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## **1. Introduction**

The impact of inflammatory bowel disease (IBD) on patients includes lower quality of life (QoL) in terms of physical functioning, emotional and social wellbeing, work performance, and disease manifestations (Parra et al. 2019). These impairments are usually associated with the duration and severity of disease and symptoms such as abdominal pain, rectal bleeding, diarrhoea, and fatigue (Seyedian et al. 2019). People diagnosed with IBD might be affected by loss of income, absenteeism, and loss of work opportunities. IBD may change patients' roles within their families, causing dependence on other family members that may lead to pressure on their relationships (Purc-Stephenson et al. 2015). A survey study about living with IBD for both patients and family members in Canada showed that the effect on interpersonal relationships was one of the major impacts when living with IBD (Becker et al. 2015). IBD not only affects the individual, but also considerably impacts all family members. A recent study of the impact of IBD on the families of adult patients found that many caregivers experienced a high level of burden and low QoL (Zand et al. 2020). An earlier study by Lui et al. (2018) indicated that the caregivers who also are family members of IBD patients had much more severe anxiety and depression symptoms than the general population. Similarly, studies by Parekh et al. (2017) and García-Sanjuánt et al. (2019) agreed that the family members of people with IBD were affected by lack of awareness of the disease and how to deal with its progress and the care needs of people with IBD, both physically and emotionally. These factors generate an impact on the psychological well-being of family members and also affects their QoL. IBD UK launched the new IBD standard in 2019 which stated that patients should be cared for by a defined IBD multidisciplinary team led by a named consultant adult or paediatric gastroenterologist, an IBD nurse, an expert pharmacist in IBD as well as accessible and precise information about IBD and IBD services (IBD UK 2019). Whilst IBD patients receive individual care, such as from gastroenterologists, IBD nurses, and psychologists, there was a

lack of intervention support and education for family members of IBD patients (Shukla et al. 2018; Mohenizadeh et al. 2020). Social support is an important part of adjustment for IBD patients. Lack of support from family and community can be a difficult challenge when living with IBD (Purc-Stephenson et al. 2015). Understanding and addressing the impact on family members is a primary part of caring for people diagnosed with IBD, especially since family wellbeing may affect patient outcomes. With increased severity of disease symptoms, family stress increases, commensurate with a decrease in patients' QoL (Liu et al., 2018). To date, no study has adequately investigated the detailed impact of IBD on family members. Therefore, a qualitative study was used to explore the lived experience of IBD patients and family members of impacts of IBD on family members and their coping strategies.

## **2. Materials and Methods**

### **2.1. Design**

A hermeneutic (interpretive) phenomenological framework, using in-depth, semi-structured interviews. Purposive sampling was adopted to capture participants with variation of clinical and demographic backgrounds, who were all experiencing the impact of IBD on their family.

### **2.2. Participants**

Eligibility criteria included:

Patients: people diagnosed with IBD confirmed by clinician (either Crohn's disease (CD) or ulcerative colitis (UC)) for at least one year.

Family members: Family members of an IBD patient, including parents, spouse, child and sibling (brother /sister), who were currently living or have lived in the same house with the patient were eligible.

All participants had to be adults aged 16-years or older and have a sufficient ability with written and spoken English.

### **2.3. Procedure**

Two UK charities (Crohn's and Colitis UK, and Bowel and Cancer Research Charity) advertised the study on their websites and social media channels. Those who expressed an interest in being interviewed were contacted via e-mail. They received the Participant Information Sheet, explaining what involvement in this project required. If interested, they completed the Eligibility Screening Form. Eligible participants were purposively selected. Those who met the eligibility criteria and who had a willing relative were contacted by the lead researcher via telephone to answer any additional questions, verify their understanding of what was involved, and confirm their interest in participating. If the patient and family member agreed to take part in the study, a date for interviews was arranged. Recruitment was continued until the target sample (5-6 pairs) was reached. No participants were interviewed face to face due to lock down during the outbreak (Covid-19), verbal consents were utilised in all cases. The verbal consent was recorded.

### **2.4. Data collection**

Individual one-off in-depth interviews were conducted, IBD patient and a family member were interviewed separately. A semi-structured interview schedule was followed, the questions and probes were developed and discussed by the research team (Tables 1 and 2). The interviews were conducted by a female Masters student and supervisor with experience in conducting qualitative interviews. There was no previous relationship between researcher and participants. The interviews were audio-recorded and transcribed verbatim by a professional transcriber and anonymised. Data were collected over 5 months (February–June 2020). Recruitment was stopped when no new themes were emerging from interviews, illustrating that data saturation had been reached. The sample size of this study was 12. The authors were satisfied with depth and scope of data collection and interpretation of the identified phenomena.

