.203):

‘…I can feel the effort to keep my eyes open, their heaviness drags my whole posture lower and lower in my chair. ‘‘ARRRGGGHHHHH’’I just let out. ‘’I hate feeling tired’.

In some instances, study participants have even adapted their family planning according to their energy levels dictated by the condition and decided to only have one child (Czuber-Dochan *et al.*, 2012). Others felt that they could not look after more children.

‘…I decided not to take the risk and bring another child into the world. I probably would not even be able to look after him.’ (Sammut *et al*., 2015, pg.2663)

The participants in the studies above were all adults. Studies looking at children and adolescents indicate fatigue is a problem but this is expressed as reduced levels of physical activity. Younger patients who led an active life prior to their diagnosis were most affected by the limitations associated with lack of energy (Moore, 2012). Some patients denied that they had reduced the level of physical activity due to illness, although during relapses all were unable to engage in exercise as a result of low energy levels (Sykes *et al.,* 2015).

2.3.4.2. Living in secrecy

Participants described living in secrecy, associated with not disclosing their condition. This theme comprised several facets, including having an invisible illness and not being believed, to lack of public awareness. These are discussed in detail below.

Having an Invisible illness

Secrecy surrounding the condition was described by participants in most of the studies. Adults and younger patients talked equally about hiding their illness because they did not want to discuss embarrassing symptoms *'Well it's just something I have to live with. Bowel disease, the subject's not right for conversation.*' (Hall *et al*., 2005, pg.451). Micalef--Konewo (2013) also identified secrecy around embarrassing symptoms as a barrier to disclosure in her study with children living with IBD.

Another reason for their secrecy resided in the difficulties of dealing with an invisible illness. There are no obvious signs of disability as the physical appearance of IBD patient is suggestive of a healthy person.

'It's only when you tell people that you've got Crohn's disease and the fact that nobody had a clue, oh what's that then, you know what I mean, that's the sort of response you get, and nobody actually thinks there' anything wrong with you, and it's one of those invisible illnesses that you look OK on the outside but on the inside is a totally different story.' (Matini and Ogden, 2015, p.2497).

In several circumstances this invisibility caused those living with the condition to avoid giving explanations that would be embarrassing or would question their credibility. Defenbaugh (2007) made a metaphoric comparison between her physical appearance and her bowel; both of which looked healthy to the naked eye -the reality being different when put under the microscope. Having an invisible illness is exacerbated by lack of public awareness surrounding the condition.

Lack of public awareness

Lack of public awareness was described by participants in several studies however, one study indicated that this might be more evident in certain cultures. Alexakis *et al* (2015) found that participants from different cultures felt that their communities had little or no awareness of IBD. Patients from ethnic minorities avoided disclosing the condition even to the close family members.

Not being believed

Having an invisible illness had also raised questions for some of the participants' friends and family, which made them feel that they were not believed. Some felt that even amongst healthcare providers were some who did not believe them*:*

'Once I was admitted to casualty with acute pain and still he (the doctor) told me that nothing was wrong…In the meantime I took tranquilizers and he (the doctor) told me to continue taking them since I was having panic attacks…. but I knew that something was wrong…I began to doubt whether my family believed me or not and I would fill up with anger' (Sammut *et al*., 2015, p.2663)

Children and adolescents similarly reported not being taken seriously (Alexakis *et al.,* 2014; Daniel, 2005) or not being believed, which ultimately resulted in not disclosing their condition. Not being believed was a constant evidence in both adult and young population who participated in the studies.

2.3.4.3. Living in a flawed body

The research literature revealed many participants experienced a sense of living in a flawed body; evidenced through a sense of loss of control over it, and the sense of having a damaged body image. These are discussed in detail below.

Losing control over your body

Frequently participants described how the inability to have control over aspects of their body gave them the perception of living in a flawed body. The fear of loss of bowel control was reported by most studies. To address this, participants described finding ways to gain some control over the situation and avoid such accidents (Dibley, 2014) (Hall *et al,* 2005), but most of them chose to avoid going Concerns related to body control or continence were evident in adult studies, whereas in young population this subtheme was more subtle, often being referred to as an inconvenience caused by symptoms of bowel urgency.

Damaged body image

Concerns regarding body image were attributed to various reasons. The side effects of the medication: *'they call me a marshmallow, and pull on my cheeks when I'm on prednisone. This bugs me*.' (Nicholas *et al*., 2007) or the surgery resulting in stoma formation also contributed to an altered body image. Defenbaugh (2007) talked about the' *grotesque body'* in her auto ethnography study which portrayed a suggestive image about her 'messy, leaky body' (Defenbaugh 2007, pg.55). Similar views were identified in Daniel (2002) who quoted a participant who felt '*damaged in some way'.* Dibley *et al* (2014) stated that life changing decisions grounded on body image issues resulted in the choice for celibacy following stoma formation in the case of a participant. No further details were given; however, it suggested the body image had a considerable role in the decision. Other excerpts from the same study showed a similar pattern:

‘From the day I was told (the stoma) is basically going to be reversed, I decided that I wasn’t even going to have any interest in relationships for the period I had the stoma.’ (Dibley *et al*., 2014, p.26)

Body image was found to be of importance mainly in younger patients in contrast to the older adults. In studies with children we identified that the peer acceptance was affected based on looking or being different. Some felt excluded by not being ‘normal’ and this also led to isolation: ‘*I feel isolated and ridiculed’* (Nicholas *et al*., 2007, p.7).

2.3.4.4. Living with restriction

Unpredictability of the symptoms, dietary changes, feeling unable to reach full potential and feeling a burden to the loved ones, together comprised as sense of a life of restriction.

Living with unpredictability

Most of those interviewed have commented on the unpredictability of the symptoms:

‘*There’s really nothing to do to prevent that because that's my biggest thing, like what can I do to prevent things when I ’m just doing what I do every day and I’m not changing anything and it’s still happening to me out of the blue. You know I just don’t know how to deal with that…*’ (Compton, 2002, p.40)

On many occasions people felt they were in a permanent state of unrest, with little or no control over maintaining some stability. In an attempt to gain some control over the unpredictability of the disease, majority decided to reduce to a minimum any social events and activities that would be hard to manage should the symptoms return.

‘...I remember the last time I went out… I was in a bar and I had an attack of pain and I needed to use the toilet, I rushed to the toilet, something which I really hate to do when I am out… By the time I was dressing up to go out I felt the need to sit on the toilet again and then I promised myself never to go out again’ (Sammut *et al*., 2015, p.2664)

Dealing with the unpredictability had limited the participants’ ability to plan for future and in many instances this was closely related to them not reaching full potential.

Feeling unable to reach full potential

Difficulties with reaching full potential has been commonly found in younger adults. Absenteeism from school as a result of the condition was found to affect their career prospects, some choose a career path that would fit their condition as opposed to what they would have liked to do (Nicholas *et al*., 2007).

‘…for like the last 2 years literally, I was literally at home unless you had to go to the hospital and I became isolated, so education wise, I kind of, I don’t see myself doing it anymore. I‘ve lost that. (Female, aged 20, CD) (Alexakis *et al*., 2015, p.670)

Adults touched on this aspect reporting adjusting their employment to their condition by taking part time employment or, in some cases, unemployment altogether.

Dietary constraints

Restriction imposed by condition was also connected to the diet. Having to change the way they eat after diagnosis has been identified in studies looking specifically at this (Palant *et al*., 2013; Price *et al.,* 2011), although in several others it was identified as a measure taken to prevent flare ups. Food has significant cultural connotations and some of those affected by the condition described the added struggle in maintaining the social norms expected by their cultural/ethnic group. This aspect was particularly emphasised in a study looking into challenges faced by black ethnic minorities living with IBD (Alexakis *et al*., 2015).

'It's just the way the ethnic community is and with food and obviously food is a big part of the culture…. everything is based around food, weddings are based around food, you go into people's houses, it's all about bringing as much food as you can and that's what entertaining is. That's the thing isn't it?' (Alexakis *et al.,* 2015, p.668).

Similarly, some patients reported that the condition interfered with their religious eating practices; the same study suggest that more than half of those interviewed could not fast during Ramadan as a consequence of their condition. Nevertheless, food restrictions or diet alteration was not only specific to minority cultures. People from dominant cultures also reported how living with IBD had changed their eating habits. Some of these were due to potential of exacerbating their symptoms others due to the food regimens required at times of bowel rest (Palant *et al.,* 2013) (Moore, 2012). Not all the patients were forced to change their eating, although one study stated that 82% of the IBD patients invited to take part had reported issues related to food (Price *et al*., 2011). Statements of those who didn’t view food as a concern were also found in Cooper *et al* (2010). In children and adolescents, the issues surrounding food were related to the food restrictions required at times for bowel rest (Nicholas *et al.,* 2007).

Feeling a burden

Some have given accounts on how IBD affected them and their family and made them feel a burden by requiring a lot of support (Sykes *et al,* 2015) (Hall *et al,* 2005). Feeling guilty or feeling a burden were found to be quite similar concepts in the studies included:

‘I think there’s got to be at least five times I can think of that I basically tried to push him (boyfriend) out of my life…It’s somehow easier to do that than to deal with the guilt of not being able to...you know…be a normal girlfriend for him’ (Daniel, 2002, p.88)

Feelings of guilt were common in parents with IBD who felt unable to provide the care they wanted for their children. Restrictions were made on where they could take the children or what activities they could do together (Mukherjee *et al*, 2002).

2.3.4.5. Living in fear

Fear took many aspects but more prevalent was found to be the fear of complications and fear of the unknown due to the lack of information from healthcare professionals.

Fear of complications

This was identified in various patient statements. Whether this was the fear of living with the condition, fear of having surgery, the fear of developing cancer or passing the disease to the next generation, it posed a heavy weight on people with IBD. Younger patients have even expressed the fear of dying:

‘It was not so much fear of having the condition but fear of dying…. You think you can avoid dying but you’re just going through hell. I was basically skin and bones….’ (Lynch and Spence, 2007, p.226)

Deffenbaugh (2007) talks about her fear of surgery: *‘I ask on behalf of my body who is scared shitless as she stares into your wounds and ponders a surgical fate. I ask because I am afraid*.’ (p.137).

Fear of the unknown

This, in many cases, resulted from lack of information from the healthcare professionals involved in the care of the participants. It appeared that the less information about the progress and complications of IBD was given, the more reported to be fearful. Cooper *et al* (2010) stated that non specialist IBD healthcare professionals involved in the care of the participants was identified to cause significant concerns to the participants, by attributing symptoms to other conditions.

2.3.5. Discussion

This review has captured the accounts of patients’ experiences and highlights the complex challenges of living with IBD. The theme that was identified in all of the studies, irrespective of the aspects explored, was Living with exhaustion. Fatigue is the subject of ample work that looks at ways to relief it and is an aspect investigated predominantly by clinicians.

Another major concern was the inability to control their bowels from Living in a flawed body theme. Continence care for IBD raises a major issue for the healthcare professionals. Being afraid of losing bowel control in public and the stigma attached to such an incident, was evident from numerous accounts. Body control is a complex process and yet very little is known about it. It is also making us socially acceptable and, although for some who have faecal incontinence may not be seen as an issue, others perceive themselves as not being competent adults (Norton, 2004). Norton *et al* (2013) suggested that incontinence is still under reported by the IBD patients. This may be because insufficient opportunities for the patients to voice such sensitive issues, or others are not being aware there are options to alleviate the severity of incontinence symptoms. In the same study IBD patients with faecal incontinence reported a lower quality of life and they were also reporting lower social functioning.

The second most common theme alongside Living in a flawed body was Living in secrecy. The difficulty in continuing to live as normal as possible was hindered by the uncertainty of the disease. They lived in a fluid state that was constantly changing and they felt powerless in maintaining some sense of control. Not being able to disclose their condition had a negative impact on the psychological and emotional health, resulting in either reducing or withdrawal from social activities. The psychological and emotional baggage attached to the condition remains an un-promoted issue which is still poorly addressed by healthcare professionals (Kemp *et al*., 2012). The difference between IBD and other invisible chronic illnesses sits in the difficulty of discussing symptoms that can be seen as unacceptable for public discussion with others from outside their close circle. This review suggests that patients with IBD perceive themselves as having a ‘spoiled identity’ (Goffman, 1963) and avoid disclosing their illness. Regardless the age of the patients, the secrecy surrounding the condition was an important finding and closely related to perceived stigma and/or fear of not being believed.

The need for secrecy adds significantly to the burden of the disease. The lack of public awareness about the condition is a key factor in daily experiences faced by some patients (Bray *et al*., 2015). Saunders (2014) argues that taboos surrounding the bowel conditions need to be addressed, however this cannot be done by research alone. But what is notable is that all five themes identified have impact on the social relationships, the interactions of IBD patients with the ‘outside’ world becoming irremediably disrupted. Looking at all the themes, we can conclude that overall, living with IBD means living in some degree of isolation and exclusion.

Evidence from this review is supported by quantitative studies emphasising the extent of the problems by measuring health related quality of life and IBD related concerns (Stjernman *et al*., 2010; Mussel *et al*., 2003; Levenstein *et al*., 2001). A large European survey looking at the international perspective of the impact of IBD on patients’ lives gives valuable data from various aspects of life, the burden of symptoms and the delivery of care. It suggests that 96% of the respondents suffer from fatigue during the flares, women aged 19-43 being the most affected. Half of the participants agreed that IBD had negatively affected their work or career pathway and reported their intimate relationships had been affected, rising to 64% for those with certain types of colitis. The study also revealed that 66% of the respondents were worried about the toilet availability and they considered the presence of a toilet when they planned a trip (Wilson *et al*., 2012).

What we found interesting is the fact that a specific age group appeared to get silenced through inclusion in adult research (over 18) in most of the studies. Satisfaction with body image and acceptance by peers are the most associated to the self-esteem in adolescence (Coleman, 2011), both aspects being of high concern for those living with IBD. This is also important as the illness is diagnosed in over half of the patients between the age of 20 to 29 (Molodecky *et al*., 2012).

Most of the evaluations on factors influencing the IBD patient quality of life are based on healthcare providers and not patients. Patient accounts of illness experiences are becoming more accepted as an important source of understanding the extent of disruption in the life of those with chronic illness Looking at patients' perspectives helps define what is of significance to the patient and ultimately helps those involved in their care to improve health related quality of life. This supports providing better care by addressing issues that are important to patients. Social isolation and withdrawal from relationships are major consequences of chronic illness (Straus, 1975) and the evidence from this review suggest that those with IBD could probably be some of the most socially isolated.

Evidence into how life changes for IBD patients places the restriction in movement as the most negative outcome (Purc-Stevenson *et al*., 2014).

2.3.5.1. Limitations

This review only included articles in English; thus, language was a barrier to including studies from non-English speaking countries. Also, there are differences between the two conditions, CD and UC, regarding the outcomes and complications and we have not analysed separately experiences particular for each condition.

2.3.6. Conclusion

The qualitative data from this review offers a deeper understanding of the major impact IBD has on their life and their daily struggles, and how their lives changed after diagnosis. We draw on research using patients' own voices to provide a succinct account of their difficulties of daily living. Thus, this information could help improve their quality of life and reduce the burden of their condition.

2.3.6.1. Recommendations for practice and research

Increasing public awareness of the condition should be prioritised as it would alleviate the need to conceal the illness. Also, healthcare professionals should be aware of patient perspective and their experience of living with IBD. This should not just cover issues such as symptom burden but also the emotional and psychological aspect if a holistic care approach is aimed.

More research is needed to explore the experiences specific to younger adults. Only 3% of the total sample had specifically looked at 16-24 years old, which is suggestive of a significant gap in the research undertaken so far. Furthermore, there is a lack of knowledge from wider cultural groups and with a different socio-economic status, all those included here having access to good healthcare systems.

2.4. Updated literature review since the published paper

The published paper had included articles published up to December 2017, therefore an updated review was undertaken for publications from January 2018 to December 2020. Same methods were used in the update as for the published review. The following section describes the updated review with details for methodology that were not included in the published paper, and includes six new studies published, involving a total of 152 participants. A table with the demographics of all studies of the review is available on Appendix 2.

2.4.1. Methodology

A critical review of the methods used to synthesise qualitative research concluded that it is important to choose the method based on the outcome desired. For the synthesis methods with a constructivist orientation, the output is more complex, often presented in symbolic forms that could be more difficult to understand, however, this is not diminishing their importance for practice as the results can inform practice as well as research. The choice for best fitting method was determined by the aim of the review, and the intention to go beyond summarising the findings from the primary data. Thematic synthesis was identified as making a clear differentiation between summarising and giving new interpretation to the data (Barnett-Page and Thomas, 2009), and was used for the published and updated review.

2.4.2. Search strategy

The same search terms (Fig.5) used in the published review were used in the update as well, across the following databases: CINAHL, Medline, PsycINFO and British Nursing Index Database. Since no search is considered fully efficient (Mattioli *et al.*, 2012) a further hand search was performed through the reference lists of the identified papers, and with citation tracking, with one new article identified as meeting the inclusion criteria.

1 (IBD or inflammatory bowel disease or Crohn’s disease or ulcerative colitis).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (99058)
2 limit 1 to (English language and humans and yr="2017 -Current") (12663)
3 (experience or perception or attitude or view).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (1534643)
4 limit 2 to (English language and humans and yr="2017 -Current") (12663)
5 2 and 4 (12663)
6 Qualitative Research/ (58359)
7 limit 6 to (English language and humans and yr="2017 -Current") (23284)
8 5 and 7 (48)

Figure 8. Search strategy.

From 48 papers identified, 11 were selected to read as full text. From full text papers retained, 5 were excluded as not answering the research question: what are the patient experiences of living with IBD? (n=2) secondary research (n=1) including participants with other conditions (n=2). One study included was identified from manual search of references resulting in six studies being included in the updated review. The results of the updated search are presented in the PRISMA diagram below (Fig. 9).

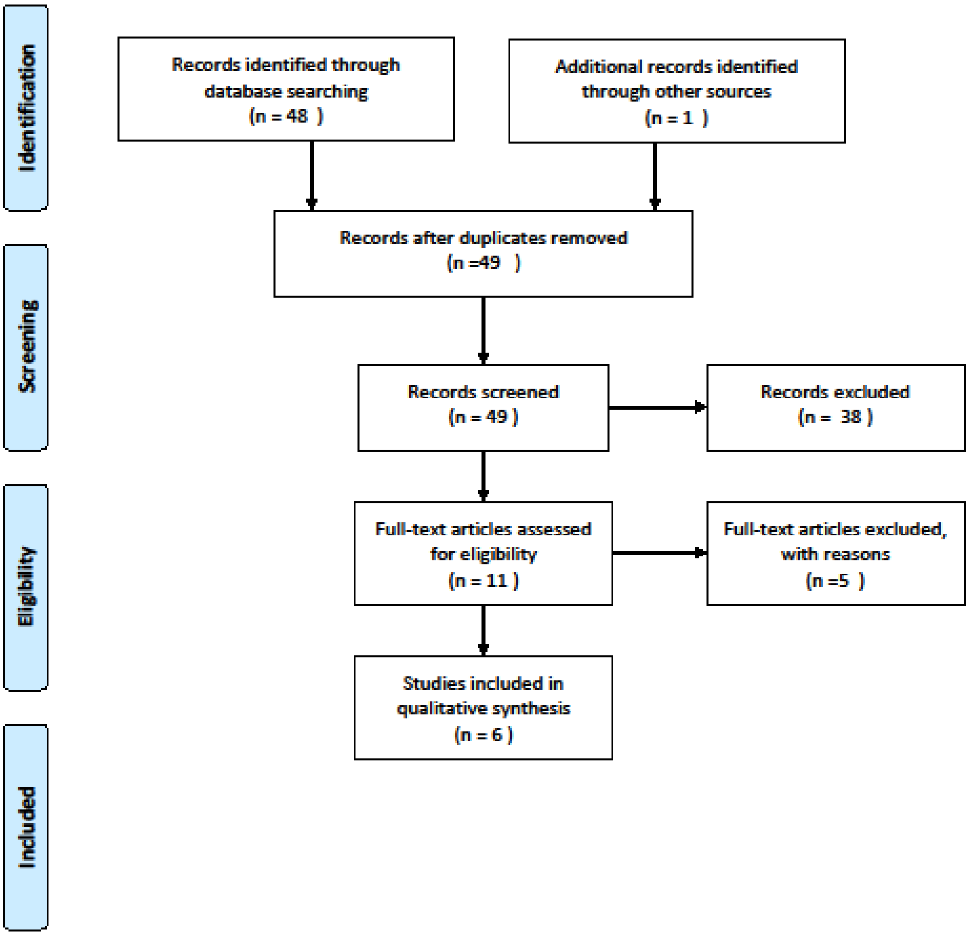

Figure 9. PRISMA diagram from updated literature review

2.4.3. Quality appraisal

The quality appraisal process was described in the published paper. Same process was followed as described in the publication. For the publication was used Enhancing transparency in reporting the synthesis of qualitative research -ENTREQ (Tong *et al.*, 2012). For each included paper CASP was used for quality appraisal, although the quality of reporting was less important for this review. Papers of lower quality can also add to the understanding of the studied topic; therefore, the content was considered more significant for the purpose of the review.

2.4.4. Thematic synthesis

As mentioned earlier, the same methodology was used for the entire review, although due to the word count restrictions for the published review, a more detailed description of the process is presented below. According to Thomas and Harden (2008) a wide range of evidence can be analysed with thematic synthesis, as they argued that the relevance of the findings from primary studies should be more important than the type of the study. Subsequently, the researcher had included qualitative studies that presented relevant findings that had answered the review's question, without using a selective approach based on study design. This would have had different outcomes, therefore would have entailed different method; for ethnographic studies for instance would have been used meta-ethnography, or, for narrative studies, meta- narratives (Aveyard, Payne and Preston, 2016).

The authors described the following steps in conducting thematic synthesis of evidence:

1 Research question identified

2 Purposive search of literature

3 Appraisal of identified papers

4 Identification of main concepts in each study

5 Codes and sub-themes generated from key concepts

6 Verify consistency of coding between studies

7 Collapsing concepts /sub-themes as ‘translated into one another’

8 Final analytical theme development - new interpretation given to data

The code identification could have been done in two ways, where the researcher identifies codes from text, or following a framework, where the researcher uses a framework consisting of previously identified codes in other publications. The decision to use a framework approach for this method meant that the main concerns of those living with IBD identified by Casati (2000) were at the basis of initial concept identification across the studies. A similar approach was described by Thomas and Harden (2008) in their original paper that described thematic synthesis. To use an a priori framework for initial coding had been useful especially for a novice researcher such as the PhD student, as it helped maintain the focus on identifying concepts. After identifying and translating into each other the concepts from Casati’s study, the researcher looked for outliers as well as new concepts, for a thorough analysis of the data.

The retained articles were analysed following the same steps described in the published paper: papers were read line by line, coded and excerpts highlighted to reflect these codes. The a priori concepts used at this stage were those found by researcher as a result of the initial synthesis. Once this stage was completed, all codes were collated and by collapsing codes into meaning concepts, and several sub-themes were developed. The sub-themes were checked against the papers for accuracy and after that, they were refined into a list of descriptive sub-themes. The interpretation given to the sub-themes founded the final analytical themes.

2.5. Results of updated literature review

Six more studies were included in this literature review (Pihl-Lesnovska *et al.*, 2019; Ghorayeb *et al.*, 2018; Lopez-Cortes *et al.*, 2018; Sweeney *et al.*, 2019: Czuber-Docan *et al.,* 2019; Rouncefield-Swales *et al.*, 2020) with an additional population of 152 participants, aged over 14, from the UK, Ireland and Sweden. These papers resonated with the findings from the published review, but two of them (Ghorayeb *et al.*, 2018; Pihl Lesnovska *et al*., 2019) highlighted the impact of IBD on the participants' intimacy and sex life, which was not directly addressed in any of the previous papers. The effect of fatigue and feelings of being dirty were the most reported by participants as affecting their intimacy and sex life, suggesting the importance of the topic on participants' lives (Pihl Lesnovska, Münch and Hjortswang, 2019). The experiences of women living with IBD and transitioning to motherhood brought valuable information concluding that healthcare professionals have limited knowledge about pregnancy and IBD, but also aligned with the findings from the initial literature review, reinforcing the negative impact of IBD on social interactions (Ghorayeb *et al.*, 2018).

Impact of IBD on friendship formation in young adults (Rouncefield-Swales *et al.*, 2020) as well as further understanding of perceptions related to nutrition (Czuber-Dochan *et al.*, 2019) and pain (Sweeney *et al.*, 2019) have broadened the knowledge on the concerns and worries of those living with IBD. These new studies were remarkably consistent about the negative aspects of IBD on most aspects of life (Table 3).

Table 3**.** Themes occurrence in updated review

Author	Living with exhaustion	Living in a flawed body	Living in secrecy	Living with restriction	Living with fear
Lopez-Cortes, R. *et al.* (2018)	✓	✓	✓	✓	✓
Ghorayeb, J. *et al.* (2018).	✓	✓		✓	✓
Pihl Lesnovska *et al* (2019).	✓	✓	✓	✓	✓
Sweeney, L *et al.* (2019)	✓	✓		✓	✓
Czuber-Dochan *et al* (2019)		✓	✓	✓	
Rouncefield-Swales, A. *et al.* (2020)	✓			✓	✓

2.6. Discussion

The findings of this updated literature review reflect a clear pattern of concerns and worries amongst those living with IBD, and the impact of the condition on their lives, despite different study aims. In addition to the initial review presented in the published paper, some novel research topics were addressed, but without major impact on the overall findings of the review.

In this review of the qualitative evidence what was identified is that the impact of IBD on romantic relationships, intimacy and sexuality was mostly unaddressed in the research studies from 2000 to 2020, with few addressing the topic directly, and most revealing inferred findings related to these topics, but offered little or no discussion, although the participants have mentioned experiences pertaining to their sex life.

Following the synthesis of the existing qualitative evidence the researcher identified potential recommendations for practice and research for each main theme (Table 4).

Table 4 Recommendations for practice and research from the literature review

Living with exhaustion	Fatigue should be monitored and underlying issues and personal circumstances should be addressed. Research on strategies to cope with fatigue should be of priority.
Living in a flawed body	Referral to specialist continence /pelvic floor services to provide support in incontinence management. Healthcare providers should assess if continence issues are present due to being under reported. Further research into how IBD affects romantic relationships, intimacy and sexuality, especially in the under researched group of young women, aged 16-24.
Living with secrecy/ Living with restriction	Increasing public awareness of the condition should be prioritised as it would alleviate the need to conceal the illness. Further research on ethnic minorities living with the condition should be considered, as well as into strategies to reduce social isolation as much as possible.
Living in fear	Wider availability of information materials should be considered. In clinical environment, targeting especially those newly diagnosed. HCPs should assess the information needs for each individual and sign post them to reliable sources if these are not available in written form at the time of clinical appointment. Further research is needed on what are the patients' information needs, including on sensitive issues (i.e. sexual wellbeing, conception, fertility)

2.7. Summary of literature review

A comprehensive literature review of qualitative research on experience of living with IBD conducted between 2000-2020 was undertaken. A total of 30 papers and a population of 973 participants were included, as they have answered the review question and met the criteria for inclusion. The findings were summarised in five main themes: *Living with exhaustion*, *Living in a flawed body*, *Living in secrecy, Living with restriction* and *Living in fear*, with an overarching theme of *Living in isolation and exclusion* suggesting the essence of their worries and concerns, where isolation and self–exclusion were the essence of the condition's impact on their lives. People living with IBD suffered a significant change of lifestyle as result of their condition, with a negative impact on every aspect of their life, and they experienced daily an array of worries and concerns, irrespective of their disease (CD or UC) or disease activity (relapse or remission).

This review highlighted a gap in research on aspects of romantic relationships, intimacy and sexuality, although some of the studies have presented inferred findings on these aspects of life. A published review on sexuality in the context of chronic illness reported that sexual well-being is influenced by disease severity, disease progress, psychological adjustment to the chronic illness as well as medication (Verschuren *et al.*, 2010). Studies with people living with diabetes, multiple sclerosis, and cardiovascular disease were included in that review, which concluded that evidence was narrowly based on sexual function, and there was a lack of healthy controls in most studies included. Furthermore, an absence of qualitative research on the sexual experience in the context of chronic illness was noted.

The findings from the qualitative review and the existing evidence shaped the research questions for this thesis:

- What are the experiences of intimacy and sexuality of people living with IBD?
- What are the experiences of people living with IBD discussing intimacy and sexuality with healthcare professionals?

CHAPTER 3. Methodology

3.1. Philosophical underpinnings and theoretical frameworks

Methodology encompasses philosophical assumptions and frameworks that include the views on knowledge and being in the world associated with a certain research method (van Manen, 2010). The researcher's beliefs and philosophical assumptions need to be written in the reports of research studies (Creswell and Poth, 2018). There are two main questions used in research: WHY and WHAT. In quantitative research most of the research questions will attempt to answer the WHAT, as the methodology is concerned with the occurrence of events, causality and relationships between events, and measurement of outcomes. In contrast, qualitative research is concerned with WHY, and is exploratory, heavily based on approaches that support the finding of a deeper understanding of phenomena rather than frequency of phenomena occurring. The philosophical beliefs underpinning the two methodologies are fundamentally different, quantitative research being grounded in positivism (an assumption that there is only one truth in the world), whereas qualitative methodologies are grounded in interpretivism (there are multiple truths in the world). Qualitative research explores phenomena within the human world to gain insight into human experience, it places value on individuals and their experiences (Polit and Tatano Beck, 2017). This thesis is based on qualitative methodology.

Choice of theoretical and methodological approaches in qualitative research has been a subject of debate. There are two different currents, one argues that a traditional approach should always be followed, whilst the other encourages researchers to leave behind the straight jacket of conventionalism and develop new methodologies. Choice of methodological approach should follow careful consideration of the aims and objectives of the study (Ritchie *et al.*, 2014). Patton (2002), Li and Seale (2007) and Barbour (2008) are all in favour of pragmatism, chose the approach that best answers the research question. However, without trying new approaches, progress in research methodology would not be possible. Similarly, the communication and technology development must be considered and new ways of collecting data should be aligned with these, as well as with the preferences of the population studied. As Ritchie *et al* (2014) argued such implementations must be made with good judgement and not accepting that everything goes. Therefore, when new approaches are employed in research, a clear justification for the choice and also a detailed description of how the approach was used are needed in order to be carefully evaluated and peer reviewed.

Researchers have their own philosophical beliefs that influence the choice of methodology. Individual assumptions about the nature of truth- known as ontology, and knowledge about how the truth is gained- epistemology, inform researchers as to how the research questions are posed and answered, although these are not always evident to the researcher (Crotty, 1998). For example, ones' choice of qualitative research would suggest an interpretivist approach. Creswell and Poth (2018) presented a concise description of the four philosophical assumptions of what was defined by Denzin and Lincoln (1994) and Crotty (1998) as epistemologies and ontologies. For writing the philosophical stances in a research project, interpretative frameworks are often used to position the researcher in the research process (Creswell and Poth, 2018). Denzin and Lincoln (2011) argued that interpretative frameworks incorporate philosophical assumptions as fundamental approach for qualitative research. They are sets of beliefs, or theories that guide the research brought into the process by researchers. In this thesis the researcher’s philosophical stance was identified as rooted in social constructivism. Interpretative phenomenology, employed to conduct this research, is also rooted in social constructivism (Creswell and Clarke, 2011; Dwyer, Davis and Emerald, 2017). Social constructivism highlights the importance of the culture to create knowledge in a context and is based on the assumption that reality is constructed through human activity, and knowledge is a result of social and cultural constructs (Kukla, 2000). Response to illness is rooted in the society’s response to it, and in the case of a condition that has stigma attached like IBD, subsequently those living with the condition respond to the challenges thrown up by the condition in a way that is socially acceptable at the time and place where they live. For example, in the late 1980s, human immunodeficiency virus (HIV) was attributed to concepts related to promiscuity and homosexuality, through a social profiling created at the time, making it very difficult for those infected to disclose their condition. Over the years the society had become more educated and acceptant of those living with HIV, and although stigma was probably not fully removed, having HIV these days is less stigmatising. This is just an example of how society influences the response to illness, by stigmatising a symptom, or a condition. The societal response can adjust, usually as a result of raising awareness, education and influencing the political powers by giving voice to those who were silent due to their condition.

3.2. Literature review on methodology

Multiple approaches in qualitative research can lead to confusion on how research is conducted and reported (Bradbury-Jones *et al.*, 2017). Absence of research evidence on the topic of the impact of IBD on sexuality and intimacy suggested the need to identify a qualitative research design adequate to provide the most information on the topic. A decision on an appropriate design to answer the research question required a review of the methodologies used to research intimacy and sexuality experiences in illness. Therefore, in this section the researcher concentrated on methodologies previously used to research the experiences of intimacy and sexuality. For the purposes of this search, the methodology review question was '*What are the qualitative methodologies used in primary research studies on experiences of intimacy and sexuality in illness?'*

The search included electronic databases (CINAHL, British Nursing Index PubMed, Scopus, and PsycINFO). The MeSH terms (Medical Subject Headings) used singly, and/or in combination were: *sexuality OR intimacy AND experience OR perception AND qualitative research OR qualitative study.* From 504 articles published until December 2019 identified in the search, 212 were removed as duplicates, and a total of 33 were retained for full text reading. Of these, 25 were included in this review (see Table 4) as they met the inclusion criteria (see Table 5).

Table 5. Criteria for included papers

Inclusion	**Exclusion**
Primary research	Review articles
Patient experience of intimacy/sexuality	Healthy population experience
Published in English	Published in other languages
Published from 2010-2020	Published before 2010

As reporting quality in qualitative research in social and healthcare sciences had changed over the past decade, the decision to only include papers from the past decade was made, as these were deemed to provide a more detailed description of methodology and methods, in line with the reporting tools currently used by journals (COREQ, CASP, and EQUATOR).

Table 6. Methodology review papers.

	Paper	**Methodology**	**Sample**	**Analysis**	**Discipline**
1	Cooper, S. *et al.* (2018) '"My wife's mistrust. That's the saddest part of being a diabetic": A qualitative study of sexual well-being in men with Type 2 diabetes in sub-Saharan Africa', *PLoS ONE*, 13(9), pp. 1–17. doi: 10.1371/	Not reported	47	Thematic analysis Braun& Clarke (2006)	Health sciences/ Medicine
2	Hamilton, K. *et al.* (2015) 'Sexuality and exercise in men undergoing androgen deprivation therapy for prostate cancer', *Supportive Care in Cancer*, 23(1), pp. 133–142. doi: 10.1007/s00520-014-2327-8.	Not reported	18	Thematic analysis Braun & Clarke (2006)	Health sciences/ Physiotherapy
3	Fredericks, E., Harbin, A. and Baker, K. (2017) 'Being (in)visible in the clinic: A qualitative study of queer, lesbian, and bisexual women's health care experiences in Eastern Canada', *Health Care for Women International*, 38(4),	phenomenology	18	Thematic analysis/ Boyatzis (1998)	Health sciences/ Medicine

	pp. 394–408. doi: 10.1080/07399332.2016.1213264.				
4	Davison, J. and Huntington, A. (2010) '"Out of sight": Sexuality and women with enduring mental illness', *International Journal of Mental Health Nursing*, 19(4), pp. 240–249. doi: 10.1111/j.1447-0349.2010.00676.x.	Critical theory feminism	8	Thematic analysis/ Ryan & Benars (2000)	Nursing
5	Josefsson, K. A. and Gard, G. (2010) 'Women's experiences of sexual health when living with Rheumatoid Arthritis - An explorative qualitative study', *BMC Musculoskeletal Disorders*, 11(1), p. 240. doi: 10.1186/1471-2474-11-240.	descriptive phenomenology	10	Giorgi (1970)	Health sciences/ Physiotherapy
6	Jefferies, H. and Clifford, C. (2011) 'Aloneness: The lived experience of women with cancer of the vulva', *European Journal of Cancer Care*, 20(6), pp. 738–746. doi: 10.1111/j.1365-2354.2011.01246.	descriptive phenomenology	12	Spielberg (1976)	Nursing
7	Klaeson, K., Sandell, K. and Berterö, C. M. (2012) 'Sexuality in the context of prostate cancer narratives', *Qualitative Health Research*, 22(9), pp. 1184–1194. doi: 10.1177/1049732312449208.	Empirical phenomenological psychology	10	Merleau Ponty (1945)	Health sciences/ Medicine

8	Fritz, H. A., Dillaway, H. and Lysack, C. L. (2015) '"Don't think paralysis takes away your womanhood": Sexual intimacy after spinal cord injury', *American Journal of Occupational Therapy*, 69(2), pp. 1–10. doi: 10.5014/ajot.2015.015040.	Grounded theory	20	Glaser	Health sciences/ Occupational Therapy
9	Ramirez, M. *et al.* (2009) 'Figuring out sex in a reconfigured body: Experiences of female colorectal cancer survivors with ostomies', *Women and Health*, 49(8), pp. 608–624. doi: 10.1080/03630240903496093.	Grounded theory	30	Charmaz	Nursing
10	Shaw, L. K., Sherman, K. A. and Fitness, J. (2016) 'Women's experiences of dating after breast cancer', *Journal of Psychosocial Oncology*, 34(4), pp. 318–335. doi: 10.1080/07347332.2016.1193588.	Grounded theory	22	Glaser & Strauss (1967)	Psychology
11	Robinson, L., Miedema, B. and Easley, J. (2014) 'Young adult cancer survivors and the challenges of intimacy', *Journal of Psychosocial Oncology*, 32(4), pp. 447–462. doi: 10.1080/07347332.2014.917138.	Grounded theory	55	Strauss & Corbin	Psychology

12	Sekse, R. J. T., Råheim, M. and Gjengedal, E. (2015) ‘Shyness and Openness—Common Ground for Dialogue Between Health Personnel and Women About Sexual and Intimate Issues After Gynecological Cancer’, *Health Care for Women International*, 36(11), pp. 1255–1269. doi: 10.1080/07399332.2014.989436.	Hermeneutic phenomenology	16	Giorgi (1970) Kvale (1996)	Health sciences/ Medicine
13	Moules, N. J. *et al.* (2017) ‘“A Tribe Apart”: Sexuality and Cancer in Adolescence’, *Journal of Pediatric Oncology Nursing*, 34(4), pp. 295–308. doi: 10.1177/1043454217697669.	Hermeneutic phenomenology	10	Moules et al (2015)	Nursing
14	Ervik, B. and Asplund, K. (2012) ‘Dealing with a troublesome body: A qualitative interview study of men’s experiences living with prostate cancer treated with endocrine therapy’, *European Journal of Oncology Nursing*, 16(2), pp. 103–108. doi: 10.1016/j.ejon.2011.04.005.	Hermeneutic phenomenology	10	Gadamer (1999) Dahlberg (2001) van Manen (1997)	Nursing
15	Taylor, B. (2014) ‘Experiences of sexuality and intimacy in terminal illness: A phenomenological study’, *Palliative Medicine*, 28(5),	Hermeneutic phenomenology	27	Thematic analysis/ Not reported	Nursing

	438–447. doi: 10.1177/0269216313519489.				
16	Tuohy, D. and Cooney, A. (2019) ‘Older Women’s Experiences of Aging and Health: An Interpretive Phenomenological Study’, *Gerontology and Geriatric Medicine*, 5, p. 233372141983430. doi: 10.1177/2333721419834308.	Hermeneutic phenomenology	23	Thematic analysis/ Not reported	Nursing
17	Schantz Laursen, B. (2017) ‘Sexuality in men after prostate cancer surgery: a qualitative interview study’, *Scandinavian Journal of Caring Sciences*, 31(1), pp. 120–127. doi: 10.1111/scs.12328.	Hermeneutic phenomenology	4	Kvale (1996)	Nursing
18	Traumer, L., Jacobsen, M. H. and Laursen, B. S. (2019) ‘Patients’ experiences of sexuality as a taboo subject in the Danish healthcare system: a qualitative interview study’, *Scandinavian Journal of Caring Sciences*, 33(1), pp. 57–66. doi: 10.1111/scs.12600.	interpretive/ descriptive phenomenology	10	Thematic analysis/ Braun & Clarke (2006)	Nursing
19	Haag, H. L. *et al.* (2016) ‘Being a woman with acquired brain injury: Challenges and implications for practice’, *Archives of Physical Medicine and Rehabilitation*, 97(2), pp. S64–S70. doi:	Interpretive/ descriptive phenomenology	16	Thematic analysis	Health sciences

	10.1016/j.apmr.2014.12.018.				
20	Villa, G. *et al.* (2018) ‘Life with a urostomy: A phenomenological study’, *Applied Nursing Research*, 39(August 2017), pp. 46–52. doi: 10.1016/j.apnr.2017.10.005.	Interpretive phenomenological analysis IPA	23	Not reported	Nursing
21	Dewinter, J. *et al.* (2017) ‘Adolescent boys with an autism spectrum disorder and their experience of sexuality: An interpretative phenomenological analysis’, *Autism*, 21(1), pp. 75–82. doi: 10.1177/362361315627134	IPA	8	Not reported	Psychology
22	Anderson, D. L., Murray, C. D. and Hurrell, R. (2013) ‘Experiences of intimacy among people with bladder exstrophy’, *Qualitative Health Research*, 23(12), pp. 1600–1612. doi: 10.1177/1049732313509409.	IPA	6		Psychology
23	Chapple, A., Prinjha, S. and Salisbury, H. (2014) ‘How users of indwelling urinary catheters talk about sex and sexuality: A qualitative study’, *British Journal of General Practice*, 64(623), pp. 364–371. doi: 10.3399/bjgp14X680149.	Narrative / Grounded theory	36	Thematic analysis/ Tuchy et al (2013)	Health sciences/ Medicine

24	Beal, C. C. and Millenbruch, J. (2015) ‘A Qualitative Case Study of Post stroke Sexuality in a Woman of Childbearing Age’, *JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 44(2), pp. 228–235. doi: 10.1111/1552-6909.12553.	Narrative	1	Content analysis/ Not reported	Nursing
25	Fallbjörk, U., Salander, P. and Rasmussen, B. H. (2012) ‘Different Meanings of Mastectomy’, *Cancer Nursing*, 35(5), pp. 41–48. doi: 10.1097/NCC.0b013 e31823528f.	Narrative	15	Thematic analysis/ Not reported	Nursing

The selection process of the included papers is evident in PRISMA diagram (Fig.10).

Figure 10. PRISMA diagram for methodology review

Twelve studies that met the eligibility criteria were nursing studies (conducted by nurse researchers), and the remaining were other health sciences studies (medicine, physiotherapy, occupational health, or psychology). The studies have been included without a rigorous CASP appraisal of their quality, as the review was not on the content of the evidence, but on the methodology used. Two of studies provided no details of the approach used, one only stated 'qualitative study' and used thematic analysis for data analysis (Cooper *et al.*, 2018), the other describing the qualitative arm of a mixed method study (Hamilton *et al.*, 2015). Fourteen of the studies were reported as phenomenological, however in one of the papers, authors did not provide details of the phenomenological approach used, or the philosophical underpinning of their study (Haag *et al.*, 2016). In another study, authors stated they have based their study on existential phenomenology and employed a combination of descriptive/interpretative approaches, without reference to any frameworks used (Sekse, Råheim and Gjengedal, 2015). The majority of the studies provided very limited description of data analysis, with the exception of the interpretative phenomenological analysis (IPA) studies, narrative and grounded theory studies, where information was more detailed and focussed on aspects of thematic analysis, rather than providing any description of the employed frameworks.

The sample size across the phenomenological studies in this review ranged from 4 to 27 participants; where descriptive phenomenological studies had the highest number of participants.

All phenomenological studies have used thematic analysis for their data sets, however, there were seven frameworks used, including van Manen (1990) and

Braun and Clarke (2006). The only framework used in more than one study was Kvale's (2007) interview study thematic analysis. It was noted that one study used a combination of frameworks that authors deemed to fit best their data analysis (Ervik and Asplund, 2012). The complexity of the aspects that could be of interest in sexuality and intimacy research, with theoretical frameworks incorporating theories of embodiment, identity or stigma gives the researchers a diversity of frameworks to use, yet sexuality and intimacy in illness remains an under researched topic.

The term ‘phenomenology’ was found across a range of studies, some appeared to claim to use phenomenology just because they explored experience (van Manen, 2016). van Manen (2016) criticised the authors who rephrase text from interviews without any depth of analysis into so-called themes. van Manen also stated that some of the misconceptions often associated with phenomenological research is that all studies that explore lived experience are phenomenological studies, and the outcome of the analysis consists of a list of themes that paraphrase the quoted text, suggesting a superficial understanding of phenomenology and superficial data analysis.

After reviewing studies that explored intimacy and sexuality in the presence of a health condition over the past ten years, it was apparent that, overall, studies lacked reporting information on methodology and the data analysis frameworks used, especially in the ones that claimed to use a phenomenological approach. It is possible that their methodology was strong, however, the reporting process of the methodology was not sufficiently robust to suggest that one framework could be adopted to answer the research question of this thesis. The quality of qualitative reporting has improved in the past decade, but some argue that it had turned into a ritualistic approach which is more suited for quantitative research (Cleary, Horsfall and Hayter, 2014). The researcher was aware of the potential pitfall of undertaking a box ticking approach by some authors in order to publish their studies. Researchers should not attempt to imitate a phenomenological study, but the methods and practices associated with a specific phenomenological approach (van Manen, 2016). Norlyk and Harder (2010) found similar problems across 38 studies included in their review of the phenomenological studies conducted in nursing, with many authors failing to articulate a clear methodology or philosophical underpinning. In their review, 27 studies were guided by Giorgi (1985), Colaizzi (1978) and van Manen (1990).

The researcher had to make a decision as to what methodology and interpretative framework could enable her to produce the most detailed and accurate report of experiences that would provide a body of knowledge that could improve the care of those living with IBD. The researcher initially considered a narrative approach; however, the critique below outlines the decision making process for methodology choice.

3.3. Critical review of approaches used in the review

3.3.1. Narrative

Three of the studies (Fallbjörk, Salander and Rasmussen, 2012; Chapple, Prinjha and Salisbury, 2014; Beal and Millenbruch, 2015) reported using a narrative design in their research. Narrative has several definitions; the variety of definitions attributed to narrative research led to finding terms for this methodology that are more generally accepted. Frank's (2012) analogy to the fable of blind men declaring what beast they were describing based on what part of the elephant they held, sums up the difficulty in choosing one correct definition. Riessman (1993) defined narrative:

> *"In contemporary usage, narrative has come to mean anything beyond a few bullet points; when someone speaks or writes more than a few lines, the outcome is now called narrative by news anchors and even some qualitative researchers.'(pg*219)

Riesman makes the distinction between story and narrative, although the two terms are used interchangeably in the literature. This distinction between the two terms was debated in the early 90s, and subsequently narrative had more development around it, as considered to be more meditative and theoretical, as opposed to stories that were seen as less formal, although both accepted as having therapeutic dimensions (cathartic) for the narrator (Wiltshire, 1995). Others suggested that stories direct the reader towards what is told, and narratives towards how stories are told, as narratives need performance, agency and empathy to be brought to life (Plummer, 2019).

Narrative is predominantly used in health, social sciences and educational research. Hurwitz (2004) stated that inclusion of a patient story in research is more effective than the traditional use of a medical model, by reducing misunderstandings. Narrative can be used to make sense of lived experiences or as a tool for social construction by using language to share stories. Lived experience is a position of interest for nursing researchers and has at origin three philosophies: phenomenology (van Manen, 1990) social constructivism (Vygotsky, 1978) and cognitive psychology (Bruner, 1990). In the case of narrative studies, the researcher is concerned with individual truths in an existing social context, what a certain experience means to the participant, or how they made sense of their experience. This approach requires a hermeneutic analysis where the researcher goes back and forth to the story for a deeper understanding and interpretation. Nursing scholars have embraced the "*reconceptualization of* *human beings as narrators'* (Sandelowski, 1991) as stories offer solutions for analytical problems such truth and its ambiguity. This could mean that truth for one culture is a lie in another one. Truth is essential in science, as one of the aims is to create a truthful image of reality. The subjective nature of truth in qualitative research adds to the complexity of the concept, due to the interpretative nature of the reality as well as the social construction of reality (Moilanen, 2000). The works of Polkinghorne (1988), Riesman (1993), and Clandinin and Connelly (2000) are some of the most representative for narrative research.

This methodology has the potential to bring to light phenomena that are not well known. This is especially valuable when the light is shed on life experiences of people who are silent or excluded due to the nature of their illness. In narrative research, the researcher gives a voice to those unheard by retelling their stories (Andrews, Squire and Tamboukou, 2013). The narratives can be analysed from a linguistic stance and then the structure has temporality, a cast and a plot. Nonetheless nursing researchers are interested in the meanings of experiences, so they must accept that a story is not necessary mirroring the exact event, nor is it providing 'truth' that is acceptable to the wider world. The existence of multiple 'truths' in qualitative research is a main aspect of the ontological and epistemological difference between the positivist and interpretivist paradigms, and the multiple truths are constructed through the subjective nature of social reality, where social factors are interpreted differently in different societies (Moilanen, 2000). One event will cause a series of other events that affect the cast, and truth is what it means to that one person in making sense of an event, in a social context existing at that moment (Bold, 2013b). '*Narrative is not an objective reconstruction of life -it is a rendition of how life is perceived'* (Webster and Mertova, 2007). Since narratives do not attempt to establish certainty but show many interpretations of a phenomena, this makes the approach vulnerable to criticism. Nevertheless, the researcher aims to render a multifaceted truth in narrative studies, that may have commonalities with others' experiences, though not necessarily as a whole. Denzin (1989) claimed that a life story is fictional as being made out of experiences, truth being a result of what is believed to have happened and how the experience has been facilitated by interaction with others, hence the same story told at a different time or audience will have different meanings. In essence, narratives are not the result of a description of events, but of what one constructed from that event to make sense of that particular experience.

Critique of the narrative approach

Critics have mainly addressed the authenticity of narrative research (Woods, 2011). Others have argued that short episodes are not reflecting a full story (Strawson, 2004). Furthermore, narrative inquiry as a newer form of qualitative research seems to be heavily criticised for the perceived lack of clarity on the methodology and, as a result, it is seen as a less trusted method of inquiry in the field of qualitative research (Creswell and Poth, 2018).

The research questions in this study could have been answered with a narrative approach, however, the findings would be representations of several views of a phenomena by telling the stories of individual experiences. Although this would be useful for giving voice to participants, was thought to be less influential in capturing the essence of the experiences, therefore with a diminished potential for getting the attention of healthcare professionals and influencing practice. While the potential for influencing practice was not an objective of this study, the researcher hoped that the study would produce reliable results that ultimately should lead to change in practice.

3.3.2. Grounded theory

Four of the included in the review studies (Ramirez *et al.*, 2009; Robinson, Miedema and Easley, 2014; Fritz, Dillaway and Lysack, 2015; Shaw, Sherman and Fitness, 2016) have researched intimacy and sexuality experiences in illness using grounded theory. This research approach was formulated by Glaser and Staruss(1967,1995,1999, 2006) and entails theory development from data, through constant comparison methods, until a theoretical hypothesis is generated for future research. Grounded theorists believe theories should be grounded in data that is rooted in the interactions of people and the social processes around them. The final outcome of analysing the data through grounded theory leads to discovery of a theoretical explanation for a process that had been observed across a group of participants who have all experienced that particular process (Creswell and Poth, 2018).

In nursing research this approach is still developing and in the 1990s a split between Glaser and Straus led other currents to form within grounded theory approach: (Corbin and Strauss, 1990) and (Charmaz, 2006) which have developed their own interpretations of the approach (Parahoo, 2014). Charmaz has advocated for introducing a different perspective and developed a constructivist grounded theory which gained terrain in nursing (Creswell and Poth, 2018).

Corbin and Strauss (2015) adopted a more systematic approach to grounded theory, and they suggest the data analysis starts at the time of data collection. Data are collected from 20 to 30 interviews, coded following line by line reading and aggregating the codes in concepts that would lead to axial coding, in which one open coding category becomes the core of interest in the research. Going back to the data and comparing it to the core in an attempt to prescribe categories around the identified core, defines further categories that determine the core phenomenon, actions that were taken as a response to this, and consequences of such actions. Charmaz (2014) has taken this further and proposed introducing more than a core phenomenon, by including different worlds, multiple realities as a social constructivist approach to grounded theory. Her emphasis is on views, beliefs and feelings of participants, as opposed to the methods of research, but not without laying down a useful description for data acquisition (Creswell and Poth, 2018).