## **2.5. Analysis**

Inductive thematic analysis based on the (Braun and Clarke 2006) method was employed to analyse interviews. NVIVO, version 12 (QSR International Pty Ltd, Doncaster, VIC, Australia) was utilised to manage data. To enhance rigour of the study, four authors (WCD, CN, HT and PT) were involved in the data analysis, three experienced in qualitative research in IBD and one student.

## **3. Ethical Considerations**

Ethical approval for the research was obtained from the King's College London Research Ethics Committee on 5<sup>th</sup> February 2020 (reference number: HR-19/20-17185).

## **4. Results**

There were 12 participants (6 pairs of a patient and a family member) purposively selected from 14 volunteers. The length of interviews ranged from 28-83 minutes (mean 57 minutes; approximately 11 hours 35 minutes of interviews in total).

### **4.1. Participant characteristics**

All sets were couples in a heterosexual relationship, as no volunteers for the study were in single-sex relationships or were parent/child or child/parent or sibling sets. Two patients had a pre-existing diagnosis of depression, one patient was on anti-depression medication. Three partners were diagnosed with depression; two partners were treated by medications. Table 3 shows demographic and health data of participants.

### **4.2. Study themes: Our relationship with IBD, for better or worse**

Figure 1 illustrates the main themes and subthemes which emerged from the analysis. There was constant and frequent change, going from good to bad, and from bad to good. The frequent changes and unpredictability of the condition were reflected by the overarching theme “our relationship with IBD, for better or worse”.

Four main themes emerged from the analysis: “our relationship”, “our relationship with others”, “our emotional and mental well-being”, and “our everyday life” (Figure 1). These included further subthemes, described below with supporting quotes with participant identification data in brackets (set number, UC or CD, patient or partner, and sex).

### **4.3. Theme 1: Our relationship**

All of the participants spoke explicitly about the impact of IBD on their relationship with each other and their management of this impact. The impact of IBD on partners seemed to be influenced by the length of time since diagnosis (new onset versus long-term onset), and the number of relapses in the past two years. New onset couples explicitly described difficult times since the diagnosis and difficulty coping with the situation because of inadequate knowledge and experience. Those with long-term experience living with IBD also spoke about their difficult and stressful times, but also about the positive impacts that the disease had, such as bringing them closer together as couples. However, they had a lot of negative experiences, especially during the early stages of being diagnosed, such as lack of information and not feeling empowered to cope with the crisis. During the process of treatment and consultations, patients with IBD have received further information from their GP, gastrologist, IBD nurse, and from charity website. However, the information was provided in an ad hoc and unstructured way. The long-term diagnosis couples tried to find better and more positive ways to solve the challenges such as a closer relationship, honest communication, and resilience. In relation to the frequency of relapse, when a patient’s condition was out of control, including need for surgery and having crisis symptoms, it unsurprisingly had more negative impact and was a more challenging time for both patients and partners.

Not only the new-onset couples but also the long-term onset couples who experienced this issue in their early stages of the diagnosis. During the process of treatment and consultations, patients with IBD have received further information from their GP, gastrologist, IBD nurse, and from charity website. However, the information was provided in ad hoc and unstructured way.

#### **4.3.1. Intimate relationship**

The intimate relationship between patients and their partners was expressed from all participants in terms of both positive and negative impacts. They thought IBD was a major issue in their lives. Four couples constantly thought about IBD in their lives, leading to anxiety and strain on relationships. Feeling uncomfortable as a result of IBD, related pain, or fatigue or having a stoma affected the physical or sexual relationships of all participants. Constant impacts on intimate relationships were described as causing psychological stress among both patients and their partners. Three couples had consulted individual psychologists; only one of these three couples had met a family therapist together. No one had consulted specifically about stoma related sexual relationships

*It does feel uncomfortable, sometimes there is pain. He understands that, so*

*I think in terms of intimate relationships I think it has affected it somewhat.*

*(Set 1 CD patient, female)*

Although there are many complexities in their relationships, some had learned to live with IBD and to become more resilient, learning to adapt well from difficult experiences, leading to more bonding in their relationship over the course of time. Almost all participants, both partners and patients, especially couples with a long- term diagnosis, noted that IBD ultimately had a positive impact by improving the closeness of their relationship.