Critique of grounded theory

One of the difficulties in using grounded theory lies with the decision of when categories become saturated. Some critiques have noted that Corbin and Strauss's approach lacks reflexivity and can appear as being rather rigid in use, as opposed to Charmaz's which is more adaptable and does not minimise the researcher's role in the process (Creswell and Poth, 2018). A grounded theory approach was found to not be suitable in answering the research questions of this study, as the researcher's aim was not to develop a theory on the views of participants, but to understand the essence of the experience.

3.3.3. Phenomenology

In this methodology review, 13 of the studies, excluding interpretative phenomenological analysis (IPA) studies (Anderson, Murray and Hurrell, 2013; Dewinter *et al.*, 2017; Villa *et al.*, 2018) claimed they had a phenomenological approach although few described the methodology used (Davison and

Huntington, 2010; Josefsson and Gard, 2010; Jefferies and Clifford, 2011; Ervik and Asplund, 2012; Klaeson, Sandell and Berterö, 2012; Taylor, 2014b; Sekse, Råheim and Gjengedal, 2015; Haag *et al.*, 2016; Fredericks, Harbin and Baker, 2017; Moules *et al.*, 2017; Schantz Laursen, 2017; Traumer, Jacobsen and Laursen, 2019; Tuohy and Cooney, 2019). Used as a way of exploring life experience, phenomenology is also a philosophy. Some described the main purpose of phenomenology as to '*reduce individual experiences with a phenomenon to a description of the universal essence'* (Creswell and Poth, 2018). Developed by the mathematician Husserl (1859-1938) in the late 19th century, considered the founder of the phenomenological movement (Koch, 1995) it had transformed over the past decades through the works of Heidegger, Sartre and Merleau-Ponty into three distinct schools: descriptive phenomenology - based on Husserl's ideology, interpretative or hermeneutic, based on Heidegger's ideology, and the Dutch school, which combines both descriptive and interpretative approaches (Creswell and Poth, 2018). The latter was adopted by American phenomenologists and is also known as *modern phenomenology*. A particular current in the modern phenomenology is known as *phenomenology of practice*, and is promoted by health sciences, education and psychology (Parahoo, 2014; Polit and Tatano Beck, 2017; van Manen, 2007; Moran, 2018).

Phenomenology focuses on describing and interpreting what the majority participants have in common as they experience a phenomenon, but similarly what other forms of experiencing the phenomenon are identified. This implies that only those who had a certain experience can communicate it, therefore one must have experienced that phenomenon in order to articulate an experience.

3.3.3.1. Descriptive phenomenology

Husserl's descriptive phenomenology is concerned with rich description of the phenomena and requires the researcher to suspend any personal beliefs and preconceptions about the studied experience, process called *bracketing* (Parahoo, 2014). His phenomenology aimed to answer questions about the objects within the world and world itself. His goal was to study how people experience phenomena in their consciousness, and argued that one should concentrate on the essence of the phenomenon, without an interpretation, by employing *bracketing*, in order to allow the experience to be revealed in its pure state (Moustakas, 1994). Husserl argued that *intentionality*, as a process where the consciousness is directed to a phenomenon (Koch, 1995) sits at the heart of how one knows reality (Laverty, 2003). Husserl's teachings retained certain elements of positivism, and were the foundation for descriptive phenomenology. Colaizzi (1978), Giorgi (1985), Polkinghorne (1988), and Moustakas (1994) continued his work towards development of current descriptive phenomenology, but it was acknowledged that bracketing is hardly ever achieved (Creswell and Poth, 2018). Therefore, bracketing became accepted in phenomenological practice as a method through which the researcher examines and acknowledges their own biases and prior knowledge, and allows views of participants that align with own prejudice, as opposed to suspending researchers' prior knowledge and preconceptions (Dowling, 2004; Horrigan-Kelly, Millar and Dowling, 2016).

Descriptive phenomenologists described their analysis method as reducing the data to significant statements that are later collated in themes. These themes evoke what was experienced and how it was experienced, concluding in an overall essence of that experience, where essence of experience is viewed as the main outcome of descriptive phenomenology (Lin, 2013). After Husserl, each phenomenologist developed a distinct approach (Moran, 2018), some stating that there are as many phenomenologies as phenomenologists (Dowling, 2004), but most kept at the core of their philosophy the way life is experienced.

3.3.3.2. Interpretative phenomenology

Interpretative approaches are suited for understanding phenomena rather than explaining them (MacKey, 2005). Heidegger (1889-1976), a student of Husserl, advocated for an interpretation of the experience and the researcher's own understanding and experiences regarding the studied phenomena. His focus was on the details that can be taken for granted from experiences, in an attempt to achieve a deeper understanding by interpreting the experience (Wilson and Hutchinson, 1991). For Heidegger "*Being in the world*" requires approaching understanding in a certain way, as time and space are parts of the perspective of being. The term *Dasein* was introduced by him as the term defining the state of existence, meaning that a human being presents as existing 'authentically' in Dasein (1962, pg.68), since it gives awareness to his own being. Heidegger also brought the notion of *fore–structures,* which are in essence an anticipation of meaning, therefore understood before awareness and interpretation. According to him awareness exists and *'interpretation functions as disclosure'* (Heidegger, 1962, pg.62). Heidegger used the fore–structures for a hermeneutic circle of understanding (Heidegger,1962). The notion of hermeneutic circle was in Heidegger's view a circular process, and involves our *background (*understanding from the surrounding world that is handed down), *pre-understanding* (time, language and culture pre-existing to understanding an experience, therefore presuppositions influencing interpretation of an experience), and *co-construction* (understanding gained through interpretation from interaction with others)

(Dowling, 2004). Essentially, the hermeneutic circle means moving between the fragments of what is described, and the whole description, and returning to the fragments acknowledging what are the presumptions brought in with the interpretation, and looking at possibilities to get a deeper understanding, and enriching the understanding of the experience as well as the interpretation. Later the hermeneutic circle was adopted and adapted by various phenomenologists in describing their methodology. In interpretative phenomenology the existence of suppositions and assumptions is widely accepted, however, these are identified and acknowledged early on and throughout the data analysis, rather than removing the existing assumptions and presumptions through bracketing (Polit and Tatano Beck, 2017).

3.3.3.3. Modern phenomenology

The Dutch school that originated in Utrecht, has applied phenomenology as methodology to disciplines from education to medicine, and developed an approach called phenomenology of practice (van Manen, 2007), with a view that it is applied in various professional settings providing a valuable contribution to the professional knowledge through solid methodology (Errasti-Ibarrondo *et al.*, 2019). The Dutch School was adopted by North America under the name of *modern phenomenology*, and is based mostly on van Manen's work, but also on other Scandinavian phenomenologists (Creswell and Poth, 2018).

In van Manen's perspective, phenomenology is a human science studying lived experience in a pre-reflective presentation, not in a conceptualised way: '*Phenomenological human science is the study of lived or existential meanings: it attempts to describe and interpret these meanings to a certain degree of depth and richness'* (van Manen, 2016 pg.32). This enables studying one's world, as is lived in the essence, therefore it highlights what *'is, without which it might not be* *what is'* (van Manen, 2017, pg. 5), suggesting that an experience would be different without the essence that was given to it. Phenomenology does not seek for discovery of a certain conclusion, but acknowledges that the experience is multidimensional and it is impossible for a single concept to capture the meaning of the studied phenomena, as it is one interpretation of the phenomena, and that is the interpretation of the researcher (van Manen, 2015).

According to van Manen, phenomenology attempts to articulate in the form of text what the meaning of a certain experience is, from describing and interpreting that experience through the questioning and reflecting of the researcher (van Manen, 2016). The phenomenological text that is the result of the data analysis is organised in an attempt to communicate the essence of the experience with its variants through text. This text embodies the knowledge that has the potential to lead the reader to engage with the lived experience presented and to turn to reflection.

van Manen argued that descriptive phenomenologists failed to offer full descriptions, as lived experiences have hidden aspects to them. van Manen's approach is considered hermeneutic, although he combines descriptive aspects and simultaneous interpretation (Dowling, 2004) since lived experiences are given hermeneutical importance when recollected as a certain level of reflection is involved during recall. Phenomenology is not focused on the facts or differences of the particular meanings or experiences, but answers the questions of what it is really like experiencing the phenomena, by going back again to the things, until something is revealed in its essential nature. Going back to things involves questioning every aspect of the experience, and examining these aspects in a meditative way, incorporating the researcher's presumptions and eliminating any emotional artefacts that may 'clutter' the interpretation, in an attempt to give the deepest meaning to that experience, which should remain the same regardless the time and social construct attached to it.

van Manen’s phenomenology is based on the works of Heidegger (1962) and Merleau-Ponty (1962), and has four existential domains at the core of reflection on the phenomena of interest: lived time, lived space, lived relationships and lived body.

3.3.3.4. Interpretative phenomenological analysis (IPA)

Several studies involved IPA, which is not aligned to either descriptive or interpretive phenomenology, but borrowed aspects of both, although with an emphasis on an approach embedded in psychotherapy (Smith, 1996). Rooted in hermeneutic phenomenology and ideography, IPA is a ‘double hermeneutic’ (Smith, 2011), which means that attention is given to the experience that sits at the core of the study, and at the same time at the way that participants make sense of that experience. Developed to conduct qualitative research in psychology (Brocki and Wearden, 2006), IPA is focused on meanings, understandings or views of participants regarding a phenomenon of interest (Reid, Flowers and Larkin, 2005). It was developed in an attempt to create a theoretical framework for analysis that addressed a gap in interpreting the body in health psychology. It was argued that the results of IPA provide accounts of how patients deal and think about complex health questions (Smith, 1996). Predominantly based in the United Kingdom, it had gained popularity in other Englishspeaking countries since first described by Smith in the late 1990s.

The researcher viewed IPA as not being suitable for answering the research questions of this thesis, as the aim of the study was to explore the lived experiences, and not how participants thought or dealt with the intimacy and sexuality in the context of IBD, although the benefit of knowing participant's thoughts and coping was recognised.

Critique of phenomenology

Over the past decades, criticism over the use of phenomenology in nursing research emerged. Crotty (1998) argued that nursing phenomenology lacked critique, and criticism was mainly aimed at van Manen's hybrid phenomenology as well as the 'scientific' one described by Giorgi. Crotty further said that nurses should not claim they use Husserlian or Heidegerrian influences in their philosophies as nurses had adopted a modern one instead of developing their own (Dowling, 2005). Crotty's criticism extended further, claiming that nurses should refrain from cultural contextualisation of illness experience, claim that was contested. Benner (2002) responded to this arguing that culture and society are strongly intertwined in the way the illness experiences are formed, in other words, in a world where society sees the healthy person as the epitome of perfection, illness experiences will be framed around this. Crotty was particularly critical of Benner and Diekelmann, as they both challenged traditional methodologies where theory was viewed as superior to practice, his position on this being attributed to a potential misunderstanding of Heidegger (Darbyshire, Diekelmann and Diekelmann, 1999).

Paley (1997, 2018) also critiqued the methods followed by Giorgi, Smith and van Manen, as they failed to answer the question *how was a phenomenological study done?* Giorgi (2017) argues that Paley did not understand Husserl and also failed to grasp a basic understanding of phenomenology. Paley's work was widely criticised by nurse researchers as they argued he simply suggested research into lived experience should not take place (Deary *et al.*, 2002).

Several nursing studies mentioned the modern approaches by stating their study being guided by phenomenology, but failing to acknowledge their frameworks' origin, which leaves the use of phenomenology in nursing open to criticism. Dowling (2007) stated that nurses perhaps put too much emphasis on the method, losing sight of the philosophies. Phenomenology is no longer phenomenology if is not rooted in one of the philosophical currents, but when phenomenology is used, there is no need to over-emphasise the philosophy (Zahavi and Martiny, 2019).

3.3.4. Methodology not used in the review: Ethnography

It was noted that none of the studies have used ethnography. Ethnographic research focuses on the culture sharing group, examining the patterns, rituals and customs that are shared within the group (Borbasi, Jackson and East, 2019). It usually involves larger groups and is conducted over an extended period of time, it has its origin in anthropology (Creswell and Poth, 2018).

There are numerous subtypes of ethnography as they are based on different theoretical orientations, from feminism to postmodernism (Hammersley and Atkinson, 2019) therefore, various frameworks are advocated by each subtype (Creswell and Poth, 2018). There is particular subtype used in nursing research, ethnonursing. Ethnonursing is an established qualitative approach which has as main aim exploration of human care. (Leininger and McFarland, 2006) developed a framework for conducting ethnonursing described in their *Theory of Culture Care*, and involves a three-stage process: observation, participation and reflection. The approach is more suitable for nursing education, as it explores beliefs and customs within the nursing culture.

In the past decade another subtype, **autoethnography,** has gained interest within the research community as a method of inquiry of illness experience. In the case of autoethnography the researcher is also the participant, and combines the ethnography with autobiography (Schwandt, 2015). (Ellis, Adams and Bochner, 2015) defined autoethnography as a personal analysis of personal experience, whilst (Butler, 2016) states that is an invite to a personal aspect of research that engages the reader through active critique and interpretation. Some examples of autoethnography in IBD that are widely cited as a source of knowledge for patient experience (Defenbaugh, 2007; Moore, 2013).

Critique of ethnographic research

Conducting any type of ethnographic study demands a significant period of time that is not always compatible with the resources of a doctoral project, but also, following participants for observation on this particular sensitive topic was deemed not possible by the researcher. Furthermore, the narratives resulted from an ethnographic study employs a literary style which can be challenging for some researchers used to a more scientific approach to writing (Creswell and Poth, 2018). The researcher found this approach unsuitable to answer the research questions as intimacy does not lend itself to observation.

3.4. Rationale for methodology choice

The literature review on methodology used to explore experiences of intimacy and sexuality in illness concluded that no framework was identified to be sufficiently detailed to enable the researcher to be fully comfortable to adopt it, nor that one framework would be methodologically stronger than others. However, it was evident that phenomenology was one of the most used for inquiring the topic in studies from other specialities. Phenomenology was found to more likely to enhance the view of holistic care, since aligned closely to the notion of holistic research (Patton, 2020). The general view when choosing the methodology is that it should respond the research question (Harper, 2011) although more should be considered: researcher's' preference and experience in a certain approach, and relevance of the findings from the chosen design to a certain audience (Slade and Priebe, 2006). For the purpose of this thesis, phenomenology offered the potential for an understanding on how aspects of life are experienced in illness, and could enable healthcare professionals to help patients once this knowledge is produced (Paratoo, 2014).

The main differences between descriptive and interpretative phenomenology are found in methodology. The first is concerned with describing a structure of the studied phenomenon, whereas the latter with the further development of these meanings through interpretation in an historical /social context that the individual is situated (Laverty, 2003). The researcher's interest lies within the interpretative phenomenology, since her own beliefs are that what is rendered as description by the participants is already the result of an interpretation. Heidegger's' philosophy aligned with the need for human interaction in generating knowledge, and the researcher found this as most suitable to guide the theoretical framework for this thesis. Therefore, the analysis frameworks compatible with hermeneutics were assessed, to find the best fit for the data analysis. Furthermore, hermeneutics add a deeper understanding of the experience by paying attention to the language used to describe the experience (Robertson-Malt, 1999).

Amongst nursing researchers Diekelmann’s (1989) framework has been used for more than two decades now, and consists of seven stages that are repeated cyclically. Themes are identified through team analysis and a relational system between the constitutive themes and relational ones is developed. Although the framework was found to be similar to a thematic analysis, the researcher, as a PhD student, did not have access to a team in interpretative work.

Thematic analysis frameworks are becoming increasingly popular in many qualitative approaches, but not without bringing a lot of controversy on the ease of claiming that everything that can be grouped in themes is necessarily thematic analysis. It gained momentum in late 2000s when Braun and Clarke (2006) published their thematic analysis framework, a framework that is widely used amongst qualitative researchers and which is appealing to novice researchers. Their reflexive thematic analysis could be employed to support data analysis in an interpretative phenomenological study, as being theoretically flexible, with researchers’ transparency and knowledge of the philosophical underpinnings of the theory that is applied (Braun and Clarke, 2019). The element of interpretation as the last stage of their framework was appealing, however the researcher felt that an alternative framework with a stronger philosophical underpinning could be applied.

After these two frameworks were considered, van Manen’s framework was the last to be compared and contrasted with the others presented above. van Manen (2017b) acknowledged there is no right or wrong way to conduct and analyse lived experience and he suggested different ways to analyse phenomenological studies. Although his framework is a combination between descriptive and interpretative approaches, he offered a guide on how one can undertake data analysis of a phenomenological study grounded in Heidegerrian philosophy. van Manen detailed the six steps of his methodology which was a major factor helping in the decision making, as the elements of descriptive and interpretive analysis were flexible, and the emphasis of the methodology is on the phenomenological process rather than on the framework. Furthermore, the ways data collection could be conducted had an impact on the decision; van Manen 's data collection not being restricted to interviews, but written descriptions of experiences and also the researcher's observations all contributing to the interpretation of the phenomenon (Parahoo, 2014; van Manen, 2017a). Additionally, van Manen's approach was appealing to the researcher as the framework not only guides the data analysis, but also incorporates aids that should enable the researcher to practice and develop phenomenological understanding and interpretation, through the use of phenomenological reading and artistic descriptions of lived experiences, making phenomenology as a philosophy, more accessible. The framework seemed flexible in terms of suggesting ways of presenting the phenomenological text of the results and interpretation, which felt less prescribed and allowed the researcher to have a more individual approach to the writing, without compromising the philosophical tenets in the text.

In his works van Manen presented three main ways of dealing with data analysis: by doing thematic analysis, a themed approach to data analysis, and an existential reflection on the data. These could be used singularly or in a combination and van Manen offered succinct examples in his book *Researching lived experience* (van Manen 1990, 2016).

Phenomenology is not only a philosophy and methodology but also, a way of understanding the world (Adams and Van Manen, 2017). van Manen's methodology presented an opportunity for the researcher to question how to act thoughtfully in future practice as a result of understanding patient experience. Therefore, van Manen’s hermeneutic phenomenological design was chosen as being appropriate for understanding the lived experience from the patient’s perspective. It is suitable for exploring phenomena of interest through participant’s narratives. Narratives are also intricately woven into ones’ very existence, how life experiences are perceived is best illustrated through them. Illnesses that have a stigma attached have a profound effect on the individual and their own personal life story. Sharing stories of personal illness can bring understanding and meaning into the illness experience within an individual’s particular life circumstances (Kleinman, 1988).

CHAPTER 4. Methods

4.1. Overview

The chapter outlines the methods for data collection employed, data analysis and the ethical implications for conducting the research study.

4.2. Data collection in a digital world

Methods are the tools that a researcher uses to collect data to answer the research questions. Considering the potential criticism of phenomenological studies described in the previous chapter, multiple ways of data collection were employed, interviews alone being considered by some as insufficient to uncover phenomena (Paley, 2018)

The internet has become a phenomenon engraved in how society operates in large parts of the world, and this had also changed how research is conducted. Today data can be collected online, participants can be accessed through the internet, and digital technology is widely accepted in research. Software is often used to help analyse data collected for research purposes, and data are also stored with the aid of digital technology in many cases. Not surprisingly, qualitative researchers are encouraged to assess their projects and decide what routine activities could be improved by the use of technology (Moylan, Derr and Lindhorst, 2015). In terms of engaging in computer mediated communication (such as internet interviews) there are clear differences between men and women, women being more likely to disclose sensitive information in a digital context (Harper, 2005). When assessing the options for data collection for the study, a great deal of consideration was given to the population that the study was aimed at, and their preferred ways of communication, in order to maximise the study participation, and offer choice of method to participants.

Digital technology is at the base of defining the millennial generation as the first generation that embedded the digital world into their daily living (Ito *et al.*, 2009). Millennials and teenagers have developed and negotiated friendships, romantic relationships (Rosenfeld and Thomas, 2012) and sexual relationships (Goluboff, 2016) using digital technology. It is obvious that people of all ages access digital technologies more than ever before in their everyday lives. As a result, people who were considered hard to find or hard to access in research a decade ago, now can take part in research through the Internet. Moreover, sensitive research had benefited from computer mediated communication data collection, increasing participation in research, eliminating time for travel, and saving time and resources on transcription (East *et al.*, 2008). The use of social media platforms, such as Facebook, is now accepted as means to data collection, and a recent example is a study that used Facebook to capture experiences of women living with cerebral palsy on their sexual health related issues (Shah, Bradbury-Jones and Taylor, 2020).

In phenomenological studies, interviews are used as the main data collection method, verbal interviews (face-to-face, telephone or video calling interviews) as oral means for data collection. Email interviews are an alternative to oral interviews as they are a method for written data collection, and since the essence of an interview is language, an email is also capturing this essence (Hamilton and Bowers, 2006). Google Forms and instant messaging offer the possibility to collect data online, and both methods are described in this chapter. These are suitable alternatives to email interviews in order to preserve partial or complete anonymity of the participants, and capture narratives of experiences in a valuable way (Fourie, 2020). Considering the intention to reach all age groups within our population, and giving the participants a choice of communication, written text on an electronic device was deemed as a suitable alternative for oral data collection methods. Furthermore, the sensitive nature of the topic contributed to the choice for these methods, as well as traditional data collection tools (face-to-face / telephone interviews). This way participants were given more flexibility in terms of time, location and anonymity of taking part in the study.

4.3. Population and sample

Research ***population*** refers to those who are considered to take part in a research study. Definitions of ***sample*** were found to be inconsistent in a systematic review of sampling in qualitative research, with a final conclusion that ***sampling*** is broadly '*the selection of specific data sources from which data are collected to address the research objectives*' (Gentles, Charles and Ploeg, 2015, pg.1775)***.*** There are various ways of sampling*,* depending on the nature of the study. For those who share a common feature that is being researched, ***purposive sampling*** would be the appropriate sampling technique. ***Snowball sampling*** entails chain referral, whereas a ***convenience sampling*** draws on an available population (Creswell and Clarke, 2011).

For this thesis, a purposive sampling technique was found to fit the best, as the potential participants had to all live with inflammatory bowel disease. A varied population was sought within the IBD population, to ensure that the researcher has access to experiences of a population as diverse as possible, for a better representation of the experiences sought in the study. This was ensured by finding ways to increase the access to the study information through advertisements on a web page of a national IBD charity, additionally to local National Health Service (NHS) recruitment. However, during the course of the data collection it became apparent that snowballing sampling had also taken place, as participants had contacted the researcher following referral from other participants.

No sampling technique is flawless. In spite of finding ways to give the opportunity to participate to as many as possible, the access to one NHS Trust and the use of only one website for advertising the study, it was very likely that some barriers to participation were introduced in this way (those with mild illness not attending regular clinical appointments, and those with no means of accessing the internet, or visually impaired people).

The full details of participants included in the study are available in Chapter 6.

4.3.1. Sample size

The size of the population that should be included in a qualitative study is a question asked by many (Sandelowski, 1995; Charmaz, 2006; Creswell, 2018) without a definitive answer. Decisions on sample size in qualitative research at the time of research design is problematic, as knowing how many participants would be needed in order to gain sufficient understanding pertaining to the research question is illogical (Saunders *et al.*, 2018). Others also argue that a priori sample size calculations in qualitative research are incompatible with the methodology, although is always necessary to indicate a number at the design stage, and for ethical approvals needed (Sim *et al.*, 2018). In spite these arguments, the sample size seems to be relatively consistent across disciplines and with a tendency to go higher over the past decade, potentially in an attempt to align with quantitative standards (Guetterman, 2015). Mason (2010) explored sample size in qualitative PhD studies across different disciplines, and found that the sample size decision in PhD studies was pre-determined, and not necessary in line with the methodological approach, with a potential to negatively impact on resources. Another review concluded that the bigger the sample sizes were used in ethnography, with phenomenology at the opposite pole, having the smallest sample sizes (Guetterman, 2015). Sample size is usually dictated in qualitative research by an expected number of participants that would be needed in order to determine that nothing new is found, or to reach what grounded theorists call *data saturation*. Also named '*information redundancy'* (Lincoln and Guba, 1985) and described by Dey (1999, pg.257) as an '*unfortunate metaphor'*. Dey (1999) suggested the alternative' *theoretical sufficiency'* to define when an adequate depth of understanding of a phenomenon is reached in qualitative research. As data saturation approach for sample size is suitable for grounded theory, van Manen (2014) has argued that data saturation is not relevant for hermeneutic phenomenology, which sets phenomenology apart from other qualitative methods, where stopping short of achieving data saturation is discouraged (Charles, Ploeg and Mckibbon, 2015).

In interpretative/hermeneutic phenomenology the sample size is often small, commonly ten being the sample size of choice as the richness of the data is more important than the sample size (Mapp, 2008). A review of nursing phenomenological studies (Norlyk and Harder, 2010) identified in the 46 studies reviewed a sample size ranging from1 to 76. However, from these, the majority of the studies with a sample size between 6 and 10 have considered that a limitation of their project, which suggested a sample size larger than 10 should be sought. For the purpose of this thesis, a sample size of 20 to 40 participants was identified as reasonable to provide the researcher with rich data, and to address the research question.

After data were collected from approximately 25 participants it became obvious that the researcher had access to rich data and no new information was being gathered. The recruitment continued at this stage as the population sample was not very diverse, the majority at this stage being women aged 30 to 40 years, and it was an assumption that a different age range and more male participants might provide different data. Richness of data and heterogeneity of the population that provides the data were both sought by researcher during the data collection stage, as indicators for when data saturation was reached. The type of data collected had also implications in the decision for sample size, as it was expected that data collected from GF would not be rich enough to collect rich data from this source alone. Interviewing small numbers can capture a wide array of issues that could provide an understanding of the topic of research however, it would not provide sufficient richness to understand those issues (Hennink, Kaiser and Marconi, 2017).

In the methodology review presented in the previous chapter, the sample size ranged from 4 to 27 participants across the 9 studies that had used interpretative phenomenology, of which 4 studies had a sample size of 10. This is consistent with van Manen's view on the sample size needed for conducting studies using his framework as being around 10, and aligns with Creswell's (2018) suggestion to have 10 to 20 participants in phenomenological studies. However, the decision to collect data from more participants was based on the fact that GF were short narratives, and researcher felt that the interviews should at least be same number as GFs received, to ensure that rich data is available for analysis.

4.3.2. Inclusion and exclusion criteria

Participants in the study had to be able to answer the study question. For this thesis eligible participants met the following inclusion and exclusion criteria:

Inclusion

- Had a confirmed IBD diagnosis
- Were over the age of 16
- Male or female
- They were of any sexual orientation
- Able to read, understand and express in English

Exclusion

- Had no confirmed IBD diagnosis
- Under the age of 16
- Unable to understand and speak English language

Due to the nature of experience investigated it was decided that participants from any geographical location were eligible to take part, in an attempt to have a population as varied as possible.

4.3.3. Setting, recruitment and consent

Initially the study was aimed at exploring the intimacy and sexuality experiences of young women aged 16-24, although after a period of 6 months due to the difficulties in recruitment, a new ethics application was submitted extending the research questions to all adults that accessed Crohn’s and Colitis UK charity website. Recruiting young people in clinical setting to studies exploring sensitive topics was difficult, and only 5 participants consented to have an interview by the beginning of March 2020 (when Covid-19 pandemic started) from around 80 that had been given study information by the clinical team.

The second application was submitted to the University of Oxford Ethics as the researcher is employed by the organisation and two supervisors were also included in the application (Prof Simmons from initial supervisory team, Prof Norton from the current supervisory team). Therefore, the recruitment was covered by two separate ethics approvals, but with same research questions and research design (IRIS study Research Ethics Committee reference 18/ES/0139, IBD Ask Reference CUREC RE60900_Re001). Details of the approvals granted and the associated study documents are found in the Appendix. (1.7, 1.8, 1.12).

Participants were recruited in 2 different settings:

- **Recruitment from gastroenterology clinics in an NHS Trust**

The study was introduced by the clinical care team to patients attending gastroenterology clinics in one NHS Trust, and those interested were consented for face-to-face interviews, or had the option to send a narrative account of their experience in an anonymous GF. These participants had signed a written informed consent following a thorough discussion of the study with the researcher, who had answered any questions raised after the participants have read the Patient Information Sheet (Appendix 1.9). All participants understood the purpose and procedures of the study, the voluntary nature of it, and how their data was protected.

- **Recruitment from Crohn’s and Colitis UK website**

The study was advertised by Crohn’s and Colitis UK and their members could choose between responding anonymously using a GF, or contacting the researcher to discuss a face-to-face or telephone interview, based on their location, their willingness and possibilities to travel. Those responding anonymously via GFs had to tick a box acknowledging that they agreed to take part in research, as well as an optional box stating they consented for excerpts from their narrative account to be used in publications resulting from the study. All but one consented to have quotes from the interview/narrative account published under pseudonyms.

Those who opted for a face-to-face interview signed a written informed consent form in the same manner as those who had been recruited from the clinical area. In the case of telephone interviews, the consent was audio recorded at the beginning of each interview. The Participant information leaflet for CCUK was slightly different form the one used for the clinical setting, as a result of the way that potential participants are approached in clinical settings, where the clinical team has to be the first to introduce the study to those deemed as eligible. (Appendix 1.13).

4.4. Data collection

4.4.1. Google Forms

Email interviews were found to be a satisfactory data collection form for exploratory studies (Jones, Bowden and Galindo-Gonzalez, 2015). The option of fully anonymous participation would have been compromised through an email interview, as the email addresses would be likely to include the name or surname of a participant, therefore GFs were found as a suitable alternative. Due to the sensitive aspect of the phenomena of interest, coupled with the stigmatising nature of symptoms, alternatives to face-to-face or telephone interviews were sought, in an attempt to provide privacy and anonymity to those who wanted to participate. It was expected that GF would not generate the same richness of data as an interview since the prompts from a face-to-face interview can’t be fully achieved in GF format. However, the decision to use it was made to give an opportunity to participate to those who would otherwise not participate in a face-to-face or telephone interview. Giving a voice to those less likely to engage in sensitive topics was important to the researcher's personal beliefs of inclusion and diversity. The GFs were accessed via a link included in the participant information leaflets. This also gave an option to those who were approached in the clinical setting to respond anonymously, if they preferred. Each participant could enter one single response from an email address, and no email addresses were visible to the researcher, supporting full anonymity of this participant group.

The same introductory questions were used as for interviews, allowing the participant to describe their experiences in a narrative way, in the free text box enclosed (Appendix 1.10). Responses to the advert were almost immediate, GFs starting to be received within a few days from advertisement. The length of the GF responses varied from a couple of paragraphs to 2 pages, mostly focusing on the aspects important to participants from the topic of interest.

The value of these forms to the overall project was substantive. In the first stages data obtained via GF helped with drawing up a list of categories of interest for investigation during in depth interviewing, and at the later stages, whilst preliminary data analysis was ongoing, it helped the researcher with the decision not to continue further interviewing as the GF that were received during this period confirmed the themes identified through analysis.

4.4.2. Interviews

Qualitative interviews are often chosen for sensitive research (Liamputtong, 2007), and in nursing studies, face-to-face interviews have been successfully used (Dibley and Norton, 2013; Dibley Lesley *et al.*, 2014; Taylor, 2014; C. Jones *et al.*, 2019). The interviews aim to gather experiential material narrated by participants (van Manen, 1990). Interviews stand as the gold standard for most of qualitative research, especially in phenomenological studies (Silverman, 1998; Bevan, 2014; Creswell and Poth, 2018). However, few authors have indicated how a phenomenological interview should take place (Moustakas, 1994; Brinkmann and Kvale, 2018). There are three different types of interviews in qualitative research: *structured*, which are almost similar to questionnaires, *semi-structured*, which contain a few core questions to keep the focus on the research item but flexible enough to allow seeking clarification, and *unstructured*, where there is no agenda for the interview (Bold, 2013a). Semi structured interviews are most commonly used to keep the dialogue grounded to the explored phenomena, although when a purposive sample is used, as in the case of this thesis, all had in common inflammatory bowel disease, the use of less structured interviews was possible. Furthermore, the use of a long list of questions was viewed by the researcher as a limitation to exploring the phenomena. Open ended questions were used inviting the participants to describe their experiences,

Narrative interviews became popular in health research the late 1990s. As opposed to the more structured interviews, which follow questions guided by the researcher, narrative interviews follow little structure, allowing the participant to describe what is of importance to them. The decision to use a narrative approach for interviews was based on the assumption that narratives are central to give meaning to experiences (Floersch *et al.*, 2010). A framework for novice researchers was presented by Dempsey *et al.*, (2016) covering all the relevant areas for consideration prior to interviewing on a sensitive topic. The framework was used in this project as a guide for considering ethical aspects of the study, interview schedule, time and location of the interviews as well as aspects pertaining to conducting the interview.

Phenomenological interviews are usually semi structured, to maintain the focus on the phenomena of interest, although there are elements of narrative interviewing, such as allowing the participants to bring up for discussion aspects they find important related to the topic. A common misunderstanding regarding phenomenological interviewing is that interviewers should elicit personal views on something; opinions, feelings and explanations about a phenomena (Adams and Van Manen, 2017). Phenomenological interviewing should ask questions like: *'Can you think of an example?'* or '*Can you tell me more about the (described experience)*?'

Field notes are important to note the researcher's observations during and after an interview, and address the assumptions, asking questions about the described experience. Frequently participants come prepared to share opinions rather than experiences during interviews, and the researcher has to access the pre reflective descriptions of that experience rather than the opinion, which is the result of reflection and interpretation. It is also important accepting that not everyone can remember and describe vividly an experience (Adams and Van Manen, 2017), as it places the task on the researcher to find the deeper meanings in simple descriptions. The study interview guide can be found in Table 7.

Table 7. 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 experience of intimacy and sexuality from your perspective of living with IBD?
Can you explain more about it?
Can you tell me about occasions when you have discussed this with health professionals?
Do you think such conversations should take place at the time of clinical visits?
How would you like such conversations to take place?

Face-to-face interviews took place in a distraction free location (Creswell, 2018) away from clinical areas for those recruited from the NHS. The guide was oriented to specific lived experiences, and mainly used to help the researcher to keep the focus on the topic and redirect the participant, if necessary, to the topic of the study. To ensure consistency in the data collection, the interview guide used in face–to-face (or telephone) interviews was also used for GFs. However, the GFs had open ended questions, allowing the participants to talk about experiences that were important to them, in a narrative manner.

A few introductory demographic questions (*How old are you? What age were you diagnosed with BD? Are you partnered or single?)* were followed by an invitation to share their experiences on how IBD had affected the main aspects of their life. This was a good starting place for the researcher to assess the severity of the symptoms for each participant, and to make a swift move to more sensitive questions. The next step was asking participants '*what do they understand by the intimacy and sexuality',* as this was seen important in ensuring that participants had a clear understanding of the terms used in the Participant

Information Leaflet (Appendix 1.14). The next step was followed by asking the main question of the study*: 'what was your experience of intimacy and sexuality from the perspective of living with IBD?'*

Context elicitation was prompted by questions asking participants to detail and clarify aspects of their experiences (Giorgi, 1989), such as '*Could you tell me more about it?'* or *'Could you think of an example when that happened?'*. The interviews were done in a relaxed, informal way, constantly keeping within the boundaries of the study question, being respectful and with few questions, and avoiding giving advice (Creswell, 2018). The researcher avoided interruptions and allowed silence breaks, which were seen as a way for participants to gather their thoughts, self- reflect and verbalise their experiences (Dixon, 2015) as well as allow them to decide on the level of disclosure desired. Responses and attitudes to experience were different for each participant (Bevan, 2014), lived experiences are not tangible, therefore expressing feelings was difficult for some, or they failed to articulate the experiences lived, as van Manen (1990, 2016) argued that for those exposed recently to an experience, therefore 'less experienced'', would encounter difficulties in finding an adequate language that represents the best description of what was lived.

All the techniques described above, specific more to narrative interviews, were engaged in an attempt to let each individual to bring up their own version of events. At the end of the interview, a summary of the discussion was recounted to the participant to assess if there were any misunderstandings, and to prompt them to recollect if they had anything more to add. In two cases, where the participants were slightly distressed by recounting painful experiences, it was necessary to continue the discussion further, outside the research context, and offer some support in agreement with researcher's professional stance.

Nonetheless, during the interviews if anyone showed signs of distress, the researcher asked if a break was needed, or if they wished to continue the interview.

On reaching 35 participants recruited, the researcher discussed with the supervisory team the possibility for commencing preliminary data analysis, and to continue further recruitment where certain aspects arising from the data analysed needed further investigation were primarily discussed with the participants. Five more interviews were conducted where different aspects identified during analysis were discussed in more detail with participants. The additional questions asked in the last interviews as a result of the preliminary analysis findings were: '*Could you explain more why you avoid discussing sexuality issues with your partner?'* and '*Could you explain more why you would not ask HCPs about issues related to sexuality?*'

Telephone interviews were chosen by most participants and enabled participation from those who would have otherwise been excluded due to geographical or travel restrictions (Sweet, 2002). These took place mostly after work hours and on weekends, in response to participants' availability. No evidence was found to suggest the telephone interviews produce lower quality data in sensitive research (Novick, 2008). It was notable that several participants had made arrangements to be away from their partners during the interviews, which was suggestive of how they have dealt with the sensitive nature of it. This had an impact on the sound quality which was less adequate for a couple of the interviews, especially for a particular participant who decided to do this from a parking lot, where reception was not ideal.

Interviewing on sensitive topics is highly reliant on the researcher's skills, and is recommended to be tackled by researchers with experience in the field (Hayter, 2010). The researcher had worked for a number of years as a specialist pelvic floor nurse and felt comfortable to initiate conversations on sensitive topics, and also to create a level of comfort with the participants that was conducive to discussing sensitive topics. However, during the interviews, the researcher was more of a member of an audience, engaged in a dialogue with the participants. Before each interview, either face-to-face or telephone, the equipment was fully checked to avoid data loss through equipment malfunction. At the end of each recording, the quality of the audio files was verified, files were named and stored securely as per study protocols.

4.4.3. Benefits of interviews from participant perspective

Some argue that participants can benefit from taking part in sensitive research, and interviews could have a cathartic effect on them (Crowther and Lloyd-Williams, 2012). Participants in this study made comments supporting these claims, several concluded the interviews stating they felt relieved to be able to share deep, personal feelings:' *The things I'm saying to you now I haven't said to anyone before, you see, what I mean is that it took a study to say 'Here is a forum to talk about these things.* '(Daniel, 31, M, CD)

Crowther and Lloyd-William (2012) have also reported interviewing being received as a positive experience in spite of an element of distress, as participants accepted the nature of the emotions that could surface during a sensitive interview.

Clear patient information had given potential participants sufficient information to ensure they were aware of the nature of the interviews, and the researcher felt that there was a real need for participants to talk about personal experiences of sexuality in the context of IBD, even if this was facilitated through taking part in a study with this topic. Furthermore, some argued that silent stories struggle to be told as they are seen as ‘*subordinated standpoints’*, but as they start to be voiced they enter the world of stories that become accepted in society, and have potential of becoming dominant stories (Plummer, 2019).

4.4.4. WhatsApp instant messaging

A second digital data collection method chosen for the study, aimed at younger participants, was instant messaging which is embedded in their daily life. Turkle (2011) found that millennials and teenagers were more likely to communicate their emotions through texting. Labelled as a synchronous computer mediated communication form, instant texts exchange was previously used by researchers for data collection on sensitive research topics (East *et al.*, 2008). At the time of submitting the study protocol for ethics approval this method was intended to aid recruitment and substitute the face-to-face interviewing, and an interview protocol was developed for WhatsApp (see Appendix 1.16). The advantages identified to the method were maintaining the individual’s privacy, allowing the chat to take place at times convenient for the participants, and to maintain visual anonymity. A separate phone was allocated for the purpose of these chats to maintain the privacy of the researcher by not using her own phone.

However, no participants chose to participate via WhatsApp. A possible explanation could be that WhatsApp would have revealed the phone number of the participants, removing their anonymity. The ethics committee suggested ways to fully anonymise the participants’ data (phone number/name) that involved a rather complex method for this and would have still occurred after first contact with researcher. The process could have been rather cumbersome for the potential participants and was not favoured by researcher. Some have reported that is not uncommon for researchers to alter the design of their studies in response to regulatory bodies (such as an ethics committee), with a possible threat to the academic value of the project (Mustanski, 2011), which was the case in this instance.

4.4.5. Field notes

Field notes are commonly used in ethnographic research, and they collect the researcher's observations in the field as well as emotions or reactions to the topic of interest (Friedelmann, 2011). The content of field notes is not usually visible in the findings reported, and some have argued that these are too subjective (Montgomery and Bailey, 2007).

In sensitive research field notes could support the researcher in dealing emotionally with the topic (Malacrida, 2007). In this study the researcher found field notes a good tool for dealing with emotional interviews through reflection on the interview, as well as supporting in data analysis, where data were compared with field notes to ensure an accurate interpretation of the event, as well as reminders on what was noticeable at the time of interview and warranted deeper questioning.

Field notes were taken during telephone interviews only, as the researcher did not want to take notes in front of participants during face-to-face interviews. Outcomes of interviews could be influenced by how questions are asked (Bold, 2013), as well as how well the researcher engages with participants through active listening. Face-to-face interviews were followed by researcher reflections on the interview, and notes on what was found at odds with what participants said or, what questions need to be more investigated in following interviews. GFs responses also triggered the researcher’s reflection, and a diary of such **notes** (see Box above) was kept throughout the duration of the study.

23/10/18

Today I received the first anonymous email as a response to my study, from a young woman who I will call Angela. First reaction was excitement, finally someone had the courage to open up on such a delicate and personal issue. What followed had confirmed my assumptions when I was finalising the research question. But I was not prepared to read such a short and yet brutally honest account of how a body engulfed by illness can change a life.... It is sad, it is too common for what the condition does to a person. It is difficult to think of a young woman who should have endless opportunities ahead, the way Angela makes me think. And she does it in such few words, almost detaching herself from her body and resenting it for all the shame it brought her. I feel powerless and unable to comfort someone who suffers. This goes totally against my nature and everything I’ve been doing for most of my life as a nurse. I realised how unprepared I am to let such personal and complex issues be laid out in front of me without the option of responding, even just by making a simple gesture to support the one who trusted me with some of their most hidden secrets.

This allowed a return to the data during the analysis process and interpret the data using the whole perspective, at the time and after. First reflection was dated 23/10/2018 and was a result of first set of data collected. As it is obvious from this example, the researcher's lack of experience in identifying the phenomenological aspects for reflection, and writing them down alongside with the refection on her own feelings.

4.5. Recording and transcribing of data

Recording of the interviews was done on two different devices (laptop and digital recorder) to avoid data loss through malfunction. Both devices were encrypted and data were saved in line with data protection provisions. Once it was established that the interview on the laptop was of good quality, this was saved in an encrypted research audio file, on the One drive as per local protocols and procedures. The recordings on the Dictaphone were subsequently deleted.

All interviews were audio recorded and transcribed verbatim by the researcher, as there are two different approaches to this, to be done by the researcher or by professional services. The time spent on transcription was considered invaluable by the researcher, as it allowed secondary reflection on the interviews and immersing in data. No transcript was returned to participants for comments or verification, as there is little evidence that transcripts checked by participants changes the research results (Thomas, 2017).

4.6. Data management

Privacy and anonymity were maintained throughout the duration of the study; all the participants had a pseudonym allocated. Due to the sensitive nature of the study (Lee and Renzetti, 1990) maintaining anonymity of participants was considered important in enhancing participation. None of the personal information about the participants was kept once the interview took place. Those who emailed the researcher had their emails deleted after the interviews, as per study protocol. The participants from the clinical setting had their name and date of birth kept on a separate enrolment sheet, which is kept safe in a locked cabinet, for the purposes of audit and quality assurance, as per local policies. All participants were informed about the nature of their data held in relation to the participation to the study, their rights, and length of time the data will be kept, in accordance with the General Data Protection Regulation (GDPR) (2016) provisions and Data Protection Act (2018). A data protection impact assessment was undertaken with the help of the IT department prior to using GF, for security assessment of using a third party data collection tool.

4.7. Ethical approvals and considerations

Principles of research ethics are defined in universally accepted documents such as Declaration of Helsinki (1964, 2013), The Nuremberg Code (2017), and these have at the core the tenets of fundamental human rights such as dignity, autonomy, justice and beneficence. As in all studies involving human participants, all the research activities were preceded by ethical review. Ethical approvals were obtained from University ethics committees (University of Oxford, REC ref: R60900/RE001, NRES) as well as further approvals for National Health Services (NHS) based research from Health Research Authority (HRA). Approvals can be found in the Appendix (1.7, 1.8, and 1.12).

4.7.1. Risks related to participating

Remembering certain episodes could potentially cause distress during oral interviews, or when writing responses on Google Forms. The researcher took measures to minimise the potential distress. Though, some argue that talking about their experiences can be therapeutic for participants. When participants displayed signs of distress, the researcher checked if they wished to continue the interview, or to pause. All effort was made to include all the potential participants in the study, although the study is based on narrative English. The justification for this resides in the fact that this research concentrates on the experience of illness, if the participant is unable to express this in English, their views will not be captured accurately in the study. As a result, participation was limited only to those who were communicating with confidence in English.

A particular ethical concern was related to the nature of consent, as it is debatable the nature of an informed consent when the researcher is unsure as to what exactly will be discussed during such interviews (Ziebland *et al.*, 2013). The participant information sheet was clear on the sensitive nature of the study. Before any interviews were initiated, participants were told that they are in control of the level of disclosure, therefore the researcher will not ask about any issues other than what participants raised during the interviews.

Other aspects pertaining to the risks associated with participation in the study were related to potential identification of domestic abuse, or less than adequate care provided by healthcare professionals. These risks were mitigated by provision of helplines for participants at the end of Participant information leaflets, and agreement with the NHS Trust where recruitment took place that any complaints about the care provided would be passed onto the department for investigation. No such issues were identified during the study period.

In this project, some difficulties were encountered as one University ethics committee suggested the need to seek parental consent for those under the age of 18. The argument for waiving the need for parental consent for those aged 16 /17 years old was that parental consent would introduce barriers to research participation, infringe the concept of justice, and the risk of generating findings that are not include the experiences of adolescents (Fourie, Aveyard and Jackson, 2019). Arguing the researcher’s position led to delays in gaining Faculty ethics approval, however, the researcher recognised these discussions were beneficial for the inclusion of desired study participants and value of the study, and as experience for future ethics applications.

4.7.2. Risk to researcher

Qualitative research can make it difficult for the researcher to remain detached from the study. The researcher was aware of the potential for ‘*vicarious traumatisation’* attached to the project, as engaging with participants who were traumatised by some of their experiences, or had their care needs unmet could lead the researcher to develop feelings of anger and/or grief as a result (Dunkley and Whelan, 2006). Debriefing was included in a plan of action for risk prevention to researcher (required to be submitted with an application to university ethics committee). There was no need for debriefing during the conduct of the study, however, a supervision meeting was scheduled immediately after the first face-to-face interviews where emotional aspects related to the interviewing were addressed.

4.8. Recruitment difficulties for studies on sensitive topics

As stated earlier in the chapter, the thesis is based on two separate ethics applications, due to difficulties in recruiting young women alone, and the researcher’s transfer to a King’s College London. The initial study aimed to exclusively recruit young women aged 16 to 24 as these were the least represented in all the evidence to date (Chapter 2), therefore research specific to this age group would have produced valuable information for healthcare professions. However, difficulties in recruitment in the clinical environment finally led to extending the study to all genders and ages, running in parallel with the initial one. Both studies posed difficulties with recruitment, but of a different nature.

Recruiting participants to studies on sensitive topics was known to be difficult. In this case, most of the recruitment was done via voluntary responses to an advertisement on Crohn’s and Colitis UK website. Although all participants contacted the researcher and indicated their interest to participate, seven of them decided later on to not take part, and did not respond to the researcher’s invite to suggest suitable times/dates for a subsequent phone call to discuss the study in detail.

Nonetheless, the most problematic area was found to be recruitment to the first study, within the clinical environment. The clinicians that approached potential participants were involved in the transitions clinics (transitioning from paediatric care to adult care) and were clinicians from adult care team. This could have been a barrier, as at the transition stage there could be a period of adult care team gaining a young patient’s trust. Furthermore, in most cases the parents were accompanying those over the age of 16 to their clinical appointments, and numerous times parental gatekeeping was found to be a critical impediment. In spite of patient information being introduced by the care team and potential participants agreeing to discuss the study, the researcher felt that conversation on the potential to participate in the presence of parents was counterproductive, with only 5 participants who consented from over 80 approached. The discussion in such circumstances was vague and brief, as the researcher did not want to infringe adolescents' privacy, since there is evidence that interest in research of this nature could suggest that participants admit to being sexually active (Flores *et al.*, 2017).

The decision to increase chances to recruitment and extend the NHS recruitment to all aged over 16 (initially limited to16 to 24 years old) was halted with the Corona virus pandemic that occurred in March 2020. This translated into pausing all non Covid-19 patient recruitment, as well as pausing all ethical applications if not Covid-19 studies. In the absence of any possibility to resume normal activities in NHS anytime earlier than 3-6 months from March, the whole project had to be reviewed. The second study enabled continuing the recruitment during the pandemic, as it allowed telephone interviews. Fortunately, the need for shielding of those with IBD during pandemic led to a spike in their interest to participate in research, which translated into completing the data collection by the end of July 2020. The ethical approvals in place were for recruitment end date as 31st of December 2020.

4.9. Exploring researchers' preconceptions- positioning of self

It is no longer accepted that researchers are detached from the research processes and writing, and this is also supported by van Manen (1990, 2016). Reflexivity is being self-aware of ethical and political stance of the researcher, and becoming part of their own enquiry (Pelias, 2018). Today it is acknowledged that a qualitative text is not separated from researcher, or from its audience (Creswell and Poth, 2018). The researcher's interest in this topic stemmed in her clinical experience as a pelvic floor specialist, and issues surrounding offering reliable, evidence-based information for patients undergoing surgical treatment for pelvic floor disorders were the most influential. Exposure to the patient's experiences and questions pertaining to sexual well-being also contributed to developing an interest on sensitive topics, as it was noticed in clinical practice not many healthcare professionals were inclined to broach these discussions. Patient experiences of living with chronic conditions was one of the features that dominated the researcher's entire career, both working in her native country as a physiotherapist for 12 years, then returning to nursing when immigrating to England. Lately, work with IBD patients had exposed a whole new array of issues that warranted exploration, but it was difficult to decide what aspects of living with a chronic condition would need more consideration. This had driven the published literature review incorporated in this thesis, as means to developing a research question that was most in need of some evidence and knowledge base. Researching a topic that raised genuine interest for the researcher was found helpful in maintaining the orientation to the topic throughout the duration of the study. In the process of bringing self-awareness the researcher examined own beliefs, prejudices and related those to the participants' voices in the social and historic context.

Furthermore, aligned with van Manen's position on exploring existing preconceptions, the researcher had reflected on her previous knowledge on the topic, as well as biases and assumptions throughout the duration of the study. For instance, the initial assumptions that including only young women in the study, highlighted how assumptions brought from clinical experience into research could influence decisions. The researcher's clinical experience of seeing young women for pelvic floor disorders fuelled the confidence that this would be possible. However, upon reflection, after recruitment failed to meet the researcher's expectations, it was acknowledged that the young women seen in clinics were older than 24 years, therefore the upper age limit set for inclusion was not thoroughly considered. Another aspect based on assumptions and pre-existing experience that was not fully explored at the time of design, was the fact that responding to sensitive questions for clinical reasons is very different from volunteering to disclose such information for research purposes.

Acknowledging some existing biases and preconceptions, it was also evident for the researcher that it would be impossible to be fully free from these. Accepting what can be seen in our society as potentially deviant behaviour, and being comfortable discussing taboo topics associated with IBD and sex, the researcher became aware of the need to create an interview environment free of judgement. Previous experience and knowledge in how illness affects sexual function enabled the researcher to not appear surprised by any information disclosed by participants, and also, to avoid limiting the level of disclosure. However, the researcher had to recognise her own presumptions, 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. Further details on researcher reflexivity are given in the Conclusion chapter (Chapter 9).