*It probably has a very positive effect on our life because what we've been*

*through together has brought us closer, we have a brilliant relationship now*

*and we can talk about everything really freely (Set 4 partner of CD patient,*

*female)*

#### **4.3.2. Family planning**

Across the interviewees, the physical symptoms of IBD and the hereditary nature of the condition caused a delay in starting a family and reluctance to have a child. Two couples

discussed this issue with their consultant, and although they were aware of the low risk of their offspring inheriting IBD, they were still worried and reluctant to have a child.

*We were really concerned about whether the hereditary aspects (...), whether it's even responsible to have a child if there's an increased risk of Crohn's (Set 2 partner of CD patient, female)*

One interviewee in a long-term relationship wondered if having more children would create too much financial and lifestyle pressure; consequently, they decided to have just one child, in order to provide the highest QoL.

*... We were happy with one child we didn't really want to have a huge family so we stuck at one and I think we wanted to give our daughter the best life we could and I think perhaps we felt there would be too much pressure (Set 4 CD patient, male)*

#### **4.3.3. Relationship as partner and carer**

The partners of IBD patients took on the role of carers as well as partner, particularly when symptoms were flaring up. The caregiver role included worrying about the worsening condition of the patient and the complexity of associated family issues. In a few families, during a flare up or a hospital admission for medical or surgical treatment, the partner had to take over the responsibilities of being the breadwinner from the patient, and also looking after their children. The burdens of additional roles which otherwise would have been shared between both partners caused the partner of an IBD patient to experience greater stress, with emotional impacts and lower QoL.

*I think given the mental pounding that my wife had had in holding together the family, working and also helping to care for me when I was pretty emaciated and weak, that took a toll. She had a sick husband, she had a very demanding job, and also, she had a young daughter (Set 4 CD patient, Male)*



#### **4.3.4. Honest communication**

The majority of participants, both patients and partners, agreed that truthful and open communication about their feelings related to IBD helped to create a deeper understanding in the relationship.

*We've got a good relationship so if something is bothering me, I am happy to talk to him about it and I know that although he doesn't really like to talk... but I know he will talk to me if something is bothering him (Set 6 family member of CD patient, female).*

#### **4.4. Theme 2: Our relationship with others**

In addition to the relationship between patients and their partners, relationships with others, such as wider family, friends, and other people in society were also affected by IBD.

##### **4.4.1. Wider family conflict**

One family member with IBD reported that it affected their wider family. The absence of understanding between members of the wider family could lead to conflicts. The impact of IBD was described as systemic, not only in terms of relationships but also the emotional well-being of across the whole family.

*She [mother in-law] does this is a big deal, makes me really sad because she tries to control our lives and my opinion about my husband illness (Set 3 Partner of UC patient, female).*

##### **4.4.2. Transition stage of family members (children)**

Two couples who have children were quite concerned that knowledge about their condition would affect their child's development. It was a difficult decision for them to consider and choose between honestly telling their child about the disease or shielding them from the complexity of the situation.

*She certainly had a very difficult mid-teenage years and I know that's not an unusual thing with teenagers, but I think there was some resentment there that she hadn't been kept in the loop as much as she, in hindsight, thought that she should have been. So, the impact on the family was quite profound really (Set 4 CD patient, Male).*

#### **4.4.3. Social life**

Several IBD patients also thought their condition restricted their partner's' friendships and social lives, including feeling tired, and being limited due to toilet considerations when going outside. Whilst few partners worried about patient's the immunity and safety causing some couples to withdraw from social connections and activities..

*I know it has an effect on him because I know sometimes, he'll want to do things and I may be extremely tired. One of the bigger issues now is not urgency it has sort of morphed into extreme tiredness so that effects on what we do privately socially with friends (Set 1 UC patient, female)*

#### **4.4.4. Teamwork**

Teamwork among the family, including the wider family network, was a good source of support for relationships to overcome the IBD issues. Some partners experienced a patient's worsening condition, which they found more bearable with wider family support compared to going through it alone.

*If something untoward was to happen she would be on the phone immediately and I would call the boys immediately, we'd call her sister. Everybody knows, everybody has been there and helped out and they'd just run and do it until I turn up. So, we've got a good back-up system (Set 1 partner of UC patient, male).*

#### **4.5. Theme 3: Our emotional and mental well-being**

Emotional and mental well-being was the major theme of the impact of IBD on families. This related to all other thematic aspects expressed by all participants.

##### ***4.5.1. Living in constant fear***

All of the partner participants expressed the frequent feeling of fear linked to IBD flare-up. The sense of an unknown or an unpredictable future condition resulted in constant anxiety. Some participants clearly disclosed their worries about complications of IBD, medications, surgery, and the disease developing into cancer in the future. Several participants worried about losing the patient earlier, or thought about dying earlier from IBD, and partners feared being left alone.

*Life expectancy and with the condition actually getting really bad and therefore that will just have a massive impact on us. That was worrying and they wanted to operate with her colon and all the rest of it and it all got really heavy. It really was. So yes, it was extremely worrying, extremely worrying at that point (Set 1 partner of UC patient, male)*

##### ***4.5.2. Guilt***

Several patient and partner participants expressed a feeling of guilt in relation to IBD. Patients felt their disease might be difficult for their loved ones to face, including a worsening condition increasing pressure and burdens on their partners and family. Partners felt guilty because they were not the one who was ill, and they felt they could not do anything to alleviate their loved one's suffering.

*I'm sometimes angry at my Crohn's, at my condition and I think similarly I think the loved ones sometimes can feel some sort of anger or resentment not towards me but just at the situation. And people feel guilty about it because I'm the person who is ill, but I think it's just very, very difficult if only one person is always ill (Set 2 CD patient, male)*

For a partner, the feeling of guilt associated with feeling helpless, as they were unable to help their loved one (patient) when they were unwell. Guilt was also about not feeling it was legitimate to ask for help as the partner is not the patient.

*I think at the time I would have loved to have somebody to talk to who understood the guilt of it not being you and wondering why or feeling I shouldn't be feeling bad because this isn't happening to me. The feeling of, well it's a horrendous thing to, you know any operation that's happening to your loved one it's difficult because you can't do anything about it (Set 4 Partner of CD patient, male)*

#### **4.5.3. Humour helps**

Humour was a strategy that many participants employed to cope with the situations created by IBD, and they used it to cope with different situations. Even in severe conditions, including feeling out of control with IBD symptoms, a positive attitude could help them go through the worse feelings and enjoy their lives after the crisis.

*I think we laugh and joke and smile an awful lot in our situation. So, we laugh and joke and enjoy ourselves a lot. So, if the attitude is right, I think everything else falls into place (Set 5 family member of CD patient, male)*

#### **4.5.4. Knowledge of disease empowers**

Lack of easy to access information about IBD for both the patient and family members, poor knowledge of the disease, and lack of understanding of the importance of early treatment at relapse led to poor self-management abilities and confidence to cope with difficult situations. A few partners who lived with a new onset IBD patient reported that they did not know about the disease, the symptoms of IBD, and the best way to cope with crisis and flare-ups, due to a lack of knowledge, experience, and confidence to overcome such challenging situations. Whilst

long-term onset couples expressed that the information on IBD, how to live with IBD, and their experience could empower them to overcome the complexity they faced.

*I just didn't know anything about that, I really didn't know anything about Crohn's related fatigue. So I think reading up on that could help. I think more information at onset. I found a lot of the information on Crohn & Colitis UK and there's obviously and awful lot of information for people with Crohn's (Set2 family members of CD, female)*

Almost all participants mentioned that social support from organisations such as IBD charities have a crucial role in providing good sources of information about IBD for patient, but only Four participants mention the information for family members. Social media was talked about learning from the experiences of others who face similar situations, and dedicated “self-help groups”, were found to be positive strategies for both patient and family members.

*We're both signed up to the Crohn's & Colitis UK charity so we both receive, or we know we can access information and support as well through there and I know that he does do that. (Set 6 family member of CD patient, female)*

#### **4.6. Theme 4: Our everyday life**

The chronic nature of IBD, which has a fluctuating clinical course, affects the daily lives of patients and their partners. Everyday life with a chronic disease involves concern and anxiety about restrictions caused by IBD.

##### **4.6.1. Diet**

Several participants, both patients and partners spoke clearly about foods as contributor to IBD symptom deterioration, and the impacts of IBD on diet in everyday life. Dietary restrictions for IBD patients led to partners as well as patients changing their diet, including both food itself and food habits, with a need for extra care about food hygiene in order to support their partners.

*You need to be careful, maybe your partner would be upset if you had food or alcohol that he or she couldn't take. You have to tune into your partner and maybe you have to make a big change, maybe you have to stop something and start something else (Set 5 family member of CD patient, male)*

It was difficult for some patients and partners to find a diet that both of them could eat or share together. Without adequate knowledge or sufficient information about suitable dietary choices it is difficult for IBD couples to enjoy food and drink together.

*I suppose I mean there is an issue around food sometimes, finding food that the family can eat together, perhaps sharing, but then that's difficult because every IBD person you talk to has different things (Set 4 family member of CD patient, female)*

However, two patients mentioned seeing a dietician who provided them with information about food.