4.10. Van Manen's framework for data analysis

The six-step methodological guide (van Manen, 1990; Errasti-Ibarrondo *et al.*, 2018) was described as following:

1. Turning to the nature of experience
    - Orienting to the phenomenon (identify the experience of interest, evaluate the existing evidence)
    - Formulating the phenomenological question
    - Explicating assumption and pre -understandings
2. Investigating experience as we live it
    - The nature of data - given or granted
    - Using personal experiences, a starting point (researcher to write own experiences and familiarise with the process)
    - Obtaining experiential descriptions from others (data collection via interviews, personal narratives, dialogue etc.)
    - Art as a source of lived experience
    - Consulting phenomenological literature (reading philosophical texts)
3. Hermeneutic phenomenological reflection
    - Conducting thematic analysis
    - Isolating thematic statements
    - Lifeworld existentials as guides to reflection
    - Determining incidental and essential themes
4. Hermeneutic phenomenological writing
    - Attending to the language

    - Silence (the hidden message behind silence, what is not talked about, or physical silence during interview and its meanings)
    - Varying the examples (observe outliers, explore, interpret various qualities of the experience)
    - To write and rewrite (go back to the parts, and reinterpret in the context of the whole)
5. Maintaining a strong and oriented relation
    - Maintain the text orientation towards the profession of researcher (text to be accessible to a professional group)
    - Seek to produce valuable body of knowledge for the profession of researcher
6. Balancing the research context by considering parts and whole
    - Structure the phenomenological text (finalise the phenomenological text in a manner that is describing the interpretation of the intimacy and sexuality with all the variables and qualities of what make the essence of the experience).

The analysis of the data set in this thesis was not seeking for the truth, but aimed to create an interpretation of it. van Manen's framework was suitable to interpret the findings in a way that would produce a valuable text for healthcare professionals, but a text that is also recognisable to participants as depicting experiences in forms that they have experienced.

Most of the published phenomenological studies in nursing and healthcare sciences have used adapted frameworks or more than one framework in order to make sense of their data. However, only a few have given details of what were the stages in their analysis, which explains some of the criticism attributed to the use of phenomenology in nursing. van Manen stated that there is no recipe for how to do analysis, and is a '*learn as you go'* process for most researchers. Although it is imperative to the study that researchers are able to explain step by step the process, especially when thematic analysis is used, as this will reveal the structure of the analysis. It may be difficult to articulate the interpretations that researchers give to their data, however, a detailed account of how they have given certain interpretations to their data should be given and explained.

The analysis process entailed familiarising 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 lifeworld existential was of particular importance as it moved the analysis from description to interpretation. The themes generated at this stage were organised under each existential domain and were the essence of the phenomenological text presenting the interpretation of the findings. In the first stage thematic analysis was conducted. The theme analysis refers to identifying themes found in the data and the process of defining the essences of the experiences with the variations found in each theme (van Manen, 1990, 2016).

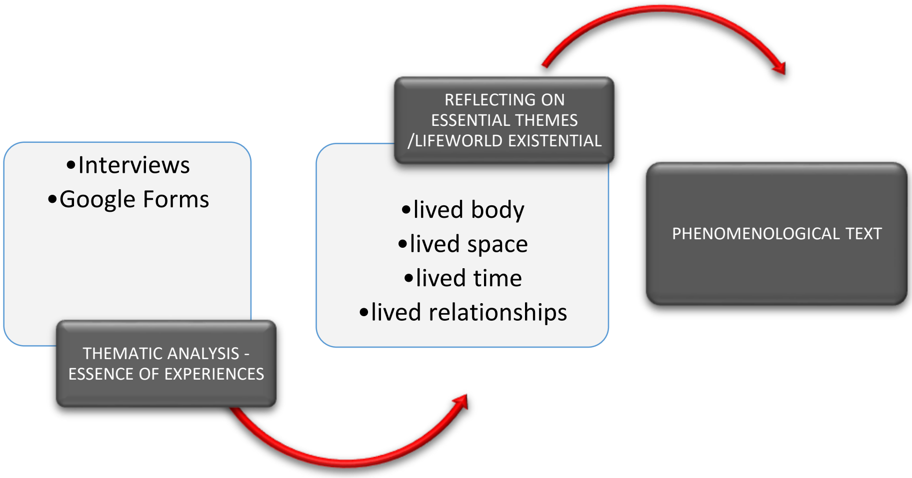

Figure 11**.** Process of data analysis

The main requirement for interpreting narratives phenomenologically, is to familiarise with the data. The researcher transcribed the interviews verbatim, and this provided an opportunity to get accustomed to data from each interview (Braun and Clarke, 2006). Data were read and reread, checking for transcription accuracy. Once all the data were transcribed, each file was uploaded in to the NVivo 12 software, which provided the researcher with better options for organising, storing and coding the data. Each transcript was read individually and coded, highlighting the essential phrases, but only those reflecting the phenomena of interest. The selective approach was used as a way of maintaining focus on the experience of interest and avoid diverting. NVivo provided a good platform to visualise the statements and codes on the same page, therefore the coded text could be moved around to the more relevant codes when the researcher felt that these were not fully representative of the code initially allocated. This function was found to be time saving compared to manual highlighting of text and organising clippings with selected text in codes, as was done for the literature review presented in Chapter 2.

Within this framework there were three different options for coding: *the wholistic approach*, where the text was viewed as a whole and the researcher extracted the main essence of that text, *the selective approach,* where the text was read and reread in order to highlight the statements that stand out as revealing the essence of the experience, and *the detailed approach*, where each sentence was analysed in search for meanings of the experience (van Manen, 2016). Although each text was read line by line, the researcher decided that a selective approach of to the coding was suitable for analysis, as significant parts of the text were not directly related to the topic of interest, but set sexuality in context of their condition.

The detailed approach was not appropriate as many sentences from the transcripts were not necessarily related to the phenomena of interest and would have not added any value to the analysis. Participants also talked about general experiences of living with IBD, therefore a careful selection of the experiences pertaining to intimacy and sexuality was necessary. The researcher had to ask the question: *Is this experience specific to intimacy and sexuality?* every time a less obvious code was highlighted. This helped keep the focus on the researched phenomena. It was less complex to maintain the focus on the experiences of discussing sexuality with healthcare professionals. An example of highlighting the phrases that answered the research questions and reflected the phenomena is found in the Appendix 1.4.

At the end of coding all the transcripts, the researcher had the initial codes across the whole set of data. A total number of codes identified across the full data set was 98, and across each file the number of codes varied: 3-6 codes on a Google Form file, and 8-15 codes on interview data. A copy of the codebook can be found in Appendix 1.5. Once the researcher was satisfied that the whole dataset was fully coded, she moved to the next level of analysis. This was checking the text against the codes to confirm they fitted each code, then collating some of the codes with similar meaning into one which was most reflective of the experience. The researcher has kept, where possible, the codes as participants' own words, in an attempt to retain the accuracy of description in the analysis of the experience. All the codes that shared same meaning were collapsed into clusters of thematic statements or meaning units (Creswell and Poth, 2018), which consisted of threads around which the descriptions were formulated. These meaning units were indicative of the commonalities found across the dataset, providing the full extent of participants' experiences and opinions. At this point all the meaning units were checked again against the data set to confirm that each excerpt was reflecting the diversity of each unit. It is important to mention that for each unit that contained statements describing a certain structure of experience, had also included statements that were contradicting the main statements, as being identified to be outliers. For example, in the initial summary of the codes under meaning for '*I never discussed sex with my HCP'*, some excerpts indicating the opposite were also included, under' *I have discussed it'*. This was important, as van Manen had argued that a good analysis will surface statements that go against the majority, but also, it gives dimension to the experience, as a variable of the experience. An example of how codes were collapsed in meaning units and sub-themes is presented in the figure 12, which shows how the main theme 'Otherness of the sick body' was developed from the two sub-themes 'Being unattractive' and 'Unrecognised body'.

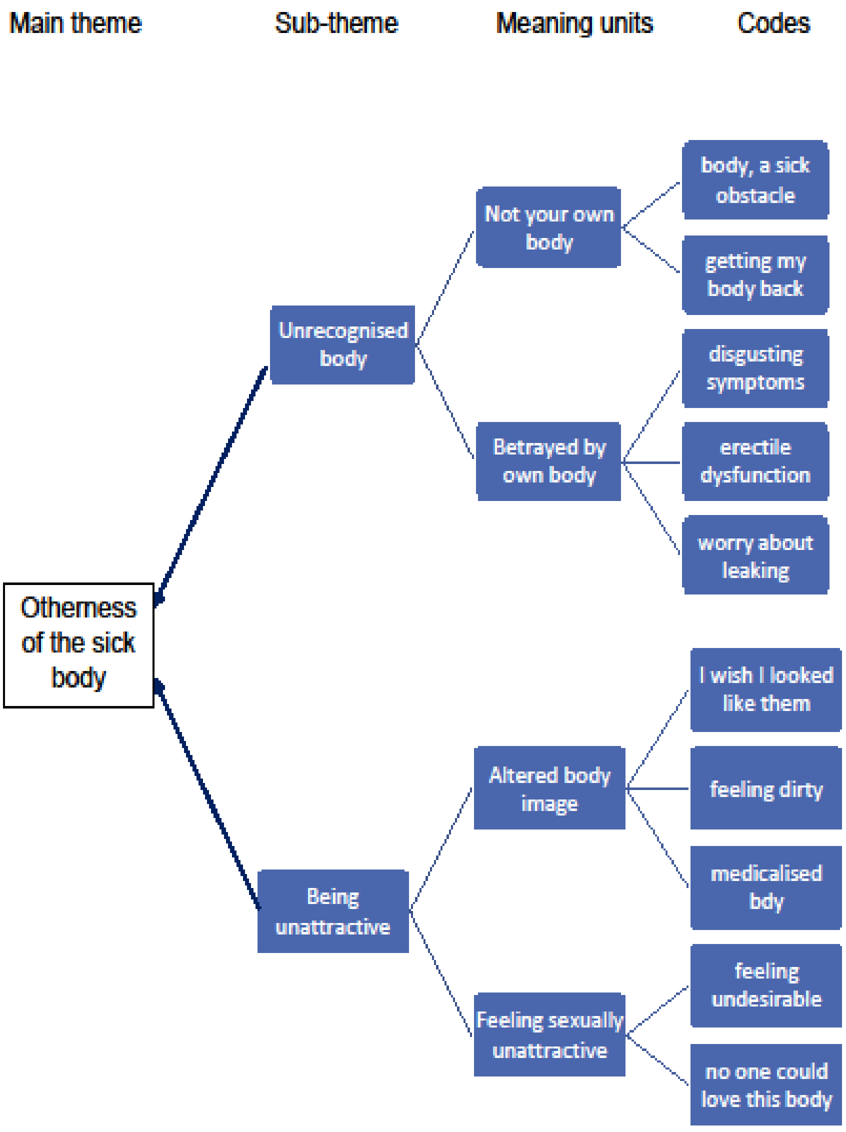

Figure 12. Main theme development from codes.

In visualising and organising the meaning units was taken a different approach to analysis, as researcher found the software was limited in giving flexibility and a visual organisation of the domains was needed to support sub-theme naming. At this point the units were copied in Word, printed and cropped in strips to be easily moved around for further organisation in sub-themes (textural description) and themes (structural description).

Creswell and Poth (2018) coding template for a phenomenological study was also found beneficial and used by researcher. These were the detailed steps:

- Identify significant statements (codes)
- Meaning units (collapse/group codes)
- Textural descriptions (sub themes)
- Structural description (themes)
- Essence of the experience (overarching theme)

This guided the researcher in progressing with analysis, and following an acceptable structure for phenomenological analysis. A table with codes identified in an interview fragment, and the sub -themes that were later developed from these codes is shown in table 8.

Table 8. In-text coding and sub-theme allocation to text.

Martha's transcript (fragment)	**Codes identified**	**Sub- themes containing these codes**
And so here I am, while this is happening, and it happens so slowly it kind of creeps upon you and you've normalised it for such a long time, and so you're not really looking at it as something that's happening like a specific thing that's happening to you, but I can see now looking back how much it was affecting me. So, I lose my virginity to this guy, and so then he's like, well you can stay round my house. I don't want to stay round his house because I've got constipation and toilet problems and I'm having all these problems and they're embarrassing, I don't know how to talk about them. And so I wouldn't go to his house and I wouldn't have a physical relationship with him. That was what I would see or what people would tell me is normal. I've almost avoided, I've started to have intimacy with him, sex with him and then I'm immediately trying to avoid it. And very shortly after that, of course, you know a young guy, well not	Embarrassing symptoms Embarrassed to discuss issues with partners Distancing from love Break ups	Betrayed by own body Silent relationships

of course, but this guy he decided to just end the relationship. I suppose why I'm mentioning that is that IBD immediately has affected my outlook to sex, my outlook to relationships. And I think when you're diagnosed with IBD, you know, I end up in hospital emergency, going through emergency and being diagnosed being so young, immediately affected my self-esteem my outlook in life, much more than I ever thought it had, now when I look back on it. I thought I was coping really well but I think over the period following my diagnosis, I stopped going out, I had to drop out of university… for a year I couldn't socialise as much as I could because the symptoms were so bad, so extreme. So I wasn't going out and meeting people, I wasn't having the same social lives and experiences as other people, ability to make relationships with other people, I didn't feel like I was as good as other people I didn't think that people should be with me because I got sick all the time I was boring. You know why would anybody want to be with me? And I managed to go back to university and I met a guy, and we had a relationship, but I think IBD it's what made me be I think, and I don't know if other people said, but I'm quite impulsive about relationships and sex, because if I think about it, and think about that in any detail, I [stuttering] find it so frightening! So what I think I've done over the years is I meet someone they're interested in me, and I just go for it.	IBD destroys your sex life Not same with peers in adolescence Missing out on love No one could love me IBD affects your relationships Low self esteem	Reticent disclosure Broken down relationships Striving for normalcy

Meaning units were grouped in sub-themes, which were refined and classified into main themes by organising them in a structure that demonstrated the meaning within the theme (Braun and Clarke, 2006). Some of the main themes names were 'borrowed' from the meaning units, as they covered the essence of each unit. The text was verified again, to ensure that was reflecting the meaning given to each theme, and no meanings were missed. According to van Manen (2016) phenomenological themes are *structures of experience*, therefore, each theme could be considered as a conceptual structure for the specific experience. However, lived experiences cannot be reduced to a statement nor to a conceptual formulation (van Manen, 2016).

Once the main themes were defined, the next step was finding the essence of the experience. In order to determine the essence of the experience, or the relevance to the overarching theme, researcher assessed if the themes were *essential* or *incidental*, as 'In *determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is'* (van Manen, 2016, pg.153). Each named theme was tested at this stage by exploring how the experience would be defined if was removed from the main structure under the overarching theme, in an attempt to identify if the theme was indeed essential in maintaining the essence of the experience, or not. Researcher was satisfied that all main themes were indeed main constructs of the essence of the experiences of interest in the study. The full details of each theme definition that were found to be the structures of experiences, and detailed representations of all the subthemes are discussed in the Chapters 6, 7 and 8.

After the descriptive themes were formulated, the interpretative stage was the next step in giving an interpretation of what is the essence of the phenomena of interest. For this stage the researcher has interpreted the themes found in the context of the four existentials- lived body, lived space, lived time and lived experiences. Using the hermeneutic circle, the cycles of interpretation were at the basis of hermeneutic writing (van Manen, 1990) and entailed developing a hermeneutic text which is the Results chapters (Chapters 6,7 and 8). Additional details related to the analysis process are found in the Conclusion chapter (Chapter 9), as result of reflecting on the methodology used and researcher's reflexivity account.

A brief summary of the steps undertaken by researcher to demonstrate adherence to the methodology is presented below (Table 9).

Table 9. Adherence to van Manen's framework during the study

Framework steps	Procedures/activities
Turn to the nature of experience	• 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	• 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	• 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 tine and lived space) and organised identified themes around each domain • Name the overarching theme-essence of the experience • Establish incidental and essential themes
Write the phenomenological text	• 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 • Maintain the balance between the researchers' voice and that of participants • Orient the interpretation to the professional audience • Write a rich text as a resource of professional knowledge (published results paper)

4.11. Artistic and linguistic dimensions of IBD

4.11.1. Artistic dimensions of illness

Participants in qualitative research use linguistic help through metaphors, similes and repetition, to describe experiences that researchers could have not probably grasped by use of day-to-day language. In this way, participants in this study tried to make themselves better understood, and depict the seriousness of the experiences in a way that was equally dramatic to the audience as it was to them. Linguistic aids are commonly used in cases where the language fails to adequately capture an experience, and are more common in artistic works, although they are used in everyday language quite often.

The use of art and language in research is known to enhance understanding of human experience and as a result, medical humanities are an interdisciplinary field of medicine that uses art amongst other disciplines to train medical practitioners. Therefore, it is natural to make use of language in an artistic form in an interpretive phenomenological study, as Heidegger (1971) believed that truth is illustrated through literary art. Drawing parallels between the literary works on the sick body and the findings from this thesis revealed other ways of reality of being in the world.

The complexity of experiencing an ill body was also subject to literary works, Virginia Woolf's book **On being ill** took a closer look at the body affected by influenza and lack of interest from the outside world of how an ill body is experienced (1930): '*The creature within can only gaze through the pane-smudged or rosy; it cannot separate off from the body. But of all this daily drama of body there is no record. Those great wars which the body wages with the mind a slave to it, in the solitude of the bedroom against the assault of fever or the* *oncome of melancholia, are neglected. Nor is the reason to seek'* (pg.29). Illness made the perception of the body real, as long as the body performed well, it was never perceived. Illness disturbed the sense of wellness of the body, and '*body reflects on itself as body'* when the unity between body and lived world is broken (van Manen, 1998). *'But bodies are not simply associated with or dissociated from'* (Frank, 1998, pg.33). What once was a familiar body, in illness becomes an unfamiliar body (Corbin, 2003). The unfamiliar body acquired in chronic illness disrupts its holders' identity, as it is forced to re-examine the expectation for the future (Bury, 1982). Therefore, finding a new identity becomes a journey. Sontag (1978, pg.45) wrote: *'Illness is the night –side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of the other place*.' The journey for those living with IBD moves to the onerous citizenship and *'serious illness is a loss of the destination and map that had previously guided the ill person's life: I'll have to learn to think differently'* (Frank, 1995). It seemed obvious that the loss of map led to *body*'s loss of identity, the new 'citizenship' needed a new identity, and the body needed a voice to find this new acquired identity. In this new journey, stories of the body were told, participants didn't simply describe the sick body, they also gave new shapes and directions to the body, and bodies created the person in the stories. (Frank, 1995).

By reading literary texts on illness, the researcher gained a deeper understanding of aspects important to participants, and also, being exposed to evocative writings of an experience, it supported the process of writing involved, as most of the analysis process of this thesis was based on writing and rewriting.

4.11.2. Idioms, repetition and figures of speech

Metaphors are used in everyday life in describing something unfamiliar and abstract with another concrete term that is more familiar (Lakoff and Johnson, 1980). Figures of speech, such as metaphors have been used in healthcare for decades, as they hold a certain pervasive power to shape one's experience (Stilwell *et al.*, 2020). These metaphors create categories by comparing past experiences to new ones, and can provoke novel ways of experiencing the world. Similes are a different type of metaphors that use *like* instead of a direct comparison. Analogies are more complex metaphors that make stronger statements in order to make a point. Examples of figures of speech used by participants are described in the Chapters 6, 7 and 8.

CHAPTER 5. Sexuality as lived incompleteness. Study results

5.1. Overview of the chapter

In this chapter are presented the findings from the study's 43 participants who answered the research question: what is the experience of intimacy and sexuality in the context of living with IBD?

The four main themes under the overarching theme **Sexuality as lived incompleteness** generated following van Manen's existential analysis framework on the four domains: corporeality, relationality, temporality and spatiality (otherwise known as lived body, lived relationships, lived time, and lived space). These four themes contained the main elements of the experience and were: **Otherness of the sick body** (theme on corporeality), **Interrupted connectedness** (relationality), **Missing out on life fullness** (spatiality), and **Fragmented openness** (temporality). The findings are explored under each main theme, which was defined and supported by relevant excerpts from interviews. Direct quotes were used, with participants' pseudonyms, diagnosis, age and sex.

5.2. Study results

At the beginning of each interview and in the Google Forms, all 43 participants (see Table 10) 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).

Most of descriptions came in narrative form, with analogies, and chronologies that were used to point out significant events pertaining to the experience (Bevan, 2014).

The face-to-face interviews had a duration between 15 to 65 minutes, younger participants being the ones who had been interviewed for a shorter period, in spite of researcher 's attempts to elicit more information. Data collected during telephone interviews proved to be the richest, with the longest duration for the interviews, from 35 minutes to over an hour.

Table 10. Study population

	Pseudonym	**Gender**	**Age**	**Diagnosis**	**Method**	**Surgery/ VCD***
1	*Adele*	F	30s	CD	GF	
2	*Carina*	F	40s	CD	GF	
3	*Ana*	F	40	CD	I	
4	*Daniel*	M	31	UC	I	surgery
5	*Denise*	F	36	CD	GF	
6	*Emily*	F	42	CD	I	
7	*Emma*	F	36	CD	I	
8	*Frank*	M	56	CD	I	surgery
9	*George*	M	27	CD	I	surgery
10	*Julia*	F	20s	CD	GF	
11	*Kate*	F	47	UC	GF	
12	*Laura*	F	30s	CD	GF	

13	*Martha*	F	38	CD	I	VCD
14	*Michael*	M	31	CD	I	surgery
15	*Maria*	F	30s	UC	GF	
16	*Angela*	F	20	CD	GF	
17	*Bea*	F	22	UC	GF	
18	*Corine*	F	23	UC	GF	
19	*Delia*	F	20	CD	GF	surgery
20	*Elena*	F	19	UC	GF	
21	*Florence*	F	24	CD	GF	surgery
22	*Hannah*	F	17	CD	GF	
23	*Gemma*	F	19	UC	GF	
24	*Klara*	F	19	CD	I	
25	*Nora*	F	18	CD	I	
26	*Melania*	F	17	UC	I	surgery
27	*Jasmine*	F	17	CD	I	
28	*Adrian*	M	26	UC	I	surgery
29	*Sara*	F	46	CD	I	surgery/VCD
30	*Orla*	F	41	CD	I	
31	*Catriona*	F	43	CD	I	surgery/VCD
32	*James*	M	42	CD	I	
33	*Lisa*	F	47	CD	I	
34	*Anton*	M	30s	CD	GF	surgery
35	*Zara*	F	20s	UC	GF	
36	*Ben*	M	64	UC	I	
37	*Amanda*	F	40s	CD	GF	

38	*Daria*	F	40s	?	GF	
39	*Sandra*	F	60	CD	I	
40	*Richard*	M	62	CD	I	
41	*Mark**	M	26	CD	I	surgery
42	*Sonia*	F	47	UC	GF	
43	*David*	M	40	UC	GF	

Key: *VCD- vulvar CD, I-Interview, GF- Google Form response, surgery- had surgery due to IBD

The themes and subthemes are presented in table 11, indicating the essence of the experience of expressing intimacy and sexuality 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 (van Manen, 1990), and were interpreted from explanations of the issues as described by participants. Each subtheme is summarised below with the help of most poignant excerpts from the participants’ interviews.

Table 11. Themes and subthemes

Sexuality as lived incompleteness

Otherness of the sick body

- Unrecognised body
- Being unatractive

Interrupted conectedness

- Silent relationships
- Not being a suitable partner
- Broken -down relationship

Missing out on life fullness

- Sex is important
- Sex is difficult
- Embarrassing symptoms shame me during sex
- Striving for normalcy

Fragmented openness

- Reticent disclosure
- Aloneness

5.3. Otherness of the sick body

The 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.

5.3.1. Unrecognised body

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

‘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 incontinence episodes during intimate moments were a concern and this was whether 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 [participants’ 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 IBD had ‘medicalised’ 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’ (Carina 40’s F, CD).

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

'M*y labia was swelling up really bad and then all of a sudden my labia was hanging, and then the Crohn's starts eating into 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 support belt on' (Adrian 26 M, UC).

Low self-esteem and loss of confidence were perceived to be caused by changes in their 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 & my partner feels like he's got a new woman! ‘(Adele 30s 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.

For one participant issues related to their body were more complex than body image, as their body went thorough premature menopause and the participant attributed the experience to IBD. This physical transformation in body image and body function were also linked to their identity, with devastating effect on their life:

‘I went through premature menopause at the age of 16 so I’ve never been able to have children and I’m on permanent hormone therapy. And that’s changed my body a lot! When they first put me on hormone therapy I put a stone on in like 3 days and then I went from 5 foot 3, to 5 foot 8 and a half, from a size 12 to a size 18 and from an A to an F cup [brassiere size] in 6 months’ (Orla 41 F, CD).

5.3.2. 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 lovable' (*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 younger 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).

5.4. 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 should exist in the couple. Everything suddenly needed a lot of planning and preparation, sometimes with little room for 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, 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.

5.4.1. 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' (Flo 24 F, CD).

Participants shared that feeling unable to be the partners they desired to be, added to the embarrassment of bringing up issues that they felt 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).

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

5.4.3. 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 maintain the role of a partner as a result of less spontaneous intimate moments due to their

IBD, would jeopardise 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' (*Carina 40's F, CD*).*

Notably, there were participants who suffered broken down marriages or relationships, where their IBD 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 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 break up:

'…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).

5.5. Missing out on life fullness

Lived time reflections were based on the past, present and future intimacy and sexuality experiences, and how IBD robbed participants from 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 sex and Striving for normalcy.* 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 out 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).

5.5.1. 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 was found to lay the basis 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.

5.5.2. 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, including vulval Crohn’s disease had 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).

For gay and bisexual participants, perianal disease was a significant barrier in pursuing sexual activities, either expressing concerns over their less aesthetic *'Crohn's bum'* or extended periods of having a seton in situ, which inadvertently interfered with their sexual activity.

5.5.3. 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. Stigmatising 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 on the future aspects of their temporality domain, with a significant effect on their mental health, particularly when their condition was active:

'*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*).*

'It's really knocked me sexually the thought of having Crohn's in my vagina' (Catriona 43 F, CD)

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).

5.5.4. Striving for normalcy

Although this was indirectly related to intimacy and sexuality experiences, it was important to retain the status of 'normal' people as potential sexual partners, 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 inferred from narratives of 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 IBD 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).

5.6. 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 from 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*****.**

5.6.1. 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 stigmatising 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).

5.6.2. Aloneness

A few took a more extreme decision and gave up the potential of 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 IBD related concerns 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).

It appeared to be particularly difficult for sexual minority participants, one interviewee suggesting that celibacy was not by choice. When gender reassignment involved anatomical sites affected by IBD, this prevented an active sexual life with a partner:

'*Crohn's has been in the way; I have not been able to have a relationship since my gender assignment*' (Richard 62 M, CD).

From a phenomenological perspective, all the linguistic aids used to describe the experiences had the role of articulating what is hard to be described by words, and these aids had attempted to create a depiction of what was lived by the participants, in the best recognisable way for someone who did not have that experience. Moreover, reflecting on the references to language used in society to talk about sex, as a result of a lack of 'polite' language, references to sex became sanitised, and association to' dirty' words lowered the conversations about sex in society (Ruth, 1987). It was noticed that most of the participants did not 'sanitise' their language, in contrast, they used strong words, possibly in an attempt to draw the researcher's attention to the seriousness of their situation, or, potentially as a way of protesting for not being listened in the past. One example of how strong words were used is quoted later in results: '*That really, really fu...s you up'* (Carina 40's F, CD). Younger participants in the study were the ones that had used a more 'polite' language in describing their experiences, although they sanitised words related to bowel function, and the example of a young participant in the study talking about her 'inflammation' as opposed to her 'rectum/anus' is discussed in Chapter 8.

Metaphors and similes were used at times in the narratives, depicting certain experiences explored in the study. Besides, idioms like '*the elephant in the room' w*ere also used to convey the significance of difficulty to discuss sex.

Repetition was used less frequently, although is easy to understand why it was used, like in the following sentence, where the point of being treated holistically was made with the aid of repetition: *'<u>You treat</u> my sexual health problem you're treating my Crohn's, <u>you treat</u> my eyes you're treating my Crohn's, <u>you treat</u> my anxiety you're treating my Crohn's, <u>you treat</u> my self-esteem, you're treating my Crohn's …'* (Martha 38 F, CD).

Use of metaphors and repetition as a way of making a point are found in another example: '[IBD] *<u>stole</u> a good ten years of my marriage; it <u>stole</u> my sex life in what should have been my prime. It <u>stole</u> my self-esteem'. (*Orla 47 F, CD). IBD is compared to a thief, and the importance of the loss following the theft is punctuated by repetition of the word *stole.*

One participant used an analogy to describe how the condition had affected parts of her body: '*parts of It [labia] missing <u>like</u> a caterpillar eating the leaf'* (Catriona 43 F, CD*).* The choice of words had a strong effect on the researcher, the analogy was powerful and had achieved what was potentially the aim of such choice of words, specifically to provoke a novel way of understanding the experience described.

5.7. Summary of the chapter

Intimacy and sexuality experiences in the context of living with IBD manifested as **Sexuality as lived incompleteness**, which was found to be the essence of the experiences described by participants. Every aspect of their intimate lives was affected as a result of their condition, with a significant impact on their body, relationships, future prospects and freedom in engaging in romantic relationships/sexual activities as they would have wanted. Linguistic exploration of the interviews was presented in this chapter as well, highlighting how linguistic aids were used in participants' descriptions of their experiences as a way of enhancing the response of audience to their narrative.

CHAPTER 6. ‘*These discussions aren’t happening’*. Experiences of people living with inflammatory bowel disease talking about sexual wellbeing with healthcare professionals (published paper)

6.1. Overview of the chapter

In this chapter are presented the results from data analysis of the same dataset, which answered the question ‘what are the experiences of discussing intimacy and sexuality with healthcare professionals?’ The reason for writing separate chapters with results was the word limit imposed for publication. As this is a thesis with incorporated publications, this chapter includes a published paper. Same methods as those used in Chapter 5 were used for data analysis, but results were coded in a different Chapters, as they answered to different research questions.

The published paper (Fourie *et al.*, 2021) is included in the Appendix 1.18. therefore, section 6.2 is the verbatim reproduction of the publication text. All the references for the published paper are included in the reference list.

6.2. Published paper


Original Article

‘These Discussions Aren’t Happening’: Experiences of People Living with Inflammatory Bowel Disease and Talking About Sexual Well-being with Health Care Professionals

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Wladyslawa Czuber-Dochan[b]

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Abstract

Background

Inflammatory bowel disease affects all aspects of life, yet little is known about the impact of the condition on intimacy and sexuality, and if such concerns should be discussed with healthcare professionals. This hermeneutical phenomenological study aimed to explore the experiences of people living with inflammatory bowel disease discussing their sexuality concerns with healthcare professionals.

Methods

Participants (n=43) aged 17-64 years were recruited. Data were collected via in depth interviews and anonymous narrative accounts (Google Forms). Thematic analysis was used to analyze the data.

Results

An overarching theme *These discussions aren’t happening* with four main themes were generated. The main themes were: *I can’t image talking about sex; I am a person not my IBD; We need to talk about sex, and Those who talked about sex, talked badly.* Participants described the lack conversations with their healthcare professionals on sexual wellbeing issues, in spite of the importance they gave to the topic, and identified barriers to having such conversations. They made suggestions for future clinical practice that would better meet their needs. The few who had discussed sexual wellbeing issues with healthcare professionals reported negative experiences.

Conclusion

Patients' needs and preferences about addressing concerns related to their sexual well-being during clinical appointments should be addressed routinely and competently by HCP. Understanding the implications of IBD on intimate aspects of the lives of those living with IBD could improve the quality of the care provided.

Key words: IBD, intimacy, sexuality, well-being, healthcare professionals, interviews.

6.2.1. Introduction

Intimate relationships in people living with inflammatory bowel disease (IBD) are challenged by fatigue, bowel symptoms, perianal disease, and having a stoma (Byron *et al.*, 2019), with between 15-30% reporting a negative impact of IBD on their sex life (Rivière *et al.*, 2017) (Bokemeyer *et al.*, 2013). Since IBD has a negative effect on intimacy and sexuality, it might be expected that healthcare professionals (HCPs) would routinely assess and discuss sexual wellbeing. Current literature showed no evidence that HCPs routinely discuss sexual wellbeing with those living with IBD, although this has been previously suggested to IBD multidisciplinary teams (Sanders, Gawron and Friedman, 2016).

Sexual wellbeing refers to '*the perceived quality of an individual sexuality, sex life and sexual relationships*' (Laumann *et al.*, 2006)(p.146). It does not imply the absence of disease, and should not be confused with *sexual health*, which refers to preventing or treating sexually transmitted infections. The concept is related to a more holistic approach to sexuality and intimacy. The definition of sexual wellbeing remains controversial due to the complexity of the concept, and the difficulty of measuring it. However, the accepted notion refers to not just what a person wants to do in terms of intimacy and sexuality, but also what is their physical capacity to do what they desire(Lorimer *et al.*, 2019).

The aim of the study was to explore the experiences of people with IBD discussing sexual well-being issues, or intimacy and sexuality related concerns, with health care professionals, and patients' perspectives on how such conversations should take place.

6.2.2. Materials and methods

Hermeneutic phenomenology designs are concerned with interpretation of written text, and van Manen's (van Manen, 1990) framework is an established stand-alone methodology used in social and health sciences for interpreting lived experiences.

Participants approached the study team in response to an advertisement on the research webpage of a national IBD charity. Those with a self-reported IBD diagnosis, age 16 years old and over, of any sexual orientation, and English speaking were included. Data were collected either as a single semi structured interview via telephone or face-to-face, or from narrative accounts submitted anonymously via Google Forms (GF), as participants chose, following written or verbal consent. Due to the sensitive nature of the study, and in an attempt to encourage participation were used GF as an anonymous alternative for data collection (Fourie, 2020). This aligned with the aim of letting the participants elaborate on issues that are important to them based on their experiences, rather than investigate researcher-directed concepts. The interviews were audio recorded and transcribed verbatim.

Table 12. Interview guide

What is your condition?
How long did you have the condition for?
Can you describe your experience of intimacy and sexuality from your perspective of living with IBD? Can you tell me about any occasions when you have discussed your sexual well-being with health professionals?
Do you think such conversations should take place at the time of clinical visits?
How would you like such conversations to take place?

Van Manen's framework for thematic analysis was used (van Manen, 2016). NVivo 12 software was used for data organisation and storage. The final themes depicted aspects important to participants, and were strictly derived from interview data in an inductive way. The results represent an interpretation of personal experiences of participants and these are aimed both at interdisciplinary and patient understanding.

6.2.2.1. Ethical considerations

Ethical approval was obtained from University of Oxford ethics committee (R60900/RE001). Privacy and anonymity was maintained throughout the study. All participants were allocated a pseudonym and consented for the publication of anonymised excerpts. Direct quotes are presented in italic, verbatim and giving the participant's pseudonym, age, sex, diagnosis (ulcerative colitis, UC, or Crohn's disease, CD).

6.2.3. Results

A total of 43 participants consented to take part in the study between March 2019 and July 2020, 23 opted for interviews that lasted between 20 to 60 minutes, and 20 sent anonymous narrative accounts. (see Table 13). Participants were mainly from UK. Over 75% of participants were in a long-term relationship or married. One participant identified as a gay man, one participant identified as transman and two (male and female) identified as bisexual. The full demographic details for anonymous participants were not known, neither was their geographic location. Based on their narratives all but one participants who responded via Google Forms identified themselves as female, although the study was open to all genders, as were non-binary excluded. No direct information about their age was given via Google Forms, however, most of them stated the length of their diagnosis and their approximate age when they were diagnosed, which made possible to establish an age range for all but two the study participants.

Table 13. Study population

Age range	17-64
CD	31
UC	12
Male	11
Female	32
Married/ Partnered	34
Single	9
UK participants	40
Other (Ireland, United States of America, South Africa)	3

Participants reported various IBD disease activity, from mild to severe forms. Eleven had previous surgery resulting in permanent stoma formation or an ileo-anal pouch, over a third had surgery for perianal disease, and three women had diagnosed vulval Crohn's disease.

Figure 13 summarises the themes and sub-themes. The dominant narrative from interviews and Google forms was that in general, conversations about intimacy and sexuality are not taking place. ***These discussions aren't happening*** was the overarching theme generated by interpretation of the common thread through the themes, integrating some of the reasons why these conversations were not happening, or were avoided, in spite of the topic being important to participants:

'*before you have surgery you should talk about the impact of surgery. That's an opportunity to talk about sexual relationships and intimacy post-surgery. But these discussions aren't happening'* (Martha 38 F, CD)

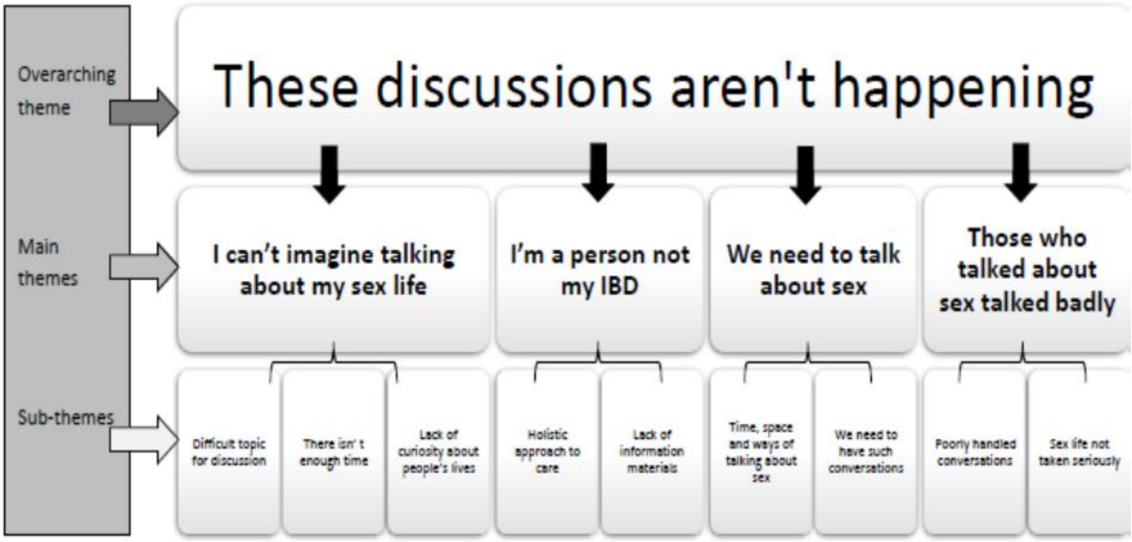

Figure 13. Themes and sub –themes.

6.2.4. Theme 1: I can’t imagine taking about my sex life

This theme includes patient reported barriers in discussing their concerns with HCPs, and the feeling that, due to the sensitive nature of such discussions, lack of time and privacy, as well as lack of initiative from HCPs, contributed to these conversations not taking place: ‘*I can’t imagine talking about my sex life’* (Laura 30s F, CD).

Difficult topic for discussion

The sensitive nature of the topic was the greatest barrier from participants’ perspective, they felt uncomfortable to initiate such conversations with HCPs:

‘[Sex] it’s never been mentioned to me by any consultant or other person. I guess I feel a bit uncomfortable bringing that up’ (Emma 36 F, CD).

‘I would find it very hard to discuss it face-to-face with my care team.’ (Emily 42 F, CD).

Some suggested that clinical appointments were not providing an adequate forum for more personal issues, although the need to address these was present:

‘Of course women don't bring this stuff up to doctors easily. We are doubly shamed - as women about our sexuality in general, and because we have this disgusting disease that you're not supposed to talk about. Add being queer to that and it's pretty much hopeless.’ (Carina 40 F, CD).

Participants from sexual minorities found it particularly difficult to open up and discuss with HCPs, although most of them had previously disclosed their sexual orientation to the clinical team. Some assumed that HCPs' awareness of them identifying as a sexual minority added a barrier to discussing sexual wel-lbeing:

'Maybe it is just because they're trying so hard to be careful with me as a trans man…Nobody asked. It's like your bowel is in a different body from your sexual organs' (Richard 62 M, CD).

'*I feel like people in my HCP team either haven't got the knowledge to discuss with me, the ways that it [IBD] affects it [sex], or haven't been willing to discuss. And I sensed a certain reluctance among them cos I'm bisexual*' (Mark 26 M, CD).

For younger participants attending clinics with a parent was seen as adding to the difficulties of HCPs in bringing the topic up for discussion:

'*I feel like it may also be because my mum comes to all my appointments with me just because, I mean me and my mum are close, so it's not a problem for me to talk about intimacy or anything in front of her, but I feel like, perhaps that made the consultant or whoever I was talking to, more reluctant to bring it up because obviously, some people are more awkward in front of their mums talking about stuff like that.'.* (Melania 17 F, UC).

There isn't enough time

Perceived time constraints were often recognised as barriers to discussing aspects of participants' sexual well-being. Current pressures in the United Kingdom National Health Service to see large numbers of patients in clinics only allowing appointments of 10 to 20 minutes was perceived as a deterrent to discussing anything outside treatment efficacy or symptoms with the HCPs:

'*There is no time or space to discuss anything else that may seem trivial'* (Denise 36 F, CD).

It was also suggested that discussion of sensitive topics requires a rapport between patient and HCPs, which involved time as well:

'*I know they actually there are huge differences in how comfortable people are asking these questions, but sometimes even if you're comfortable it's clear that the issues the person is bringing, they need more time'* (Ana 40 F, CD).

Lack of curiosity about peoples' lives

HCPs reticence to initiate discussions on sexual well-being topics was negatively perceived by some:

'*The lack of curiosity about people and about people's lives I think goes throughout the multidisciplinary teams' (*Martha 38 F, CD).

Furthermore, participants indicated that they were troubled by the lack of initiative from HCPs. This assumption of lack of curiosity was made mainly by participants who had negative experiences of asking HCPs questions related to intimacy and sexuality. Lack of HCP experience and knowledge in discussing these issues, as well as lack of time to do this, could have been wrongly interpreted as lack of curiosity, or interest. The absence of questions other than strictly medical ones from HCPs involved in the care of the participants was seen as a barrier to any attempt to bring up other topics for discussion during clinical appointments, some concluding that HCPs were uninterested in their patients' lives.

'I sometimes feel that any, even sort of medical, strictly medical questions, are sort of not really encouraged. So… it would never occur to me to talk about more intimate things. '(Daniel 31 M, UC).

6.2.5. Theme 2. I'm a person, not my IBD

This theme proposed ways of moving forward as participants felt that they were not approached holistically by their HCPs, starting from the feeling that participants did not want to be identified as just their IBD and, as a result, suggested their expectations for future practice:

'I just I don't like to be identified by my condition because I don't feel like it's part of me, I just think that it [IBD] is what I have '(Nora 18 F, CD).

A holistic approach to care

The expectation of holistic care was found to be unanimously sought by participants. Whether they described experiences where this was not the case, or they made suggestions for how they wanted to be seen, the concept had an important place in the participants' narratives:

*'You don't necessarily get the sense that they're thinking of your complete life in all its sort of aspects. Its: "Right! I'm seeing you as a colon, or lack of one, and that is what I'm treating and I'm not really interested in something else' (*Daniel 31 M, UC*).*

People living with IBD expressed a wish to have holistic care, which would include routinely addressing sexual well-being concerns:

'*You treat my sexual health problem, you treating my Crohn's! You treat my eyes; you're treating my Crohn's! You treat my anxiety; you're treating my Crohn's! You treat my self-esteem, you're treating my Crohn's and we're gonna get to treat me whole. We're both on the same journey! But they're only looking at one aspect of it, and they miss it completely' (*Martha 38 F, CD*).*

Lack of information materials

Alongside the main suggestion to be treated holistically, participants consistently described their experiences of the absence of sources of information on the topic in clinical settings. Our participants' information needs varied, depending on age, gender and severity of symptoms, and they suggested various sources for information. If the possibility to have a discussion with their HCPs was excluded as a result of the participant's choice, or dictated by clinical circumstances (lack of time or privacy), they still expected HCPs to signpost them to the appropriate support available:

'If there was a leaflet particularly about sex that would be helpful, especially for people who really don't want to talk about it to anyone and then they can at least pick that up and be left alone in that way…. I think charities should be a lot more open about sex as well. I think Crohn's and Colitis UK have a leaflet about sex, but from what I remember it's pretty vague it just says you should talk to your partner about sex, you can still have a loving relationship, and I just found that pretty annoying! [Be]cause that does reinforce the feeling that you're on your own or making up something about nothing I think.' (Emma 36 F, CD*)*

The insufficient or complete lack of information received from HCPs about sexuality, sexual function, or symptoms that may interfere with sex life, was perceived by participants as a poorly handled topic, as their expectations were not met. Information was sought by a number of participants, especially in the early stages after their diagnosis, or at the time of surgery. Even those who had been diagnosed many years ago, argued that such information should be offered to all patients newly diagnosed with IBD, or when their circumstances changed, for example undergoing surgical procedures, or changing medication.

Those who had been given information on sexual well-being, or those who sought sources of information felt that information found was often insufficient, and they questioned the reliability of potential sources. Gathering information from other patients' experiences was frequently mentioned in interviews as a way of accessing information:

'*There's a lot of forums because people on there will talk about it [sex] and you know they're quite open about it as well. So it's, and there's all sorts of people like different sexualities in there as well, it's kind of interesting to speak to them. And there's a wide range, some people have got their colostomy bags. You know they'll find it difficult just to be like intimate with somebody. I suppose you'll get a lot of support from them [the forums]'* (James 42 M, CD).

6.2.6. Theme 3. We need to talk about sex

The message that participants wanted to give to HCPs was that there is a need for breaking the taboos surrounding these discussions, and a call for discussions about intimacy and sexuality to take place in the clinical environment, as IBD has a negative impact on their sexual well-being:

'*Sex is a normal part of life. And if there's something in your life that is stopping you from doing something that is normal, you go along to a doctor or specialist to try get help with it. And this is absolutely no different'* (Sandra 60 F, CD).

Although, as a previous subtheme highlighted, these are difficult conversations to have with HCPs, a few had no issues in opening such conversations when needed:

'I've talked about it a lot; I'm not worried about talking about it. I may have been when I was younger, but as I've got older and I've seen my past relationship break down, and I want to go on and have children again' (Martha 38 F, CD*).*

We need to have such conversations

Many participants felt that such conversations should take place, sex is an important part of their lives:

*'... for some people it [sex] might not be such a big issue, but for others it's going to be... For me, it is an important part of my life '(*Ana 40 F, CD).

People claimed that sexual well-being in IBD demands similar attention as sexual well-being in cancer, therefore they argued the importance of talking about it:

'Crohn's affects people's bodies, and its every bit of your body and therefore it's going to affect your sexuality as well. Your choice of partner, whether you can go out dating or not, how you can go out dating, all of it. And it needs to be brought up. Like I said, they do it with cancer, they talk to you about how you can live your life to the fullest with cancer, but nobody does it with us. And IBD goes on for a hell of a lot longer than cancer' (Orla 41 F, CD).

Moreover, the need to bring up the topic in the clinical environment was advocated as participants felt that HCPs do not fully understand the negative impact IBD has on their sex life:

'Doctors need to understand that sex is one of the basic everyday things that gets wrecked by IBD, just like eating or socialising or school or work or exercise. They need to imagine what it would be like for them if they were worried about shitting themselves during intimate moments' (Carina 40 F, CD).

Although the general consensus was that there is a genuine need for such conversations, a deviant finding came from one participant who felt the opposite about such conversations:

‘*Having such a conversation will not help, just expose me more to another person’* (Kate 47 F, UC).

It was largely accepted that talking about intimacy and sexuality issues may not necessarily offer a solution, yet participants looked for an acknowledgement from the HCPs on what they experience, and to validate their feelings by being believed. This was particularly important for those with perianal disease who disclosed issues related to their sexual well-being, but felt they were not listened to, or their concerns were not fully understood by HCPs:

‘Awareness should be made about how hard life is with fistulas and how complicated it is living with the pain of setons... If you go in as an emergency surgery, you could end up with a cable tie in your bottom, that makes you cry for the rest of your life until its removed’ (Sara 46 F, CD).

Moreover, most stated that there was a great need to discuss these issues with someone, and in absence of such opportunity, the present study had offered them a platform to talk:

‘I saw your study and thought I’d be interested to take part, because it felt like the door that was opened up as a forum to talk about these things… I have not felt [door] has ever been opened conspicuously to me and I haven’t talked to anyone about this. The things I’m saying to you now I haven’t said to anyone before, so clearly I haven’t felt that that door was open’ (Daniel 31 M, UC).

Time, space and ways of talking about sex

Finally, participants suggested as a way forward, that HCPs should routinely address sexual well-being concerns with those whom considered it was relevant, and for younger participants possibly alongside family planning:

*'I would like to have access to a specific clinic/appointment for family planning, sexual health for IBD patients. A place where I know these are the main aspects discussed and where I can ask questions, receive information and feel normal' (*Julia 20's F, CD).

The need to address sexual well-being in IBD was perceived by those living with the condition as an important step forward in providing a good quality of care. Although the need for time and space was acknowledged, the majority expected that HCPs should be more engaged in these conversations, have knowledge of the impact of IBD on their intimacy and sexuality, and to initiate this conversation at least once with each patient.

In this way HCPs can identify those who are responding to this invite for a dialogue, and open up about their sexual well-being concerns:

'*Healthcare professionals should be prepared to talk about it…Maybe fill in a small questionnaire before clinical appointment and know who wants to have this conversation'* (Richard 62 M, CD).

6.2.7. Theme 4. Those who talked about sex, talked badly

The few experiences of previous conversations with HCPs about sex related issues were elements of the last theme. Participants described poorly handled conversations and fear of sexual concerns being trivialised, therefore not considered important, by HCPs.

Poorly handled conversations

From those who had discussed sex with HCPs, some recounted having bad experiences of such conversations:

'*The only people that talked about it, and really badly I think, was the stoma nurse that I saw'* (Ana 40 F, CD).

Negative experiences diminished the potential to raise such topics with their HCPs during subsequent appointments. Either because of perceived lack of sensitivity from HCPs or from disparities between patients and HCPs views on what is a fulfilling sexual life:

'I was 21 and I had my first stoma and a 65-year-old nurse came out to the house. I was having problems with getting bags to stick on. I was sent home over weekend with no understanding of my bags and I said that we haven't had sex for a long time because I've been in hospital for 19 weeks, and he is trying to be intimate. She told me to just give him oral sex, [this] was the nurse advice to me. *That is the only piece of advice I've had over the 25/26 years and 40 operations, no one has ever discussed sex with me'* (Sara 46 F, CD*).*

My sex life is not taken seriously

Another perception was that sex life concerns were not seen as important by HCPs. Particularly for those who had experienced delays in their diagnosis, talking about sexual well-being made them fear that the topic would again involve effort in convincing HCPs that their concerns were real:

'I've talked about pain [during sex] on so many occasions with an IBD specialist, with GP's, with my surgical team, and I've never ever once had someone take it seriously' (Martha 38 F, CD).

The struggle to be believed when participants disclosed issues related to sexual well-being was mostly challenging for those with severe perianal disease and vulval Crohn’s, delays in being diagnosed or receiving treatment reinforced the feeling that their sexual well-being warranted less significance for HCPs:

’ *I got to the point where I said: this is my labia going black and falling off, and I’m still not getting any answers’ (Catriona* 43 F, CD).

6.2.8. Discussion

To our knowledge this is the first qualitative study to investigate the experiences of those living with IBD discussing their sexual well-being with HCPs, and highlighted the absence of such dialogue between patients and HCPs. Most importantly, details on perceived barriers for discussing sexual well-being were present in their narratives. The sensitive nature of the topic, limited time, topic not being considered important, and the perceived lack of interest from HCPs were the most frequently reported barriers to discussion. Additionally, our findings highlighted that those living with IBD felt that aspects of how one’s life is affected by IBD may not be known to HCPs. Experiences of not having a holistic approach to their care, one which would include addressing sexual well-being explicit and implicit, prompted suggestions for future practice from all participants.