#### **4.6.2. Leisure time and travelling**

Due to the impact of IBD symptoms such as diarrhoea, abdominal pain, incontinence, and fatigue, both patients and their partners limited their leisure time, activities and travelling. Going on holiday for family members was also affected by IBD. Unpredictability and restricted toilet access were reasons that made travelling difficult for IBD patients and family members. In addition, some activities were not suited for IBD patients because of fatigue (tiredness), such as climbing and hill walking. Therefore, leisure time of family members as well as patients was restricted by IBD.

*I mean sadly that there are things that probably we can't do. I think also in terms of more day-to-day stuff. I like going walking. We do go walking, but I would say we probably do less adventurous walking than we might otherwise*

*do because again, if you are doing hillwalking then there obviously aren't any loos. (Set 2 Family member, female)*

#### **4.6.3. Financial**

Having IBD imposes a substantial financial burden on patients and their family members, including direct costs of healthcare (e.g. hospitalisation and medication). Expenditure related to IBD was high and affected the family's financial situation. Indirect costs included lost productivity, leading to loss of income. As the result of this, financial issues affected the patient with IBD and the partner, who was at times compelled to be the sole breadwinner, often in relationships where the patient had formerly undertaken this role.

*There was more of a financial pressure on trying to deal with the family. I suppose there was the worry of my husband being off work and not knowing when he was going to be able to work again and if he was going to be able to work again. I suppose there were lots of external pressures that at that point in time bothered me more. (Set 4 partner of UC patient, female)*

#### **4.6.4. Planning for an uncertain situation**

Almost all participants employed planning for uncertain situations to deal with the impact of IBD on family life. In order to decrease restrictions and enjoy their lives, when going out or on holiday, they planned toilet facilities in advance, using toilet maps, and preparing mobile caravans that included toilets. Furthermore, some of them prepared health insurance for flare-ups or unpredicted symptoms of IBD when going to an area away from home.

*I think the first holiday was fine and I think it started to get worse around 2014, holidays I mean we still went, but I mean as I said we needed to plan everything around toilet facilities. (Set 2 CD patient, male)*

## 5. Discussion

This is the first qualitative study to explore the lived experiences of IBD patients and family members as regards to the impact of IBD on family members, including coping methods that they utilised. The study highlights that there are various IBD impacts on participants' lives, identifying several challenges for family members, especially partners, as well as some positive effects arising from coping with a common adversity. The nature of chronic IBD is often ongoing and unpredictable, creating constant change affecting patients and partners, interpreted under the underlying central theme of "Our relationship with IBD: for better or worse".

The impact of IBD on participants' couple relationships is consistent with previous studies which identified that partners of IBD patients reported decreased emotional and physical intimacy, especially during flare-ups (Becker et al. 2015; Nutting and Grafsky 2018). From many IBD patients' viewpoints, in line with previous studies, impairments in sexual functioning are frequently attributable to particular symptoms such as abdominal pain, diarrhoea, and fatigue (Ogilvie et al. 2008; Riss et al. 2013). IBD-related impairments of sexual functioning and body image have been associated with reduced QoL and increased psychological problems such as stress, depression, and anxiety (Lichtenstein et al. 2006; Jedel et al. 2015). Partners in this study provided the role of caregiver for the patient, especially during flare-ups or uncontrolled symptoms of IBD. The caregiver role is practical and emotional. Other studies have found that the role of carer increases the chances of a partner experiencing anxiety and depression and this psychological well-being dramatically affects IBD caregivers' QoL (Shukla et al. 2018). There is research on patient knowledge and understanding of the risks of IBD in terms of having children and fertility is poor. The participants reported that IBD also affected family planning, due to concerns about disease heredity; previous research showed that 12% of UC patients and 2% of CD patients had a family history of IBD (Childers



et al. 2014; Hong et al. 2016). Some couples were reluctant to have children unless IBD symptoms subsided.

IBD and unpredictability of the symptoms had a considerable impact on the emotional and psychological well-being of patients and partners, related to other impacts such as their relationship, the couple's relationship with others, and everyday life. These findings were consistent with previous studies reporting that family members of IBD patients have a high level of distress and negative mental status that affects their functionality and QoL (Magro et al. 2009; Parekh et al. 2017). Several partners reported experiencing depression and anxiety in demographic questionnaires, but they did not talk about their mental health problems related to the IBD patient during interviews. However, the patients expressed a sense of guilt that their condition had caused stress and burden in their partners. Some partners reported their mental distress in terms of worrying about the patient's condition, assuming more roles and burdens (such as carer and breadwinner), but they seemed reluctant to fully disclose and attribute such stressors to mental health problems *per se* during interviews.

These interviews uncovered a widespread need for psychological support for partners of IBD patients that is largely unmet by healthcare services, despite potential positive impacts of psychological interventions for IBD patients as well as their partners from the latter receiving such care, including alleviating anxiety symptoms and stress. The new IBD standard by IBD UK in 2019 emphasises the support and education from multidisciplinary teams such as gastroenterologists, IBD nurses, psychologists, and consultancy for IBD patients (IBD UK 2019). Previous reviews reported a lack of intervention support and education for family members of IBD patients. (Shukla et al. 2018; Mohenizadeh et al. 2020). Living with constant fear was the one impact that participants mentioned, especially during the initial diagnosis and during flare-ups, when participants worried about uncertainty, early death, and cancer, which also caused constant fear in partners of IBD patients (Magro et al. 2009).

There were a variety of coping strategies that participants employed to overcome the challenges of living with IBD. Couples learned to build resilience to generate understanding about relationship issues, and honest communication was a major strategy to cope and promote a positive relationship and emotional outcomes, to enhance QoL. This reflected previous studies where honesty and open communication with families about diagnosis, IBD symptoms, and treatment led to more successful coping and adaptation strategies, with family members being more understanding of physical restrictions and needs (Nutting and Grafsky 2018). Humour was reported to be a helpful and frequently used strategy to overcome difficult situations. A study about the use of a humour intervention in the nurse-patient interaction concluded that the use of humour enhances both communication and promotes emotional and mental well-being; helps cope with difficult and unpleasant situations; and reduces stress, discomfort, and tension (Sousa et al. 2019).

One of the ways used by the study participants to cope with IBD was to gain more knowledge about the disease, which empowered them and prepared them for different situations. However, previous studies identified that information about IBD remains insufficient, the majority of IBD patients and their family members lack self-knowledge about their illness, its treatment, and self-management (Wong et al., 2012; Bernstein et al. 2019). This study found that different ways of coping were reported between newly diagnosed and long term IBD patients. During the new on-set period, patients and partners did not know much about the disease and the best source of knowledge, exacerbating fear and concern about complications and treatment choices, thus the period following diagnosis was associated with more mental health challenges for both patients and partners. Living with IBD for a longer period of time, participants gained more knowledge of disease, identified credible sources of information such as charities (e.g. Crohn's & Colitis UK, or learned from the experiences of others living with IBD and their wider IBD community. Improved knowledge resulted in less fear, and more experience or

ability to share experiences with others and the support system, whereby participants gained more confidence in self-management and greater resilience to cope with some impacts of IBD. Planning for uncertain situations was also helpful for participants to overcome restrictions caused by IBD. The uncertain nature of IBD, flare-up, and toilet access limited opportunities for patients and their family members to travel far from home and meet other people for social activities, which affects relationships and emotional well-being (Liu et al. 2018). However, the participants from this study talked about the importance of having adequate information about toilet facilities and used the IBD passport website to find a toilet map. The website [www.IBDpassport.com](http://www.IBDpassport.com) has details of toilet map apps for different countries. In addition, previous studies suggest that preparing medical care supplies, such as medication, medication documents, or insurance, could help patients and their family members reduce anxiety and concern about IBD (Rahier et al. 2009; Rahier et al. 2014).

## **6. Conclusions**

IBD affects patients and their families with many challenges faced in their lives due to IBD. Family therapists, healthcare providers (GPs, IBD nurses, psychologists, and social workers), and researchers could incorporate a bio-psycho-social approach into their work with IBD in order to provide the best services to help individuals, couples, and their families affected by these conditions.

### **6.1. Strengths and limitations**

This study reports the first research into the impact of IBD on the partners of IBD patients in the UK, and it is an important step in understanding the impact of IBD on partners and families. The findings should be interpreted in the light of some limitations that provide avenues for further research. First, the main limitation of phenomenological studies (and qualitative inquiries in general) is that they recruit a small number of participants, and the findings apply

predominantly to particular individuals, and cannot necessarily be generalised to a wider population. Second, all of the family members of IBD patients in this study were partners, and no other family members (e.g. parents, children, or siblings) came forward for interview. The final limitation was interviewing participants during the global pandemic outbreak (Covid-19). The outbreak and lockdown policies affected everyone's state of mind and behaviour, which has some implications for the data (e.g. possibly higher levels of anxiety being reported).

## **6.2. Recommendations for further study**

To help improve QoL in people with IBD and their family members, the results of this study might be used to develop future studies. To have a strong evidence base to benefit patients and their partners or practitioners, further research utilising different approaches (qualitative, quantitative, and mixed- methods) is needed. Longitudinal qualitative studies should be conducted to enhance understanding of the impact of IBD as well as a study exploring the impact of IBD on wider family members (parents, children, siblings). Research on interventions to develop coping strategies for family members of IBD patients are required.