Patient perspectives on discussing intimacy, sexuality or sexual well-being issues with HCPs remains under researched generally, not just in IBD. The literature is predominantly based on HCPs’ views, and not patients’ views. Studies have mostly covered views of oncology (Traa *et al.*, 2014) (Leonardi-Warren *et al.*, 2016) (Traumer, Jacobsen and Laursen, 2019) cardiovascular disease (Byrne *et al.*, 2013), rheumatology (Helland *et al.*, 2017), and dermatology patients

(Barisone *et al.*, 2020), but no literature was found on views of those living with IBD.

Although it is hard to estimate the prevalence of sexual and relationship difficulties in IBD, one study showed that up to 90% of women surviving gynaecological cancer encountered such difficulties (Alappattu *et al.*, 2017), and 64% of cancer survivors would want HCPs to discuss sexuality issues (Albers *et al.*, 2020). Our study brings for the first time the perspective of IBD patients, who have identified barriers to these conversations, that could be classified as being personal, HCP and environmental barriers.

It is accepted that a satisfying sexual relationship enhances quality of life (QoL) (McCann *et al.*, 2018) and sex is an important aspect of QoL (Davison and McCabe, 2006; Tierney, 2008). Sexuality issues are much more than biological concerns, they encompass intimacy and relationships, which warrants a holistic approach from the HCPs, although the participants in our study reported the absence of such an approach. Looking at the age range of IBD diagnosis, it is reasonable to argue that a large number of those who have IBD are either at a stage in their life when sexual identity emerges, or at the peak of their conceiving period., which sets sexuality issues as high priority for those living with IBD. In spite of this, our study showed that older participants who were likely past fertility, were still identified as wanting to be able to engage in sexual expression and activity, and further challenged the common stereotype that older people are asexual (Gott and Hinchliff, 2003).

Personal barriers were directly linked to the participants themselves, as they did not feel comfortable to open the discussion. Participants reported feeling ashamed, or embarrassed and having a fear of being negatively judged by HCPs.

These fears were more acute in the case of participants who self-identified as belonging to a sexual minority, as it was too much to overcome the fear of being judged. It is, consequently, not surprising they were reluctant to engage in such dialogues. Young adults from sexual minorities have reported infrequent discussions on sexuality related issues with their clinicians in a previous study in the general population (Fuzzell *et al.*, 2016). HCPs should be aware about information seeking behaviour in patients, as it changes with age, and it is also gender dependant, older men being more likely to engage in such conversations with their HCP (Whitfield *et al.*, 2013).

HCP barriers point to HCPs not initiating the discussion. Our participants' perceptions are consistent with those of oncology, rheumatology, heart disease and dermatology patients (Leonardi-Warren *et al.*, 2016) (Traumer, Jacobsen and Laursen, 2019) (Helland *et al.*, 2017) (Barisone *et al.*, 2020). Participants in cancer studies wanted to be asked about their sexuality issues and preferred to receive information on the topic from their HCP (Southard and Keller, 2009) (Albers *et al.*, 2020). One barrier was the perceived lack of interest from HCPs in discussing sexuality/ sexual well-being with the participants. This was similar to the findings from a study with patients after a stroke, which suggested HCP lack of motivation to discuss sexual well-being was one of the barriers to addressing sexual well-being (Mellor *et al.*, 2012). In the absence of professional advice participants had explored various sources of information, and a review looking at information needs in the IBD population found existing online resources unreliable (Khan *et al.*, 2016).

Environmental barriers were time to have a discussion and space to ensure confidentiality. Participants feared that time constraints would not allow anything that was not symptom or treatment related to be discussed during their clinical appointments. Previous cancer studies exploring patients and HCPs views also found that an appropriate space to maintain privacy had the potential to support sensitive discussions, as well as sufficient time allocated to clinical appointments (Leonardi-Warren *et al.*, 2016) (Traumer, Jacobsen and Laursen, 2019) (Dyer and das Nair, 2013) .

Participants had unmet needs as a result of personal, HCP and environmental barriers when they sought information, especially those who had undergone surgery, or had perianal disease The third British National Survey of Sexual Attributes and Lifestyles has also identified similar unmet needs in the general population, suggesting that less than half of those who reported sexual difficulties have sought help (Hobbs *et al.*, 2019). HCPs should acknowledge that patients' needs stretch further than achieving IBD remission or reduction of symptoms. The sexual well-being of those living with IBD is woven deeply into their relationships, concerning their psycho- emotional balance, not just the absence of physical symptoms of IBD, or a remission status.

6.2.8.1. Limitations

Since this was a phenomenological study, its aim was to produce an interpretation of participant experiences, which may not be generalizable. The study population was predominantly female, aged over 35 years, with moderate to severe Crohn's disease, in a long-term heterosexual relationship, therefore, potentially not representing a diverse IBD population. Sexual minorities were well represented in our study as the percentage participants' self-identified as belonging to a sexual minority in the study was higher compared to the percentage found in general population. The findings cannot be extended to those who have mild disease, are single, or aged 16 to 35, as these groups were also underrepresented in our study. No ethnicity data were collected, although the researchers acknowledge that this would have added to the richness of the results.

6.2.9. Conclusion

To our knowledge, this is the first study providing evidence on what IBD patients want from their HCPs in terms of addressing this sensitive topic. Sexuality and sexual well-being were important to those living with IBD as they aimed to continue normal living whilst having IBD. The study highlighted negative patient experiences in raising their sexuality concerns with their HCPs, and their perceptions of HCPs attitudes to their concerns and needs. Similarly, it gives an interpretation of the essence of their experiences on the topic. Patients recognized the influence of several barriers to these conversations with HCPs, and suggested the topic should be addressed as a component of the holistic care they desire.

6.2.9.1. Implications for practice

HCPs should be cognisant to the concerns and needs of those in their care, and actively seek ways of enabling such conversations to take place.

It is important for HCPs to recognise that ignoring sexual well-being puts pressure on patients to raise this issue, potentially causing them to feel ashamed and negatively judged. Training needs for HCPs involved in the care of those living with IBD should be identified and addressed. Sexual well-being should form part of routine care for all patients with IBD, and HCPs should facilitate dialogue, particularly with those with perianal disease.

As an alternative to verbal discussions, signposting to reliable sources of information was proposed to address specific age, gender, sexual orientation and disease severity needs.

Further research on tool development to assess the sexuality needs in patients should be explored, as well as the need for setting services to address this specifically. Information materials should be designed with the help of the patients, and made available in written form in clinics, and online, to cover the unmet needs of those living with IBD.

Raising awareness of sexual well-being issues within the wider patient and HCP population should also be considered.

6.2.9.2. Acknowledgments

We are grateful to all participants for their courage to speak openly about their experiences, as some confessed they never shared these details with anyone. We acknowledge Crohn's and Colitis UK for their support to reach their members, by advertising our study on their research page. We also acknowledge Prof Alison Simmons for her support.

6.3. Summary of the chapter

In this chapter were presented the results from one of the research questions that were published in Journal of Crohn's and Colitis. Participants experiences of discussing sexual well-being with HCPs, and suggestions from participants on how such discussions should take place were discussed, concluding with recommendations for practice.

CHAPTER 7. Being intimate when living with vulvar Crohn's Disease

7.1. Being intimate with vulvar Crohn's

One particular subgroup of participants was those living with vulvar Crohn's disease (VCD). Although the findings were integrated in the previous results chapters, their particular issues warrant a more detailed discussion, which is given in this chapter. Three participants shared their difficulties of having vulvar Crohn's, as they revealed distressing experiences:

'I don't tell my partners that it's so painful. I don't tell them, you just get through it, you grin and bear it, you grit your teeth and you smile, and make the right noises. But it can be horrifically painful, really painful and relationships suffer, relationships break down' (Martha 38 F, CD).

An overview of the condition, known as an extra intestinal manifestation of Crohn's disease was presented in the first Chapter. The current evidence on the topic is scarce and no qualitative literature was found on the life experiences of women with VCD. The study participants with VCD were all over 30 and had a stoma or other surgeries related to their IBD, active perianal disease, other extra intestinal IBD manifestations, and displayed symptoms of a more severe course of disease. Consequently, the discussion was developed around the most important aspects of results, what is it like to be intimate when you live with vulval Crohn's, and what should HCPs know to support this sub-group from the IBD population. The findings are presented here under the same themes/sub-themes that were developed for all participants from this study. No new concepts were identified from these three participants with VCD however, their experiences with discussing sexuality concerns with HCPs were more negative. As a result, the overarching theme defining their experiences of discussing this with HCP was different from the rest of the participants. Although all three reported that 'These discussions aren't happening', their essence of the experience was more accurately defined as 'A decade of waiting'. The most significant aspect of the experience in discussing sexuality with HCP was reflected in this overarching theme, as they struggled to get their concerns across, to be believed and ultimately, receive the diagnosis and appropriate care for VCD. The researcher decided to not discuss each theme in detail, only to discuss those aspects of the experiences that were more specific to this group: bodily changes and image, impact of VCD on romantic relationships, and interactions with HCPs.

All three women who had been diagnosed with VCD had negative feelings regarding their bodies. Martha described how IBD affected her body immediately after starting the interview:

'*with my vulva …. I have a very engorged, enlarged vulva …its very swollen and lots of fissuring. And fissuring it goes purple in colour so my skin goes purple, discoloured, it gets very dry, it peels…. lots of oedema, so water comes out of the skin and, because I've got a rectovaginal fistula, I have some discharge and I often get infections' (*Martha 38 F, CD)

Another participant described in detail what had happened to her body since she was diagnosed with IBD:

'So, at the moment I've got a stoma, I've had that for near 15 years. My Crohn's in my stomach and stuff its fine, it's not too bad, but I now have vulval Crohn's. I had to have stoma surgery because I've got a fistula on the outside of my rectum so I had that removed, the rectum, the whole lot was taken away when I was 25, and the wound for the rectum wouldn't heal and I ended up spending 9 months

in hospital…. That kind of healed up after 9 months of intensive treatment and the next thing is, I started getting sores on my private area. And obviously, with the Crohn's skin and the discharge my life has been miserable. I've had lots of surgery on my labia, plastic surgery to remove lesions because they are like really deep ulcers and they end up going black and I've had to have my labia removed' (Catriona 43 F, CD)

Another description of how VCD affected her body was given by the third participant:

*'Currently, I have got a J pouch, I've got four active fistulas and an active recto-vaginal fistula. I've just went in for surgery cos I've got vaginal Crohn's, because I've got a hole in the side of my vagina' (*Sara 46 F, CD).

The extent of the physical problems described by these three participants was hard to anticipate as although the information from the literature regarding VCD had been graphic and objective, it was insufficient to enable constructing a picture of the trauma that it could cause. The evidence in the literature on VCD is based on under 200 participants worldwide (Lally, Orenstein and Cohen, 1988; Graham, Tishon and Borum, 2008; Leu *et al.*, 2009; Andreani *et al.*, 2010; Bhoyrul and Lyon, 2018; Noël *et al.*, 2020), hence the rich data from the three women taking part in this study offered valuable information to be used in practice, giving HCPs a better understanding of the severity of the symptoms and the negative impact on their lives.

The participants' romantic relationships appeared to be affected even more than the rest of the participants in the study. This was possibly due to the lesions directly affecting genital areas, which added to the sexual dysfunction already experienced as a result of intestinal IBD. Two of the three women with VCD reported broken down relationships as a consequence of their IBD, one chose to remain childless, and another was single at the time of the study interview, explaining that she felt VCD was the cause for her being single:

‘I’ve had four boyfriends since I’ve had my stoma and no, they’ve all been fine with it, but I think the Crohn’s vulva thing eventually causes [sexual] issues…’ (Catriona 43 F, CD).

7.2. Interactions with healthcare professionals

The most notable theme in this sub-group was the struggle to get the diagnosis of VCD. This is consistent with the evidence found in the literature (Foo *et al.*, 2011; Parades, *et al.*, 2014). But for the three participants the issue of not having their needs met was felt more acutely than other participants in the study:

‘I was explaining my new hole in my labia to the registrar and he popped back into the consultant, who I could hear in the other room, and he said “Who is it?” and he said “Oh, its [participant name]” and the consultant said “Oh, let sleeping dogs lie” and the registrar came back in the room and said to me: “Oh no, we’re not going to do you an MRI, we’ll just leave it” (Sara 46 F, CD).

The response in addressing her concerns by her clinical team had damaged the patient/doctor relationship to the point of accessing a new clinician that better recognised the importance of the issue for participant:

‘*…and the letter I’ve got from her [Consultant] saying today is “Your labia shows that it is swollen particularly on the left side and is symptomatic for Crohn’s”. So, I just feel quite like a lot of weight has lifted that someone is believing me that I’ve got this thing in the side of my vagina*’ (Sara 46.F, CD).

Apart from the difficulties in conveying to HCPs the distressing symptoms participants had, all three of them had struggled with getting a diagnosis for almost a decade. VCD is known to be a rare extra intestinal manifestation of IBD. Participants perceived that HCPs were reluctant to acknowledge symptoms related to anatomical parts of the sexual /reproductive system. In spite of openly instigating discussions with HCPs about their symptoms, these women were identified as having had more negative experiences compared to all participants from the study.

*'Yeah my journeys been hard, but nobody would know to look at me from the outside or what I share. So it's hard. Yes, because it is very real' (*Sara 46 F, CD).

It appeared that the unsatisfactory response given by HCPs to the distressed participants had eroded the patient/HCP relationship, and issues of trust emerged. It is unclear what was the cause for participants to feel their symptoms were not taken seriously, but the need for talking about the problem appeared to have greater importance than a search for solutions:

'Maybe just the amount of times I've been to clinics and its only when I start bleeding in that area and its suddenly a cancer issue, and therefore they are mandated to do something about me. That is how I got my gynaecological referral, but me going for two or three years, me not being able to get pregnant, me, you know all these problems I'd experienced, they somehow meant nothing until they were mandated by guidelines to push for me to go on a cancer referral' (Martha 38 F, CD)

Lack of HCP knowledge of the condition was also evident from the participants' reports:

'So again, they had never seen vulval Crohn's; they had all sorts of doctors involved like sexual health doctors and nobody could figure it out and then in the end it was a nurse who worked it out' (Catriona 43 F, CD).

HCPs that recognised the impact of the VCD were appreciated by participants, which suggests the need for HCPs to be more cognisant of the effects of illness and the plethora of new symptoms, fears and concerns that it brings with it:

*'Actually, it's the colorectal doctor who's been amazing and said to me, "Jesus, there's no way you could be intimate like that, and you're so sore. I hope you've got someone looking after you"(*Catriona 43 F, CD)

However, the lack of guidance regarding a multidisciplinary approach for VCD treatment left one of the participants felt that her needs would continue to remain unmet for some time:

'The gynae say it's not a gynae problem, and it's my Crohn's. And I go to my Crohn's doctors and they haven't got a clue because it's all to do with my gynae bits. So, I'm being passed from pillar to post you know. Or dermatology so nobody's like, I'm just getting passed around and it is getting very hard '(Catriona 43 F, CD).

The complexity of the VCD, also known as the 'great imitator' due to the various forms it can take and similarities with other genital conditions requires a multidisciplinary approach (Bhoyrul and Lyon, 2018). There is evidence that suggests those with VCD have an increased risk of developing malignancies, especially those presenting anal fistulas as well (Noël *et al.*, 2020). A study on a cohort of 13 women with VCD found an increased level of vulval malignancy in their cohort, as 23% of them developed vulvar dysplasia and /or malignancy (Foo *et al.*, 2011).

The greater impact of IBD on intimacy and sexuality was suggested by the unusual number of respondents to the study with VCD. The rate of VCD respondents may be also of significance in terms of potential of underreporting symptoms pertaining to the condition. The nature of the symptoms and the potential for invasive physical examination could be a major deterrent for reporting such symptoms for certain groups, particularly younger women, or of different cultural backgrounds. There is limited data on vaginal complaints of those with VCD, but a case series of 50 found that 22% of the women had reported vaginal symptoms. It was possible that other associated symptoms present at the time, minimised the vaginal manifestations (Graham, Tishon and Borum, 2008).

Similar to all other participants who did not have VCD, the need to discuss these issues was brought up, even if there were no solutions at the end of the conversation:

‘I thought this would be a time for me to be very honest, and I haven’t not been honest in the past, I just haven’t been as graphically honest as I have with you. I thought it was important to be very honest with you, because I think what you’re going to do is going to potentially change how peoples care is in the future’ (Sara 46 F, CD)

Those who searched for peer support when the information from HCPs was not found, suspected that others may be still undiagnosed:

*‘I’m seeing that on my Crohn’s groups like I'm on a bit of a weird one. I watch it, I don’t really comment much, though I have seen two ladies who are having the same problems and I’ve said to them it’s your Crohn’s, and demand that you have a test because it does a lot of damage very quickly’ (*Catriona 43 F, CD).

7.3. Suggestions for practice and research

There seemed to be significant delays in diagnosis of VCD that added distress and led to poorer outcomes, as some would need excision surgery if not treated in time (Barret, De Parades, *et al.*, 2014). Considering the increased risk of malignancy associated with VCD, better algorithms for early diagnosis should be introduced, especially as paediatric VCD cases have been reported (Lally, Orenstein and Cohen, 1988; Andreani *et al.*, 2010).

Also, the multidisciplinary approach was found by participants to be largely non-existent. Better communication between the MDT members could improve patient satisfaction with service delivery, alongside improved health related outcomes. Actively asking patients about intimacy issues could potentially help earlier detection of vaginal symptoms related to VCD. A holistic approach to care is imperative, as those living with VCD are more likely to experience negative mental health comorbidities as a high number of them undergo surgical procedures for CD (Mahadev *et al.*, 2012). Psychological assessment and support should be integrated in the care of all those with VCD:

‘I think yeah we need to speak about it, and even offering counselling or something…At the moment I am told I will have to live with this for the rest of my life, and how can I do that? Nothing like that, there’s just antidepressants because I’ve got so much going on and I’m depressed and I’m kind of feeling a bit desperate that I’m not getting any answers’ (Catriona 43 F, CD).

Better detection strategies, potentially during fertility/family planning clinics within IBD services, where discussing issue of a sensitive nature would be expected, and early MDT discussion should improve the health outcomes for this group. tool for early detection of VCD could be developed, although a questionnaire could be also effective. An existing IBD related disability self-assessment tool (IBD Disk) could be potentially used to identify and discuss issues specific to each patient (Ghosh *et al.*, 2017), and could be helpful in detecting (by discussion with patients) any VCD symptoms if the sexuality component of the tool scores low.

A pilot study and a cost evaluation of long-term effects of undetected VCD could offer further information. More research is needed to try and establish the extent of VCD, as it is possible that it is more prevalent than current evidence suggests.

CHAPTER 8. Discussion

8.1. Chapter overview

In this chapter are discussed the results from exploring the sexual well-being experiences of those living with IBD in the context of the literature review and current evidence. A brief discussion on the nature of memory and recollection in the description of experience narratives is included, as well as placing sexuality of those living with IBD in a current social context.

8.2. Findings in the context of current evidence

In this thesis intimacy and sexuality concerns are identified in the context of IBD, and how these aspects of their life should be discussed with HCPs is explored. The findings are related to other work in the field and recommendations for future clinical practice and research are made.

8.2.1. Findings in the context of the literature review

The literature review included in this thesis was published in 2018 and updated in 2020. It aimed to identify the worries and concerns of people living with IBD, in an attempt to explore areas that were under researched. The review added new information about the wide array of the concerns and worries of those living with IBD, and the impact of these on their psychological well-being. Furthermore, it highlighted that those living with BD live in isolation and exclusion. A gap in the evidence demonstrated that more research was needed with young adults diagnosed with IBD and around the issues of intimacy and sexuality. This lead to formulation of the research questions for the study, as the review did not cover the experiences of intimacy and sexuality in the context of living with BD.

As was shown in Chapter 2, of the qualitative studies published in the past two decades there are only a few that have directly explored concerns related to intimacy and sexuality, with a majority reporting inferred findings pertaining to the topic, and as a result this was given little space in the discussion section of Chapter 2.

The overarching theme from the literature review, **Living in isolation and exclusion,** primarily addressed the experiences of living with IBD. Although the sexual well-being of the participants was not specifically explored in the literature review, interpreting the findings in the light of the new information from the research in this thesis, it is almost impossible to delineate the impact of IBD on intimacy and sexuality from the day- to-day life impact of the condition. The work from this thesis makes clearer the intimacy and sexuality experiences, although more work is needed. Features of the condition have been associated with reports of feeling isolated, unattractive and ashamed (Casati *et al.*, 2000). Findings from this thesis brings more light on the isolation and exclusion from the normal life scene. The impact of IBD has ripple effects on romantic/couple relationships, intimacy and sex life of the participants in the study. Furthermore, living with restrictions echoes the limited spatiality detailed in the theme **Fragmented openness.**

A paper included in the literature review, which explored the experience of people living with UC had findings similar to this thesis findings, suggesting that symptoms were negatively affecting intimacy, (Sammut, Scerri and Borg Xuereb, 2015). Other studies included in the review exploring stigma driven non-disclosure of illness (Saunders, 2014; Barned *et al.*, 2016) and perianal disease symptoms as having a negative impact on participants' sexual function (Compton, 2002), yet sexual function alone is only one aspect of the complex concept of sexual well-being. These issues resonated with the findings of this thesis, with both the literature review and the research project discussing in depth the concerns surrounding the non-disclosure of their condition in people living with IBD. Although in the literature review this aspect was explored more generally, comparing the findings from both primary and secondary research, it suggests how deeply woven sexuality is in the life experience. **Living in secrecy**, a theme found in the literature review, could be broadly covering aspects of what participants reported about their difficulties in disclosing their condition to prospective romantic partners, and found in the study’s sub theme **Reticent disclosure**. It was highlighted in the review that people living with IBD avoid disclosing their condition in general, in some cases the existence of IBD being known only to the close circle of family and friends. The negative effect of the non-disclosure was found to affect the intimacy and sexuality experiences. Worries about forming and maintaining romantic relationships after being diagnosed with IBD were mentioned in some of the papers included in the review (Defenbaugh, 2013; Sammut, Scerri and Borg Xuereb, 2015). Embarrassment surrounding loss of body control, and how faecal incontinence had impacted intimate relationships was discussed by Dibley and Norton (2014) in their findings when they examined the experiences of faecal incontinence in people living with IBD. The impact of embarrassing symptoms associated with IBD was explored in this thesis and covers essential aspects of the lived body as well as lived relationships, offering further understanding of how faecal incontinence (and fear of this) impacts sexual well-being. Strained relationships as a result of IBD is also an important finding of the study, and is consistent with the reports from two studies included in the literature review (Devlen *et al.*, 2014; Nutting and Grafsky, 2018). Furthermore, attractiveness and loss of sexual drive are discussed in this thesis, but are also found amongst the worries and concerns of people living with CD included in the literature review (Stjernman *et al.*, 2010; Dibley, 2014).

Exploring further the potential effects of isolation on those living with IBD, there is evidence to illustrate the negative effects of social isolation and exclusion on mental health in the general population (Best *et al.*, 2020), and it is known that psychological distress negatively affects quality of life in IBD (Guthrie *et al.*, 2002; Mikocka-Walus *et al.*, 2015). Psychosocial distress in IBD reflects the level of emotional upset and is closely associated with disease activity (Drossman *et al.*, 1991). People living with CD or UC have reported lower health related quality of life scores (HRQOL) with low scores on social functioning in an earlier study looking at the HRQOL and psychological disorder in IBD (Guthrie *et al.*, 2002). HRQOL in IBD measures the global impact of the condition, including mental and emotional well-being (Jones *et al.*, 2019).

The COVID-19 pandemic experiences have brought more insight of the negative effects of the absence of social interaction, and the impact on mental health of isolation during quarantine periods was recognised to affect everyone (Best *et al.*, 2020), expectably more evident in those who already experience feelings of isolation due to IBD. Over 10% of those living with IBD have reported abnormal levels of anxiety, that persist during remission periods (Ayman Bannaga, 2015), and over 30% of those living with IBD report psychological distress (Mikocka-Walus *et al.*, 2007). Interest in quality of life aspects of IBD, including sexual well-being was initiated in the mid-1990s, with inclusion of outcome measurements of sexual function in clinical trials (Irvine, 2004), but the research continued to predominantly report the psycho- emotional impact of IBD on sexual function in quantitative studies.

8.2.2. Findings in a wider evidence context

Analysis of data from this study was guided by van Manen's framework (1990) and incorporated both thematic analysis and existential analysis described in the methodology chapter.

To the researcher's knowledge, this is the first 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 described previously by phenomenologists such as Merleau-Ponty, Sartre and van Manen. The themes representing each domain are discussed separately for the purposes of the thesis, however these are not possible to separate in lived experience.

8.2.2.1. Lived Body

Body was a dominant feature in the intimacy and sexuality experiences of those living with IBD and took centre stage in the participants' narratives. Sartre (1956) was the first to introduce the notion of *lived body* in his 'Being and Nothingness', and Merleau-Ponty (1962) further located the lived body in the context of time and space. van Manen's methodology has at the core the four existential domains developed earlier in phenomenological philosophy.

In this thesis it became obvious that most of the participants talked about their body as a separate entity, *The Sick Body* was suddenly noticed, it simply became something alien, unwanted and uncontrollable, a disengagement between self and body happened with the illness, as opposed to the *invisible* healthy body described by Sartre (1943). The broken relationship with the body is found in almost all experiences of illness or injury (van Manen, 1998), body is only seen as whole for as long as it can perform as expected (Corbin, 2003). Similarly, others have described how the body has an *organic silence,* its function goes unnoticed until it stops performing well (Madjar, 1997).

'Otherness' is another phenomenological term used to describe the disembodiment that is experienced in illness, and was also used in naming the first theme. The sick body turned out to be something *Other- than- me* (Toombs, 1988)*.* Zaner (1964) argued that body performances are naturally implicating others, where body, consciousness and the world constitute a '*complexure'*, in which all components are distinct, yet they are inseparable. Hence the inability of the sick body to operate/perform in the desired way will intrinsically have an effect on others (Toombs, 1988). Participants from this thesis reported an altered performance of their bodies, which led to a *disintegration* of their world. The usual way of being in the world changed, and illness becomes a *dis-ability to engage* the *complexure* (the body, consciousness and the world) in the known ways (Toombs, 1988).

Furthermore, the otherness of the body could be interpreted as a *hidden presence* (Zaner, 1964), which was inferred by participants in describing their experiences of intimacy. The sick body, often perceived as a separate entity through being objectified, or *disembodiment*, becomes an intruder in the bedroom, bringing a sense of loss of privacy in the lives of those living with IBD.

To better understand the disembodiment experienced by the participants in this study, the notion of embodiment needs to be addressed. The concept of *embodiment* refers to the bodily basis for experiencing phenomena*,* and as a result of the interest the concept had gained in the past two decades, some terms like embodied mind, embodied action, embodied cognition are now used, but these have different meanings for different disciplines (Ziemke, Zlatev and Frank, 2007).

Merleau-Ponty's (1962) view on body and embodiment has done most to resolve the controversy of the meaning, by introducing the notion of *lived body* (Williams, 1996). Throughout this thesis the body was seen as the way through which the world is experienced, therefore, the researcher explored how Merleau-Ponty's theory of embodiment was supported by the findings of this thesis, especially as disembodiment was a clear theme from interviews. Merleau-Ponty argued that no matter how much the mind attempts to accomplish, it is the body that takes one where the mind wants to be. Therefore one is limited by the abilities of the body, and mind and body cannot be separated (Morrison, 2020). Merleau-Ponty's stated that in embodiment:

'The relationship between subject and object is no longer the relationship of knowing…wherein the object always seems the construction of the subject, but a relationship of being, in which paradoxically, the subject is his body, his world, and his situation, by a sort of exchange' (Merleau-Ponty, 1980, p298).

Illness often leads to extreme forms of the experience of the embodiment, as the body is the forefront to experience, which in illness can be of a distressing nature (Gadow, 1982).

The findings of this thesis bring empirical evidence to Merleau-Ponty's embodiment theory; participants displayed such extreme forms of embodiment due to their condition, and had gone through disembodiment and re-embodiment in order to make sense of their new body, and align it to a new identity. The (linguistic) separation from their own body is in itself, evidence of the extreme embodiment they experienced, as an attempt to deal emotionally with upsetting circumstances they faced as having a sick body.

Some participants in the study had eventually ‘surrended to the sick body’ (Charmaz, 1995) in an active process, they accepted the loss of what the healthy body represented, and created a new identity. The control over the new, alien body needed to be regained as part of adapting to live with the illness. A new identity was created, new ways of interacting with outside world were made. New ways of bringing the sick body in the constrains of time and space were found, as well as new ways of how the sick body could forge new relationships.

For others though, as they had a more severe disease course with multiple relapses, they have experienced almost each relapse a new loss, which led to difficulties in accepting the body changes and creating a new identity reflecting the change. Gadow (1982) also stated that in illness, the unity of the body and self is lost, and identity is questioned each time loss is experienced.

The findings also relate to Frank’s (1995) work on the body in illness. Frank proposed four problems of embodiment in illness: control, body-relatedness, other-relatedness and desire. He claimed that these are problems that one encounters during life in general, however, during illness, the body becomes central to self-conscious solutions to these problems. Illness was changing the way how the body was experienced by participants, moving from ‘passed-over-in-silence’ (Sartre, 1956) to something more than a body sensation: a need to objectify their own body and explore it from the perspective of an outsider. The way embodiment was experienced by participants in the study, was confirmed as illness changed the sense of body and self, the sense of time and relationships, as well as the sense of space (van Manen, 1998).

Disruptions of the lived body that occur with illness pose a threat to the body, and subsequently to the person that is the body. In response to this threat arises the need to rebuild a new world by adapting to the chaotic situation that illness created (Toombs, 1988). Participants' responses to a threat (i.e. faecal incontinence or fear of it) led to avoidance behaviours, avoiding new romantic relationships, and subsequently, to social isolation.

Body image satisfaction was considerably diminished in all participants, whether they had or not surgery, and apparently independently to the severity of the disease. For those who had a stoma, the stoma bag affected their body image and function, and there is evidence of comparable conclusions of feeling sexually unattractive after a stoma formation (Muller *et al.*, 2010). There are similar findings in people with urostomies, who felt that urinary diversion altered their body image and strained their intimate relationships (Villa *et al.*, 2018). In the current literature there is an underrepresentation of studies on how sex and relationships are affected by the existence of a stoma. A review on psychosocial concerns of people living with a stoma, but not exclusively due to IBD, found that those living with a stoma had reported more concerns related to sexual function and also, poorer sexual activity than the healthy controls (Ayaz-Alkaya and Sultan Ayaz-Alkaya, 2019).

Poor body image was found to be associated with lower sexual satisfaction and general quality of life in those living with IBD (McDermott *et al.*, 2015), but no studies were found which looked more deeply at the reasons behind this. Another study exploring sexuality in chronic illness had similar findings, concluding that in illness, the body became troublesome (Ervik and Asplund, 2012).

It was noteworthy that some participants stated that their body had been medicalised, and this had changed their relationship with their body, and affected their response to subsequent intimate encounters. Sometimes physical examinations carried out by HCPs can be very invasive, crossing the borders from private space to public. In these cases, some patients deal with the situation by objectifying their body, and in a Cartesian way of thinking, they hand it to over to the clinician for examination (Leder, 1984). Sartre also discussed the objectifying of the body from the perspective of medical examination (1943), and Merleau-Ponty adds to that the notion that of body-me-mine, and body as an object to others (1962). This notion of body as an object is noted throughout the narratives depicting sexual well-being experiences in this thesis.

Over half (29) of the study participants had CD, of whom about 10 had perianal disease, therefore one third of the CD participants in this study had perianal disease, with significant negative effects on participants' body image as well as sexual well-being. The researcher expected this group to experience most disruption in their sex life, mainly due to affected areas being in close proximity to sexual organs, or affecting these directly. Similarly, one line of treatment for perianal disease is placing a seton, which was discussed in Chapter 1; seven of those with perianal disease having had one inserted at different times during since their diagnosis. During interviews, those who had perianal disease mentioned the impact of the seton on their ability to be intimate and sexually active. The preference for seton material was also identified in a study exploring the experiences of those living with perianal fistulas, as some harder materials can cause more discomfort for patients than others (Adegbola *et al.*, 2020). The same study found similar experiences as those reported by the participants in this thesis, stating that some refrained from starting new romantic relationships as a result of their perianal disease. Although there is lack of data on burden of perianal disease (Panes *et al.*, 2018), a study assessing the important aspects of QoL in perianal disease from the patient perspective, where 42% of the participants in the study rated the domain of sexual function as important, concluded that physical symptoms were rated as being most important for sex from a patient perspective (Mahadev *et al.*, 2011). However, a subsequent study looking at self-reported anxiety and depression symptoms in people living with perianal disease, found high rates of depression with13% feeling suicidal at some point due to their condition (Mahadev *et al.*, 2012). This was an important finding that denotes the significance of the emotional distress suffered by those with perianal disease. A high level of emotional distress was recognised in the participants from this thesis. A potential explanation could be the delay in getting diagnosed, which was discussed in Chapter 8 for those with vulvar CD. The delays in diagnosing perianal disease was also discussed in a case review from three UK tertiary centres. The conclusion of the review was that care pathways presented two main challenges: delay in diagnosis of perianal disease, and potential issues with service design leading to anti TNF treatment at around 200 days post diagnosis, which was considered a long period (Lee *et al.*, 2018). Furthermore, considerable unmet needs for IBD patients were found in a systematic review looking at burdens and concerns in people living with perianal disease (Panes *et al.*, 2018).

8.2.2.2. Lived relationships

The relationship dynamic became complex, and intimacy and sexuality were dictated by the condition’s highs and lows, but with much deeper connotations than just a less satisfactory sex life. A sense of lost spontaneity was prevailing, everything needing more planning and preparation, sometimes with little room for conversation about it, which only deepened the distress and frustration for some participants. Sexual function, body image and sexual well-being are influenced by relationship dynamics, with suggestions to assess partners' psychosocial functioning in the IBD population (Jedel, Hood and Keshavarzian, 2015). In this thesis the effect of IBD on relationships was found to equally affect men and women, and is consistent with findings from another study that found that up to 40% of men felt that IBD had an impact on their relationships (Muller *et al.*, 2010). The desire to remain sexually active among those living with IBD was found in earlier studies (Pihl-Lesnovska *et al.*, 2010) as well as difficulties to disclose the condition to potential partners (Devlen *et al.*, 2014), both suggesting that the findings of this thesis are not isolated.

In terms of the strain put on marital relationships by IBD, this was also found in other studies (Bernstein *et al.*, 2001; Mukherjee *et al.*, 2015; Nutting and Grafsky, 2018), which was consistent with this thesis findings. The participants who were in long term relationships have attributed the resilience of the relationship to supportive partners. Similarly, those who had a failed relationship and were in a new relationship, had reported the importance of a supportive partner. There is a small number of participants in the study pertaining to this thesis, therefore the researcher was unable to identify cultural aspects that may be involved.

8.2.2.3. Lived space

Reflecting on spatiality implied thinking beyond the physical space one lives in; therefore other aspects, such emotional space, division between public and private space, or personal boundaries were considered (Rich, Graham, Dip Epi Biostats, *et al.*, 2013). Physical space is where one can perform and be an individual, be oneself. Participants in the study lived their intimacy and sexuality experiences in a constricted space. The space is constricted when some of the body ‘s actions become circumscribed; elaborate preparation for intimate encounters was one example of how the participants’ body actions interfered with their space. Incorporating objects into the bodily space (i.e. incontinence pads, setons) also contribute to constricting the space of those living with IBD.

Furthermore, reflection on spatiality highlighted the complexity of sexual well-being, as emotional space is deeply embedded in the experience. Feelings of shame, embarrassment and guilt, especially related to the partners, or potential partners were strongly linked to isolation, and isolation is an indication of a constricted space. Isolation is synonymous with separation, or segregation, which both imply a restricted space. Isolation is known as a sign of avoidance behaviour in an attempt to regulate shame feelings about their condition, and avoiding exposure to social encounters that would involve self-disclosure or potential for judgmental remarks (Trindade *et al.*, 2018). It was previously identified that those living with IBD are susceptible to social isolation (Fourie, Jackson and Aveyard, 2018) with negative implications for their mental health (Best *et al.*, 2020).

It is also important to establish the place that those living with IBD have in the current social context, especially in relation to their sexuality and sexual expression, as the belief that illness excludes sex still persists. In a society and culture that situates perfect bodies in a desirable sexual partner, people with IBD struggle to meet such expectations, in spite of having an invisible illness. Living in a world of the ‘healthy’ has shaped the significance of living with an unpredictable chronic disease and imposed a restricted spatiality on those living with IBD. Often people with IBD, and those chronically ill, are ‘*like those trapped at a frontier, wandering confused in a poorly known border area, waiting* *desperately to return to their native land'* (Kleinman, 1988, pg.181). Participants in this study also wish the state of normalcy that was known to them prior to their diagnosis.

8.2.2.4. Lived time

From the perspective of lived time, past, present and future are all areas for investigation. The study identified the struggle to plan for the future as participants felt pulled back by their wish to be as they were in the past, or fear of the future due to past and present experiences. Illness led to *obstructed possibilities* (Zaner 1964) and the loss of future also constricted their world (Toombs, 1988). Previous studies described similar experiences, where concerns were raised from anticipating future disruptions based on the past experiences, and felt like 'going in circles' (Saunders, 2017) or being 'pulled back' (Kemp, Griffiths and Lovell, 2012), although without direct reference to sex life experiences. Unpredictability associated with the condition also limited their ability to plan for future. A fluctuating normality was previously attributed to those living with IBD (Burger, 2005). Negative past experiences had added anxieties about the future, therefore the lived time took an important place in the described experiences. Participants could no longer have the future they planned whilst healthy; celibacy and voluntary childlessness being noteworthy findings of a disrupted future. Interestingly, women in a large study exploring voluntary childless in IBD were found to potentially chose this unnecessarily, one of the factors contributing to their decision being poor knowledge of their condition (Selinger, Ghorayeb and Madill, 2016). The study findings echoed those from a systematic review on the effects of IBD on reproductive health, which concluded that poor knowledge should be addressed in order to enable patients to make an informed decision regarding voluntary childlessness (Purewal *et al.*, 2018).

Largely unaddressed in IBD (Ma *et al.*, 2020), male reproductive health issues were amongst the topics that participants brought up in their experiential narratives. Some evidence showed that in male patients medicine safety and maintaining remission were more important to them than IBD treatment when planning for a family (Sato *et al.*, 2010).

Aspects of a culturally sensitive role of women in the family (household and childcare duties) were major concerns in the South Asian IBD population (Mukherjee *et al.*, 2020) which seem to not be dissimilar to fears expressed by participants in this study, in spite of a different world view on the woman's role in a Western society. These fears may have contributed to decisions regarding family planning.

Equilibrium between the past and present, and achieving a new normal are central to adaptation in those living with IBD (Matini and Ogden, 2016), and this was correspondingly reflected in this study, through participants' search for normality. But the relapse /remission pattern found in IBD alter one's ability to continue as normal, leaving some to wander in the *'empty landscape of love'* (Defenbaugh, 2007).

This thesis has offered new knowledge that could be useful in understanding the full extent of the impact of IBD on peoples' intimacy and sexuality, as well as general well –being and care needs, and could help providing adequate care and increase not only QoL in patients, but also patient satisfaction with IBD services.

8.3. Grieving multiple losses

It is apparent that most of those living with IBD are caught in a struggle to maintain normalcy, whether that means maintaining a state of remission, or to appear to others as normal. 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. 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 safe to conclude that these performances take their toll on mental health, especially in a population where energy levels are low. The negative effects of anxiety and depression on sexual function is already known in IBD (Timmer *et al.*, 2007; Marín *et al.*, 2013; O'Toole *et al.*, 2018), 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 IBD. Sexual function is closely linked to quality of life (de Silva *et al.*, 2018; O'Toole *et al.*, 2018) which implies that in absence of a satisfactory sexual function, the overall sexual well-being is disrupted. The existing evidence is primarily based on evaluation of sexual function or fertility and pregnancy issues, with no studies to date that specifically explore how IBD impacts on peoples' intimacy and sexuality. An earlier study found that the main reason for reporting lower sexual function in women with IBD was fatigue, followed by abdominal symptoms (Marin *et al,* 2013). Compared to healthy controls, women with IBD have an impaired sexual function regardless of disease activity (Timmer *et al,* 2007). Mantzouranis *et al.* (2015) have concluded in their review that sexual function is important and often impaired in women living with IBD. They recommended further research on aspects of sexual function. Women who had surgery for IBD are more likely to have sexuality concerns but around 80% of them said they would not discuss this with their healthcare professionals (Rosenblat and Kane, 2015). Nee and Feuerstein (2015) recommended that adolescent women should receive adequate advice on all aspects of women's' health, particularly on those aspects of IBD that have an impact on QoL, such as body image. Findings from this thesis 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 anxiety, low self-esteem, embarrassment and shame.

During interviews the researcher perceived an acute sense of grief amongst the participants. Regardless of how long the participants were diagnosed with IBD, 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 disease. They lived with a constant reminder of their lost self, their lost opportunities, and lost freedom, and self-worth. Grief is an expression of being in the world and defines our relationship with love, and it is only possible to 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, although it is reflecting the level of awareness of significant values held in the world (Brinkmann, 2018). Grieving has a multitude of effects on one’s mental health, and those living with IBD are anyway known to have higher depression and anxiety scores than patients with any other chronic illness (Marín *et al.*, 2013). Grieving over lost health and declined confidence, altered body image as well as feelings of shame are all illness 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 their time as lost future expectations, and the loss of their space in society, as IBD remains seen as a stigmatising condition, and sex issues are taboo. In spite of 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 recognised 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 recognised, accepted and acted on, by giving appropriate support. The complex interrelation between the four existential domains, the main themes, and what the researcher perceived as loss in each domain, showing how each domain is affected and affecting the others is depicted in figure 14**.**

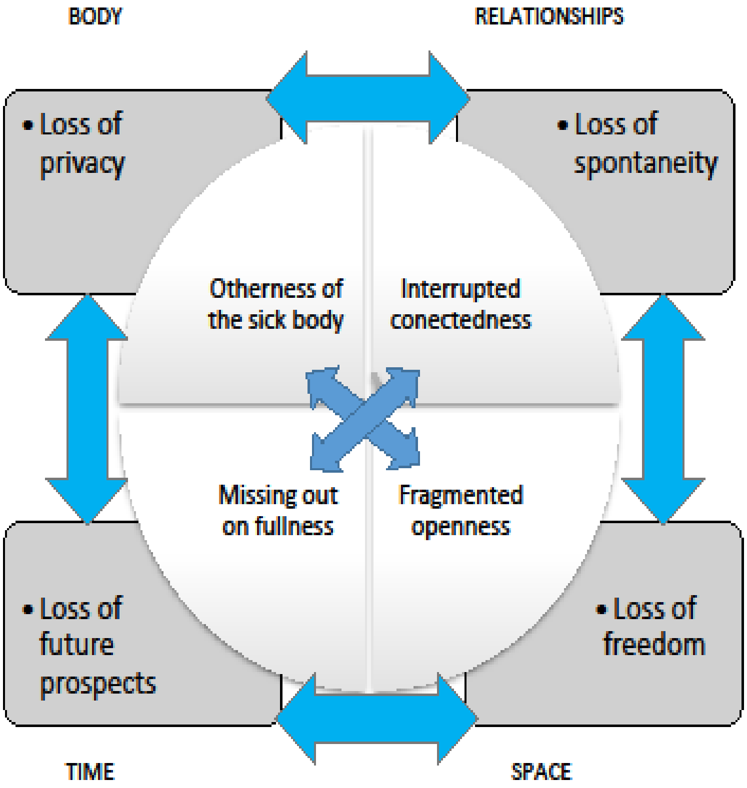

Figure 14. Existential domains and loses

8.4. Lived experiences and memory or recollection

The experiences explored in this study, as in all qualitative research, were recollections based on participants' memories. Clearly some interpretation was inherently introduced when the narratives of the experiences unfolded, as they lost the pre-reflected aspect, since the experiences were reflected upon, and could not be recounted in the pure, non-reflective way they were experienced. Therefore, it is important to investigate what is the reliability of the memories, as a way to increase the reliability of the study, and its trustworthiness. Moreover, since several participants discussed previous experiences, some even from adolescence, in their attempt to show how these experiences shaped responses to similar experiences later on, the researcher further explored in the analysis the nature of memories in recounting lived experiences. From the perspective of their narratives, another issue was the coherence of the narratives in the experience descriptions given during interviews, and what made a 'good story' in the eyes of the researcher.

Qualitative researchers rely heavily on recollecting memories, especially autobiographical memories. Yet memories are influenced by social and emotional factors, therefore they are constructed in a context (Baddeley, Hitch and Allen, 2019). The recall is far from perfect and each recall modifies the memory, potentially distorting it by emphasising the aspects that gave meaning to the experience recalled. Therefore, what is collected as autobiographical memory during qualitative research had already been given meaning and issues of identity are intertwined, leaving the researcher to unpick what is important from the memory (Pascale Blakey *et al.*, 2019). This was evident during the interviews for this study. It was particularly noticed how negative emotions influenced memories, and the researcher had to carefully explore the meanings given by participants' interpretation to such experiences, and recognise the impact of these in the interpretation given to data.

Past experiences and future response to similar circumstances was discussed by Heidegger (1985) as *throwness,* explaining how old experiences throw us in a way of interpreting something in a particular manner, based on what was lived and how the experience was co-constructed. Similarly, Toombs (1988) discussed '*what-is-to-come'* as a manifestation of temporality that has pushed actions of the body in future, where certain experiences trigger fear of repeating in the future, and the responses to future similar experiences. The researcher questioned herself during analysis as to what was really the experience described by participants, knowing that the post reflective nature of recollecting these memories would introduce interpretations based on the aspects that occurred later on from that experience. van Manen's phenomenology does not exclude such descriptions, but rather invites the researcher to reflect on the post reflective nature of the narrated descriptions, and also to reflect the preconceptions and assumptions that the researcher has brought to the interpretation. This was done throughout the data analysis, during the writing and rewriting, when the researcher had challenged her own assumptions, as described in the Chapter 9 of this thesis.

Some have argued that what a qualitative researcher should look for in a narrative is to ensure that is reliable, relatable and liveable (Bischoping, 2018). Reliability of a story as truth of it can suggest a lack of understanding of the narrative truth that is different from the positivist notion of truth. A narrative is reliable if it makes sense, when similar stories are recognised in it (similar experiences are recognised), and presents an appeal to an audience (Sandelowski, 1991). Denzin (1989) argued that emphasis should be on the coherence that is made in one’s life as result of the experience, qualitative researchers accept that stories about lived experiences are not in an ‘authentic’ form; the way the stories are told and what is found in their content should be accepted, even by those with a more rigid methodological preference. Coherence in a narrative is given by a sequence of events, as well as by making a point. From the perspective of the storyteller, the coherence is not their main aim, they also want to make a point, consequently, they think before giving an answer, and edit their narratives, to reach the point they want to make (Gubrium and Holstein, 1998). The researcher had recognised similar stories in the participants’ narratives from past clinical experience, and noticed during the interviews that most participants had a point to make, therefore their participation in the study somehow had an ulterior motive, that the researcher tried to identify for each participant. When cues from direct observation are not possible in establishing reliability, as in the case of telephone interviews, there are other aspects that can help a researcher establish which stories are deemed to be truthful. The researcher’s previous clinical experience helped to ascertain what experiences ‘fitted’ the IBD clinical presentations, by recognising symptoms, worries and concerns specific to the group, but also accepting what was unknown to her. The researcher recognised other stories from the past within those told by participants, and all participants made a point, which was satisfactory in the researcher’s assessment for coherence of the narratives used in the study.

Ultimately, if there is knowledge to be gained through lived experience stories, that in itself should be sufficient proof of truth and reliability for the qualitative researcher. In the case of this study, the researcher felt that important information was found from participants, especially related to their discussions with HCPs on sexual well-being, which added to the existing evidence in the literature.

8.5. Social construction of sexuality in the context of IBD

Sexuality is not simply the biological side of a sexual act, it involves emotional aspects of sexual relationships (Webb, 1985). As described in Chapter 1, this study adopted the WHO’s (2006) definition of sexuality, which includes aspects related to sexual activity when person is healthy or having a health condition. Moreover, sexuality is only partly in the material/object form (as sexual act), and more a result of social interactions; it is relational and it is an activity of active social relations (Gott, 2005), therefore it has strong socially constructed components. Self-esteem, body image and own value in the eyes of others challenges the taken for granted status of sexuality (Webb, 1985), and it becomes noticed. Similar to the way that body is silent in health, (Madjar, 1997) therefore it is unnoticed unless illness affects bodily function, sexuality could also be silent for many. And since the sick body, as a problem, has personal, sexual and existential dimensions, and is managed in a manner that is dictated by society (Lawler, 1991), it is inherently safe to assume that managing sexuality as well is dictated by society. Sexuality should be understood in the context of its place within the cultural beliefs held in a society. It is a combination of biological and social aspects, and as a link between private and public, has other factors that contribute to sexual image in society, such as political and /or economic implications (Padgug, 1979). Therefore, it is key to place sexuality of those living with IBD in the current social context. Sexual stories resulted from studies conducted in past decades are deeply woven into social existence of the storytellers, as embedded in daily life (Plummer, 1995)

The common myths that older and people with disabilities are asexual are slowly being dispelled (Pangman and Seguire, 2000; Gott and Hinchliff, 2003), yet it remains the fact that some of those living with IBD cannot fully express their sexuality, due to their circumstances (Fourie *et al*, 2021). The past decade had shown a shift within society from the androgenic centrality to a more equlaitarian stance, and some of the silent groups, like those with a disabilty, or belonging to a sexual minority, are recognised as equal members of the society. This is also largely due to social media platforms that offer a voice to those who are in less dominant positions socially, and stories are not silent when there are listeners (Plummer, 1995).

Social media has a significant impact in raising public awareness of the problems faced by those living with IBD, and campaigns such as '*It takes guts'* , or '*get your belly out'* (https://getyourbellyout.uk.org) where people are encouraged to post pictures of their stoma, help to normalise a "problem" body in the society. These campaigns are only a few that help those living with IBD, especially young women, for whom social media could have exacerbated the exclusion and isolation by what is known as *fear of missing out* (FoMO). FoMO concept is linked to heavier use of smartphones and engaging with social media, which could be seen as a way of connecting with the outside world for those living in isolation, such those living with IBD. However, there is evidence that FoMO is negatively associated with mood and life satisfaction (Przybylski *et al.*, 2013).

Although sex had become *The Big Story*, and sexual stories are everywhere making a difference in society and politics (Plummer, 1995), there is plenty of work needed to break down taboos and discuss issues related to sexuality, especially in the clinical emvironment, where aspects of sexuality are often reduced to simple biological and physiological function.

8.6. The hidden message or the untold story

In line with van Manen's methodology after observing the linguistic choices used in the narratives the researcher looked for the hidden, what was not told, or what was hidden behind the told stories. Yet again, the dissociations between participants and their sick body was evident from their descriptions that suggested alienation from their body, but also, avoiding the contact with the reality of the situation (Cassell, 1975). One particular participant stood out for this reason. A young woman, only 17 at the time of the interview, who had UC for almost 10 years, had a colectomy in the past 2 years, which resulted in a permanent stoma formation. In such cases, the patients have a rectal stump, that is in fact defunctioned, but it involves a daily routine that helps to excrete any mucus that may accumulate in the rectal stump. In this particular case, the young woman had constantly referred to her rectal stump as *the inflammation*. Careful attention was paid to the interview, revisiting it several times after transcription, and reading the reflection written immediately after the interview, where the researcher asked herself the question 'what was the reason for the choice of words behind *the inflammation?* 'The interview was limited in terms of experiences of intimacy, the participant was young, single and clearly had limited romantic relationship experience, but the essence of her experiences on the topic was the strive for normalcy, thus being accepted by potential romantic partners. It became obvious that she was struggling to accept her altered body, and the manipulation involved in emptying her rectal stump was another thing that was bringing her in touch with the reality of this new body. The assumption that she accepted her stoma more easily (and never referred to it in a negative way, by contrast) was the anatomical positioning of this, compared to the rectal stump. Her attempt to distance from the harsh reality she was facing was by using language that was impersonal, and objectifying a part of her that she did not want to accept. This could have been exacerbated by the anatomical part in discussion, the rectum being associated with faeces, a taboo topic. Or, in the context of the interview question, with the rectum being adjacent to the genital area, it made the difficulties of intimacy more evident, and the participant tried to avoid the reality through her choice of words for that part of her body. On reflection, the researcher would have liked to ask further about the use of this specific choice of words and understand better what was the reason the participant chose it.

In spite of the severity of their condition and the sensitivity of the topic discussed during interviews, many participants laughed or giggled, which was in the beginning, unexpected for the researcher. Listening to some of the interviews that had laughter in transcription, the researcher searched for a pattern laughter, and in what context. It became apparent that describing embarrassing situations was often accompanied by laughter. In embarrassing situations people instinctively try to avoid showing their feelings and cover this with laughter, implying that the situation is therefore enjoyable, and not uncomfortable (Morreall, 1982).

The nature of the topic instigated involvement of a certain group of participants, willing to expose their most intimate experiences, and bring them to the attention of a public audience. At the end of the study, the researcher concluded that perhaps only some of those more comfortable to discuss such topics have come forward. Moreover, there was a hidden message in each and every interview, as there was a point that each participant made with disclosing their story. This was not always obvious, some were easier to identify while going through the narratives, whilst others needed more effort from researcher to answer the question *what could have been the participants' motive for taking part in the study?* One case that researcher felt particularly curious about what was the hidden message, was that of a young man who had unanswered questions, and probably felt the study could offer a platform to getting some of these questions out in the public domain.

Another observation as a result of analysing the data from this study was that the longer they had experienced living with the condition, the more articulate the participants were. This could support the researcher's perception that those much younger, although they had volunteered to participate, so they had something to say about the topic, appeared to struggle to articulate their experiences. van Manen (2016) had discussed the aspect of how one becomes more articulate through reflexivity, and an entire vocabulary is created that eventually renders the experience coherently to an audience.

CHAPTER 9. Conclusion

9.1. Contribution of the study, strengths and limitations

9.1.1. Contribution of the study

The aim of this thesis were to explore the experiences of intimacy and sexuality (or in a wider context, sexual well-being) of those living with IBD, and also, to explore the experiences of discussing sexual well-being with healthcare professionals. The research questions were developed as a result of a qualitative synthesis of lived experiences in the context of IBD.

The literature review included in the thesis found that people living with IBD have a wide array of worries and concerns that affect their everyday life and lead to social isolation, with serious implications for their psycho-emotional health. These findings were added after publication to the NIHR evidence resources (NIHR, 2018). The expert commentary on the NIHR evidence page related to the review highlighted the importance of illness experiences becoming an integral part of the patient care, as at times clinicians' and patients' views on illness experience differ. The findings from this thesis literature review could be used by specialists and non-specialist HCPs from primary and secondary care, and could be relevant to developing new guidelines on the impact of psycho-emotional impact of IBD that remains an under-addressed in the current services.

This study has produced an original body of knowledge on patient perspectives on how the topic of sexual well-being should be addressed within clinical settings. Also, it is the first study to present qualitative data on vulvar Crohn's disease, as the condition is rare and largely under researched, and little is known about the experiences of those with this form of illness. The knowledge generated should help healthcare practitioners to gain a better understanding of the complexities that people living with IBD encounter regarding their sexual well-being. Exploring the needs of those living with IBD in discussing such topics in clinical environment highlighted that there is a need for broaching the subject, although probably with some caution, either by finding ways to open the conversation, or for signposting those interested in the direction of finding reliable information.

9.1.2. Strengths of the study

The study had relatively large sample size for a phenomenological study, and included a varied population, with a good representation of sexual minorities (see Chapter 6). 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 as' *phenomenology is, in some sense, always descriptive and interpretive, linguistic and hermeneutic'* (van Manen, 2014, pg 26). The researcher's access to a rich source of resources written by van Manen facilitated understanding of the methodology, and helped develop philosophical phenomenological thinking. Phenomenological studies strength is that they give a voice to participants, the essence of their experiences is based on their recount of such experiences, and are not driven by researcher in a prescriptive way. By using van Manen's methodology, added layers of understanding were uncovered through examination of the language used by participants, as well as examining silence, or what was untold. Another study strength is the fact the results show the facets of the experiences are lived, without the claim that all experiences are similar to those presented.

9.1.3. Study limitations

The nature of the study renders the findings as being unreproducible, and not generalisable, in phenomenological study the findings are one interpretation of the data, which could be different if interpreted by different researchers.

One limitation regarding the population was that those responding to the study were potentially more affected by the condition in the intimate aspects of their life, therefore it is assumed, that others could have different experiences to those reflected in the study. Furthermore, the majority of the participants were members of Crohn’s and Colitis UK, or had accessed a hospital for clinical care in the UK. Therefore, the population was mainly from the UK, and had access to NHS care, hence their experiences related to HCPs reflects this.

No ethnicity data were collected as at the time this aspect was omitted, although researcher recognises the value of such information would have been available for analysis. Also, only few young participants aged 16-24 responded to the study, leaving this group underrepresented in the study.

9.2. The wonder of a reflexive researcher

In evaluating the quality of the study, the term reflexivity was introduced, but with a word of caution to the other extreme, where the researcher can become egocentric in the research process (Bradbury-Jones, 2007). Reflexivity is addressing the self throughout the study conduct, as well as in data analysis process, and van Manen’s methodology recognises that researchers come with a pre-existing knowledge to analysis, however, that knowledge is constantly questioned and considered in interpretation of data, and he called this questioning ‘wonder’ (Van Manen, 2015). However, reflexivity was employed further by assessing the use of methodology, at every step of the research conduct. This suggests the researcher’s concern with the processes involved, representing the methodology.

As a practitioner with specialist knowledge on aspects pertaining to sexual well-being in IBD (pelvic floor specialist nurse) I had some pre-existing knowledge that had influenced me for a good part of the study conduct. For instance, at the study design stages, assuming that people would be responding to the invitation to participate in the clinical environment, proved to be wrong. The assumption was based on clinical experience, however, those who had accessed pelvic floor services were potentially those with the most concerns regarding their health, yet I failed to recognise that at the time. Moreover, I assumed that younger women would be equally willing to discuss issues surrounding sexual well-being as women in their thirties. I had based my assumption on my pre-existing experience of those accessing the pelvic floor services being mostly in their thirties to their fifties. The difficulties in recruiting young women aged 16-24 as per the first study protocol determined the need to develop the study design and extend it to a wider population (including all adults) and take the recruitment outside the clinical setting.

Interviewing participants was also a learning curve, and in the initial stages I struggled to remove my ‘nursing hat’ and find other ways of supporting participants from the usual ways known to me through clinical practice (i.e. comforting, affirming their feelings). Therefore, instead of giving advice and /or comfort in situations described, I became more comfortable to accept silence at times, and limit my intervention to checking if the participants were not too distressed and were happy to continue the interviews. I had also understood after the first interviews that my choice of questions did not really fit phenomenological interviewing. As a result of reflexivity and reflection on the methodology, I stopped asking patients what did they think about a certain experience, and rather ask them how it felt for them living through that episode.

Most questions regarding my correct understanding of methodology surfaced during the data analysis stage. At the same time that I had questioned if my interpretation of data was a true representation of what was the essence of the experiences described, I was questioning if I had correctly employed the framework that I was claiming to use. Hence, at this stage I read more phenomenological texts recommended by van Manen to help me better understand how to constantly challenge each layer of a given interpretation, and try to question deeper. Throughout all the stages of the thesis, there were a few questions that kept me returning to the phenomenological methodology. Perhaps the question that haunted me the most during the time was around my understanding of the methodology, and I questioned if I was being true to what I said I was going to do (van Manen, 2017a).

As a phenomenological researcher I learnt to examine cautiously every *lived experience.* It became apparent that the term is used generously and inconsistently across different qualitative methodologies, yet only towards the end of the thesis I felt I gained the ability to 'detect' a true lived experience, in the phenomenological meaning. At the same time, I realised that understanding phenomenology only comes once you do it (van Manen, 2016). As van Manen (2016) said, phenomenology is a methodology where there is no method, meaning that no matter how detailed description of each step is given in phenomenological frameworks, it is impossible to prescribe how one can fully reach the understanding of applying the framework.

I often questioned my approaches to data collection and analysis, my understanding of the methodology used, and revisited the literature numerous times. In the beginning I followed the steps described by van Manen in his framework, only later to realise that following the steps was not enough, and I only realised the meaning of ‘write and rewrite’ after months of going back and forth to the data and my interpretations of it. The steps of the framework were helpful in my reflections, especially for maintaining focus on the lived world. The more I dwelled in the stories collected during the interviews, the more I felt that my analysis lacked depth of understanding, and I could not see where I was wrong. Reading examples of other studies that used van Manen’s framework (Thomé *et al.*, 2004; Dattilo and Brewer, 2005; Rich, Graham, Taket, *et al.*, 2013), I realised that each one was unique, and it was clearly hard to try and replicate the methodology, and what I was actually searching for was validation for my own interpretations. I fully embraced the Heidegerrian circle by going back and forth to the interviews, and wondering about my own interpretation in relation to the interpretations of the participants’ experiences, from interviews. Assembling a collection of what was the most commonly found across the interviews, as well as what stood out as different, and contradictory to the commonalities, was the basis for developing themes around this collection of meanings.

Once the main themes ‘showed themselves’ (van Manen, 2017b) a long process of writing and rewriting started. Each theme was interrogated, and reflected on, attempting to capture what makes the experience unique, and if the theme was removed, would it be still capturing the same meaning in the overall description of the experience? What I thought was the end, was barely the beginning. But only by constantly going back to the same question: Is it phenomenology? I grasped what going back to things themselves was, and the importance of writing.

Deconstructing the experiences and constructing them into concepts of what is like to be intimate when living with IBD was only possible by writing and reflecting on each essence, one at a time. However, the difficulties in articulating my understanding of each essence, was the biggest challenge.

Initially I thought it was the language barrier as I speak English as second language, but soon I realised that it was in fact not reflecting sufficiently on each aspect and its' associations to the surrounding world, by stripping of all assumptions and access the experience in a true 'pre –reflective' manner. At this point I found helpful reading pure phenomenological texts, such as ***The Sickbed*** and ***On falling asleep*** (van den Berg, 1966). I found several other examples in van Manen's book ***Writing in the dark*** (2014)***.*** Heidegger argued that lived experiences are raw, but when we stop and reflect on them, they are already in the past, therefore we reflect on a memory of that experience and that memory is already loaded with a certain degree of interpretation. Later on, Gadamer (1960) introduced the term 'pre-reflective' without giving a clear definition of it. In essence, the notion refers to one's views on a specific phenomenon, views that are challenged during and after reflexive processes (Maxwell *et al.*, 2020). Understanding this determined my attitude to be aware of my own presumptions and preconceptions, and focus on the experience in a different manner, and concentrating on the experience alone. In this way phenomenology offers a correction, by protecting against the inclination to superficially interpret it (van Manen, 2017b). I tried thinking about each essence of the experience in a meditative way, eliminating anything that may have been the result of interpretation and prejudice, and immersing in reflection, and challenging each interpretation as soon as it was developed.

I came to understand that each story had to be treated as fictional and not a personal experience, in an attempt to eliminate any sentimental artefacts that influenced the interpretation of the phenomena. That did not mean that the experiences were treated as fiction in the real meaning, but I had to try and detach emotionally especially from the most evocative experiences, and try to not let emotions influence my interpretation. My positioning as a researcher and my existing assumptions about the phenomena were discussed in Chapter 4. I have discussed there on the emotional response that I have developed over the time I worked as specialist nurse, and some of the interviews evoked some of my experiences from that time. Stepping aside from stereotyping tendencies towards data, and from the 'emotional clutter' (van Manen, 2016) found in superficial interpretation, then moving towards a thoughtful interpretation took a lot of time and practice. I had to fight the temptation to theorise or bring in an emotional response to anything that was recognised from my past experience as a specialist nurse. Reflecting on interpretations of various meanings of the experience was not an easy process, and sometimes 'letting go' and seeing things as they were, led me to stumble upon insights that made me accept that the linguistic explanation of that essence/experience reached the best form I could give to my interpretation of the phenomenon.

True to van Manen's teaching, I have wondered extensively about each theme uncovered by the findings of this thesis, and was '*haunted by the need to understand and 'see' something for what it is or how it gives itself*' (van Manen, 2016; pg. 822) in its original sense.

Interpretation of the findings still feels somewhat unfinished, as no interpretation is fully complete in phenomenology (Sandelowski, 1986). I have accepted that I may be in a continuous search for the best way of transforming the narratives into meaningful explanations of the essence of intimacy/sexuality when living with IBD. I felt that my understanding of how they experienced the phenomenon was reached, by deconstructing the experiences in parts that were essential in the full picture, yet the most difficult aspect was to find the language that was closer to how I perceived the experience and interpret it. I built my interpretation as a collection of different essences, and different ways of living the experience. This thesis reflects the interpretation I found to satisfy me as writer in articulating to the best of my ability, and with my understanding of being in the world, of the phenomenon of what is to be intimate when living with IBD.

9.3. Reflection on the methodology

Without a doubt, phenomenology has helped me develop a different way of seeing the world, and the way I inquire and interpret lived experience. Nevertheless, using this methodology was not short of difficulties. I had to choose from various methodologies and my choice was discussed in Chapter 3. I do feel my choice was fit for purpose, and van Manen’s framework helped me as a novice researcher to explore the experience of an aspect of life when living with a chronic illness in a holistic way. van Manen’s methodology has made phenomenology accessible for me, as a non-professional philosopher, as he clarified the fundamental phenomenological concepts (Zahavi, 2020). I underestimated the amount of time that van Manen’s methodology would entail, but perhaps similar phenomenological methodologies would have required similar time to analyse the data. The absence of adequately described studies using van Manen’s methodology added another layer of complexity, and I have discussed in Chapter 4, some issues with reporting phenomenological studies, and the implications of this for novice researchers. However, one study that used the methodology proved to be more explicit, and helped me gain a better understanding of it

(Thomé *et al.*, 2004). Similarly, a concise paper about teaching phenomenology had been a good tool in guiding me on how to correctly interpret van Manen's methodology (Adams and van Manen, 2017).

Reflecting on the choice of the methodology and having the understanding of phenomenology that can only be gained as you go through the process of doing it, I am confident that this was a good choice and, in spite of the difficulties encountered, I would use it again. This methodology is not used often in healthcare research, except for education studies in healthcare, and I have seen the potential of it in for interpreting illness experiences with a holistic approach especially in nursing research. Also, it allowed me to use language that is familiar to a range of healthcare professionals to describe this experience in a manner that is recognisable, with the potential to stimulate change in practice.

9.4. Study trustworthiness

Assessing trustworthiness in qualitative research remains a subject for debate, due to the intent to try and use positivist principles, and the fact that there are qualitative methodologies that cannot be assessed in similar ways to quantitative research (Krefting, 1991). Applying a 'one size fits all' view in evaluating qualitative studies was identified as problematic from two decades ago, as this view is a legacy to those preoccupied with a positivist epistemology (Koch and Harrington, 1998). Some have argued that qualitative research can be evaluated using the trustworthiness criteria (still referred to as *rigour* by many qualitative researchers in existing literature), which would include four standards: credibility, transferability, confirmability and dependability (Guba & Lincoln, 1985). Trustworthiness is defined as truthfulness and quality of the findings, and can lead to confusion due to complex jargon and concepts, yet the need to assess trustworthiness was shared by many (Sandelowski, 1993; Koch and Harrington, 1998; Beck, 2005). Further confusion is fuelled by the use of terms rigour, reliability and validity, as these are used in positivist inquiry (Cypress, 2017), and same words can have different meanings when used in different paradigms (Tatano Beck, 1994). The attempt to create a single set of validation criteria for trustworthiness is seen as futile (Porter, 2007), and debate on the topic of the best criteria to evaluate qualitative research continues, and could be driven by publication standards adopted by many journals, that require checklists often incompatible with reporting qualitative research.

Some interpretative qualitative researchers argue that terminology used for trustworthiness in their work should be credibility, reliability, validity and generalisability (McConnell-Henry, Chapman and Francis, 2009), although these are all terms associated with quantitative research methodology. Furthermore, amongst phenomenologists there are also disagreements on the best approach to ensure trustworthiness (Tatano Beck, 1994; Maggs-Rapport, 2001; De Witt and Ploeg, 2006). A good understanding of the philosophical underpinnings of a study and addressing the subjectivity presents a way of establishing the basis of trustworthiness (Bradbury-Jones, 2007). Below is a brief discussion of the criteria used by some interpretative researchers who argue for the use of quantitative terminology, and how the researcher could demonstrate it in this thesis.

Credibility can be ensured in a study when results offer a true reflection of the reality of the participants. This can be ensured with “prolonged engagement” and member checks. Members’ checks were advocated by Guba and Lincoln (1985) as well as Colaizzi (1978) as they argued this as final step in ensuring validity of a qualitative study. However, interpretative phenomenologists deemed this step, alongside with re-interviewing as incongruent with interpretative phenomenology philosophy (McConnell-Henry, Chapman and Francis, 2011). Others argue that member checking is pointless as stepping further away from the experience, as the story is not the experience itself, but what was told about it (Dwyer, Davis and Emerald, 2017). Instead of member-checking, a careful approach was employed, especially during interviews, by using probing, paraphrasing and open-ended questions, aimed at getting as much detail as possible during the interviews. Due the unpredictable state of the participants' health was determined the choice for single interviews (Smith, 1992).

Generalisability refers to the potential for the findings to be extended to other contexts or settings. To generalise findings from interpretative research is arguably difficult, as findings are the result of one interpretation, and could be different in another interpretation. Thick descriptions of the participants' experiences and the nature of the experiences that were recognisable to the researcher, and demonstrated credibility of the data (Maher *et al.*, 2018) as being experiences encountered in practice and specific to IBD.

Reliability requires a detailed audit trail, and a detailed description of the processes followed in the study. Descriptions of each step followed in the conduct and analysis of the study were presented in Chapters 4 and 5. Similarly, field notes were kept (see Appendix 1.6), and the researcher's reflections on the decisions made during the study conduct were included in a journal (Appendix 1.18). Ensuring adherence to van Manen's framework and including the researcher's awareness of bias and pre-existing knowledge (see Chapter 3) in the analysis also aimed to enhance the reliability.

However, the researcher decided to also use an appraisal of trustworthiness suggested by de Witt (2006), as this framework features characteristics suitable for van Manen's methodology, where criteria of trustworthiness takes form of '*expressions'* of rigour (van Manen, 1997), 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 **actualisation.** In Table 8 the researcher aims to demonstrate the quality of this study by using de Witt's framework for appraisal.

Table 14. de Witt's (2006, pg.223) appraisal of trustworthiness framework for interpretative phenomenology

De Witt's criteria	How implemented in the study
Balanced integration	The **philosophical concepts** used in the study were clearly discussed (Chapter 3), and the **researchers' own bias** was included in the discussion of results (Chapter 8), **maintaining a balance between the voice of the participants and that of the researcher's** when the interpretation was given to the work. **Researcher's reflexivity** was discussed in Chapter 8, and this was possible by returning to the **diaries** (Appendix 1.18**)** that were used for the duration of this PhD.
Openness	The **orientation towards the phenomenon** was demonstrated in the data analysis, as well as in the reflections on the methodology used. This was possible due to the use of diaries to **account for decisions taken and description of processes undertaken during interpretation** of the data, which were all detailed in the methodology (Chapter 3) and concluding chapter.
Concreteness	The **ability to connect the readers to the phenomenon studied in the context of everyday life** was made by linking the interpretations of the experiences to the lifeworld of practice (van Manen, 1997). Therefore, some of the **interpretations should be recognisable to the HCPs** as similar to certain previous examples encountered in practice.
Resonance	The felt effect from reading the findings should be found in the phenomenological text, **where the interpretations of the lived experiences should be able to provoke a deep understanding of that particular experienc**e. This was demonstrated by **theme naming and corresponding excerpts** (Chapters 5,6,7)
Actualisation	**Finding resonance in future studies** can only be demonstrated later, if the findings of the thesis are

	given further interpretation, potentially in studies involving people living with other chronic illness conditions than IBD.

9.5. Recommendations for practice

In spite of limited resources available to healthcare professionals for providing support specific to sexual well-being concerns, the topic warrants early intervention by identifying those at higher risk of developing mental health symptoms as a result of unmet care needs. The grieving processes that are described in the theoretical model developed in the thesis are important in understanding the need for adequate psychological support, particularly for those with a more severe course of disease, or those with perianal disease and vulvar Crohn’s. This study’s findings highlighted the lack of psychological support provided to those living with IBD.

Furthermore, the evidence from the literature review and the research highlighted the need to address the psychological, emotional and social impact of IBD. Similarly, the study identified the need for adequate understanding of the impact of IBD on one’s sexual well-being, and the lack of information resources available for this group. Training needs for HCPs to discuss sex related concerns should be considered, as previous evidence shows that there is a lack of such training as part of their education (O’Sullivan, Majerovich and Wuest, 2019). More training is needed within other specialist areas, such as stoma services, as the findings from this thesis identified that sexuality was not adequately considered when advise was given to participants, in spite of the known impact of stoma formation on body image.

Therefore, some recommendations for healthcare professionals are made:

- Assess the level of concern on sexual well-being existing especially for those with perianal disease and/or undergoing surgery
- Identify and address the differences in levels of knowledge between MDT members regarding the impact of IBD on sexual well-being
- Offer counselling with specialist sex therapist where deemed necessary
- Regularly assess women with perianal disease to rule out vulvar Crohn’s lesions
- Recognise 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
- Recognise the negative impact on sexual well-being especially in those with severe forms of perianal disease
- Initiate routine conversations about sexual well-being/ relationships issues without the expectation that there must be a solution for patient concerns. Involve partners wherever this is agreed with patients

Development of training programmes that support HCPs in addressing sexual well-being The thesis findings highlighted the lack of support in clinical setting regarding sexual well-being concerns, and the absence of reliable information on the topic. Therefore, the following recommendations were made:

- Assess the level of information available in the clinical setting and ensure adequate written information about relationships/sexuality issues is available to ensure adequate self-management of the condition, or signpost patients to reliable sources of information on the topic
- Explore the potential to develop information pertaining to the topic with participants’ help and existing charities

- Raise awareness amongst the wider HCP community about the negative impact of IBD on sexual well-being and the psycho emotional needs of this group as a result of strained relationships and sexual dysfunction

A proactive approach from HCPs appears to remain the best answer for detecting and treating a variety of intimacy and sexuality problems that IBD could trigger. IBD services should be better equipped to address issues of this nature, although the costs of implementing training and specialist staff for such services could be prohibitive.

9.6. Recommendation for future research

The thesis highlighted the lack of research pertaining to sexual well-being in IBD, but also in other long term conditions. The concept of sexual well-being is often conflated with sexual health causing confusion as it does not capture the diversity of the experiences (Mitchell *et al.*, 2021). Due to its complexity, further research is recommended to develop the best theoretical model that would include as many domains as possible, in order to reflect an accurate dimension of the concept. Therefore, further to the recommendations for practice, a few items could be investigated in future qualitative/mixed methods, and longitudinal 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

9.7. Impact of Covid-19 on the study

The pandemic had affected everyone’s life in some ways, and similarly my activity as a researcher has been affected. At the time all efforts were put into sustaining research capability in the Covid-19 related studies, everything else being paused. Therefore, in March 2020 I was unable to continue recruitment in the clinical setting that was aimed at younger women aged 16-24, as the local Trust had paused all non Covid-19 research until May 2021. From that time on, only Google Forms and interviews with participant that responded to the advert on CCUK continued.

There was a peak in people’s interest to take part in the study around June-July 2020, when I interviewed 14 participants. During the pandemic CCUK website was visited more for alleviating health related concerns in the absence of clinical interaction (Mir *et al.*, 2021), which had potentially made the research page more visited as well. My full-time job duties as a research manager have decreased significantly between March and September, in which time I had exclusively worked from home and had more time to transcribe and analyse most of the data collected. Although a difficult time, mostly with negative connotations for everyone, the pandemic potentially helped recruitment, as it was obvious that people were more willing to support causes that they felt it mattered to them, and they had more time to do this, since most of those living with IBD had to shield. Having more time available, I had collected rich data in a relatively short time, and this contributed to completing the PhD in over 4 and half years.

9.8. Concluding remarks

There was no prior evidence of qualitative research on the experiences of intimacy and sexuality in the context of IBD. Most of the evidence was pertaining to sexual dysfunction and was the result of quantitative research. From the qualitative evidence, some inferred findings from general illness experiences were found and presented in the literature review chapter. This was the first study to directly address the experiences of intimacy and sexuality, as well as the need for these concerns to be discussed with HCPs. The findings from this thesis uncovered some of the facets of how intimacy and sexuality is experienced when living with IBD, and the predominantly negative effect these experiences have on day to day life, and psycho emotional well-being of those living with IBD.

Furthermore, the need for routinely addressing these concerns within the clinical settings was also revealed, and an important knowledge source from the incorporated published work in this thesis was made available to the HCPs involved in the care of this group. The significance of being treated in a holistic manner implied the existence of unmet care needs within this group. Moreover, the study highlighted the need for HCPs to address sexual well-being alongside to treatment and symptom management. Participants made important suggestions for the manner in which they would like these discussions to take place, and indicated the necessity for having available reliable sources of information.

The methodology choice was explored in depth in Chapters 3 and 4, and reflections on the methodology used were made in this concluding chapter. In spite of some critics arguing that van Manen's methodology is not rooted in original philosophical works, and his take is on phenomenology is his own invention (Zahavi, 2020), it was found suitable for the study, particularly due to the holistic approach on the lived experiences, as well as the applicability of the findings in practice. As researchers it is imperative to understand the philosophical tenets that phenomenology is based on, and to apply and report them as best as possible, without the claim that this understanding would make us professional philosophers.

Practice and research recommendations were made based on the findings from this thesis and included in the published papers incorporated in the thesis.

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Appendix

1.1. Published literature review

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Living with Inflammatory Bowel Disease: A review of qualitative research studies

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ABSTRACT

Background: Inflammatory Bowel Disease is a chronic, untreatable condition represented by two illnesses, Crohn's and Ulcerative Colitis. Despite high incidence in well-developed industrialised countries, and the significant impact of symptoms on patient's quality of life, little is known about living with Inflammatory Bowel Disease.
Aim: To explore the patients' experiences of living with Inflammatory Bowel Disease.
Design: A qualitative systematic review.
Data sources: CINAHL, Medline, British Nursing Index and PsycINFO were searched using the following keywords: Inflammatory Bowel Disease AND experiences. We have limited the search to studies published in English from 2000 to 2017.
Review method: Thematic synthesis.
Results: Data from 23 studies, identified that fatigue, incontinence and uncertainty about future, body image, and lack of information from healthcare professionals dominated the experiences of those living with Inflammatory Bowel Disease. Also, patients living with Inflammatory Bowel Disease were reluctant to disclose their illness due to lack of public awareness and stigma surrounding symptoms. From these, an overarching theme has been identified: Living in isolation and exclusion.
Conclusion: Patients with Inflammatory Bowel Disease face a variety of problems, often their priorities and those of healthcare professionals differ greatly. Healthcare professionals have little evidence needed to provide adequate, holistic care to this group. With a rise in the Inflammatory Bowel Disease population in newly industrialised countries it is estimated that the condition is turning into a global disease, potentially making long term care unsustainable. More evidence is needed to understand the concerns of this group.

What is already known about the topic?

- There is little qualitative evidence on patient experiences of living with Inflammatory Bowel Disease.
- Understanding their needs and concerns helps nurses to deliver holistic patient centred care.

What this paper adds

- People living with Inflammatory Bowel Disease have a wide array of concerns with significant impact on their physiological and emotional wellbeing.
- The impact of the condition on their daily life leads to an existence in isolation and exclusion.
- Further research should be done on adolescents/young adults living with the condition as a significant gap was found in the literature.

1. Introduction and background

Inflammatory Bowel Disease (IBD) is a chronic condition broadly represented by 2 different illnesses, Crohn's Disease (CD) and Ulcerative Colitis (UC). The exact cause is still unknown and Inflammatory Bowel Disease remains untreatable for some patients. Patients can experience abdominal pain, diarrhoea, weight loss, chronic fatigue and in some cases extra intestinal manifestations such as joint or eye problems (Day et al., 2012). Symptoms are unpredictable and the condition is characterised by periods when symptoms are quiescent and acute flare ups occur (Whayman et al., 2011). Between 25% and 75% of

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Inflammatory Bowel Disease patients will experience at some stage episodes of faecal incontinence due to the illness (Norton and Dibley, 2012). Complications as a result of Inflammatory Bowel Disease can include bowel strictures resulting in surgery and stoma formation, weakened immune system and increased risk of bowel cancer.

The incidence around the world places Europe as having the highest rates of Inflammatory Bowel Disease with UC cases 505:100 000 population, and CD 322 :100 000. North America has around 249:100 000 UC patients and 319:100 000 with Crohn's, whilst Asia and Middle East reported around 5:100 000 Crohn's and 6:100 000 UC patients (Molodecky et al., 2012). We have not found data regarding racial distribution, however there are reports of increased incidence in Asian and African countries, but one can argue that this may be due to improved diagnosis. Disparity in access to healthcare in low income countries may also contribute to the low numbers reported. Given the chronic nature of the symptoms and the severity of these, the condition has a significant impact on the patients' life, not to mention costs to the health services. As an example the lifelong costs for the care of an Inflammatory Bowel Disease patient are comparable to the costs for some cancer patients (Mowat et al., 2011).

There is a wealth of quantitative studies which measure quality of life, the concerns and worries of those living with Inflammatory Bowel Disease, or the impact of symptoms on daily living, with the majority suggesting a negative impact of the condition on the health related quality of life. However, these studies do not give an insight on the patient experience. Studies drawing on qualitative data can provide rich detail about the lived experience of patients with Inflammatory Bowel Disease, attributing broader meanings and enhancing understanding.

2. Aim

In this literature review we sought to identify and synthesise the existing evidence which provided a qualitative in-depth account of the experiences of those living with Inflammatory Bowel Disease, in order to understand their concerns and impact of the illness on daily life.

Research question: What are the experiences of those living with Inflammatory Bowel Disease?

3. Design

Thomas and Harden's (2008) thematic synthesis approach was used for this review and ENTREQ guidelines were followed for reporting systematic qualitative reviews (Tong et al., 2012).

3.1. Search methods

A systematic literature search was run on several electronic databases: CINAHL, British Nursing Index Database, Medline and PsycINFO. The following search terms were used: *IBD* OR *Inflammatory Bowel Disease* OR *Crohn's disease* OR *ulcerative colitis* AND *Experiences* OR *perceptions* OR *attitudes* OR *views*. Searches were limited to 'English language' and 'human' from 2000 to 2017 (December). A further hand search was performed through the reference lists of the articles identified as answering the research question, with one thesis being identified and retained for review. We read all the abstracts in first instance as a study screening method.

3.2. Search outcome

A total of 705 studies were retrieved, and after removing the duplicates 663 papers were retained. From these, all the quantitative studies were discarded, leaving 36 full texts that were read after the abstracts were matched to the inclusion/exclusion criteria (Table 1) and were confirmed as primary research of a qualitative nature. Studies where Inflammatory Bowel Disease was not the main focus were removed due to the difficulties in correctly assessing what statements belonged to our group of interest if other long term conditions were compared to Inflammatory Bowel Disease. Similarly, those which did not represent patients' perspectives were excluded. As a result, 23 studies were included in the review, of which 5 were theses and dissertations (see Fig. 1).

Table 1
Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Primary research	Research looking solely at experiences following surgery in Inflammatory Bowel Disease (i.e. stoma)
No age restrictions	Experiences related to treatment and the provision of care.
Inflammatory Bowel Disease diagnostic	Studies where Inflammatory Bowel Disease and other chronic illness were analysed together
Experience of living with Inflammatory Bowel Disease	Quantitative research
English language	
Published 2000–2017	

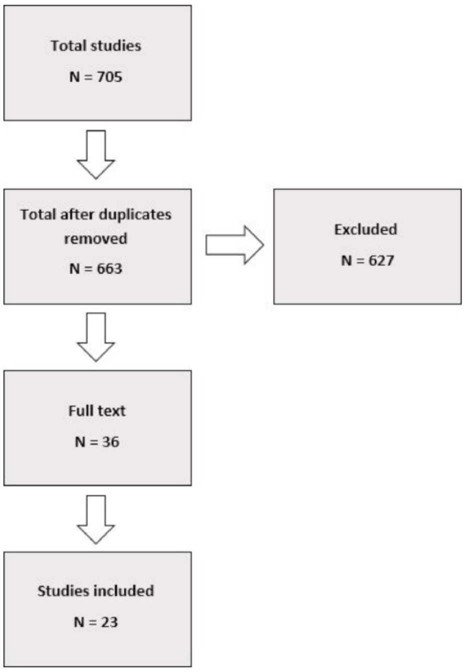

Fig. 1. Prisma diagram.

3.3. Quality appraisal

All the studies included were subject to critical appraisal guided by the Critical Appraisal Skills Practice tool (2015) for appraising qualitative research. All authors were involved in the appraisal and the decision as to which studies met the inclusion/exclusion criteria. It was concluded that all used appropriate methods for their aims, and it was noted that newer studies had a more detailed methodology than older publications. Although several papers lacked detail regarding ethical issues, the decision to include them was taken based on the fact that reporting and publishing standards have changed significantly in the past 17 years, therefore at the time of their publishing these papers have met the criteria existing at that time. Some difficulty was encountered in evaluating the auto ethnographic research, but the decision to include them in the review was taken as they provide valuable insight to the lived experience of this group, evoking a believable and possible experience (Ellis and Bochner, 2000). The autoethnographic studies included in this review were appraised following Richardson's (2000) criteria for autoethnography reviews. Autoethnography should be appraised based on credibility, accountability and dependability (Medford, 2006) and ultimately on the judgement of an experienced researcher (Le Roux, 2016).

3.4. Data abstraction

Thomas and Harden's (2008) framework was used for analysis as data originated from a range of studies that were relevant to the research question. The concerns and perspectives described by those living with the condition were identified in the studies, annotated and assigned to a code (Aveyard et al., 2016). Concerns of Inflammatory Bowel Disease population identified in previous literature (Casati et al., 2000; Stjernman et al., 2010) were used at first for coding using framework analysis. Following line-by-line coding of all data in the studies included, more codes were identified and used to define the descriptive subthemes.

3.5. Synthesis

From the descriptive subthemes, analytical themes were generated through inductive analysis; providing new interpretations to the data from the primary studies. After preliminary themes were identified by the first author, all three authors audited the process, refined the themes and a consensus was made to final naming of themes. Once the analytical themes were named, a second assessment of each studies' contribution to these themes was conducted (Dixon-Woods et al., 2006).

4. Results

Data was collected from 18 studies, 4 theses and 1 dissertation that met the inclusion/exclusion criteria. Of these, 19 used qualitative methods and 4 mixed methods; however, only the qualitative data from these was used for our review. The total sample was 825; geographical areas of the studies was mainly UK and Europe, followed by Canada, USA Australia and New Zealand (see Fig. 2).

Little information was provided in terms of ethnic diversity, some studies giving limited details regarding the sample they have included, but most of the studies' limitations suggested that a predominantly white Caucasian population was included. In terms of the age groups studied, the majority of the population included in the selected studies were adults, and from the limited information given regarding the ethnicity, it appears that around 6% were black or ethnic minorities.

Analysis of the studies demonstrated the profound impact on the everyday life of those living with Inflammatory Bowel Disease. The main finding was the overarching theme *Living in isolation and exclusion*, as all the identified subordinate themes lead to isolation and exclusion. The following subordinate themes were identified: living in isolation and exclusion, living in secrecy, living with a flawed body, living with restriction and living in fear. Each theme is comprised of a number of subthemes (see Fig. 3).

The themes were found in almost every study with few exceptions in cases where the study was looking at specific aspects of Inflammatory Bowel Disease impact, such as fatigue or diet (see Table 2).

4.1. Living with exhaustion

Fatigue has been given much attention over the years as being one of the most distressing consequences of the disease reported by patients. The lack of energy was expressed by participants in most of the studies from 2000 onwards (Cooper et al., 2010; Sykes et al., 2015; Sammut et al., 2015; Dibley et al., 2014). There are various aspects of fatigue that were investigated such as causes, management, impact on daily life and support seeking (Czuber-Dochan et al., 2010). However, the most inconvenient, from patients' perspective was the effect that fatigue had on the participants' life. The constant struggle to perform normal daily activities was highlighted in a few studies (Cooper et al., 2010; Czuber-Dochan et al., 2010; Burger, 2005; Moore, 2013; Sykes et al., 2015)

> *'It's not just the tiredness, it's this feeling of not being able to bother with anything… just losing interest (*Czuber-Dochan et al., 2010*, pg.1991).*

This is also illustrated by a statement showing the effect of fatigue depicted in an auto ethnographic study (Moore, 2013, pg.203):

> *'…I can feel the effort to keep my eyes open, their heaviness drags my whole posture lower and lower in my chair. "ARRRGGGHHHHH"I just let out. 'I hate feeling tired'.*

In some instances study participants had even adapted their family planning according to their energy levels dictated by the condition and

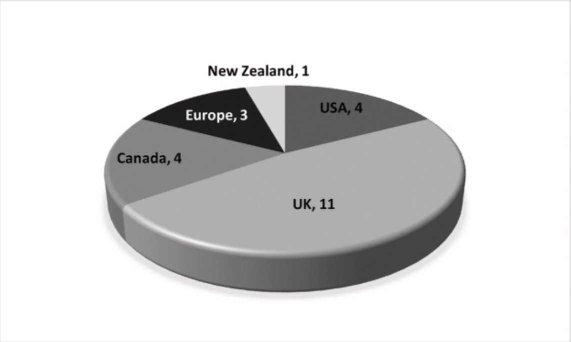

Fig. 2. Geographical area of studies.

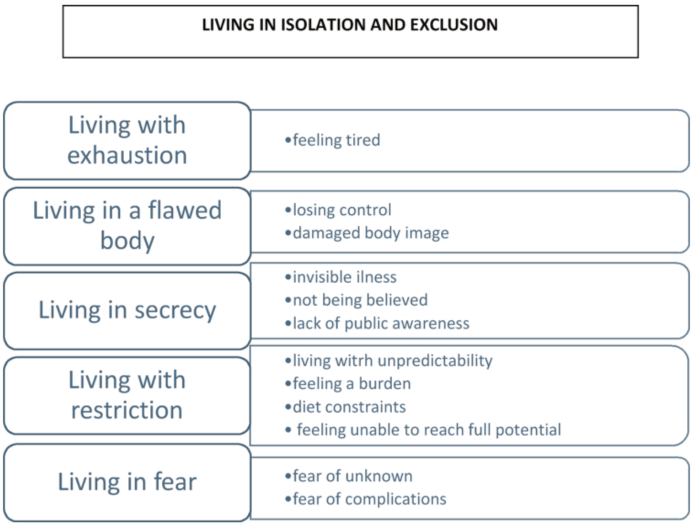

Fig. 3. Themes and subthemes.

Table 2
Strength of themes.

Author	Living in secrecy	Living in a flawed body	Living with exhaustion	Living with restriction	Living with fear
Alexakis et al. (2015)	√	√	√	√	√
Burger (2005)	√	√	√		
Barned et al. (2016)	√	√	√	√	
Compton (2002)	√		√	√	
Cooper et al. (2010)	√	√	√	√	√
Czuber-Dochan et al. (2010)	√	√	√	√	
Daniel (2002)	√	√	√	√	√
Defenbaugh (2007)	√	√	√	√	√
Devlen et al. (2014)	√		√		
Dibley et al. (2014)	√	√	√	√	√
Dibley (2014)	√	√	√	√	
Hall et al. (2005)	√	√	√	√	
Lindfred et al. (2012)		√	√	√	
Lynch and Spence (2008)		√	√		√
Matini and Ogden (2016)	√		√		√
Moore (2013)	√	√	√	√	
Mukherjee et al. (2002)	√	√	√	√	
Micallef-Konewko (2013)	√	√	√	√	
Nicholas et al. (2007)	√	√	√	√	
Palant et al. (2015)	√	√	√	√	
Prince et al. (2011)		√	√	√	
Sammut et al. (2015)	√	√	√	√	√
Sykes et al. (2015)	√	√	√	√	

decided to only have one child (Czuber-Dochan et al., 2010). Others felt that they could not look after more children '*…I decided not to take the risk and bring another child into the world. I probably would not even be able to look after him.*'(Sammut et al., 2015, pg. 2663)

The participants in the studies above were all adults. Studies looking at children and adolescents indicate fatigue is a problem but this is expressed as reduced levels of physical activity. Younger patients who led an active life prior to their diagnosis were most affected by the limitations associated with the lack of energy (Moore, 2013). Some patients denied that they had reduced the level of physical activity due to illness, although during relapses all were unable to engage in exercise as a result of low energy levels (Sykes et al., 2015).

4.2. *Living in secrecy*

Participants described living in secrecy, associated with not disclosing their condition. This theme comprised several facets, including having an invisible illness and not being believed, to lack of public awareness. These are discussed in detail below.

4.2.1. *Having an invisible illness*

Secrecy surrounding the condition was described by participants in most of the studies. Adults and younger patients talked equally about hiding their illness because they did not want to discuss embarrassing symptoms '*Well it's just something I have to live with. Bowel disease, the* *subject's not right for conversation.*'(Hall et al., 2005, pg.451). Micallef-Konewko (2013) also identified secrecy around embarrassing symptoms as a barrier to disclosure in her study with children living with Inflammatory Bowel Disease.

Another reason for their secrecy resided in the difficulties of dealing with an invisible illness. There are no obvious signs of disability as the physical appearance of an Inflammatory Bowel Disease patient is suggestive of a healthy person.

> *'It's only when you tell people that you've got Crohn's disease and the fact that nobody had a clue, oh what's that then, you know what I mean, that's the sort of response you get, and nobody actually thinks there' anything wrong with you, and it's one of those invisible illnesses that you look OK on the outside but on the inside is a totally different story.'* (Matini and Ogden, 2016, p. 2497).

In several circumstances this invisibility caused those living with the condition to avoid giving explanations that would be embarrassing or would question their credibility. Defenbaugh (2007) made a metaphoric comparison between her physical appearance and her bowel; both of which looked healthy to the naked eye - the reality being different when put under the microscope. Having an invisible illness is exacerbated by a lack of public awareness surrounding the condition.

4.2.2. Lack of public awareness

Lack of public awareness was described by participants in several studies. However, one study indicated that this might be more evident in certain cultures.

Alexakis et al. (2015) found that participants from different cultures felt that their communities had little or no awareness of Inflammatory Bowel Disease. Patients from ethnic minorities avoided disclosing the condition even to close family members.

4.2.3. Not being believed

Having an invisible illness had also raised questions for some of the participants' friends and family, which made them feel that they were not believed. Some felt that even amongst healthcare providers there were some who did not believe them:

> *'Once I was admitted to casualty with acute pain and still he (the doctor) told me that nothing was wrong…In the meantime I took tranquilizers and he (the doctor) told me to continue taking them since I was having panic attacks….but I knew that something was wrong…I began to doubt whether my family believed me or not and I would fill up with anger' (*Sammut et al., 2015, p. 2663)

Children and adolescents similarly reported not being taken seriously (Alexakis et al., 2015; Daniel, 2002) or not being believed, which ultimately resulted in them not disclosing their condition. Not being believed was in constant evidence in both adult and young population who participated in the studies.

4.3. Living in a flawed body

The research literature revealed many participants experienced a sense of living in a flawed body; evidenced through a sense of loss of control over it, and the sense of having a damaged body image. These are discussed in detail below.

4.3.1. Losing control over your body

Frequently participants described how the inability to have control over aspects of their body gave them the perception of living in a flawed body. The fear of loss of bowel control was reported by most studies. To address this, participants described finding ways to gain some control over the situation and avoid such accidents (Dibley, 2014; Hall et al., 2005), but most of them chose to avoid going out.

Concerns related to body control or continence were evident in adult studies, whereas in young populations this subtheme was more subtle, often being referred to as an inconvenience caused by symptoms of bowel urgency.

4.3.2. Damaged body image

Concerns regarding body image were attributed to various reasons. The side effects of the medication: *'they call me a marshmallow, and pull on my cheeks when I'm on prednisone. This bugs me.*'(Nicholas et al., 2007) or the surgery resulting in stoma formation also contributed to an altered body image.

Defenbaugh (2007) talked about the' *grotesque body'* in her auto ethnography study which portrayed a suggestive image about her '*messy, leaky body'* (Defenbaugh, 2007, pg.55). Similar views were identified in Daniel (2002) who quoted a participant who felt '*damaged in some way'.* Dibley et al. (2014) stated that life changing decisions grounded on body image issues resulted in the choice for celibacy following stoma formation in the case of a participant. No further details were given; however, it suggested the body image had a considerable role in the decision. Other excerpts from the same study showed a similar pattern:

> *'From the day I was told (the stoma) is basically going to be reversed, I decided that I wasn't even going to have any interest in relationships for the period I had the stoma.'* (Dibley et al., 2014, p. 26)

Body image was found to be of importance mainly in younger patients in contrast to the older adults. In studies with children we identified that the peer acceptance was affected based on looking or being different. Some felt excluded by not being 'normal' and this also led to isolation: *'I feel isolated and ridiculed'* (Nicholas et al., 2007, p. 7).

4.4. Living with restriction

Unpredictability of the symptoms, dietary changes, feeling unable to reach full potential and feeling a burden to loved ones, together comprised the sense of a life of restriction.

4.4.1. Living with unpredictability

Most of those interviewed have commented on the unpredictability of the symptoms:

> *'There's really nothing to do to prevent that because that's my biggest thing, like what can I do to prevent things when I' m just doing what I do every day and I'm not changing anything and it's still happening to me out of the blue. You know I just don't know how to deal with that…' (*Compton, 2002, p.40*)*

On many occasions people felt they were in a permanent state of unrest, with little or no control over maintaining some stability. In an attempt to gain some control over the unpredictability of the disease, the majority decided to reduce to a minimum any social events and activities that would be hard to manage should the symptoms return.

> *'…I remember the last time I went out… I was in a bar and I had an attack of pain and I needed to use the toilet, I rushed to the toilet, something which I really hate to do when I am out… By the time I was dressing up to go out I felt the need to sit on the toilet again and then I promised myself never to go out again'* (Sammut et al., 2015, p. 2664)

Dealing with the unpredictability had limited the participants' ability to plan for the future and in many instances this was closely related to them not reaching full potential.

4.4.2. Feeling unable to reach full potential

Difficulties with reaching full potential has been commonly found in younger adults. Absenteeism from school as a result of the condition was found to affect their career prospects, some choose a career path that would fit their condition as opposed to what they would have liked to do (Nicholas et al., 2007).

> '…*for like the last 2 years literally, I was literally at home unless you had to go to the hospital and I became isolated, so education wise, I kind of, I don't see myself doing it anymore. I've lost that. (Female, aged 20, CD)* (Alexakis et al., 2015, p.670)

Adults touched on this aspect reporting adjusting their employment to their condition by taking part time employment or, in some cases, unemployment altogether.

4.4.3. Dietary constraints

Restriction imposed by condition was also connected to the diet. Having to change the way they eat after diagnosis has been identified in studies looking specifically at this (Palant et al., 2015; Prince et al., 2011), although in several others it was identified as a measure taken to prevent flare ups. Food has significant cultural connotations and some of those affected by the condition described the added struggle in maintaining the social norms expected by their cultural/ethnic group. This aspect was particularly emphasised in a study looking into challenges faced by black ethnic minorities living with Inflammatory Bowel Disease (Alexakis et al., 2015).

> *'It's just the way the ethnic community is and with food and obviously food is a big part of the culture….everything is based around food, weddings are based around food, you go into people's houses, it's all about bringing as much food as you can and that's what entertaining is. That's the thing isn't* it?' (Alexakis et al., 2015, p.668).

Similarly, some patients reported that the condition interfered with their religious eating practices; the same study suggest that more than half of those interviewed could not fast during Ramadan as a consequence of their condition.

Nevertheless food restrictions or diet alteration was not only specific to minority cultures. People from dominant cultures also reported how living with Inflammatory Bowel Disease had changed their eating habits. Some of these were due to the potential of exacerbating their symptoms, others due to the food regimens required at times of bowel rest (Palant et al., 2015; Moore, 2013). Not all the patients were forced to change their eating habits, although one study stated that 82% of the Inflammatory Bowel Disease patients invited to take part had reported issues related to food (Prince et al., 2011). Statements of those who didn't view food as a concern were also found in Cooper et al. (2010). In children and adolescents the issues surrounding food were related to the food restrictions required at times for bowel rest (Nicholas et al., 2007).

4.4.4. Feeling a burden

Some have given accounts on how Inflammatory Bowel Disease affected them and their family and made them feel a burden by requiring a lot of support (Sykes et al., 2015; Hall et al., 2005). Feeling guilty or feeling a burden was found to be quite similar concepts in the studies included:

> '*I think there's got to be at least five times I can think of that I basically tried to push him(boyfriend) out of my life…It's somehow easier to do that than to deal with the guilt of not being able to…you know…be a normal girlfriend for him'* (Daniel, 2002, p.88)

Feelings of guilt were common in parents with Inflammatory Bowel Disease who felt unable to provide the care they wanted for their children. Restrictions were made on where they could take the children or what activities they could do together (Mukherjee et al., 2002).

4.5. Living in fear

Fear took many aspects but more prevalent was found to be the fear of complications and fear of the unknown due to the lack of information from healthcare professionals.

4.5.1. Fear of complications

This was identified in various patient statements. Whether this was the fear of living with the condition, fear of having surgery, the fear of developing cancer or passing the disease to the next generation. It posed a heavy weight on people with Inflammatory Bowel Disease. Younger patients have even expressed the fear of dying:

> *'It was not so much fear of having the condition but fear of dying…. You think you can avoid dying but you're just going through hell. I was basically skin and bones….' (*Lynch and Spence, 2008, p.226)

Defenbaugh (2007) talks about her fear of surgery*: 'I ask on behalf of my body who is scared shitless as she stares into your wounds and ponders a surgical fate. I ask because I am afraid.'* (p.137).

4.5.2. Fear of the unknown

This, in many cases, resulted from lack of information from the healthcare professionals involved in the care of the participants. It appeared that the less information about the progress and complications of Inflammatory Bowel Disease was given, the more reported to be fearful. Also, experiences of clinical care where non specialists had limited knowledge of Inflammatory Bowel Disease had exacerbated the fear of the unknown coupled with loss of trust in healthcare professionals (Alexakis et al.,2015).

Similar findings were reported by Cooper et al. (2010) who stated that non specialist Inflammatory Bowel Disease healthcare professionals involved in the care of the participants was identified to cause significant concerns to the participants, by attributing symptoms to other conditions.

5. Discussion

This review has captured the accounts of patients' experiences and highlights the complex challenges of living with Inflammatory Bowel Disease. The theme that was identified in all of the studies, irrespective of the aspects explored, was *Living with exhaustion***.** Fatigue is the subject of ample work that looks at ways to relieve it and is an aspect investigated predominantly by clinicians.

Another major concern was the inability to control their bowels from *Living in a flawed body theme*. Continence care for Inflammatory Bowel Disease raises a major issue for healthcare professionals. Being afraid of losing bowel control in public and the stigma attached to such an incident was evident from numerous accounts. Body control is a complex process and yet very little is known about it. It is also making us socially acceptable and, although for some who have faecal incontinence may not be seen as an issue, others perceive themselves as not being competent adults (Norton, 2004). Norton and Dibley (2013) suggested that incontinence is still under reported by Inflammatory Bowel Disease patients. This may be because insufficient opportunities for the patients to voice such sensitive issues, or others may not be aware there are options to alleviate the severity of incontinence symptoms. In the same study, Inflammatory Bowel Disease patients with faecal incontinence reported a lower quality of life and they were also reporting lower social functioning.