## **6.3. Recommendations for clinical practice and education**

In the light of the impact of IBD on partners, information and support are needed for them. The chronic nature of IBD needs individuals to adapt to long-term impacts. IBD patients should receive individual care, such as from IBD nurses, gastroenterologists, and psychologists, but considerable variations exist in the information from professionals and support for family members of IBD patients, who might particularly benefit from adaptation and building resilience over time.

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## Tables

Table 1: Topic guide for patient semi-structured interviews

<b>Opening question</b>	Can you tell me about your experience of having IBD and how this affects your life?
	<ul style="list-style-type: none"> <li>- How did you feel when you were diagnosed with IBD?</li> <li>- Were you admitted to hospital in relation to your IBD?</li> <li>- Can you briefly tell me about your symptoms of IBD since diagnosis until now?</li> <li>- Can you tell me if having IBD impacts your life and how?</li> </ul> <p>Prompt: - Career/ education</p> <ul style="list-style-type: none"> <li>- Relationship/s</li> <li>- Psychological wellbeing</li> <li>- Hobbies / leisure</li> </ul>
<b>Explorative question</b>	Please can you tell me how you think your having IBD impacts your family members?
	<ul style="list-style-type: none"> <li>- Can you tell me who are your family members?</li> <li>- What were their reactions to your being diagnosed with IBD?</li> <li>- Do you think being diagnosed /having IBD has affected your family? if so, how?</li> </ul> <p>Prompt: - Career/ education</p> <ul style="list-style-type: none"> <li>- Relationship with you and others</li> <li>- Psychological wellbeing</li> <li>- Hobbies / leisure</li> </ul> <p>- How do you feel about .....? (use reflective questioning to explore the topic that the participant brings up)</p>
<b>Follow up question</b>	Do you have any ways of making your life and that of your family easier?
	- Do you discuss the impact of IBD on your family with other family members?
<b>Follow up question</b>	Help and support needed
	<ul style="list-style-type: none"> <li>- Are there particular problems in your family related to IBD that you feel need better support?</li> <li>- Use reflective questioning to explore the topic features.</li> </ul>
<b>Closing question</b>	Is there anything else that you would like to add?

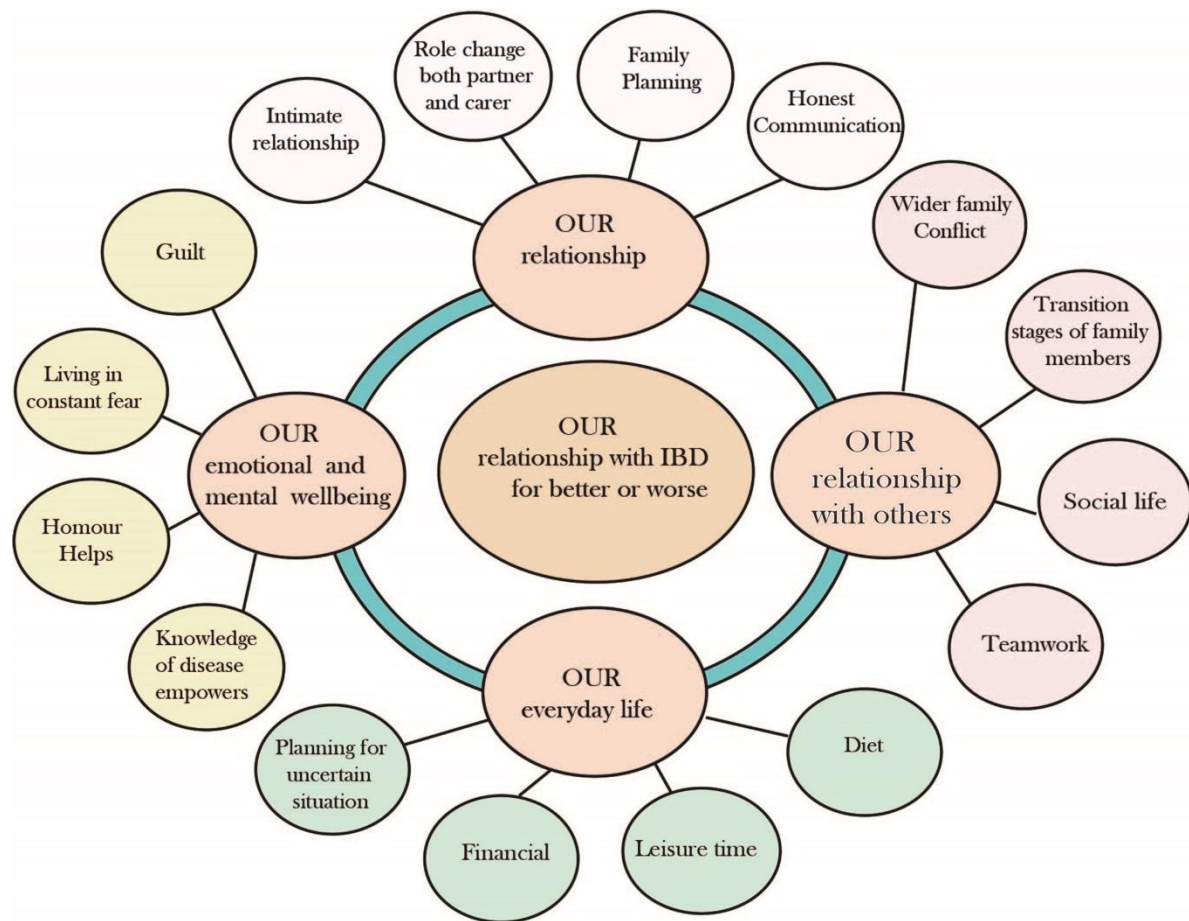
Table 2: Topic guide for family member semi-structured interviews

<b>Opening question</b>	Please can you tell me how (named person or relationship) having IBD impacts your life?
	<ul style="list-style-type: none"> <li>- How did you feel about (patient name) being diagnosed with IBD?</li> <li>- Tell me about your life since (patient name) was diagnosed with IBD? How has your life been affected?</li> <li>Prompt: - Career/ Education</li> <li>- Relationship/s</li> <li>- Psychological wellbeing</li> <li>- Hobbies / leisure</li> <li>- How do you feel about ...? (use reflective questioning to explore the topic features)</li> </ul>
<b>Explorative question</b>	Do you have any ways of making life with IBD easier in your family?
	<ul style="list-style-type: none"> <li>- Do you discuss the impact of IBD on a family with other family members?</li> </ul>
<b>Follow up question</b>	Help and support needed
	<ul style="list-style-type: none"> <li>- Are there particular problems in your family related to IBD that you feel need better support?</li> <li>- Use reflective questioning to explore topic features.</li> </ul>
<b>Closing question</b>	Is there anything else that you would like to add?

Table 3: Participant characteristics

IBD type	Education	Employment	Disease duration (years)	Last flare	Surgery
<b>Set 1 No. of children: 2</b>					
Patient, female, aged 59, White British ethnicity					
UC	School level certification	Employed (PT)	11	2019	No
Partner, male, aged 61, White British ethnicity					
-	Advanced school level certification	Employed (FT)			
<b>Set 2 No. of children: 0</b>					
Patient, male, aged 37, White (any other White background) ethnicity					
CD	Postgraduate	Employed (FT)	12	2020	No
Partner, female, aged 40, White British ethnicity					
-	Postgraduate	Employed (FT)			
<b>Set 3 No. of children: 0</b>					
Patient, male, aged 23, White (any other White background) ethnicity					
UC	Graduate	Unemployed	2	2019	No
Partner, female, aged 24, White (any other White background) ethnicity					
-	Graduate	Full time education			
<b>Set 4 No. of children: 1</b>					
Patient, male, aged 57, White British ethnicity					
CD	School level certification	Unemployed	27	2012	Small bowel resection and ileostomy; current stoma, current pouch
Partner, female, aged 54, White British ethnicity					
-	Postgraduate	Unemployed			
<b>Set 5 No. of children: 1</b>					
Patient, female, aged 58, White British ethnicity					
CD	Graduate	Employed (FT)	41	2015	Small bowel ileostomy and closure
Partner, male, aged 59, White British ethnicity					
-	Graduate	Employed (FT)			
<b>Set 6 No. of children: 2</b>					
Patient, male, aged 43, White British ethnicity					
CD	Postgraduate	Employed (FT)	20	2014	Small bowel ileostomy and closure
Partner, female, aged 41, White British ethnicity					
-	Graduate	Employed (PT)			

## Figure Legends



*Figure 1: Study themes and subthemes*

## **Abbreviations**

CD: Crohn's disease

FT: Full-time

QoL: Quality of life

IBD: Inflammatory bowel disease

KCL: King's College London

PT: Part-time

QoL: Quality of life

UC: Ulcerative colitis

UK: United Kingdom