The second most common theme alongside *Living in a flawed body* was *Living in secrecy*. The difficulty in continuing to live as normal as possible was hindered by the uncertainty of the disease. They lived in a fluid state that was constantly changing and felt powerless in maintaining some sense of control. Not being able to disclose their condition had a negative impact on their psychological and emotional health, resulting in either reducing or withdrawing from social activities. The psychological and emotional baggage attached to the condition remains an un-promoted issue which is still poorly addressed by healthcare professionals (Kemp et al., 2012). The difference between Inflammatory Bowel Disease and other invisible chronic illnesses sits in the difficulty of discussing symptoms that can be seen as unacceptable for public discussion with others from outside their close circle. This review suggests that patients with Inflammatory Bowel Disease perceive themselves as having a ‘spoiled identity’ (Goffman, 1963) and avoid disclosing their illness, regardless the age of the patients. The secrecy surrounding the condition was an important finding and closely related to perceived stigma and/or fear of not being believed. Stigma surrounding the condition was subject to ample discussions in some of the papers included, and the need for secrecy adds significantly to the burden of the disease. The lack of public awareness about the condition is a key factor in daily experiences faced by some patients (Bray et al., 2016). Saunders (2014) argues that taboos surrounding the bowel conditions need to be addressed, however this cannot be done by research alone. But what is notable is that all five themes identified have impacts on social relationships and interactions of Inflammatory Bowel Disease patients with the ‘outside’ world become irremediably disrupted. Looking at all the themes, we can conclude that overall, living with Inflammatory Bowel Disease means living in some degree of isolation and exclusion.

Evidence from this review is supported by quantitative studies emphasising the extent of the problems by measuring health related quality of life and Inflammatory Bowel Disease related concerns (Stjernman et al., 2010; Mussell et al., 2004; Levenstein et al., 2001). A large European survey looking at the international perspective of the impact of Inflammatory Bowel Disease on patients’ lives gives valuable data from various aspects of life, the burden of symptoms and the delivery of care. It suggests that 96% of the respondents suffer from fatigue during flares, women aged 19–43 being the most affected. Half of the participants agreed that Inflammatory Bowel Disease had negatively affected their work or career pathway and reported their intimate relationships had been affected, rising to 64% for those with certain types of colitis. The study also revealed that 66% of the respondents were worried about toilet availability and they considered the presence of a toilet when they planned a trip (Wilson et al., 2012).

What we found interesting is the fact that a specific age group appeared to get silenced through inclusion in adult research (over 18) in most of the studies. Satisfaction with body image and acceptance by peers are most associated to self-esteem in adolescence (Coleman, 2011), both aspects being of high concern for those living with Inflammatory Bowel Disease. This is also important as the illness is diagnosed in over half of the patients between the age of 20–29 (Molodecky et al., 2012).

Most of the evaluations on factors influencing the Inflammatory Bowel Disease patient quality of life are based on healthcare providers and not patients. Patient accounts of illness experiences are becoming more accepted as an important source of understanding the extent of disruption in the life of those with chronic illness. Looking at patients’ perspectives helps define what is of significance to the patient and ultimately helps those involved in their care to improve health related quality of life. This supports providing better care by addressing issues that are important to patients. Social isolation and withdrawal from relationships are major consequences of chronic illness (Straus, 1975) and the evidence from this review suggest that those with Inflammatory Bowel Disease could probably be some of the most socially isolated. Evidence into how life changes for Inflammatory Bowel Disease patients places the restriction in movement as the most negative outcome (Purc-Stephenson et al., 2014).

5.1. Limitations

This review only included articles in English; thus, language was a barrier to including studies from non-English speaking countries. Considering the lack of diversity within the population in this review, we acknowledge there may be publications that we were unable to access in order to give us a better understanding of the cultural issues posed by the condition. Also, there are differences between the two conditions, CD and UC, regarding the outcomes and complications and we have not analysed, separately, experiences particular for each condition.

6. Conclusion

The qualitative data from this review offers a deeper understanding of the major impact Inflammatory Bowel Disease has on their life and their daily struggles, and how their lives changed after diagnosis. We draw on research using patients’ own voices to provide a succinct account of their difficulties of daily living. Thus, this information could help improve their quality of life and reduce the burden of their condition.

6.1. Recommendations for practice and research

Healthcare professionals should be aware of the patient perspective and their experience of living with Inflammatory Bowel Disease. This should not just cover issues such as symptom burden but also the emotional and psychological aspect if a holistic care approach is the aim. Those involved in the care of people living with Inflammatory Bowel Disease must be aware of the high risk of isolation, and personal circumstance that may also contribute to it should be known to the care providers (see Table 3).

More research is needed to explore the experiences specific to younger adults. Only 3% of the total sample had specifically looked at 16–24 years olds, which is suggestive of a significant gap in the research undertaken so far. Furthermore, there is a lack of knowledge from wider cultural groups and with a different socio economic status, all those included here having access to good healthcare systems, and were mainly from white background.

Conflict of interest

No conflict of interest has been declared by the authors.

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Acknowledgment

We thank Professor Alison Simmons from the University of Oxford

Table 3
Recommendations for practice and research.

Living with exhaustion	Fatigue should be monitored and underlying issues and personal circumstances should be addressed. Research on strategies to cope with fatigue should be of priority.
Living in a flawed body	Referral to specialist continence /pelvic floor services to provide support in incontinence management. Healthcare providers should assess if continence issues are present due to being under reported.
Living with secrecy/ Living with restriction	Increasing public awareness of the condition should be prioritised as it would alleviate the need to conceal the illness. Further search on ethnic minorities living with the condition should be undertaken.
Living in fear	Raising awareness of the condition for a quicker referral to secondary care could alleviate anxiety. Appropriate level of information should be provided in terms of potential complications and long term risks associated with condition. Training for non-specialist healthcare professionals is needed for providing adequate support.

1.2. Table Demographics of included studies (updated)

	Authors/year /country	Design	Aim	Sample F/M	Age range
1	Alexakis *et al,* 2015 UK	qualitative	To understand the specific issues and service needs of young people with IBD from BME communities.	20 F7 M13	16-24
2	Barned et *al*, 2014 Canada	qualitative	Sought the perspectives of Canadian children and adolescents living with inflammatory bowel disease (IBD) to determine how they go about deciding if and when to tell others about their illness.	25 F12 M13	10-17
3	Burger, 2005 USA	qualitative	To understand how persons live with inflammatory bowel disease.	8	over 18
4	Compton, 2002 Canada	qualitative	To provide an understanding of the experience of women living with Crohn's disease (CD)	8	25-70

5	Cooper *et al* ,2010 UK	qualitative	Explore beliefs about personal control and self- management of Inflammatory Bowel Disease. It focused on the role of physical, psychological and socio-economic factors within the individual's life experience	24 F11 M11	30-40
6	Czuber-Dochan *et al*, 2012 UK	qualitative	To explore fatigue, the impact it has on daily life and the strategies used to ameliorate the symptom, as described by people with inflammatory bowel disease	46	over 18
7	Daniel, 2002 Canada	qualitative	Explore young adults' perception of living with IBD.	5	18-24
8	Defenbaugh ,2007 USA	qualitative	To explore the personal narratives behind the IBD identity, focusing on the ill body.	F1	over 18
9	Devlen *et al*, 2014 USA	qualitative	To describe the impact of inflammatory bowel disease (IBD) from the patients' perspective, and to inform the development of a conceptual model.	27 F13 M14	20-59

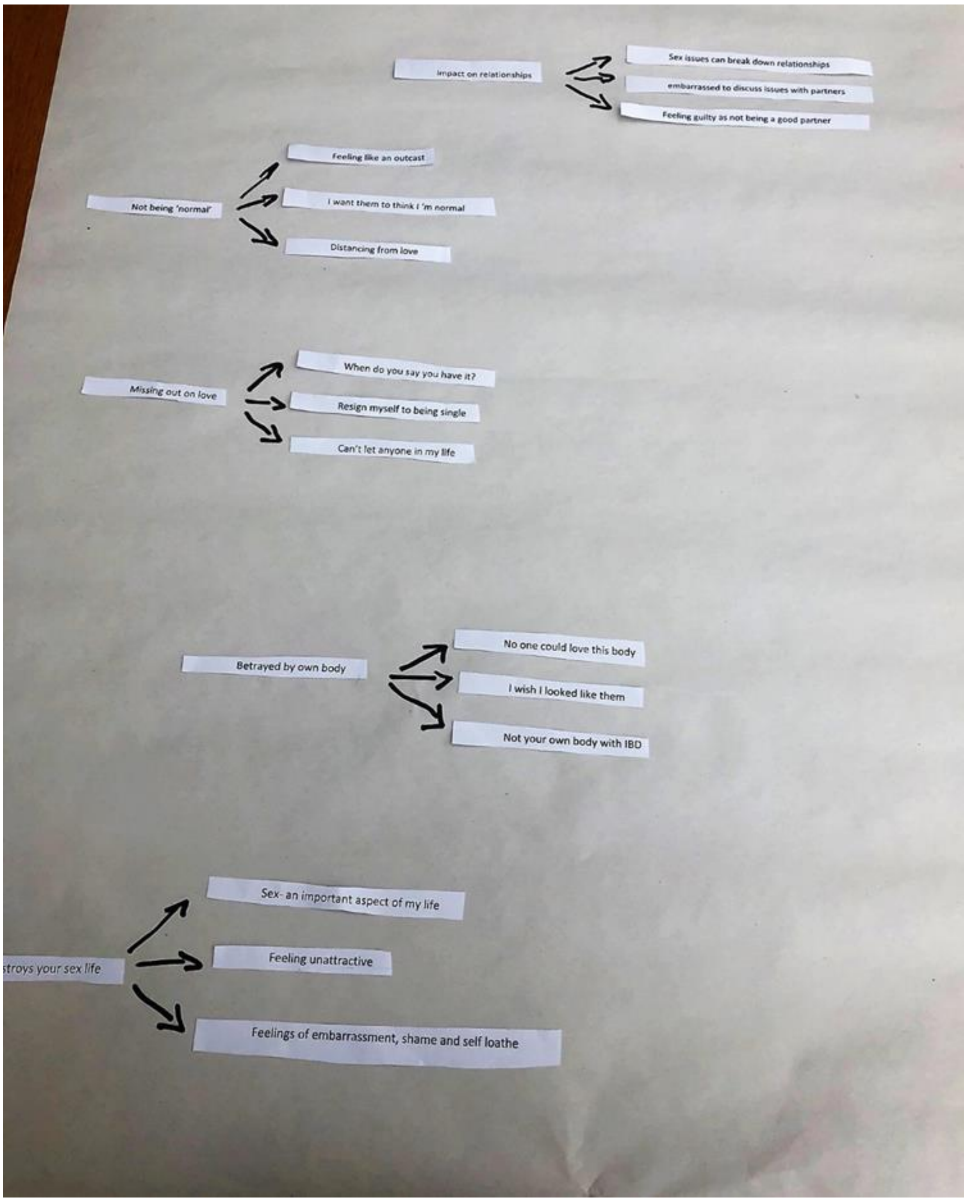
10	Dibley,2014 UK	Mixed methods	Explore the experience of stigma in IBD patients with and without incontinence.	40	over 18
11	Dibley *et al* ,2014 UK	qualitative	To extend the evidence of gay and lesbian people experiences of living with IBD.	50	over 18
12	Hall *et al,*2005 UK	Mixed methods	Explore the experiences of individuals living with IBD and coping strategies used by them	283/31 F19 M12	over 18
13	Lindfred *et al*,2012 Sweden	Mixed methods	To explore and describe adolescents 'perceptions of health, self-management and impact of living with IBD on daily life.	67 F27 M40	10 - 16
14	Lynch &Spence.2007 New Zealand	qualitative	To enable young adolescents to talk about their experiences and use their stories for improved health care.	4	16-21
15	Matini & Ogden,2016 UK	qualitative	To explore lived experience and examine the process of adapting to life with inflammatory bowel disease.	22 F14 M8	over 18

16	Micallef-Konewo,E, 2014 UK	qualitative	Interpret experiences of adolescents disclosure of IBD at school, following the transition from primary to secondary school	7	12-13
17	Moore, 2012 UK	qualitative	Author’s lived experience during a flare; an autoethnographic journey exploring issues of disclosure.	1	over 18
18	Mukherjee *et al*.2002 UK	qualitative	To identify how IBD affects parenting.	24 F19 M5	over 18
20	Nicholas et *al*, 2007 Canada	qualitative	To understand the lived experience and elements of quality of life as depicted by children and adolescents with IBD	80 F36 M44	7 - 19
21	Palant *et al* ,2015 Germany	qualitative	To understand from a patient perspective the significance of food, eating, and nutrition, including the role of food in the social life of patients with IBD.	42	over 18
22	Prince *et al,* 2011	Mixed methods	To investigate the prevalence of food and nutrition problems	72	over 18

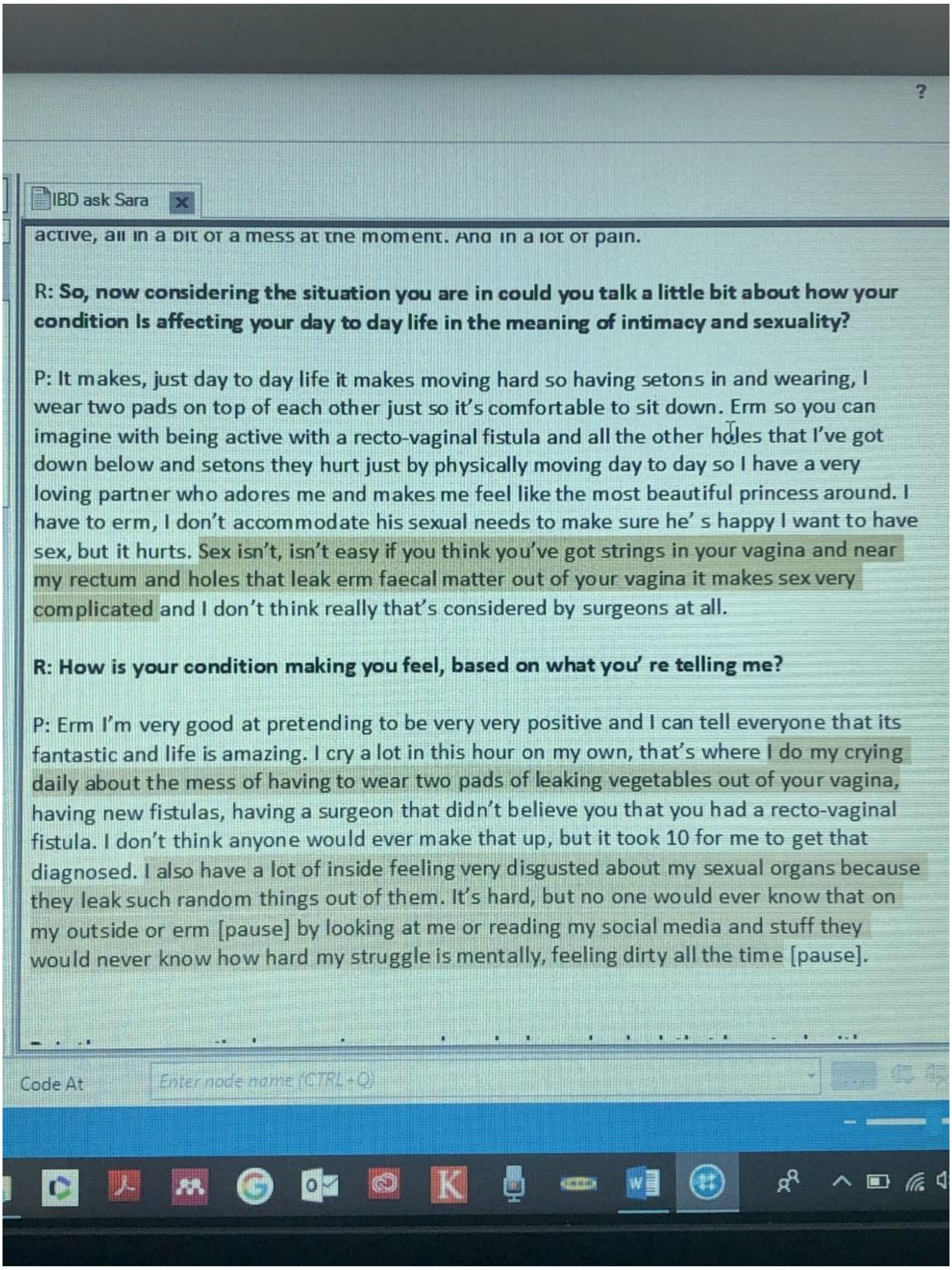
	UK		as perceived by patients with IBD and the factors associated with these. In addition, the study aimed to investigate the extent to which these problems are addressed by health services.		
23	Sammut *et al*. 2015 Malta	qualitative	Explore the experiences of adults living with ulcerative colitis	10	over 18
24	Sykes *et al*, 2015 USA	qualitative	Examine the lived experiences of women with inflammatory bowel disease, by specifically exploring their management of their illness after diagnosis	8	30-50
25	Pihl Lesnovska, et *al,* 2019. Sweden	qualitative	Explore the impact of microscopic colitis on everyday life.	15	35-76
26	Lopez-Cortes, R. *et al.*,2018. Spain	qualitative	Describe factors influencing life experiences of people living with IBD	14	19-61

27	Ghorayeb, J. *et al.*, 2018. UK	qualitative	Understanding the lived experiences of women with IBD transitioning to motherhood.	22	over 18
28	Rouncefield-Swales, A. *et al.* 2020. UK	qualitative	Explore experiences of friendships in young people with IBD	31	14-25
29	Czuber-Dochan, W. *et al.* 2019. UK	qualitative	Explore the perceptions and psychosocial impact of food, nutrition and drinking on the lives of those living with IBD.	28 15 F 13 M	Over 16
30	Sweeney, L. *et al*, 2019.UK	qualitative	Explore the experiences of pain and pain management of those living with IBD.	14	Over 18

1.3. Picture with visual aids to organising themes



1.4. Highlighted text in NVivo example



active, all in a bit of a mess at the moment. And in a lot of pain.

R: **So, now considering the situation you are in could you talk a little bit about how your condition Is affecting your day to day life in the meaning of intimacy and sexuality?**

P: It makes, just day to day life it makes moving hard so having setons in and wearing, I wear two pads on top of each other just so it's comfortable to sit down. Erm so you can imagine with being active with a recto-vaginal fistula and all the other holes that I've got down below and setons they hurt just by physically moving day to day so I have a very loving partner who adores me and makes me feel like the most beautiful princess around. I have to erm, I don't accommodate his sexual needs to make sure he' s happy I want to have sex, but it hurts. Sex isn't, isn't easy if you think you've got strings in your vagina and near my rectum and holes that leak erm faecal matter out of your vagina it makes sex very complicated and I don't think really that's considered by surgeons at all.

R: How is your condition making you feel, based on what you' re telling me?

P: Erm I'm very good at pretending to be very very positive and I can tell everyone that its fantastic and life is amazing. I cry a lot in this hour on my own, that's where I do my crying daily about the mess of having to wear two pads of leaking vegetables out of your vagina, having new fistulas, having a surgeon that didn't believe you that you had a recto-vaginal fistula. I don't think anyone would ever make that up, but it took 10 for me to get that diagnosed. I also have a lot of inside feeling very disgusted about my sexual organs because they leak such random things out of them. It's hard, but no one would ever know that on my outside or erm [pause] by looking at me or reading my social media and stuff they would never know how hard my struggle is mentally, feeling dirty all the time [pause].

1.5. Codebook

Name	Description	Files	References
betrayed by own body		6	8
body , a sick obstacle		2	2
erectile dysfunction		1	4
body image		6	6
disappointed in my body		3	4
getting my body back		3	4
i wish i looked like them		2	2
medicalised body		2	2
No one could love this body		1	1
not your own body with IBD		3	3
worry about leakage		3	3

Name	Description	Files	References
worry for having children		1	1
embarrassment, shame and self loathing		4	4
disgusting symptoms		4	4
feeling ashamed		2	2
feeling dirty		1	1
low self esteem		3	3
i cannot imagine talking about my sex life		0	0
difficult topic for clinical appointments		8	10
I m not worried to talk about it		1	1
I talked about it		3	4
lack of curiosity about people s lifes		1	1

Name	Description	Files	References
lack of understanding from hcp		3	3
time constraints		3	3
I want them to think I m normal		3	5
feeling like an outcast		1	1
sort of things that make me different		2	2
No disclosure		2	2
IBD destroyed my sex life		20	24
enjoyed sex before IBD		1	1
fear of STI		1	1
feeling sexually unattractive		7	8
feeling undesirable		2	2

Name	Description	Files	References
loss of desire		2	2
loss of pleasure		1	1
noises and killing mood		1	1
sex isn t easy		2	2
Sex worsen symptoms		1	1
impact on my relationship		10	11
appreciate a supportive partner		6	8
supportive relationships		1	1
break ups		5	7
distancing from love		2	2
embarrassed to discuss issues with partners		5	6
fear of rejection		3	3

Name	Description	Files	References
Feeling guilty as not being a good partner		4	5
life with setons		1	1
making up for lost time		1	1
Ashamed to talk about my failure		1	1
my relationship has struggled		1	1
relationships suffer because of pain		1	1
trapped in a relationship		1	1
Two sides of a story		2	2
missing out on love		4	5
can’t let anyone in my life		2	2
resign myself to being single		6	6

Name	Description	Files	References
when do you say you have it		6	9
not same with peers in adolescence		2	2
bullied		1	1
delayed sexual development		1	1
not wanted		1	1
struggle to fit in		2	2
uninterested in sex		1	1
still living whilst unwell		1	1
sex as important part of life		6	7
sex life puts pressure on relationship		4	4
suggestion forward		7	7
being listened is important		2	2

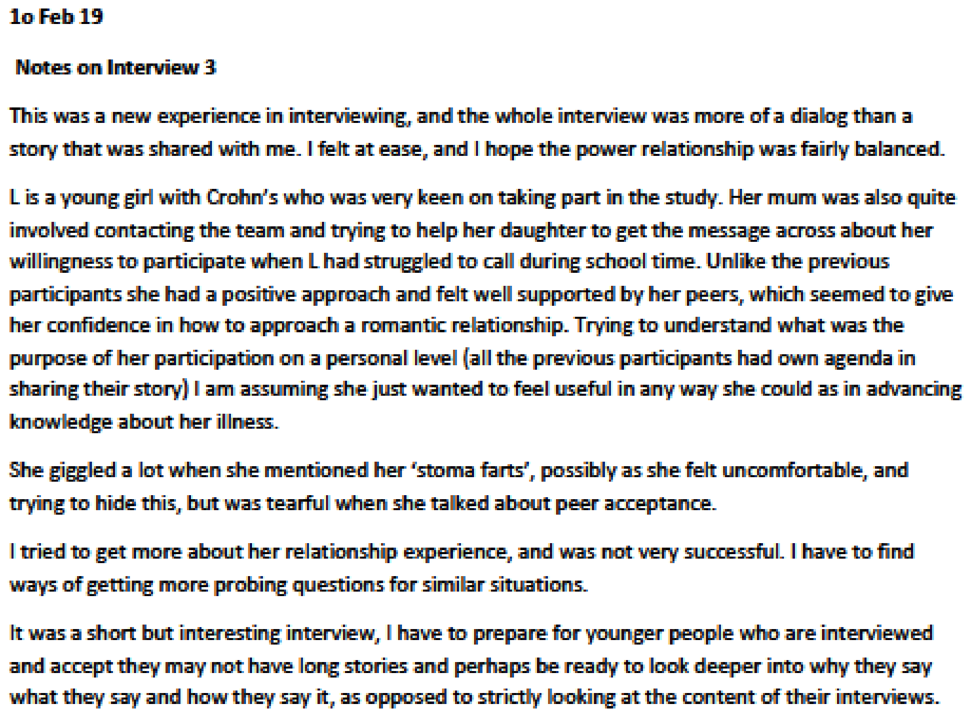
Name	Description	Files	References
find a better way of bringing up the subject		2	3
forums for discussion		1	1
holistic approach to person		5	6
nurses should help		1	1
risk of poorly handled conversations		3	3
sources of info		1	1
talking about it without pressure		3	4
these discussions aren’t happening		2	3
ashamed to talk with hcp		4	5

Name	Description	Files	References
I have never discussed my sex life with HCP		7	9
it doesn’t feel like a forum for personal issues		2	2
not being believed		1	1
not involved in own care		1	1
talk about it will not help		2	2
talking helps even when no fix		2	2
you don t feel heard		3	5
those who talked about it, talked badly		5	6
limited availability of information		7	9
missing the point		2	2

Name	Description	Files	References
never seen someone take it seriously		2	2
no clinician has ever volunteered information about sex		3	4
no one has really talked about it		2	3
sex hasn’ t come up once		2	2
unaware IBD affects intimate relationships		3	4
unimportant issues unless trigger cancer screening		1	1
we should talk about it		8	10
HCPs should not be shy		1	1

Name	Description	Files	References
not talking about it potential for missing IBD complications		1	1
talk in special forums		5	7
we must talk about it		3	4

1.6. Field note



1o Feb 19

Notes on Interview 3

This was a new experience in interviewing, and the whole interview was more of a dialog than a story that was shared with me. I felt at ease, and I hope the power relationship was fairly balanced.

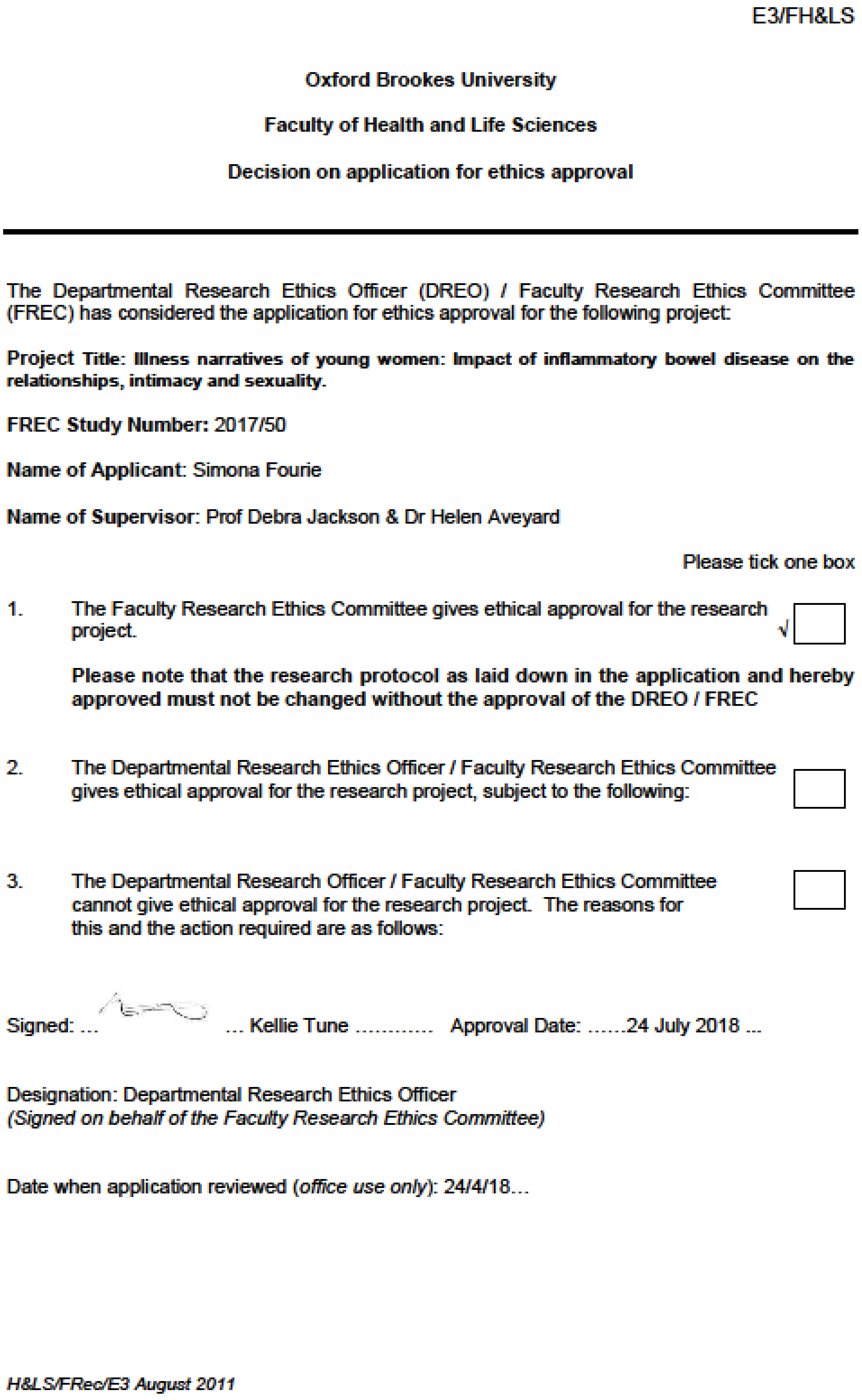
L is a young girl with Crohn's who was very keen on taking part in the study. Her mum was also quite involved contacting the team and trying to help her daughter to get the message across about her willingness to participate when L had struggled to call during school time. Unlike the previous participants she had a positive approach and felt well supported by her peers, which seemed to give her confidence in how to approach a romantic relationship. Trying to understand what was the purpose of her participation on a personal level (all the previous participants had own agenda in sharing their story) I am assuming she just wanted to feel useful in any way she could as in advancing knowledge about her illness.

She giggled a lot when she mentioned her 'stoma farts', possibly as she felt uncomfortable, and trying to hide this, but was tearful when she talked about peer acceptance.

I tried to get more about her relationship experience, and was not very successful. I have to find ways of getting more probing questions for similar situations.

It was a short but interesting interview, I have to prepare for younger people who are interviewed and accept they may not have long stories and perhaps be ready to look deeper into why they say what they say and how they say it, as opposed to strictly looking at the content of their interviews.

1.7. NHS study-Faculty ethics approval



E3/FH&LS

Oxford Brookes University

Faculty of Health and Life Sciences

Decision on application for ethics approval

The Departmental Research Ethics Officer (DREO) / Faculty Research Ethics Committee (FREC) has considered the application for ethics approval for the following project:

Project Title: Illness narratives of young women: Impact of inflammatory bowel disease on the relationships, intimacy and sexuality.

FREC Study Number: 2017/50

Name of Applicant: Simona Fourie

Name of Supervisor: Prof Debra Jackson & Dr Helen Aveyard

Please tick one box

1. The Faculty Research Ethics Committee gives ethical approval for the research project. √ ☐

   Please note that the research protocol as laid down in the application and hereby approved must not be changed without the approval of the DREO / FREC

2. The Departmental Research Ethics Officer / Faculty Research Ethics Committee gives ethical approval for the research project, subject to the following: ☐

3. The Departmental Research Officer / Faculty Research Ethics Committee cannot give ethical approval for the research project. The reasons for this and the action required are as follows: ☐

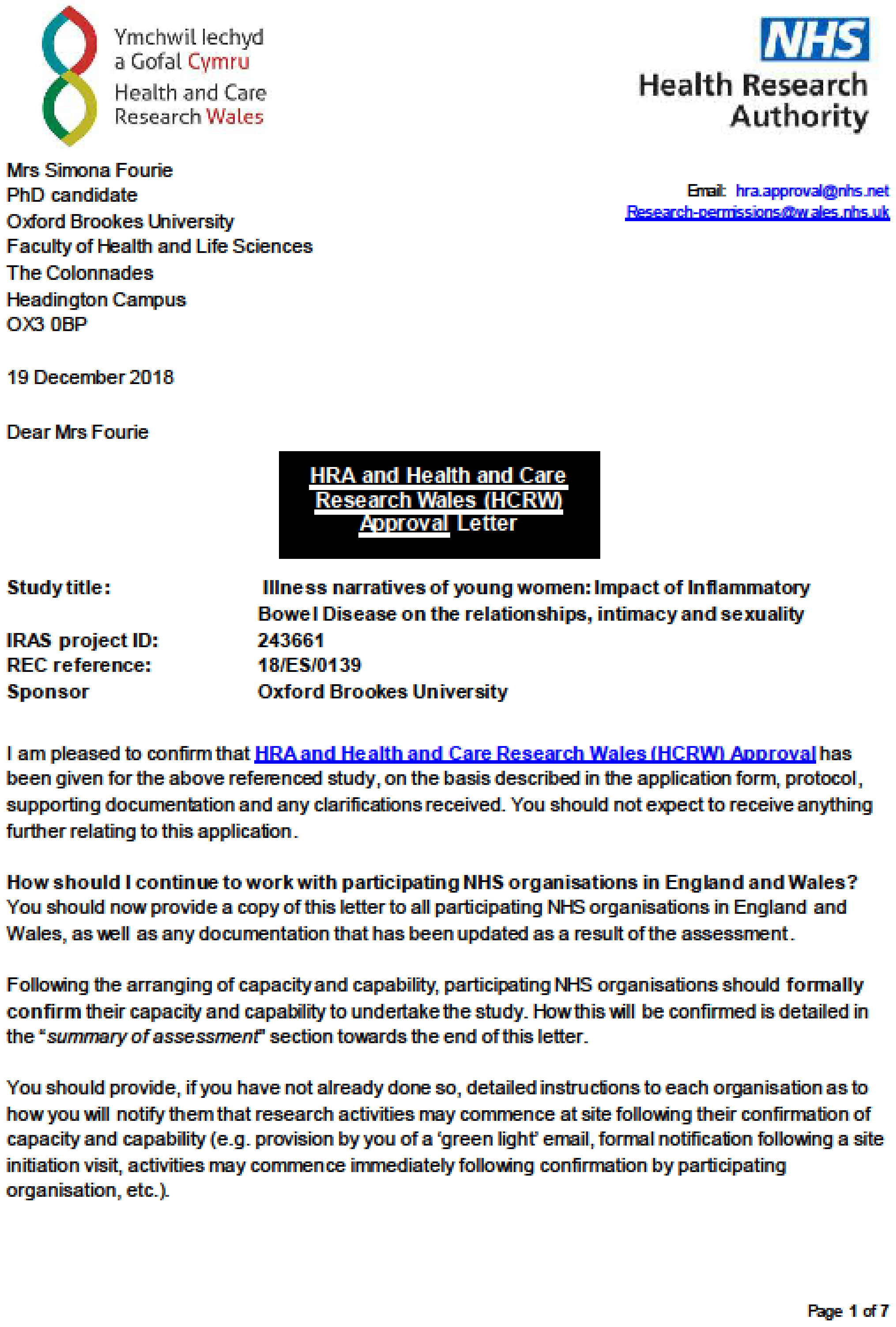
Signed: ... ... Kellie Tune .... Approval Date: ......24 July 2018 ...

Designation: Departmental Research Ethics Officer
(Signed on behalf of the Faculty Research Ethics Committee)

Date when application reviewed (*office use only*): 24/4/18...

H&LS/FRec/E3 August 2011

1.8. HRA approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Mrs Simona Fourie
PhD candidate
Oxford Brookes University
Faculty of Health and Life Sciences
The Colonnades
Headington Campus
OX3 0BP

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

19 December 2018

Dear Mrs Fourie

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Illness narratives of young women: Impact of Inflammatory Bowel Disease on the relationships, intimacy and sexuality**
IRAS project ID:	**243661**
REC reference:	**18/ES/0139**
Sponsor	**Oxford Brookes University**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

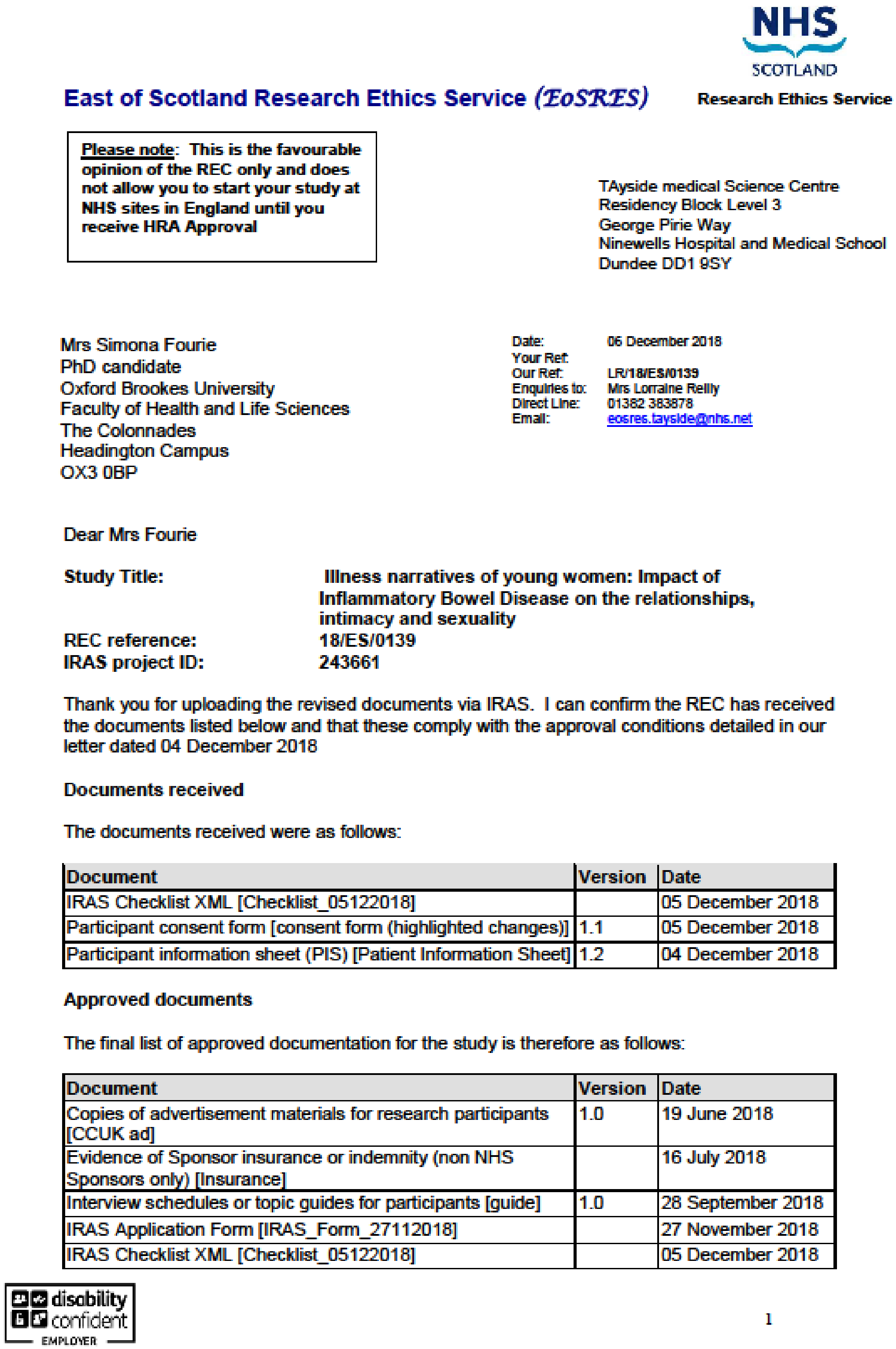
How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should formally confirm their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

Page 1 of 7

1.9. NRES approval



East of Scotland Research Ethics Service (*EoSRES*)

NHS
SCOTLAND
Research Ethics Service

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

TAyside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

Mrs Simona Fourie
PhD candidate
Oxford Brookes University
Faculty of Health and Life Sciences
The Colonnades
Headington Campus
OX3 0BP

Date: 06 December 2018
Your Ref:
Our Ref: LR/18/ES/0139
Enquiries to: Mrs Lorraine Reilly
Direct Line: 01382 383878
Email: eosres.tayside@nhs.net

Dear Mrs Fourie

Study Title: **Illness narratives of young women: Impact of Inflammatory Bowel Disease on the relationships, intimacy and sexuality**
REC reference: **18/ES/0139**
IRAS project ID: **243661**

Thank you for uploading the revised documents via IRAS. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 04 December 2018

Documents received

The documents received were as follows:

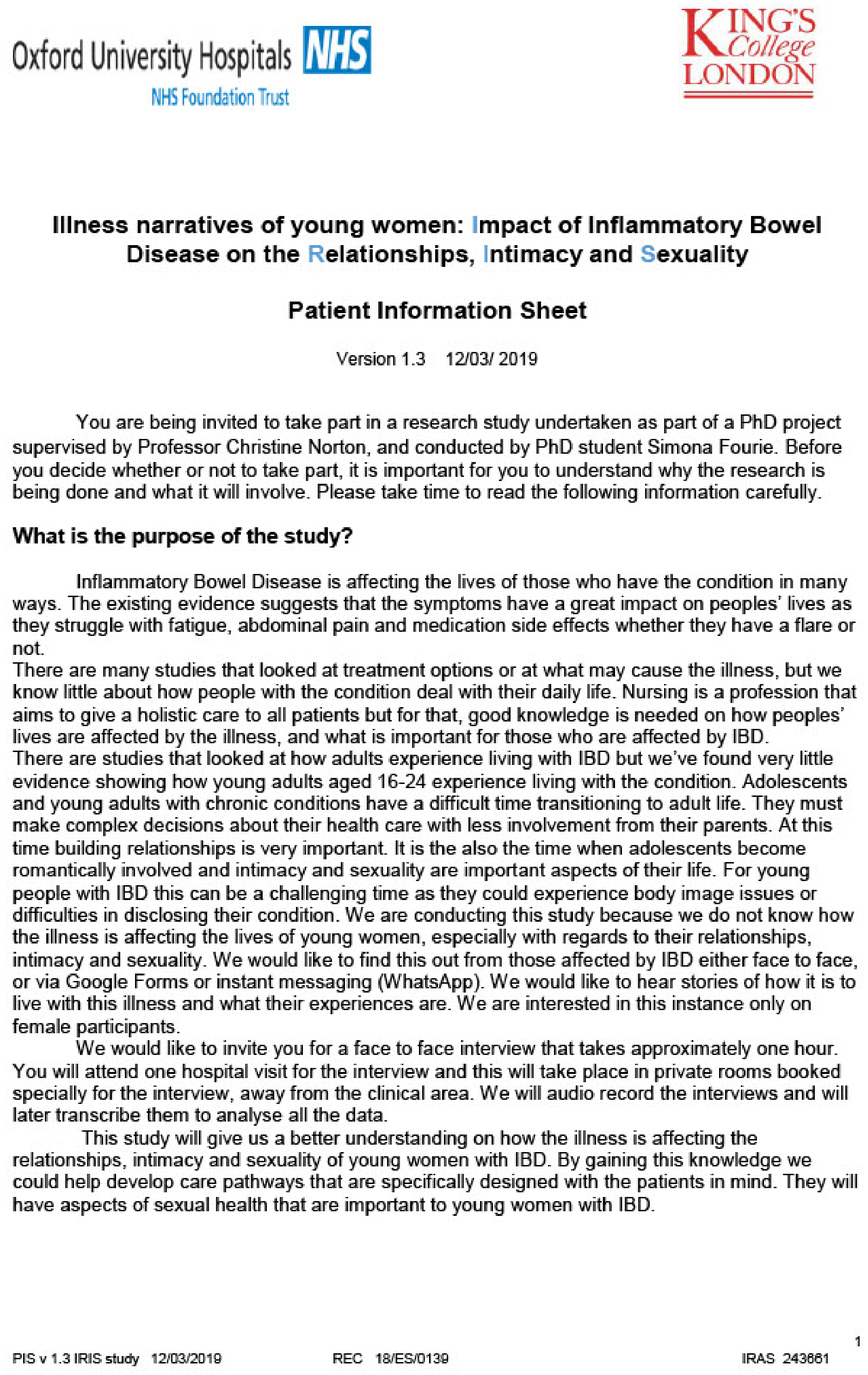
Document	Version	Date
IRAS Checklist XML [Checklist_05122018]		05 December 2018
Participant consent form [consent form (highlighted changes)]	1.1	05 December 2018
Participant information sheet (PIS) [Patient Information Sheet]	1.2	04 December 2018

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Copies of advertisement materials for research participants [CCUK ad]	1.0	19 June 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]		16 July 2018
Interview schedules or topic guides for participants [guide]	1.0	28 September 2018
IRAS Application Form [IRAS_Form_27112018]		27 November 2018
IRAS Checklist XML [Checklist_05122018]		05 December 2018

1.10. NHS Patient Information Sheet



Oxford University Hospitals NHS
NHS Foundation Trust

KING'S College LONDON

Illness narratives of young women: Impact of Inflammatory Bowel Disease on the Relationships, Intimacy and Sexuality

Patient Information Sheet

Version 1.3 12/03/ 2019

You are being invited to take part in a research study undertaken as part of a PhD project supervised by Professor Christine Norton, and conducted by PhD student Simona Fourie. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

Inflammatory Bowel Disease is affecting the lives of those who have the condition in many ways. The existing evidence suggests that the symptoms have a great impact on peoples' lives as they struggle with fatigue, abdominal pain and medication side effects whether they have a flare or not.

There are many studies that looked at treatment options or at what may cause the illness, but we know little about how people with the condition deal with their daily life. Nursing is a profession that aims to give a holistic care to all patients but for that, good knowledge is needed on how peoples' lives are affected by the illness, and what is important for those who are affected by IBD.

There are studies that looked at how adults experience living with IBD but we've found very little evidence showing how young adults aged 16-24 experience living with the condition. Adolescents and young adults with chronic conditions have a difficult time transitioning to adult life. They must make complex decisions about their health care with less involvement from their parents. At this time building relationships is very important. It is the also the time when adolescents become romantically involved and intimacy and sexuality are important aspects of their life. For young people with IBD this can be a challenging time as they could experience body image issues or difficulties in disclosing their condition. We are conducting this study because we do not know how the illness is affecting the lives of young women, especially with regards to their relationships, intimacy and sexuality. We would like to find this out from those affected by IBD either face to face, or via Google Forms or instant messaging (WhatsApp). We would like to hear stories of how it is to live with this illness and what their experiences are. We are interested in this instance only on female participants.

We would like to invite you for a face to face interview that takes approximately one hour. You will attend one hospital visit for the interview and this will take place in private rooms booked specially for the interview, away from the clinical area. We will audio record the interviews and will later transcribe them to analyse all the data.

This study will give us a better understanding on how the illness is affecting the relationships, intimacy and sexuality of young women with IBD. By gaining this knowledge we could help develop care pathways that are specifically designed with the patients in mind. They will have aspects of sexual health that are important to young women with IBD.

1

PIS v 1.3 IRIS study 12/03/2019 REC 18/ES/0139 IRAS 243661

Why have I been invited to participate?

For our study we need 20 participants who attend IBD clinics at Oxford University Hospitals NHS Foundation Trust, and 20 participants from the Crohn's and Colitis UK website. Your clinician believes you are eligible to take part in this study as you are a female aged 16-24, and have been diagnosed with IBD at least 18 months ago.

Do I have to take part?

The answer is NO. Should you decide to not take part or take part and later change your mind (for whatever reason) it is your right to do so, and you would not need to provide an explanation to the study team or anyone else. Your care will not be affected by your decision to withdraw.

Whatever you choose it's important that you are happy with your decision and it is not the role of the study team to help decide for you. We would help present the details of the study and answer all your questions so you could make an informed decision.

What will happen to me if I take part?

You will have at least 24 hours to decide if you would like to take part in the study and you can contact us directly to discuss further. We will answer any questions you have if you are interested, and we will assess your eligibility at the same time.

If you decide to take part in the study you will be invited to attend a face to face interview with the researcher who is an experienced nurse, where you will be asked to discuss how your condition had affected your relationships, intimacy and/ or sexuality (if applicable). A few details about you will be also recorded, such as age and the age you were diagnosed. This interview will be recorded and later the conversation will be fully transcribed by the student, so that the data can be analysed. Once audio recordings are transcribed and electronic anonymised copies saved on a secure server, the audio files will be kept safely until the end of the project. The duration of the interview will be approximately one hour. It will be a one off interview but we do require you to attend an additional visit to the hospital for this. Interviews may take place in university rooms. We expect that you will not be involved in the study for longer than a month, from the time you agree to take part until you are interviewed. Due to the nature of the study there will be no reimbursement for your time and travel.

What are the possible benefits of taking part?

There are no direct benefits of taking part in our study, however, there is evidence that people who openly discuss certain aspects of their life after being diagnosed with a chronic condition feel that the discussion can be therapeutic. However, the interview should not be seen as a substitute for counselling. The further understanding of the topic will help in the future to care for young women with IBD.

What are the possible disadvantages to take part?

We do not anticipate any risks in taking part in this study, however, you may feel slightly distressed when talking about sensitive issues and how illness is affecting you. You may ask at any time to stop the interview and can withdraw from the study if you change your mind. The researcher conducting the interviews has extensive clinical experience in the field of IBD and is familiar with many of the issues that may cause you distress, and she will offer reassurance and will support you during the interview. If you feel distressed or you may want to get further information about IBD and the charity, call Crohn's and Colitis UK (CCUK) Helpline on 0300 222 5700. For emotional support the Support Line is available on 0121 737 9931.
A list of other external support groups can be found at the end of this leaflet.

Will what I say in this study be kept confidential?

Your privacy and anonymity will be kept at all times, during the interview and after.

All personal details as well as the interviews will be kept strictly confidential, subject to the legal limits. If following the interview the researcher has serious safeguarding concerns (this could include concerns around standards of care you have received or challenging situations you may be living in) these may be discussed with your clinical care team.

Once you have given consent to take part in the study you will be given a study number and a pseudonym and all the data will be stored securely under that number/ name. The link between your details and the study number will be kept separately from the transcribed interviews. Only the research team members will have access to the data. Transcribed interviews will be stored in One Drive, for which the University has a security agreement. Any paper documents will be securely stored at King's College London offices, in filing cabinets that are kept locked.

Research data will be kept securely at all times, especially before being transferred back to Kings College London. Laptops and any other electronic devices used will be encrypted and 2 factor authentication will be enabled on all devices. Data generated by the study must be retained in accordance with the University's policy on Academic Integrity. Data generated in the course of the research must be kept securely in paper or electronic form for a period of ten years after the completion of a research project.

We may use quotes from the interviews with your permission, but any publication as a result of this study will not make it possible for you to be identified.

What will happen to your data?

Kings College London is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Kings College London will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting

Individuals from Kings College London and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Oxford University Hospitals NHS Foundation Trust will pass these details to Kings College London along with the information collected from you. The only people in Kings College London who will have access to information that identifies you will be people who need to or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

Kings College London will keep identifiable information about you from this study [for 10 years after the study has finished.

What should I do if I want to take part?

If you wish to take part in this study, please contact the researcher via email or phone provided at the end of this leaflet. If you verbally agreed with the clinician to be contacted by the researcher, you can meet her after your clinic and discuss the study in detail. A date for consent and interview will be agreed based on your availability. If you decide you do not wish to have a face to face interview but would still like to take part in the study anonymously, a link to a Google Form is available here: https://forms.gle/tECnGDVLZP3qLfe37

What will happen to the results of the research study?

The results from the study will be used for a PhD thesis with the aim to be published as journal articles or presented at conferences. The results will help in gaining better understanding of concerns and needs of young women with IBD. If you wish to require a copy of the final publication, please contact the researcher directly.

Who is organising and funding the research?

The study is conducted as part of a student research project from Florence Nightingale nursing midwifery and palliative care faculty, King's College London.

Who has reviewed the study?

The East of Scotland Research Ethics Service REC2 which has responsibility for scrutinising all proposals for medical research on humans, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from Kings College London and Oxford University Hospitals NHS Foundation Trust, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

Contact for Further Information

Simona Fourie
PhD student
King's College London
Florence Nightingale Faculty of Nursing and Midwifery
Waterloo Campus
Email: simona.fourie@kcl.ac.uk
Tel: 01865231460

Prof Christine Norton
James Clerk Maxwell Building
Waterloo Campus,
57 Waterloo Road, London
Tel: 07903 382505
Email: christine.norton@kcl.ac.uk

If you have any concerns about the way in which the study has been conducted, please contact the Patient Advisory Liaison Service (PALS), which is a confidential NHS service that can provide you with support for any complaints or queries you may have regarding the care you receive as an NHS patient. PALS is unable to provide information about this research study.
If you wish to contact the PALS team please contact and email from the PALS website http://www.ouh.nhs.uk/patient-guide/pals.aspx.

Thank you for taking the time to read this leaflet.

Organisations providing information and support

If you need further support for your emotional needs, you have unmet needs in your care or safeguarding issues, please find a list of external organisations available to offer information and help.

1. **Crohn's and Colitis UK** offers support and information to IBD patients.
    - Information Service https://www.crohnsandcolitis.org.uk/support/information-service.
      or call Helpline 03002225700

- For Emotional Support https://www.crohnsandcolitis.org.uk/support/emotional-support or call Support line 01207379931

2. **Patient Advice and Liaison Services** Oxford University Hospital NHS Foundation Trust

It is a confidential service that aims to:

- advise and support patients, their families, and their carers
- listen to patients' concerns, queries and suggestions
- help sort out problems quickly on your behalf
- inform patients, their families and their carers about the Trust's Complaints Procedure
- Assist you if you have any concerns about your rights as a patient and how the OUH is fulfilling its part of the NHS Constitution with regard to your own care.

John Radcliffe Hospital

- Tel: **01865 221473**
- Email: PALS@ouh.nhs.uk

Horton General Hospital

- PALS Office
  Horton General Hospital
  Oxford Road
  Banbury, OX16 9AL
- Tel: **01295 229259**
- Email: PALS@ouh.nhs.uk

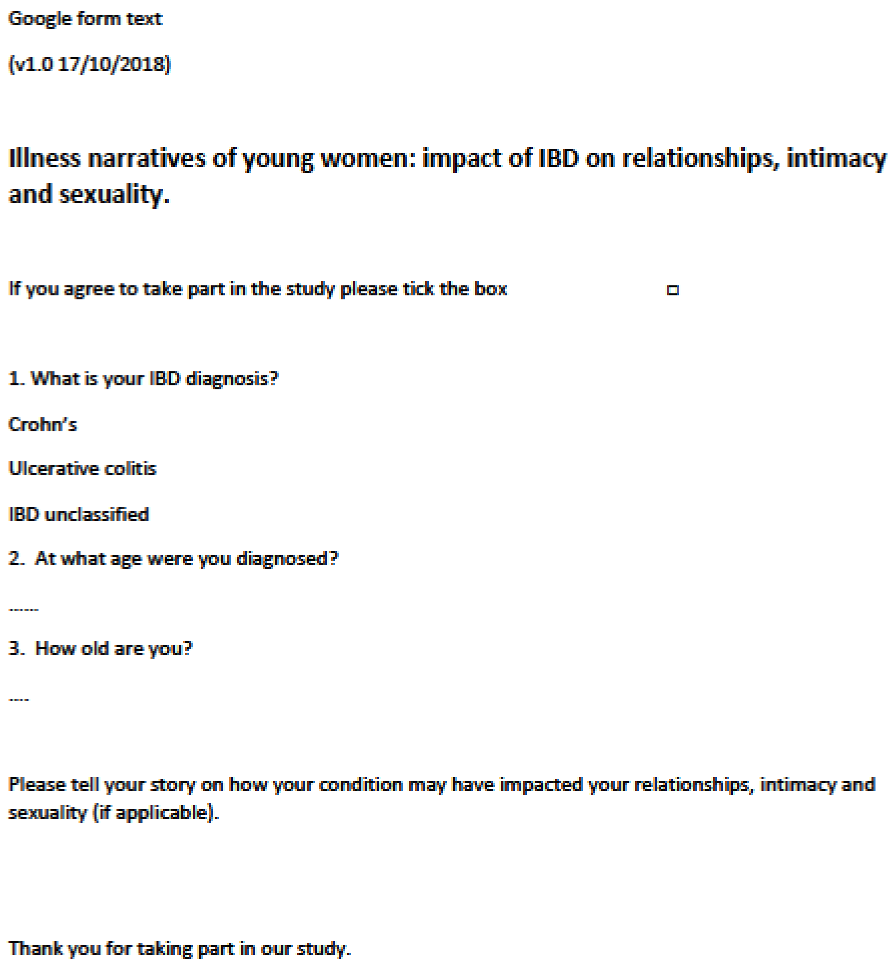
3. **Women's aid**- offer support for those who suffered domestic abuse

https://www.womensaid.org.uk/the-survivors-handbook/emotional-support-and-counselling/

4. **Relate** offers counselling and psychosexual therapy to anyone who seeks help. Search for your local centre on www.relate.org.uk

5. **The Bladder and Bowel UK** is a National Confidential helpline managed by a team of Specialist Nurses and Continence Product Information staff, who can be contacted for advice on specialist services, product information and general advice on continence promotion on (0161 607 8219) or via email bladderandboweluk@disabledliving.co.uk

1.11. Google Form text



Google form text

(v1.0 17/10/2018)

Illness narratives of young women: impact of IBD on relationships, intimacy and sexuality.

If you agree to take part in the study please tick the box ☐

1. What is your IBD diagnosis?

Crohn's

Ulcerative colitis

IBD unclassified

2. At what age were you diagnosed?

......

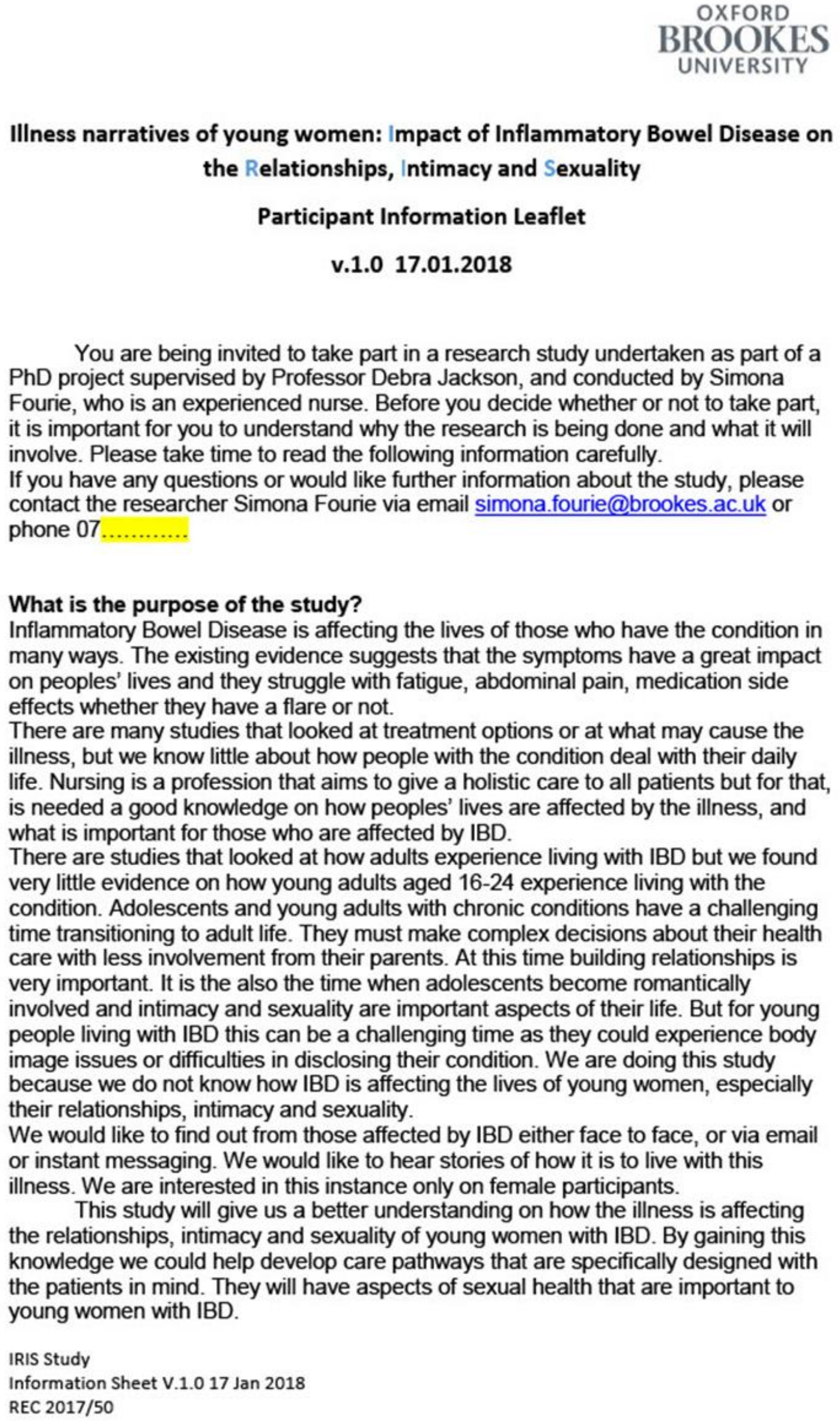
3. How old are you?

....

Please tell your story on how your condition may have impacted your relationships, intimacy and sexuality (if applicable).

Thank you for taking part in our study.

1.12. CCUK Participant Information



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UNIVERSITY

Illness narratives of young women: Impact of Inflammatory Bowel Disease on the Relationships, Intimacy and Sexuality

Participant Information Leaflet

v.1.0 17.01.2018

You are being invited to take part in a research study undertaken as part of a PhD project supervised by Professor Debra Jackson, and conducted by Simona Fourie, who is an experienced nurse. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

If you have any questions or would like further information about the study, please contact the researcher Simona Fourie via email simona.fourie@brookes.ac.uk or phone 07............

What is the purpose of the study?

Inflammatory Bowel Disease is affecting the lives of those who have the condition in many ways. The existing evidence suggests that the symptoms have a great impact on peoples' lives and they struggle with fatigue, abdominal pain, medication side effects whether they have a flare or not.

There are many studies that looked at treatment options or at what may cause the illness, but we know little about how people with the condition deal with their daily life. Nursing is a profession that aims to give a holistic care to all patients but for that, is needed a good knowledge on how peoples' lives are affected by the illness, and what is important for those who are affected by IBD.

There are studies that looked at how adults experience living with IBD but we found very little evidence on how young adults aged 16-24 experience living with the condition. Adolescents and young adults with chronic conditions have a challenging time transitioning to adult life. They must make complex decisions about their health care with less involvement from their parents. At this time building relationships is very important. It is the also the time when adolescents become romantically involved and intimacy and sexuality are important aspects of their life. But for young people living with IBD this can be a challenging time as they could experience body image issues or difficulties in disclosing their condition. We are doing this study because we do not know how IBD is affecting the lives of young women, especially their relationships, intimacy and sexuality.

We would like to find out from those affected by IBD either face to face, or via email or instant messaging. We would like to hear stories of how it is to live with this illness. We are interested in this instance only on female participants.

This study will give us a better understanding on how the illness is affecting the relationships, intimacy and sexuality of young women with IBD. By gaining this knowledge we could help develop care pathways that are specifically designed with the patients in mind. They will have aspects of sexual health that are important to young women with IBD.

IRIS Study
Information Sheet V.1.0 17 Jan 2018
REC 2017/50

Why have I been invited to participate?
For our study we need at least 20 participants who respond to our study advert on the Crohn's and Colitis UK website, and 20 participants that attend an IBD clinic at Oxford University Hospitals. You must be 16 to 24-year-old, female, and have been diagnosed with IBD at least 18 months ago.

What will happen to me if I take part?

You have seen this information leaflet by accessing ***Taking part in Research*** on Crohn's and Colitis UK website. You will have time to decide if you would like to take part in the study and if you reply to our advert we will consider this as implied consent.

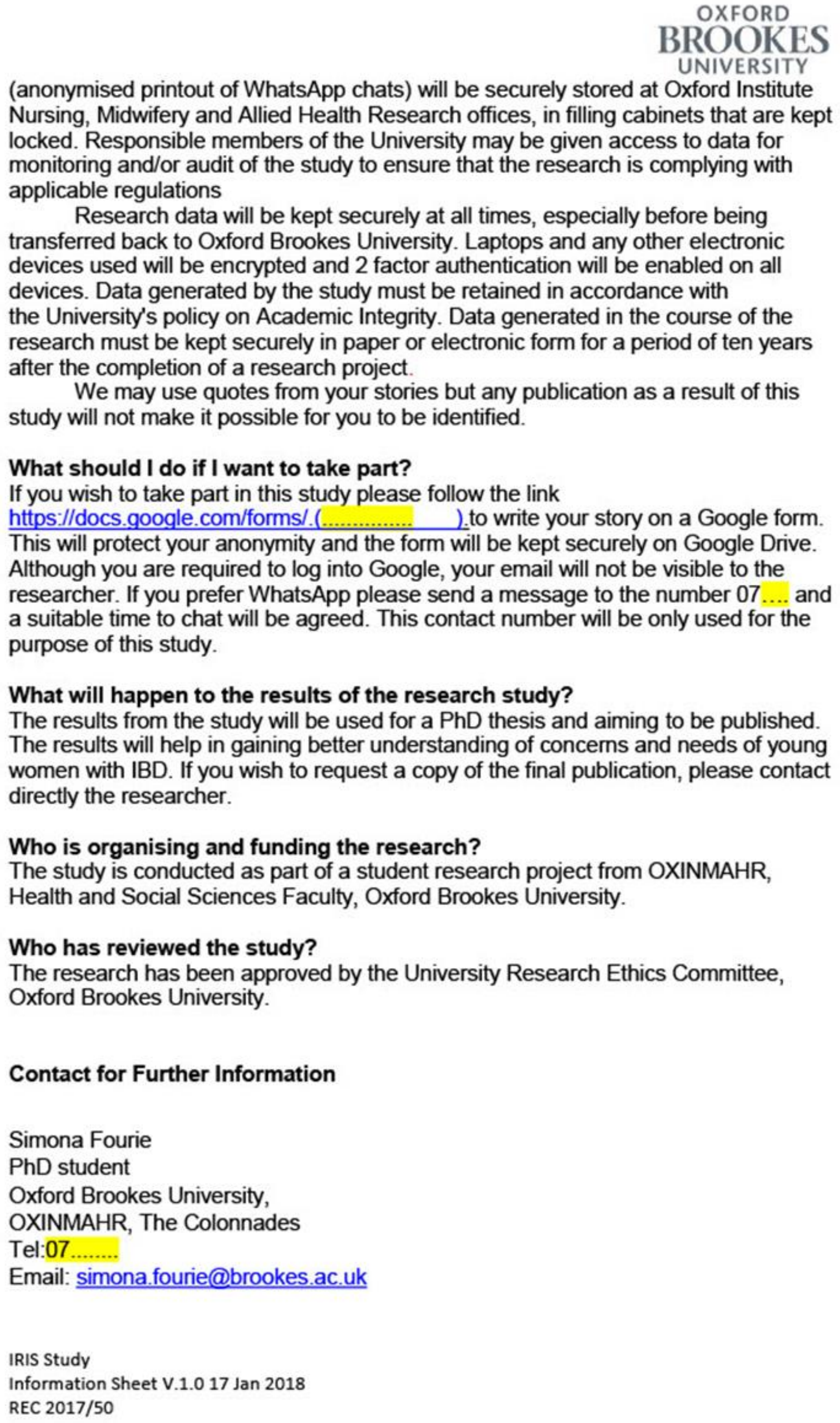
If you decide to take part in the study you will be invited to write a detailed account (your story) on how your condition had affected your relationships, intimacy and sexuality (if applicable). A few details about you will be also required, such as age, the age you were diagnosed and if you have Crohn's or Ulcerative colitis. You can do this at a time and place that is convenient to you. If you prefer to have a discussion with the researcher via WhatsApp you will need to send a text to agree with the researcher on a time that is convenient as the discussion may last up to an hour. If you chose to use WhatsApp we recommend you create an account/pseudomin that will not allow your identity to be seen by the researcher. Only your phone number will be visible to the researcher which will not make it possible for you to be identified as long as you will not sign with your name.

What are the possible benefits of taking part?
There are no direct benefits of taking part in our study, however, there is evidence that people who openly discuss certain aspects of their life after being diagnosed with a chronic condition feel that the discussion can be therapeutic. However, interviewing during the study should not be seen as a substitute for counselling. The further understanding of the topic will help in the future to care for young women with IBD.

What are the possible disadvantages to take part?
We do not anticipate any risks in taking part in this study, however you may feel slightly distressed when writing about sensitive issues and how illness is affecting you. You may want to get further support from Crohn's and Colitis UK (CCUK) Helpline on 08451303344.

Also, there is a risk of others accessing your phone or PC and read your story. We strongly recommend that you take all the necessary steps to ensure that your phone is well protected and chats are deleted immediately to avoid any potential disclosure of sensitive information to those who may access your phone/PC.

Will what I say in this study be kept confidential?
Your privacy and anonymity will be kept at all times, during the study duration and after. Your personal details (email address) will not be visible to the researcher if you complete a Google Form. The contents of the forms or the instant chat will be kept strictly confidential in accordance with Data Protection Act 1998. Only the research team members will have access to the data. The forms will be stored in Google Drive, for which the University has a security agreement. Any paper documents



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(anonymised printout of WhatsApp chats) will be securely stored at Oxford Institute Nursing, Midwifery and Allied Health Research offices, in filling cabinets that are kept locked. Responsible members of the University may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations

Research data will be kept securely at all times, especially before being transferred back to Oxford Brookes University. Laptops and any other electronic devices used will be encrypted and 2 factor authentication will be enabled on all devices. Data generated by the study must be retained in accordance with the University's policy on Academic Integrity. Data generated in the course of the research must be kept securely in paper or electronic form for a period of ten years after the completion of a research project.

We may use quotes from your stories but any publication as a result of this study will not make it possible for you to be identified.

What should I do if I want to take part?
If you wish to take part in this study please follow the link https://docs.google.com/forms/.(...............) to write your story on a Google form. This will protect your anonymity and the form will be kept securely on Google Drive. Although you are required to log into Google, your email will not be visible to the researcher. If you prefer WhatsApp please send a message to the number 07.... and a suitable time to chat will be agreed. This contact number will be only used for the purpose of this study.

What will happen to the results of the research study?
The results from the study will be used for a PhD thesis and aiming to be published. The results will help in gaining better understanding of concerns and needs of young women with IBD. If you wish to request a copy of the final publication, please contact directly the researcher.

Who is organising and funding the research?
The study is conducted as part of a student research project from OXINMAHR, Health and Social Sciences Faculty, Oxford Brookes University.

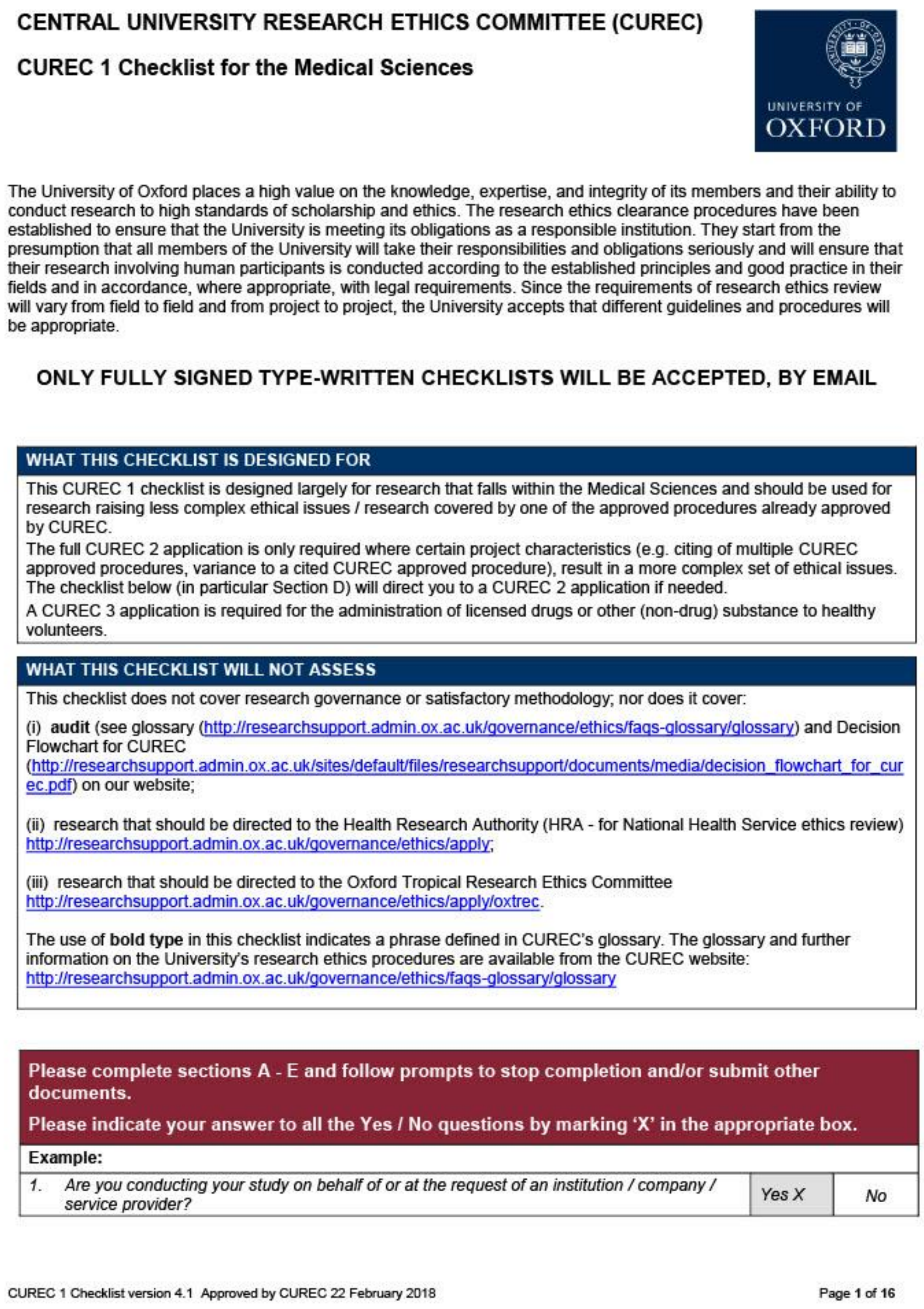
Who has reviewed the study?
The research has been approved by the University Research Ethics Committee, Oxford Brookes University.

Contact for Further Information

Simona Fourie
PhD student
Oxford Brookes University,
OXINMAHR, The Colonnades
Tel:07........
Email: simona.fourie@brookes.ac.uk

IRIS Study
Information Sheet V.1.0 17 Jan 2018
REC 2017/50

1.13. Central University Research Ethics approval



CENTRAL UNIVERSITY RESEARCH ETHICS COMMITTEE (CUREC)

CUREC 1 Checklist for the Medical Sciences

UNIVERSITY OF OXFORD

The University of Oxford places a high value on the knowledge, expertise, and integrity of its members and their ability to conduct research to high standards of scholarship and ethics. The research ethics clearance procedures have been established to ensure that the University is meeting its obligations as a responsible institution. They start from the presumption that all members of the University will take their responsibilities and obligations seriously and will ensure that their research involving human participants is conducted according to the established principles and good practice in their fields and in accordance, where appropriate, with legal requirements. Since the requirements of research ethics review will vary from field to field and from project to project, the University accepts that different guidelines and procedures will be appropriate.

ONLY FULLY SIGNED TYPE-WRITTEN CHECKLISTS WILL BE ACCEPTED, BY EMAIL

WHAT THIS CHECKLIST IS DESIGNED FOR

This CUREC 1 checklist is designed largely for research that falls within the Medical Sciences and should be used for research raising less complex ethical issues / research covered by one of the approved procedures already approved by CUREC.

The full CUREC 2 application is only required where certain project characteristics (e.g. citing of multiple CUREC approved procedures, variance to a cited CUREC approved procedure), result in a more complex set of ethical issues. The checklist below (in particular Section D) will direct you to a CUREC 2 application if needed.

A CUREC 3 application is required for the administration of licensed drugs or other (non-drug) substance to healthy volunteers.

WHAT THIS CHECKLIST WILL NOT ASSESS

This checklist does not cover research governance or satisfactory methodology; nor does it cover:

(i) **audit** (see glossary (http://researchsupport.admin.ox.ac.uk/governance/ethics/faqs-glossary/glossary) and Decision Flowchart for CUREC (http://researchsupport.admin.ox.ac.uk/sites/default/files/researchsupport/documents/media/decision_flowchart_for_curec.pdf) on our website;

(ii) research that should be directed to the Health Research Authority (HRA - for National Health Service ethics review) http://researchsupport.admin.ox.ac.uk/governance/ethics/apply;

(iii) research that should be directed to the Oxford Tropical Research Ethics Committee http://researchsupport.admin.ox.ac.uk/governance/ethics/apply/oxtrec.

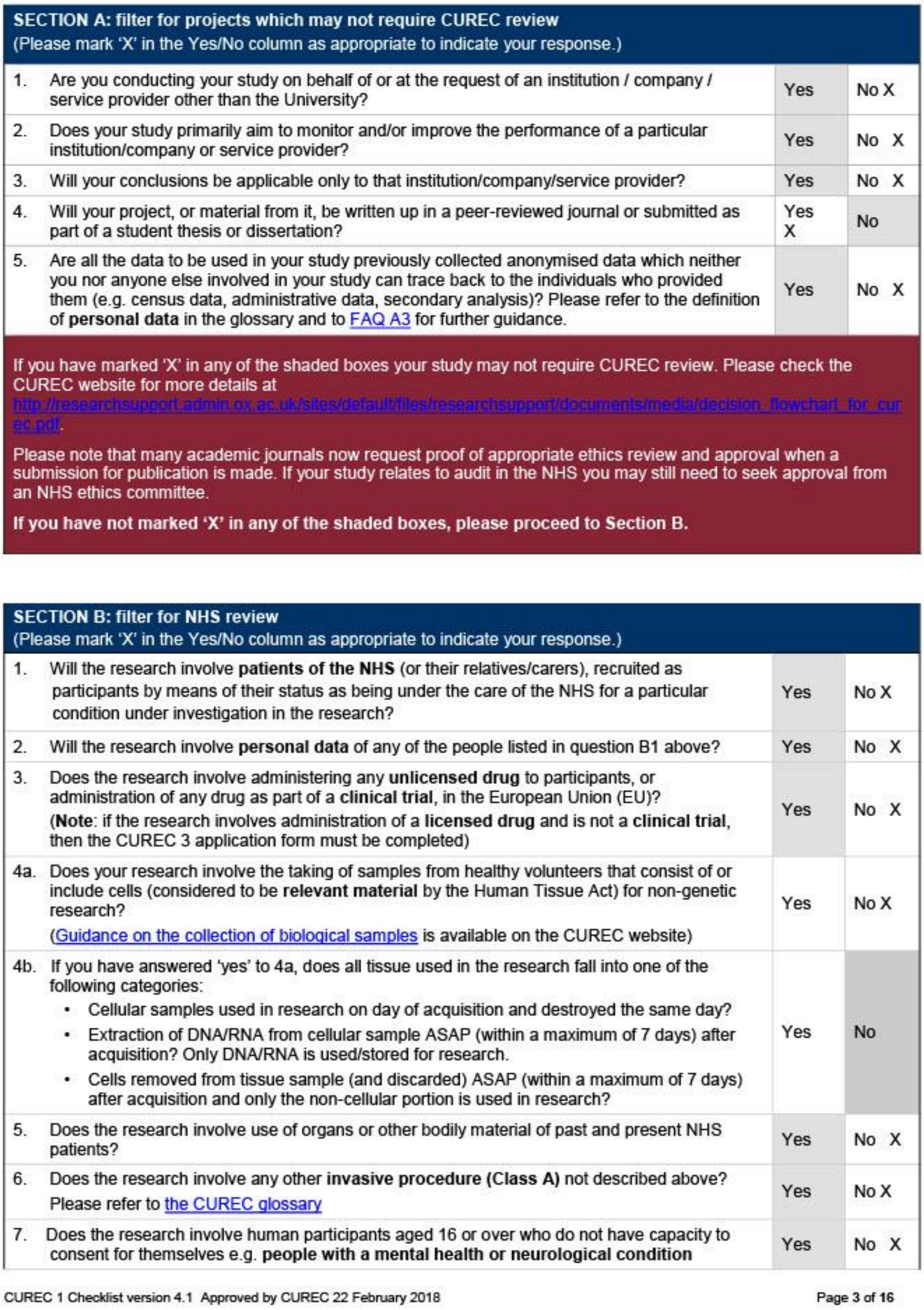
The use of **bold type** in this checklist indicates a phrase defined in CUREC's glossary. The glossary and further information on the University's research ethics procedures are available from the CUREC website: http://researchsupport.admin.ox.ac.uk/governance/ethics/faqs-glossary/glossary

Please complete sections A - E and follow prompts to stop completion and/or submit other documents.

Please indicate your answer to all the Yes / No questions by marking 'X' in the appropriate box.

Example:

1.	*Are you conducting your study on behalf of or at the request of an institution / company / service provider?*	*Yes X*	*No*



SECTION A: filter for projects which may not require CUREC review
(Please mark 'X' in the Yes/No column as appropriate to indicate your response.)

1.	Are you conducting your study on behalf of or at the request of an institution / company / service provider other than the University?	Yes	No X
2.	Does your study primarily aim to monitor and/or improve the performance of a particular institution/company or service provider?	Yes	No X
3.	Will your conclusions be applicable only to that institution/company/service provider?	Yes	No X
4.	Will your project, or material from it, be written up in a peer-reviewed journal or submitted as part of a student thesis or dissertation?	Yes X	No
5.	Are all the data to be used in your study previously collected anonymised data which neither you nor anyone else involved in your study can trace back to the individuals who provided them (e.g. census data, administrative data, secondary analysis)? Please refer to the definition of **personal data** in the glossary and to FAQ A3 for further guidance.	Yes	No X

If you have marked 'X' in any of the shaded boxes your study may not require CUREC review. Please check the CUREC website for more details at http://researchsupport.admin.ox.ac.uk/sites/default/files/researchsupport/documents/media/decision_flowchart_for_curec.pdf.

Please note that many academic journals now request proof of appropriate ethics review and approval when a submission for publication is made. If your study relates to audit in the NHS you may still need to seek approval from an NHS ethics committee.

If you have not marked 'X' in any of the shaded boxes, please proceed to Section B.

SECTION B: filter for NHS review
(Please mark 'X' in the Yes/No column as appropriate to indicate your response.)

1.	Will the research involve **patients of the NHS** (or their relatives/carers), recruited as participants by means of their status as being under the care of the NHS for a particular condition under investigation in the research?	Yes	No X
2.	Will the research involve **personal data** of any of the people listed in question B1 above?	Yes	No X
3.	Does the research involve administering any **unlicensed drug** to participants, or administration of any drug as part of a **clinical trial**, in the European Union (EU)? (**Note**: if the research involves administration of a **licensed drug** and is not a **clinical trial**, then the CUREC 3 application form must be completed)	Yes	No X
4a.	Does your research involve the taking of samples from healthy volunteers that consist of or include cells (considered to be **relevant material** by the Human Tissue Act) for non-genetic research? (Guidance on the collection of biological samples is available on the CUREC website)	Yes	No X
4b.	If you have answered 'yes' to 4a, does all tissue used in the research fall into one of the following categories: • Cellular samples used in research on day of acquisition and destroyed the same day? • Extraction of DNA/RNA from cellular sample ASAP (within a maximum of 7 days) after acquisition? Only DNA/RNA is used/stored for research. • Cells removed from tissue sample (and discarded) ASAP (within a maximum of 7 days) after acquisition and only the non-cellular portion is used in research?	Yes	No
5.	Does the research involve use of organs or other bodily material of past and present NHS patients?	Yes	No X
6.	Does the research involve any other **invasive procedure (Class A)** not described above? Please refer to the CUREC glossary	Yes	No X
7.	Does the research involve human participants aged 16 or over who do not have capacity to consent for themselves e.g. **people with a mental health or neurological condition**	Yes	No X

If you have marked 'X' in any of the shaded boxes in Section B **please stop work on this checklist as you will need to submit your proposal to the appropriate NHS ethics committee**. Further details may be obtained from the HRA website http://www.hra.nhs.uk/about-the-hra/our-committees/res/.

If you have not marked 'X' in any of the shaded boxes so far, please proceed to Section C.

SECTION C – filter for OxTREC review

(Please mark 'X' in the Yes/No column as appropriate to indicate your response.)

1.	Is the study to be funded by the US National Institutes of Health or another US federal funding agency?	Yes	No
2.	Will you conduct your research wholly outside the EU? If 'Yes', will the research involve any of the following:	Yes	No x
	(a) a medical, therapeutic, or pharmaceutical intervention of any kind?	Yes	No
	(b) participants recruited by virtue of being under the care of a healthcare professional?	Yes	No
	(c) identification of conditions which require the attention of a healthcare professional?	Yes	No
	(d) an **invasive procedure (Class A)**	Yes	No
	(e) use of CUREC approved procedure IDREC_19 for studies investigating experimentally-induced pain in adult healthy volunteers.	Yes	No

If you have marked 'X' in any of the shaded boxes in Section C **please stop work on this checklist as you will need to submit your proposal to OxTREC, which uses separate documentation.**

If you have not marked 'X' in any of the shaded boxes so far, please proceed to Section D.

SECTION D: filter for CUREC 2 or CUREC 3 review

(Please mark 'X' in the Yes/No column as appropriate to indicate your response. Refer to the CUREC glossary for terms in bold type)

1.	Have you made arrangements to obtain appropriate **informed consent** from participants?	Yes	No
2a.	Does your research involve any use of **personal data** obtained from a **third party**?	Yes	No
2b.	If 'yes', have you checked to ensure that the third party has arrangements in place to permit disclosure?	Yes	No
3.	Are research participants classed as **people whose ability to give free and informed consent is in question**? (This may include those under 18 (though see "competent youths" in FAQ C12), prisoners, or adults "at risk".) Your attention is drawn to the University's **Safeguarding Code of Practice** and its implications for researchers involving children or adults at risk, including the need for the work to be risk assessed and for researchers to undertake related training. (**Note**: If any of your participants are aged 16 or under, please answer 'Yes' here **and** also answer question 17 below.)	Yes	No
4.	Does your research raise issues relevant to the Counter-Terrorism and Security Act (the Prevent Duty), which seeks to prevent people from being drawn into terrorism? Please see advice on this on our Best Practice Guidance Web Page.	Yes	No
5.	Does the research involve any alteration of participants' normal patterns of sleeping, eating, or drinking?	Yes	No
6.	Does the research involve the administration of any **licensed drug** or medicinal product including the administration of foodstuffs or food supplements outside of normal patterns of consumption? (**Note**: if the research involves administration of any of the above and is not a **clinical trial**, then the CUREC 3 application form must be completed instead of sections F onwards of this form)	Yes	No
7.	Does the research involve the use of either a non-CE marked **medical device**, or a device that has been modified or is being used for a purpose not covered by the CE mark?	Yes	No

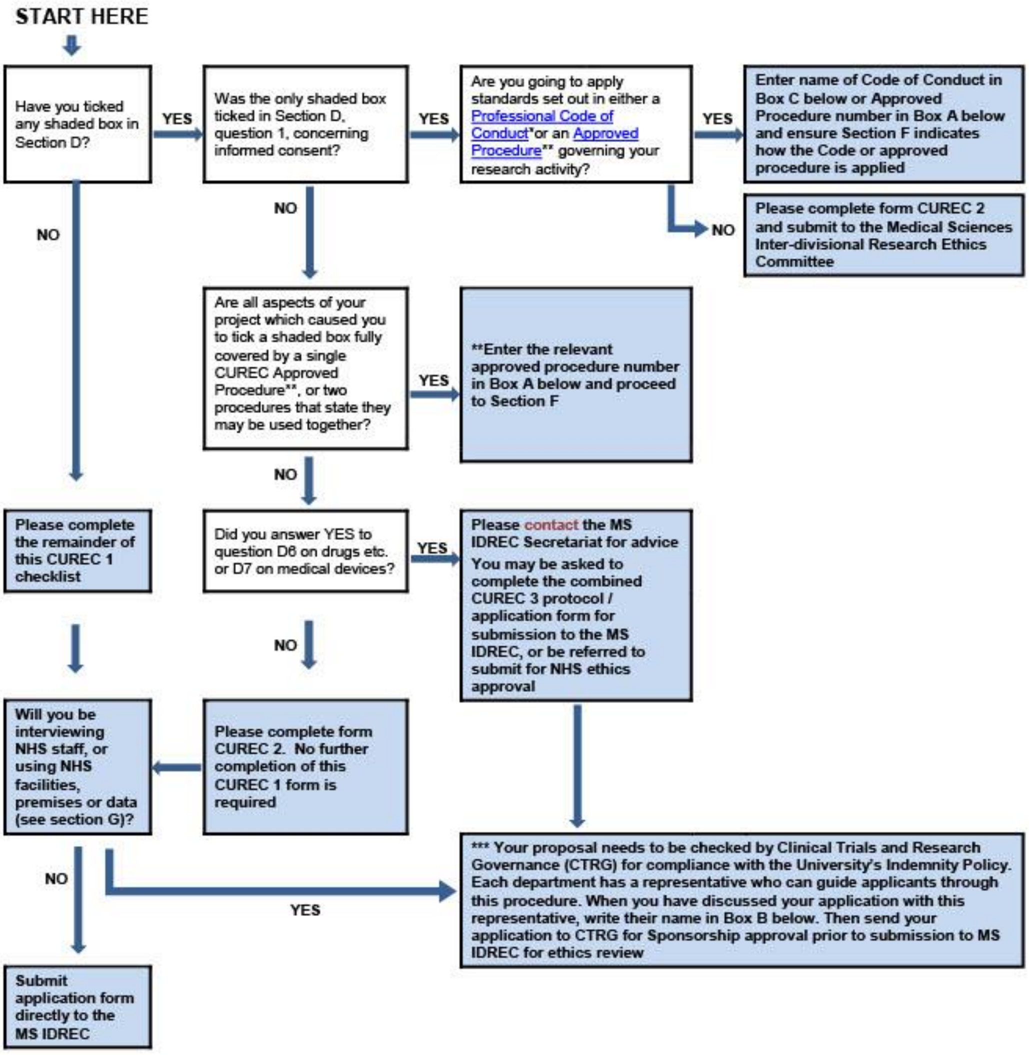
8. Is there a significant risk that the research will expose participants to visual, auditory, or other environmental stimuli of a level or type that could have short- or long-term harmful physical effects?	Yes	No X
9. Is there a significant risk that the research will induce anxiety, stress or other harmful psychological states in participants that might persist beyond the duration of the test/interview?	Yes	No X
10. Does the research involve exposing participants to any physical or psychological hazard, beyond those of their usual everyday life, not covered by questions 8 and 9?	Yes	No X
11. Does the research involve any **invasive procedures (class B)**?	Yes	No X
12. Does the research involve any of the following: • magnetic resonance imaging in the EU outside the terms of the CUREC Approved Procedure for non-invasive magnetic resonance investigations in healthy volunteers, IDREC_17, • transcranial current stimulation outside the terms of CUREC Approved Procedures IDREC_21 and IDREC_22 • pain stimulation outside the terms of CUREC Approved Procedure IDREC_19? (Note that research conducted within the terms of these Approved Procedures must cite them in Section E)	Yes	No X
13. Will the research elicit information from participants that might render them liable to criminal proceedings (e.g. information on drug abuse or child abuse)?	Yes	No X
14. Does the research involve the **deception** of participants?	Yes	No X
15. Will the research require a participant to spend more than 2 hours in any single session on activities designed by the researcher (NB this time restriction does not refer to situations where participants are observed going about activities not devised by the researchers e.g. observation of lessons in schools)?	Yes	No X
16. Will the research involve a significant risk of any harm of any kind to any participant not covered above?	Yes	No X
17a. Is your project fully covered by a CUREC Approved Procedure?	Yes	No X
17b. Does your application cite more than one CUREC Approved Procedure?	Yes	No X
17c. If 'yes', do the cited Approved Procedures state that they may be used in combination with the other cited Approved Procedure(s)?	Yes	No

IF YOU HAVE MARKED 'X' IN ANY OF THE SHADED BOXES IN SECTION D, **PLEASE CONSULT AND COMPLETE THE FLOWCHART IN SECTION E BELOW.**

FOLLOW THE GUIDANCE GIVEN FOR COMPLETION OF A CUREC 2 OR CUREC 3 APPLICATION IF THE FLOWCHART SPECIFIES THIS IS REQUIRED.

IF THE FLOWCHART OUTCOME IS THAT YOU SHOULD COMPLETE A CUREC 2 OR CUREC 3 APPLICATION THEN **NO FURTHER COMPLETION OF THIS CHECKLIST IS REQUIRED.**

SECTION E : Flow Chart



START HERE

Have you ticked any shaded box in Section D?

YES

Was the only shaded box ticked in Section D, question 1, concerning informed consent?

YES

Are you going to apply standards set out in either a Professional Code of Conduct*or an Approved Procedure** governing your research activity?

YES

Enter name of Code of Conduct in Box C below or Approved Procedure number in Box A below and ensure Section F indicates how the Code or approved procedure is applied

NO

Please complete form CUREC 2 and submit to the Medical Sciences Inter-divisional Research Ethics Committee

NO

Are all aspects of your project which caused you to tick a shaded box fully covered by a single CUREC Approved Procedure**, or two procedures that state they may be used together?

YES

****Enter the relevant approved procedure number in Box A below and proceed to Section F**

NO

Did you answer YES to question D6 on drugs etc. or D7 on medical devices?

YES

Please contact the MS IDREC Secretariat for advice

You may be asked to complete the combined CUREC 3 protocol / application form for submission to the MS IDREC, or be referred to submit for NHS ethics approval

NO

Please complete form CUREC 2. No further completion of this CUREC 1 form is required

NO

Please complete the remainder of this CUREC 1 checklist

Will you be interviewing NHS staff, or using NHS facilities, premises or data (see section G)?

YES

***** Your proposal needs to be checked by Clinical Trials and Research Governance (CTRG) for compliance with the University's Indemnity Policy. Each department has a representative who can guide applicants through this procedure. When you have discussed your application with this representative, write their name in Box B below. Then send your application to CTRG for Sponsorship approval prior to submission to MS IDREC for ethics review**

NO

Submit application form directly to the MS IDREC

A. Approved procedure number(s) (*if required at ** above*):

B. Name of departmental representative consulted: (if required at * above):**

C. Professional Code of Conduct and section applied (if required at * above):

SECTION F: Application for CUREC 1 approval	
Contact details:	
1. **Principal Investigator** / Student supervisor (title & name):	Prof Alison Simmons Co Investigators Prof Christine Norton, Simona Fourie
2. Name of student (if student research):	Simona Fourie
3. Degree programme, e.g. DPhil, MPhil, BSc, MSc (if student research):	PhD
4. Status if you are NOT employed by the University of Oxford, nor a student registered for a degree at the University of Oxford [e.g. Visiting Researcher]. In such cases a member of the University associated with the project should be named.	
5. Department or Institute name:	NDM
6. Address for correspondence (if different from 5 above):	
7. University E-mail address:	Simona.fourie@ndm.ox.ac.uk
8. Contact telephone number:	018645231460
Project description:	
9a. Full title of research project:	Intimacy and sexuality concerns of those living with Inflammatory Bowel Disease and the need for these to be addressed by healthcare professionals. A qualitative study.
9b. Short title (optional - for use on participant-facing documents):	IBD Ask
9c. (TO BE COMPLETED BY EXPERIMENTAL PSYCHOLOGY UNDERGRADUATE APPLICANTS ONLY) If the entire proposal is already covered by an existing approved CUREC 2 ethics application held by your supervisor, please enter the ethics reference here	
10. List all **sites** where project will be conducted:	Oxford
11. If your research involves overseas travel or fieldwork, have you completed and returned a travel risk assessment form? (Bear in mind that this may be necessary to ensure that the travel or fieldwork is covered by the University's travel insurance – see www.admin.ox.ac.uk/finance/insurance/travel)	N/A
12. Anticipated start and end dates of study: (n.b. A minimum approval period of 1 year and maximum of 5 years can be granted)	From: 01/11/2018 To: 31/12/2020
13. Name and status of **other researchers** taking part in the project (e.g. third year undergraduate; post-doctoral research assistant):	Prof Norton is a Gastroenterology Nursing Professor based at King's College London with extensive experience in IBD research. Simona Fourie is a research nurse, and is half way through her qualitative methods PhD.
14. External organisation (or University internal grant) funding the research (if applicable):	n/a
Does the funding body require some form of monitoring of the conduct of the research until completion (e.g. annual ethical re-approval of the study)?	No

/Section F, 15. (continued)

SECTION F: Application for CUREC 1 approval (continued)

15. Project description

As you answer the questions below, please ensure you cite the following documents which, if applicable, must accompany this form:

- recruitment and advertisement material – template poster available
- participant information sheet (guidance at http://researchsupport.admin.ox.ac.uk/governance/ethics/resources/consent)
- consent form (guidance at http://researchsupport.admin.ox.ac.uk/governance/ethics/resources/consent)
- any additional documentation required by a cited Approved Procedure

15a. Brief lay description of research

Please include (as appropriate):

- Remuneration details (if applicable)
- How professional guidelines are being applied (if applicable)
- Declare any conflicts of interest

- Study aim

To identify concerns of those living with inflammatory bowel disease related to intimacy and sexuality. We also aim to explore the need for these aspects of their life to be discussed with the healthcare professionals. The outcome of the study is to understand if those living with the condition have intimacy and sexuality concerns and how these can be addressed by healthcare professionals.

- Methodology

This is a qualitative study. We will interview face to face (where possible), via telephone or email 20 people living with IBD and are members of Crohn's and Colitis UK. The study will be posted on the **Take part in research** page on the CCUK website and those willing to take part will contact the research team if they are interested in taking part.

- Number of tasks/visits, duration & frequency

The interviews will last approximately one hour and will be audio recorded and transcribed. The email interviews will be done via Google forms to reduce the chances of potentially sensitive information being accessed on participants PC.

- Use to which the study results/data will be put

Depending on the results, they may lead to further development of tools to measure if such concerns exist in patients with IBD attending clinical appointments. Also, HCP may gain information on how to detect and address such issues in a manner that is acceptable to patients.

- There are no conflicts of interest.

15b. Description of participants and obtaining informed consent

Please include:

- Criteria for inclusion/exclusion
- Method of identification and/or recruitment
- Number you intend to recruit
- Process of obtaining consent to participate

Inclusion:

- Aged over 18
- Known IBD diagnosis for at least 18 months
- Good command of English language

Exclusion: Under 18

We are aiming to recruit up to 40 participants that have in common the experience of living with IBD, male and female, aged over 18, whether they are in a relationship or not. Potential participants will contact the research team if they wish to participate and the study will be discussed prior to a consent form being signed and returned to the research team. A PIS will be available for potential participants on CCUK website and a link for Google forms will be available to those interested.

Consent:

Those interested to have a face to face interview will sign a written consent prior to their interview starting. Those opting for a telephone interview will have the verbal consent recorded. For Google forms respondents an online consent form will be signed online.

16. Please indicate what training in research ethics the researchers involved with this study have received, e.g. the title of the online or in-person course, and date completed (online training available at http://researchsupport.admin.ox.ac.uk/support/training/ethics):

Professor Alison Simmons – GCP – 16th June 2017

Ms Simona Fourie – GCP – 4th January 2018

Prof Christine Norton –GCP- 15th November 2018

17. What are the major ethical issues connected with your research and what steps have you taken to address them?

Please do not answer 'none'. The committee needs to see evidence that you have identified potential ethical issues with respect to your research and have taken steps to address them. These issues could relate to:

- your own physical and psychological safety as a researcher;
- participant burdens and/or risks;
- data protection/confidentiality (please also see question 18)

For more guidance on ethical issues, please see http://researchsupport.admin.ox.ac.uk/governance/ethics/resources

Some participants may feel slightly distressed recounting incidents related to the interview topic. The researchers have extensive clinical experience and will re assure the participants or stop the interview giving them time to recover. A list of external support groups will be also made available to all should they ned further help. Any risks to psychological health by data uncovered in the interview are minimal however, referral to support services will be discussed if appropriate.

There will be minimal personal data held after the interview takes place. All the participants will be given a pseudonym and no link to their identity will be available except from their name on the consent form. Any distressing issues uncovered during the data collection will be debriefed with the Chief Investigator.

18. **Management and handling of personal and other research data**

Management and handling of **personal data** and **special category data** of human participants, either directly or via a third party, will need to comply with the requirements of the General Data Protection Regulation (GDPR) and the new Data Protection Act, as set out in the **University's Guidance on Data Protection and Research.** In answering the questions below, please also consider the points raised in the **Data Protection Checklist**. For advice on research data management and security, please consult with the University's Research Data Team (**researchdata@ox.ac.uk)** and/or your local IT department and the University's web pages on research data management.

a. Will your research involve the collection of **records of consent** (e.g. written forms, audio-recorded, or other recorded consent)? **If 'yes', these will be classed as fully identifiable personal data (directly linked to an individual).**	Yes x	No☐
b. Will your research involve the collection of **other** personal data?	Yes x	No
If 'Yes', specify in what form(s) this will be stored:		
• Fully identifiable (directly linked to an individual)	Yes x	No ☐
• Pseudonymised (potentially identifiable as data may be attributed to an individual if linkage information can be accessed elsewhere by researchers)	Yes x	No ☐
• Fully anonymised (i.e. cannot be linked to an individual)	Yes x	No
c. Will any of the personal data you collect classify as special category data?	Yes ☐	No x
If 'Yes', specify in what form(s) this will be stored:		
• Fully identifiable (directly linked to an individual)	Yes ☐	No ☐
• Pseudonymised (potentially identifiable as data may be attributed to an individual if linkage information can be accessed elsewhere by researchers)	Yes ☐	No ☐
• Fully anonymised (i.e. cannot be linked to an individual)	Yes ☐	No ☐
d. How will any personally identifiable data be collected, transferred and backed up? Please describe the arrangements for any physical transfer of personal data (including paper records and data captured electronically via portable media) from where it is collected to local storage		
Consent forms will be returned to the research team and retained in the site file. Consent will be confirmed verbally at the beginning of the interview and recorded on the transcript. Audio recordings will be retained in the digital memory of the dictaphone and only accessed in the university research office. These will be destroyed after the 3 year retention period is complete in case there are any future questions about discrepancy between the transcripts and the original recording.		
e. Where, and for how long, will participants' personally identifiable data be stored during and after the study? (Please outline the procedures for ensuring confidentiality, e.g. security arrangements, anonymisation or pseudonymisation of such data. Please distinguish between records of consent and other forms of personally identifiable data stored. State whether or not you will seek to retain contact details of participants beyond the duration of the study (e.g. for advertising further studies))		
Data will be collected from the in-depth interview via audio recording of the dialogue. Recordings will be transcribed verbatim, checked by an independent researcher against the original recording and loaded into NVIVO 10, the data analysis software. All data will be stored in a password protected file on a password protected computer in a locked room of the university. Signed consent forms will be stored in the study site file in a locked room of the university. Data will only be accessed by the research team, as authorised by the Chief Investigator for the purposes of this research project. Only the consent forms will be retained securely for 3 years after the end of the project. All other personal data will be destroyed as soon as is no longer needed: contact details will be destroyed after interview has taken place and audio recordings at the time of closing the data analysis. This will allow adequate time for write up, reference for peer review or analytical quality questions to be addressed with the opportunity to return to the original data set and analysis notes. Participant contact details will not be retained beyond the duration of the study.		
f. If storing pseudonymised data, please confirm that identifiers will be held separately from the research data and linked through a unique study number. Specify how and at what point the pseudonymisation will occur, how the linkage information will be stored and state whether or not (and when) the linkage will be destroyed.		
All the transcripts will be pseudonymised. Once the consent is signed each participant will have a pseudonyme allocated. The recruitment log with the consent forms will be kept separately from the transcribed interviews. All the paper files will be kept in locked cabinets in Oxford University with restricted access only to the research team. All information will be kept for 3 years after the end of the study. Linkage information will be destroyed at this time alongside all the other collected data. Interviews submitted via Google Forms will be fully anonymous.		
g. Who will have access to the personally identifiable data? If personally identifiable data is to be shared with another organisation, how will it be transferred/disclosed securely?		

The only personally identifiable data in this study will be the consent form, contact details and audio recordings from the interview component. Data will only be accessed by the research team as authorised by the Chief Investigator. Personal identifiable data will not be shared outside of the research team. Prof Norton will be involved in data analysis but only after the transcripts are anonymised, therefore no personal data will be transferred to another organisation.

h. When and how will personally identifiable data be destroyed? (NB. Personally identifiable data should be destroyed when no longer required).

. The email addresses will be deleted electronically from the research team email (gi.research@ndm.ox.ac.uk) following data collection and approval of the draft by participants who wish to review the research output before submission for publication. Consent forms and the participant log will be securely shredded through the confidential waste stream of the sponsor after the 3 year retention period is complete. Audio recordings will be destroyed once the accuracy of the transcript has been double checked by a fellow researcher. The transcripts will be retained for 3 years and shredded alongside the consent forms and participant log.

i. How, where and for how long will other research data be stored after the study has finished? For more information about University and research funder retention policies, please see the University's web pages on research data management.

The interview transcripts and site file of study documents will all be stored for 3 years after public release / publication of the study results. They will be stored in a locked cabinet in the locked university research team office on level 7 of the John Radcliffe Hospital, Oxford

SECTION G: NHS Trust Management approval

(Please mark 'X' in the Yes/No column as appropriate to indicate your response.)

Does your study involve:

1.	Use of the NHS Trust e-mail domain and/or use of poster (or leaflet) advertisement in an NHS facility to make contact with the potential participants (i.e. staff)?	Yes	No x
2.	Any study procedure (including interviews or focus groups) on NHS Trust premises?	Yes	No x
3.	Any study procedure (including interviews) using NHS Trust resources?	Yes	No x
4.	Any study procedure (including Interviews) during the working hours of the participant if they are an NHS Trust employee?	Yes	No x
5.	Use of NHS Trust data?	Yes	No x
6.	Interviewing NHS staff (including in focus groups)?	Yes	No x

If you have marked 'X' in any of the shaded boxes, please refer to the Clinical Trials and Research Governance Office (CTRG) BEFORE you submit your application to MS IDREC.

You may need Health Research Authority (HRA) approval in addition to MS IDREC ethics approval.

Please be aware that time taken to receive approvals noted above is in addition to MS IDREC review.

SECTION H: Methods to be used in the study
(Please mark 'X' against as many methods as apply: this information will help the committee understand the nature of your research and may be used for audit.)
Please ensure you have addressed any potential ethical issues related to these methods in Section F, question 17 and in your participant information sheet.

Method used:	**Please mark 'X'**
1. Unstructured interview	
2. Semi-structured interview.	x
3. Structured interview.	
4. Questionnaire (in person)	
5. Questionnaire (online)	
6. Use of social media	
7. Use of NHS Trust data?	
8. Analysis of existing records.	
9. Participant performs verbal/paper and pencil/computer based task.	
10. Measurement/recording of motor behaviour.	
11. Audio recording of participant	x
12. Video recording or photography of participant.	
13. Physiological recording from participant	
14. Taking a sample of blood or other bodily fluid from participant.	
15. Analysis of genetic material taken from a participant.	
16. Ethnographic observation.	
17. Systematic observation.	
18. Observation of specific organisational practices	
19. Other (please specify):	

SECTION I
(Please mark 'X' in the Yes/No column as appropriate to indicate your response)

Will your research involve sensitive issues? This could be information relating to race or ethnic origin, political opinions, religious beliefs, physical/mental health, sexual life or criminal activities.	Yes x	No

If you have answered 'Yes' to the question in Section I, please make sure you include supporting information in section F, question 15a and provide a copy of the questionnaire raising the issues that will be used in your research.

Full committee review by the MS IDREC, on the basis of this checklist, the questionnaire and other supporting documentation that you provide, may be necessary.

All checklists must be submitted by email to ethics@medsci.ox.ac.uk. Please ensure that the fully-signed checklist, including signature of the head of department or nominee endorsing its submission, are sent from a University of Oxford email address.
Please ensure that the sections below, **INCLUDING THE FINAL CHECKLIST,** are completed.

SECTION J: Signatures

You need to obtain handwritten (wet-ink) signatures. Please then scan this entire checklist containing the signatures to create a single PDF document and email through. **Pasted images of signatures <u>cannot</u> be accepted in the sections below.**

Please ensure this checklist is signed by:

For staff research:	For student research:
1. **Principal Investigator**	1. **Principal Investigator (project supervisor)**
2. **Head of Department (or nominee)**	2. **Head of Department (or nominee)**
	3. **Student researcher**

1. **Principal Investigator signature/supervisor signature (if student research)**

I understand my responsibilities as **principal investigator / student supervisor** as outlined on this form and in the CUREC glossary and guidance.

I understand that it is my responsibility to ensure that all researchers working on this project are qualified and either experienced, or have received appropriate ethical training, to conduct the research described.

I declare that the answers above accurately describe my research as presently designed and that I will submit a new checklist should the design of my research change in a way that would alter any of the above responses so as to require completion of CUREC 2 (involving full scrutiny by an IDREC). I will not commence any research under the revised project design until approval has been obtained from the IDREC. I will inform the relevant IDREC if I cease to be the principal investigator on this project and supply the name and contact details of my successor if appropriate.

Signed by Principal Investigator/supervisor:

Print name (block capitals) ALISON SIMMONS **Date**: 06/11/2018

I understand the questions and answers that have been entered above describing the research, and I will ensure that my practice in this research complies with these answers.

Signed by associate/other researcher:

Print name (block capitals): SIMONA FOURIE **Date**: 06/11/2018

2. **Departmental endorsement signature**

I have read the research project application named above. On the basis of the information available to me, I:

(i) consider the Principal Investigator to be aware of her/his ethical responsibilities in regard to this research;

(ii) consider that any ethical issues raised have been satisfactorily resolved or are covered by CUREC Approved Procedures, and that it is appropriate for the research to proceed (noting the principal investigator's obligation to report should the design of the research change in a way which would alter any of the above responses);

(iii) I am satisfied that the proposed project has been/will be subject to appropriate **peer review** and is likely to contribute something useful to existing knowledge and/or to the education and training of the researcher(s) and that it is in the **public interest**.

Signed by Head of Department or nominee, (Director of Graduate Studies for postgraduate student projects; Director of Undergraduate Studies for undergraduate projects):

Signature: ... .

Print name (block capitals): PROF CHRIS CONLON.................... **Date**: ...08/11/2018..

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, University of Oxford, Wellington Square, Oxford, OX1 2JD
Tel: +44(0)1865 616577 Fax: +44(0)1865 280467
ethics@medsci.ox.ac.uk

CONFIDENTIAL

Ref: R60900/RE001

14th December 2018

Professor Alison Simmons
WIMM, Nuffield Department of Medicine
University of Oxford
John Radcliffe Hospital
Oxford

Dear Professor Alison Simmons

Research Ethics Approval - CUREC 1

Study Title: Intimacy and sexuality concerns of those living with Inflammatory Bowel Disease and the need for these to be addressed by healthcare professionals: A qualitative study

Short Title: IBD Ask

The above application has been considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (IDREC) in accordance with the procedures laid down by the University for Ethical Approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted for a period of **XX** months/years, commencing on <insert approval date>. The reference number for this study is **Rxxxx/REyyy**.

This is **subject to:**

a) **it is your responsibility to comply with the requirements for administering any tests or questionnaires and, if in doubt, to contact the publisher of those tests or questionnaires.**

b) **if new research staff are engaged, the PI is responsible for ensuring they are suitably qualified by training and/or experience.**

I would like to remind you that your study may be selected for review by the MS IDREC during an annual audit.

Amendments

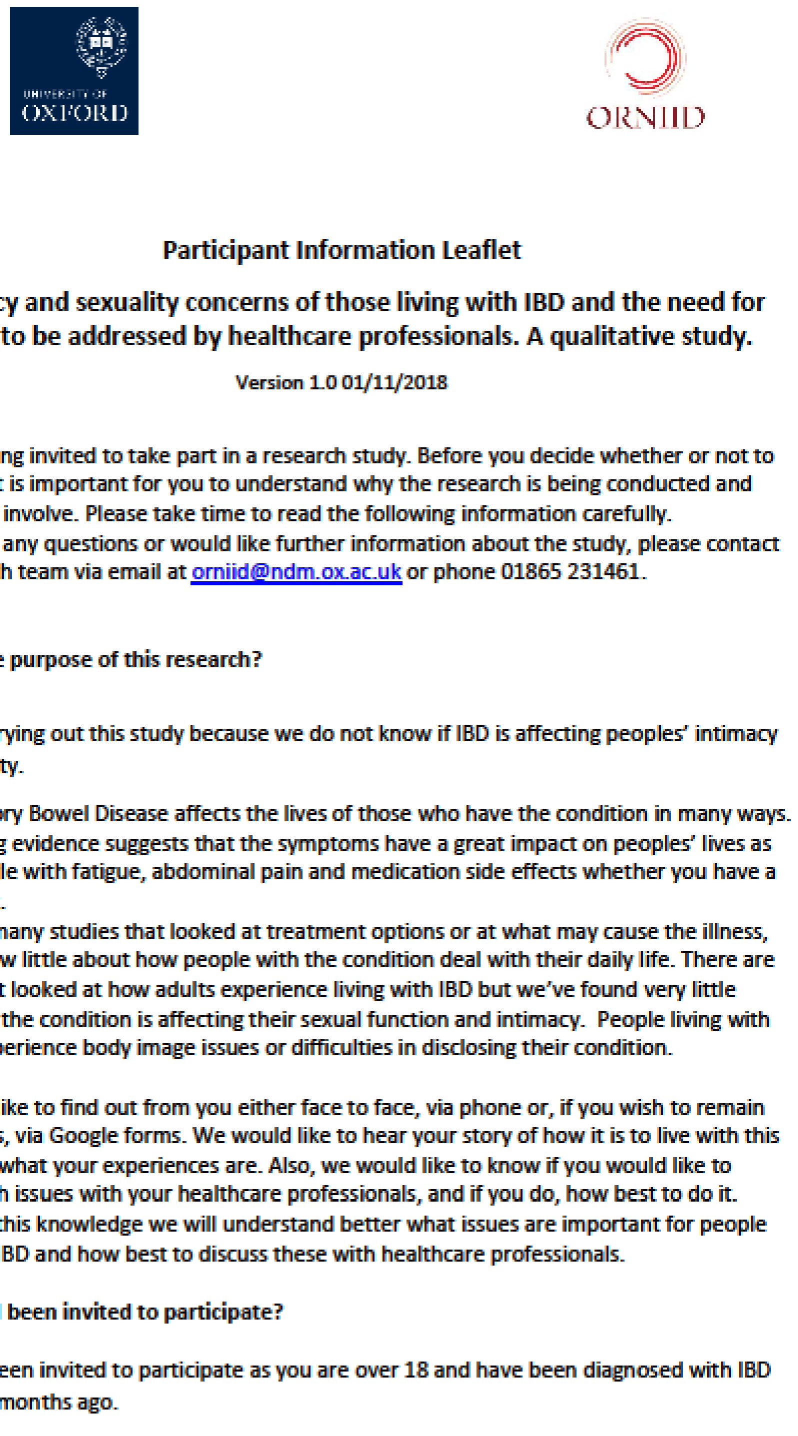
Should there be any subsequent changes to the study, you should submit details to the MS IDREC for consideration and approval. Details of changes must be listed on an amendment form. If your study received University Sponsorship through CTRG, then the amendment will first need to be submitted to CTRG for approval of continued Sponsorship.

Please do not hesitate to contact me if you have any queries.

Yours Sincerely

Dr. Helen Barnby-Porritt
Research Ethics Manager, Medical Sciences

1.14. CCUK –Adult Participant information leaflet



UNIVERSITY OF OXFORD

ORNIID

Participant Information Leaflet

Intimacy and sexuality concerns of those living with IBD and the need for these to be addressed by healthcare professionals. A qualitative study.

Version 1.0 01/11/2018

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.
If you have any questions or would like further information about the study, please contact the research team via email at orniid@ndm.ox.ac.uk or phone 01865 231461.

What is the purpose of this research?

We are carrying out this study because we do not know if IBD is affecting peoples' intimacy and sexuality.

Inflammatory Bowel Disease affects the lives of those who have the condition in many ways. The existing evidence suggests that the symptoms have a great impact on peoples' lives as they struggle with fatigue, abdominal pain and medication side effects whether you have a flare or not.
There are many studies that looked at treatment options or at what may cause the illness, but we know little about how people with the condition deal with their daily life. There are studies that looked at how adults experience living with IBD but we've found very little evidence if the condition is affecting their sexual function and intimacy. People living with IBD can experience body image issues or difficulties in disclosing their condition.

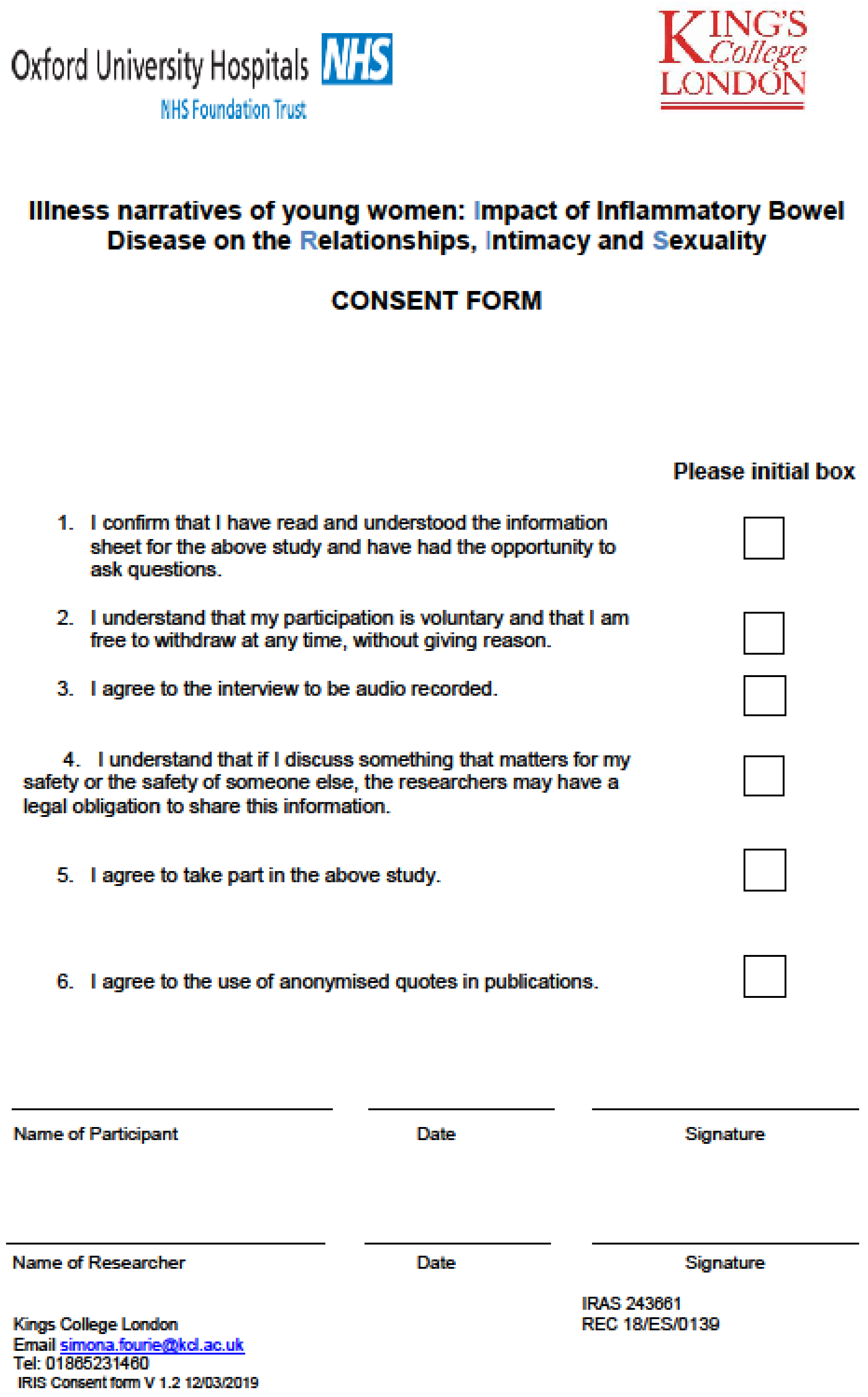
We would like to find out from you either face to face, via phone or, if you wish to remain anonymous, via Google forms. We would like to hear your story of how it is to live with this illness and what your experiences are. Also, we would like to know if you would like to discuss such issues with your healthcare professionals, and if you do, how best to do it.
By gaining this knowledge we will understand better what issues are important for people living with IBD and how best to discuss these with healthcare professionals.

Why have I been invited to participate?

You have been invited to participate as you are over 18 and have been diagnosed with IBD at least 18 months ago.

1

1.15. NHS Consent form



Oxford University Hospitals NHS
NHS Foundation Trust

KING'S College LONDON

Illness narratives of young women: Impact of Inflammatory Bowel Disease on the Relationships, Intimacy and Sexuality

CONSENT FORM

Please initial box

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason. ☐
3. I agree to the interview to be audio recorded. ☐
4. I understand that if I discuss something that matters for my safety or the safety of someone else, the researchers may have a legal obligation to share this information. ☐
5. I agree to take part in the above study. ☐
6. I agree to the use of anonymised quotes in publications. ☐

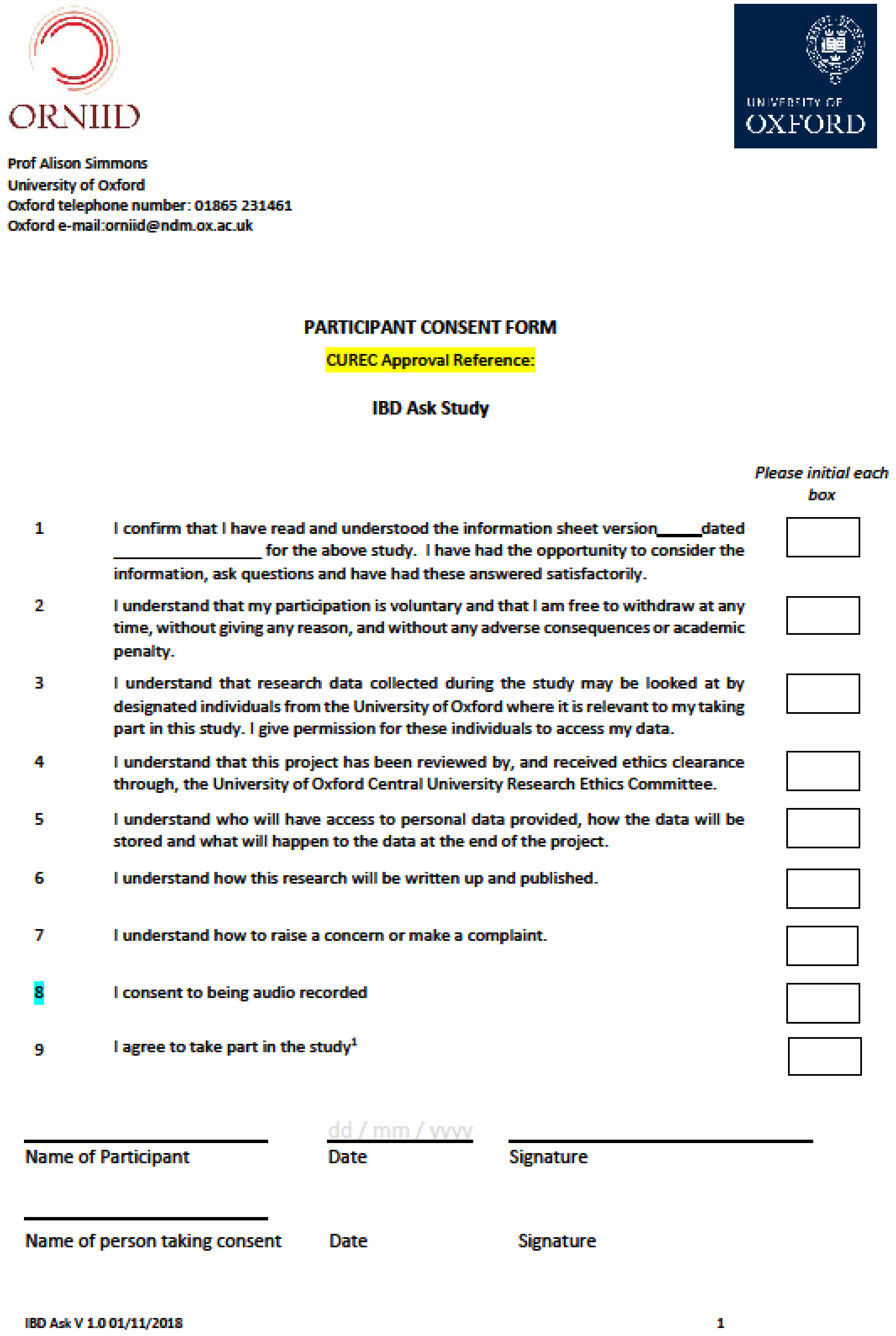
Name of Participant ____________ Date ____________ Signature ____________

Name of Researcher ____________ Date ____________ Signature ____________

IRAS 243661
REC 18/ES/0139

Kings College London
Email simona.fourie@kcl.ac.uk
Tel: 01865231460
IRIS Consent form V 1.2 12/03/2019

1.16. Consent form



ORNIID

UNIVERSITY OF OXFORD

Prof Alison Simmons
University of Oxford
Oxford telephone number: 01865 231461
Oxford e-mail:orniid@ndm.ox.ac.uk

PARTICIPANT CONSENT FORM

CUREC Approval Reference:

IBD Ask Study

Please initial each box

1 I confirm that I have read and understood the information sheet version_____dated ________________ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences or academic penalty. ☐

3 I understand that research data collected during the study may be looked at by designated individuals from the University of Oxford where it is relevant to my taking part in this study. I give permission for these individuals to access my data. ☐

4 I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee. ☐

5 I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project. ☐

6 I understand how this research will be written up and published. ☐

7 I understand how to raise a concern or make a complaint. ☐

8 I consent to being audio recorded ☐

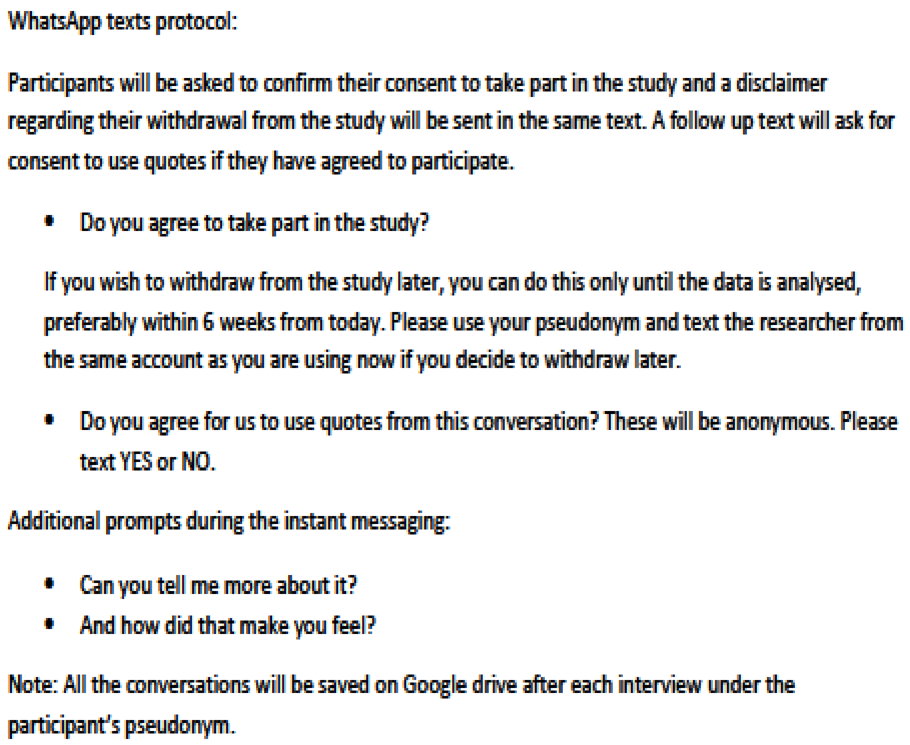
9 I agree to take part in the study[1] ☐

____________________ dd / mm / yyyy ____________________
Name of Participant Date Signature

____
Name of person taking consent Date Signature

IBD Ask V 1.0 01/11/2018 1

1.17. WhatsApp protocol



WhatsApp texts protocol:

Participants will be asked to confirm their consent to take part in the study and a disclaimer regarding their withdrawal from the study will be sent in the same text. A follow up text will ask for consent to use quotes if they have agreed to participate.

- Do you agree to take part in the study?

  If you wish to withdraw from the study later, you can do this only until the data is analysed, preferably within 6 weeks from today. Please use your pseudonym and text the researcher from the same account as you are using now if you decide to withdraw later.

- Do you agree for us to use quotes from this conversation? These will be anonymous. Please text YES or NO.

Additional prompts during the instant messaging:

- Can you tell me more about it?
- And how did that make you feel?

Note: All the conversations will be saved on Google drive after each interview under the participant's pseudonym.

1.18. Published Paper' These discussions aren't' happening'

Journal of Crohn's and Colitis, 2021, 1–8
doi:10.1093/ecco-jcc/jjab043
Advance Access publication March 4, 2021
Original Article

Original Article

'These Discussions Aren't Happening': Experiences of People Living with Inflammatory Bowel Disease and Talking About Sexual Well-being with Health Care Professionals

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Abstract

Background: Inflammatory bowel disease [IBD] affects all aspects of life, yet little is known about the impact of the condition on intimacy and sexuality and if such concerns should be discussed with health care professionals. This hermeneutical phenomenological study aimed to explore the experiences of people living with inflammatory bowel disease and discussing their sexuality concerns with health care professionals.

Methods: Participants [$n = 43$] aged 17–64 years were recruited. Data were collected via in depth interviews and anonymous narrative accounts [Google Forms]. Thematic analysis was used to analyse the data.

Results: An overarching theme 'These discussions aren't happening' with four main themes were generated. The main themes were: 'I can't image talking about sex'; 'I am a person, not my IBD'; 'We need to talk about sex'; and 'Those who talked about sex, talked badly'. Participants described the lack of conversations with their health care professionals on sexual well-being issues, in spite of the importance they gave to the topic, and identified barriers to having such conversations. They made suggestions for future clinical practice that would better meet their needs. The few who had discussed sexual well-being issues with health care professionals reported negative experiences.

Conclusions: Patients' needs and preferences, about addressing during clinical appointments concerns related to their sexual well-being, should be addressed routinely and competently by health care professionals. Understanding the implications of inflammatory bowel disease for intimate aspects of the lives of those living with the condition could improve the quality of the care provided.

Key Words: IBD; intimacy; sexuality; well-being; health care professionals; interviews

1. Introduction

Intimate relationships in people living with inflammatory bowel disease [IBD] are challenged by fatigue, bowel symptoms, perianal disease, and having a stoma,[1] with 15–30% reporting a negative impact of IBD on their sex life.[2,3] Since IBD has a negative effect on intimacy and sexuality, it might be expected that health care

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professionals [HCPs] would routinely assess and discuss sexual well-being. Current literature showed no evidence that HCPs routinely discuss sexual well-being with those living with IBD, although this has been previously suggested to IBD multidisciplinary teams.[4]

Sexual well-being refers to 'the perceived quality of an individual sexuality, sex life and sexual relationships'.[5] It does not imply the absence of disease, and should not be confused with sexual health, which refers to preventing or treating sexually transmitted infections. The concept is related to a more holistic approach to sexuality and intimacy. The definition of sexual well-being remains controversial due to the complexity of the concept and the difficulty of measuring it. However, the accepted notion refers to not just what a person wants to do in terms of intimacy and sexuality, but also what is their physical capacity to do what they desire.[6]

The aim of this study was to explore the experiences of people with IBD discussing sexual well-being issues, or intimacy and sexuality-related concerns, with health care professionals, and patients' perspectives on how such conversations should take place.

2. Materials and Methods

Hermeneutic phenomenology designs are concerned with interpretation of written text, and van Manen's[7] framework is an established stand-alone methodology used in social and health sciences for interpreting lived experiences.

Participants approached the study team in response to an advertisement on the research webpage of a national IBD charity. Those with a self-reported IBD diagnosis, age 16 years and over, of any sexual orientation, and English-speaking were included. Data were collected either as a single semi-structured interview via telephone or face to face or from narrative accounts submitted anonymously via Google Forms [GF], as participants chose, following written or verbal consent. GF were accessed via a link inserted into the Participant Information Sheet, and contained a few demographic questions followed by a free-text box where they were prompted to describe their experiences. The same questions were used as an interview guide [see Box 1]. Due to the sensitive nature of the study, and in an attempt to encourage participation, GF was used for anonymous data collection.[8] This aligned with the aim of letting the participants elaborate on issues that were important to them based on their experiences, rather than investigate researcher-directed concepts. The interviews were audio-recorded and transcribed verbatim.

Van Manen's framework for thematic analysis was used.[9] NVivo 12 software was used for data organisation and storage. The final themes depicted aspects important to participants and were strictly derived from interview data in an inductive way. The results represent an interpretation of personal experiences of participants and were aimed at both interdisciplinary and patient understanding.

Box 1. Interview guide.

What is your condition?
How long did you have the condition for?
Can you describe your experience of intimacy and sexuality from your perspective of living with IBD?
Can you tell me about any occasions when you have discussed your sexual well-being with health professionals?
Do you think such conversations should take place at the time of clinical visits?
How would you like such conversations to take place?

2.1. Ethical considerations

Ethical approval was obtained from University of Oxford Ethics Committee [R60900/RE001]. Privacy and anonymity were maintained throughout the study. All participants were allocated a pseudonym and consented to the publication of anonymised excerpts. Direct quotes are presented verbatim, also giving the participant's pseudonym, age, sex, diagnosis (ulcerative colitis [UC] or Crohn's disease [CD]). A few participants from the UK were at the time of their interview aged 17, as the legal age for consent to research is 16. The participants from other countries were all over 18, therefore not contravening their own country's legislation.

3. Results

A total of 43 participants (Table 1) consented to take part in the study between March 2019 and July 2020, 23 opted for interviews that lasted between 20 to 60 min, and 20 sent anonymous narrative accounts [see Box1]. Participants were mainly from UK. Over 75% of participants were in a long-term relationship or married. One participant identified as a gay man, one participant identified as trans man, and two [male and female] identified as bisexual. The full demographic details for those who responded anonymously via GF were not known, neither was their geographical location. Based on their narratives, all but one participant who responded via GF identified themselves as female, although the study was open to all genders and non-binary were not excluded. No direct information about their age was given via GF; however, most of them stated the length of their diagnosis and their approximate age when they were diagnosed, which made possible to establish an age range for all but two the study participants.

Participants reported various degrees of IBD disease activity, from mild to severe forms. Eleven had previous surgery resulting in permanent stoma formation or an ileo-anal pouch, over a third had surgery for perianal disease, and 3 women had diagnosed vulval Crohn's disease.

Figure 1 summarises the themes and sub-themes. The dominant narrative from interviews and Google Forms was that in general, conversations about intimacy and sexuality were not taking place. 'These discussions aren't happening' was the overarching theme generated by interpretation of the common thread through the themes, integrating some of the reasons why these conversations were not happening or were avoided, in spite of the topic being important to participants:

> Before you have surgery you should talk about the impact of surgery. That's an opportunity to talk about sexual relationships and intimacy post-surgery. But these discussions aren't happening. [Martha 38 F, CD]

Table 1. Study population.

	Numbers
Age range (years)	17–64
Crohn's disease	31
Ulcerative colitis	12
Male	11
Female	32
Married/partnered	33
Single	9
UK participants	40
Other [Ireland, USA, South Africa]	3

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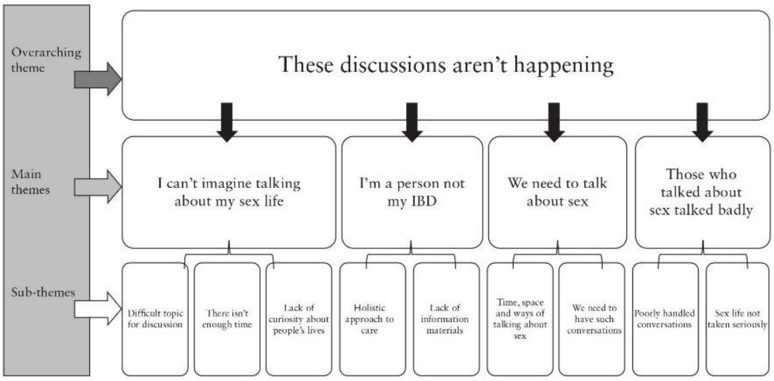

Figure 1. Themes and subthemes.

3.1. Theme 1: 'I can't imagine talking about my sex life'

This theme includes patient-reported barriers in discussing their concerns with HCPs and the feeling that the sensitive nature of such discussions, lack of time and privacy, and lack of initiative from HCPs contributed to these conversations not taking place.

I can't imagine talking about my sex life. [Laura 30s F, CD]

3.1.1. Difficult topic for discussion

The sensitive nature of the topic was the greatest barrier from participants' perspectives; they felt uncomfortable about initiating such conversations with HCPs.

> It's [sex] never been mentioned to me by any consultant or other person. I guess they feel a bit uncomfortable bringing that up. [Emma 36 F, CD]
>
> I would find it very hard to discuss it face to face with my care team. [Emily 42 F, CD]

Some suggested that clinical appointments were not providing an adequate forum for more personal issues, although the need to address these was present.

> Of course women don't bring this stuff up to doctors easily. We are doubly shamed—as women about our sexuality in general, and because we have this disgusting disease that you're not supposed to talk about. Add being queer to that and it's pretty much hopeless. [Carina 40 F, CD]

Participants from sexual minorities found it particularly difficult to open up and discuss with HCPs, although most of them had previously disclosed their sexual orientation to the clinical team. Some assumed that HCPs' awareness of them identifying as a sexual minority added a barrier to discussing sexual well-being.

> Maybe it is just because they're trying so hard to be careful with me as a trans man … nobody asked. It's like your bowel is in a different body from your sexual organs. [Richard 62 M, CD]

> I feel like people in my HCP team either haven't got the knowledge to discuss with me, the ways that it [IBD] affects it [sex], or haven't been willing to discuss. And I sensed a certain reluctance among them cos I'm bisexual. [Mark 26 M, CD]

For younger participants, attending clinics with a parent was seen as adding to the difficulties of HCPs in bringing the topic up for discussion

> I feel like it may also be because my mum comes to all my appointments with me just because, I mean me and my mum are close, so it's not a problem for me to talk about intimacy or anything in front of her, but I feel like, perhaps that made the consultant or whoever I was talking to, more reluctant to bring it up because obviously, some people are more awkward in front of their mums talking about stuff like that. [Melania 17 F, UC]

3.1.2. There isn't enough time

Perceived time constraints were often recognised as barriers to discussing aspects of participants' sexual well-being. Current pressures in the UK National Health Service to see large numbers of patients in clinics, only allowing appointments of 10 to 20 min, was perceived as a deterrent to discussing anything outside treatment efficacy or symptoms with the HCPs.

> There is no time or space to discuss anything else that may seem trivial. [Denise 36 F, CD]

It was also suggested that discussion of sensitive topics required a rapport between patient and HCPs, which involved time as well.

> I know they actually there are huge differences in how comfortable people are asking these questions, but sometimes even if you're comfortable it's clear that the issues the person is bringing, they need more time. [Ana 40 F, CD]

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3.1.3. Lack of curiosity about people's lives

HCPs' reticence to initiate discussions on sexual well-being topics was negatively perceived by some:

> The lack of curiosity about people and about people's lives I think goes throughout the multidisciplinary teams. [Martha 38 F, CD]

Furthermore, participants indicated that they were troubled by the lack of initiative from HCPs. This assumption of lack of curiosity was made mainly by participants who had negative experiences of asking HCPs questions related to intimacy and sexuality. Lack of HCP experience and knowledge in discussing these issues, as well as lack of time to do this, could have been wrongly interpreted as lack of curiosity or interest. The absence of questions, other than strictly medical ones, from HCPs involved in the care of the participants was seen as a barrier to any attempt to bring up other topics for discussion during clinical appointments, some concluding that HCPs were uninterested in their patients' lives.

> I sometimes feel that any, even sort of medical, strictly medical questions, are sort of not really encouraged. So … it would never occur to me to talk about more intimate things. [Daniel 31 M, UC]

3.2. Theme 2: 'I'm a person, not my IBD'

This theme proposed ways of moving forward as participants felt that they were not approached holistically by their HCPs, starting from the feeling that participants did not want to be identified as just their IBD, and this suggested their expectations for future practice.

> I just I don't like to be identified by my condition because I don't feel like it's part of me, I just think that it [IBD] is what I have. [Nora 18 F, CD]

3.2.1. A holistic approach to care

The expectation of holistic care was found to be unanimously sought by participants. Whether they described experiences where this was not the case, or they made suggestions for how they wanted to be seen, the concept had an important place in the participants' narratives.

> You don't necessarily get the sense that they're thinking of your complete life in all its sort of aspects. It's: 'Right! I'm seeing you as a colon, or lack of one, and that is what I'm treating and I'm not really interested in something else. [Daniel 31 M, UC]

People living with IBD expressed a wish to have holistic care that would include routinely addressing sexual well-being concerns.

> You treat my sexual health problem, you're treating my Crohn's! You treat my eyes; you're treating my Crohn's! You treat my anxiety; you're treating my Crohn's! You treat my self-esteem, you're treating my Crohn's and we're gonna get to treat me whole. We're both on the same journey! But they're only looking at one aspect of it, and they miss it completely. [Martha 38 F, CD]

3.2.2. Lack of information materials

Alongside the main suggestion to treat holistically, participants consistently described their experiences of the absence of sources of information on the topic in clinical settings. Our participants' information needs varied, depending on age, gender, and severity of symptoms, and they suggested various sources for information. If the possibility to have a discussion with their HCPs was excluded as a result of the participant's choice, or dictated by clinical circumstances [lack of time or privacy], they still expected HCPs to signpost them to the appropriate support available.

> If there was a leaflet particularly about sex that would be helpful, especially for people who really don't want to talk about it to anyone, and then they can at least pick that up and be left alone in that way… I think charities should be a lot more open about sex as well. I think Crohn's and Colitis UK have a leaflet about sex, but from what I remember it's pretty vague it just says you should talk to your partner about sex, you can still have a loving relationship, and I just found that pretty annoying! [Be]cause that does reinforce the feeling that you're on your own or making up something about nothing I think. [Emma 36 F, CD]

The insufficient or complete lack of information received from HCPs about sexuality, sexual function, or symptoms that may interfere with sex life, was perceived by participants as a poorly handled topic, as their expectations were not met. Information was sought by a number of participants, especially in the early stages after their diagnosis or at the time of surgery. Even those who had been diagnosed many years ago, argued that such information should be offered to all patients newly diagnosed with IBD, or when their circumstances changed, for example undergoing surgical procedures or changing medication.

Those who had been given information on sexual well-being, or those who sought sources of information felt that information found was often insufficient, and they questioned the reliability of potential sources. Gathering information from other patients' experiences was frequently mentioned in interviews as a way of accessing information.

> There's a lot of forums because people on there will talk about it [sex] and you know they're quite open about it as well. So it's, and there's all sorts of people like different sexualities in there as well, it's kind of interesting to speak to them. And there's a wide range, some people have got their colostomy bags. You know they'll find it difficult just to be like intimate with somebody. I suppose you'll get a lot of support from them [the forums]. [James 42 M, CD]

3.3. Theme 3: 'We need to talk about sex'

The message that participants wanted to give to HCPs was that there was a need for breaking the taboos surrounding these discussions, and it was a call for discussions about intimacy and sexuality to take place in the clinical environment, as IBD had a negative impact on their sexual well-being.

> Sex is a normal part of life. And if there's something in your life that is stopping you from doing something that is normal, you go along to a doctor or specialist to try get

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> help with it. And this is absolutely no different. [Sandra 60 F, CD]

Although, as a previous sub-theme highlighted, these are difficult conversations to have with HCPs, a few had no issues in opening such conversations when needed.

> I've talked about it a lot; I'm not worried about talking about it. I may have been when I was younger, but as I've got older and I've seen my past relationship break down, and I want to go on and have children again. [Martha 38 F, CD]

3.3.1. 'We need to have such conversations'

Many participants felt that such conversations should take place, sex is an important part of their lives.

> For some people it [sex] might not be such a big issue, but for others it's going to be… For me, it is an important part of my life. [Ana 40 F, CD]

People claimed that sexual well-being in IBD demands similar attention as sexual well-being in cancer, therefore they argued the importance of talking about it.

> Crohn's affects people's bodies, and it's every bit of your body and therefore it's going to affect your sexuality as well. Your choice of partner, whether you can go out dating or not, how you can go out dating, all of it. And it needs to be brought up. Like I said, they do it with cancer, they talk to you about how you can live your life to the fullest with cancer, but nobody does it with us. And IBD goes on for a hell of a lot longer than cancer. [Orla 41 F, CD]

Moreover, the need to bring up the topic in the clinical environment was advocated as participants felt that HCPs do not fully understand the negative impact IBD has on their sex life.

> Doctors need to understand that sex is one of the basic everyday things that gets wrecked by IBD, just like eating or socialising or school or work or exercise. They need to imagine what it would be like for them if they were worried about shitting themselves during intimate moments. [Carina 40 F, CD]

Although the general consensus was that there is a genuine need for such conversations, a deviant finding came from one participant who felt the opposite about such conversations.

> Having such a conversation will not help, just expose me more to another person. [Kate 47 F, UC]

It was largely accepted that talking about intimacy and sexuality issues may not necessarily offer a solution, yet participants looked for an acknowledgement from the HCPs of what they experience, and for validation of their feelings by being believed. This was particularly important for those with perianal disease, who disclosed issues related to their sexual well-being but felt they were not listened to, or that their concerns were not fully understood by HCPs.

> Awareness should be made about how hard life is with fistulas and how complicated it is living with the pain of setons… If you go in as an emergency surgery, you could end up with a cable tie in your bottom, that makes you cry for the rest of your life until it's removed. [Sara 46 F, CD]

Moreover, most stated that there was a great need to discuss these issues with someone, and in absence of such opportunity, the present study had offered them a platform to talk.

> I saw your study and thought I'd be interested to take part, because it felt like the door that was opened up as a forum to talk about these things… I have not felt [door] has ever been opened conspicuously to me and I haven't talked to anyone about this. The things I'm saying to you now I haven't said to anyone before, so clearly I haven't felt that that door was open. [Daniel 31 M, UC]

3.3.2. Time, space and ways of talking about sex

Finally, participants suggested as a way forward that HCPs should routinely address sexual well-being concerns with those for whom considered it was relevant, and for younger participants possibly alongside family planning.

> I would like to have access to a specific clinic/appointment for family planning, sexual health for IBD patients. A place where I know these are the main aspects discussed and where I can ask questions, receive information and feel normal. [Julia 20's F, CD]

The need to address sexual well-being in IBD was perceived by those living with the condition as an important step forward in providing a good quality of care. Although the need for time and space was acknowledged, the majority expected that HCPs should be more engaged in these conversations, have knowledge of the impact of IBD on their intimacy and sexuality, and to initiate this conversation at least once with each patient. In this way HCPs can identify those who are responding to this invitation for a dialogue and may open up about their sexual well-being concerns.

> Health care professionals should be prepared to talk about it… Maybe fill in a small questionnaire before clinical appointment and know who wants to have this conversation. [Richard 62 M, CD]

3.4. Theme 4: Those who talked about sex, talked badly

The few experiences of previous conversations with HCPs about sex-related issues were elements of the last theme. Participants described poorly handled conversations and fear of sexual concerns being trivialised, therefore not considered important, by HCPs.

3.4.1. Poorly handled conversations

From those who had discussed sex with HCPs, some recounted having bad experiences of such conversations.

> The only people that talked about it, and really badly I think, was the stoma nurse that I saw. [Ana 40 F, CD]

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Negative experiences diminished the potential to raise such topics with their HCPs during subsequent appointments, either because of perceived lack of sensitivity from HCPs or because of disparities between patients' and HCPs' views on what is a fulfilling sexual life.

> I was 21 and I had my first stoma and a 65-year-old nurse came out to the house. I was having problems with getting bags to stick on. I was sent home over weekend with no understanding of my bags and I said that we haven't had sex for a long time because I've been in hospital for 19 weeks, and he is trying to be intimate. She told me to just give him oral sex, [this] was the nurse advice to me. That is the only piece of advice I've had over the 25/26 years and 40 operations, no one has ever discussed sex with me. [Sara 46 F, CD]

3.4.2. 'My sex life is not taken seriously'

Another perception was that sex life concerns were not seen as important by HCPs. Particularly for those who had experienced delays in their diagnosis, talking about sexual well-being made them fear that the topic would again involve effort in convincing HCPs that their concerns were real:

> I've talked about pain [during sex] on so many occasions with an IBD specialist, with GPs, with my surgical team, and I've never ever once had someone take it seriously. [Martha 38 F, CD]

The struggle to be believed when participants disclosed issues related to sexual well-being was mostly challenging for those with severe perianal disease and vulval Crohn's; delays in being diagnosed or receiving treatment reinforced the feeling that their sexual well-being warranted less significance for HCPs.

> I got to the point where I said: this is my labia going black and falling off, and I'm still not getting any answers. [Catriona 43 F, CD]

4. Discussion

To our knowledge this is the first qualitative study to investigate the experiences of those living with IBD and discussing their sexual well-being with HCPs, and highlighted the absence of such dialogue between patients and HCPs. Most importantly, details on perceived barriers to discussing sexual well-being were present in their narratives. The sensitive nature of the topic, limited time, topic not being considered important, and the perceived lack of interest from HCPs were the most frequently reported barriers to discussion. Additionally, our findings highlighted that those living with IBD felt that aspects of how one's life is affected by IBD may not be known to HCPs. Experiences of not having a holistic approach to their care, one which would include addressing sexual well-being explicit and implicit, prompted suggestions for future practice from all participants.

There is no doubt that conversations about such as sexual well-being are often difficult. Furthermore, there are no measurement tools available in the context of IBD to assist the HCP; hence it is not clear how they should assess sexual well-being. In the absence of a tool or guidance in IBD, simply asking the patient for their perspective would seem to be a good initial approach. Patient perspectives on discussing intimacy, sexuality, or sexual well-being issues with HCPs remain under-researched generally, not just in IBD. The literature is predominantly based on HCPs' views and not on patients' views. Studies have covered views of oncology,[10–12] cardiovascular disease,[13] rheumatology,[14] and dermatology patients,[15] but no literature was found on views of those living with IBD.

Although it is hard to estimate the prevalence of sexual and relationship difficulties in IBD, one study showed that up to 90% of women surviving gynaecological cancer encountered such difficulties,[16] and 64% of cancer survivors would want HCPs to discuss sexuality issues.[17] Our study brings up for the first time the perspective of IBD patients, who have identified barriers to these conversations which could be classified as being personal, HCP, and environmental barriers.

It is accepted that a satisfying sexual relationship enhances quality of life [QoL],[18] and sex is an important aspect of QoL.[19,20] Sexuality issues are much more than biological concerns, they encompass intimacy and relationships, which warrants a holistic approach from the HCPs, although the participants in our study reported the absence of such an approach. Looking at the age range of IBD diagnosis, it is reasonable to argue that a large number of those who have IBD are either at a stage in their life when sexual identity emerges, or at the peak of their conceiving period, which sets sexuality issues as high priority for those living with IBD. In spite of this, our study showed that older participants, who were likely past fertility, still identified as wanting to be able to engage in sexual expression and activity and further challenged the common stereotype that older people are asexual.[21]

Personal barriers were directly linked to the participants themselves, as they did not feel comfortable to open the discussion. Participants reported feeling ashamed or embarrassed and having a fear of being negatively judged by HCPs. These fears were more acute in the case of participants who self-identified as belonging to a sexual minority, as it was too much to overcome the fear of being judged. It is, consequently, not surprising that they were reluctant to engage in such dialogues. Young adults from sexual minorities have reported infrequent discussions on sexuality-related issues with their clinicians, in a previous study in the general population.[22] HCPs should be aware about information-seeking behaviour in patients, as it changes with age and it is also gender dependent, older men being more likely to engage in such conversations with their HCP.[23]

HCP barriers point to HCPs not initiating the discussion. Our participants' perceptions are consistent with those of oncology, rheumatology, heart disease, and dermatology patients.[11,12,14,15] Participants in cancer studies wanted to be asked about their sexuality issues and preferred to receive information on the topic from their HCP.[17,24] One barrier was the perceived lack of interest from HCPs in discussing sexuality/sexual well-being with the participants. This was similar to the findings from a study among patients after a stroke, which suggested that HCP lack of motivation to discuss sexual well-being was one of the barriers to addressing sexual well-being.[25] In the absence of professional advice, participants had explored various sources of information, and a review looking at information needs in the IBD population found existing online resources unreliable.[26]

Environmental barriers were lack of time to have a discussion and lack of space to ensure confidentiality. Participants feared that time constraints would not allow anything that was not symptom or treatment-related to be discussed during their clinical appointments. Previous cancer studies exploring patients' and HCPs' views also found that an appropriate space to maintain privacy had the potential to support sensitive discussions, as well as sufficient time being allocated to clinical appointments.[11,12,27]

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Participants had unmet needs as a result of personal, HCP, and environmental barriers when they sought information, especially those who had undergone surgery or had perianal disease The third British National Survey of Sexual Attributes and Lifestyles has also identified similar unmet needs in the general population, suggesting that less than half of those who reported sexual difficulties have sought help.[28] HCPs should acknowledge that patients' needs stretch further than achieving IBD remission or reduction of symptoms. The sexual well-being of those living with IBD is woven deeply into their relationships, concerning their psycho-emotional balance, not just the absence of physical symptoms of IBD or a remission status.

4.1. Limitations

Since this was a phenomenological study, its aim was to produce an interpretation of participant experiences, which may not be generaliable. It is possible that the participants in this study were more likely to have sexual well-being issues than the wider IBD population: although participants who had mild disease volunteered to take part, they may have been a minority. Participants were recruited outside the clinical environment, and therefore they have self-reported as living with IBD, which is one of the limitations of the study. The study population was predominantly female, aged over 35 years, with moderate to severe Crohn's disease, and in a long-term heterosexual relationship, therefore potentially not representing a diverse IBD population. Sexual minorities were well represented in our study, as the percentage of participants self-identified as belonging to a sexual minority in the study was higher compared with the percentage found in general population. The findings cannot be extended to those who have mild disease, are single, or are aged 16 to 35, as these groups were also under-represented in our study. No ethnicity data were collected, although the researchers acknowledge that this would have added to the richness of the results.

4.2. Conclusion

To our knowledge, this is the first study providing evidence on what IBD patients want from their HCPs in terms of addressing this sensitive topic. Sexuality and sexual well-being were important to those living with IBD, as they aimed to continue normal living while having IBD. The study highlighted negative patient experiences in raising their sexuality concerns with their HCPs and in their perceptions of HCPs attitudes to their concerns and needs. Similarly, it gives an interpretation of the essence of their experiences on the topic. Although several of the findings are similar to those from cancer, cardiovascular disease, rheumatology, and dermatology studies, we have identified IBD-specific issues, mainly related to perianal disease and vulvar Crohn's. Patients recognised the influence of several barriers to these conversations with HCPs, and suggested that the topic should be addressed as a component of the holistic care they desire.

4.3. Implications for practice

HCPs should be cognisant of the concerns and needs of those in their care, and actively seek ways of enabling such conversations to take place. It is important for HCPs to recognise that ignoring sexual well-being puts pressure on patients to raise this issue, potentially causing them to feel ashamed and negatively judged. Training needs for HCPs involved in the care of those living with IBD should be identified and addressed. Sexual well-being should form part of routine care for all patients with IBD, and HCPs should facilitate dialogue, particularly with those with perianal disease. As an alternative to verbal discussions, signposting to reliable sources of information was proposed to address specific age, gender, sexual orientation, and disease severity needs.

Further research on tool development to assess sexuality needs of patients should be explored, as well as on the need for setting services to address this specifically. Information materials should be designed with the help of the patients and made available in written form in clinics and online, to cover the unmet needs of those living with IBD. Raising awareness of sexual well-being issues within the wider patient and HCP population should also be considered.

The data underlying this article cannot be shared publicly, for the privacy of individuals who participated in the study. The data will be shared on reasonable request to the corresponding author.

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Conflict of interest

All authors declared no conflict of interest.

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Author Contributions

SF: design of the study, data acquisition, and analysis. SF, CN, DJ, WCD: interpretation of data, drafting the article, and final approval of version submitted. Part of this work was presented as a poster abstract at the 15th Congress of ECCO in Vienna, February 2020.

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