



The Dual Challenge of Pregnancy and IBD

**Investigating self-management among pregnant
women with Inflammatory Bowel Disease**

January 2024

Lorna Orriss-Dib

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*' Hopefully someone will see this and be like,
"Oh, I'm not alone. It's not just me."'*

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Acknowledgements

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Introduction

Inflammatory Bowel Disease

Inflammatory bowel disease (IBD) is an umbrella term for two chronic gastrointestinal conditions: Crohn's disease (CD) and ulcerative colitis (UC). Both conditions are typically characterised by chronic inflammation of the gastrointestinal tract. Epidemiological studies suggest that incidence and prevalence of IBD is on the increase globally, with incidence consistently increasing among industrialised and newly industrialised countries (Burisch *et al.*, 2013; Li *et al.*, 2022). A recent study commissioned by Crohn's and Colitis UK (2022) found that previous estimates have severely underestimated the number of people living with IBD in the UK. The most recent data shows that 1 in 123 people are living with IBD. This equates to approximately over half a million individuals in the UK (Crohn's & Colitis UK, 2022).

Symptoms of IBD can be unpredictable and both Crohn's disease and ulcerative colitis are characterized by cycles of relapse (often referred to as 'flare-up') and remission. Symptoms include chronic fatigue, anaemia, abdominal pain, rectal bleeding, weight loss and diarrhoea (Fourie, Jackson & Aveyard, 2018). These symptoms can result in episodic disability when coupled with the unpredictability of intermittent relapse. Complications due to IBD can include toxic megacolon, bowel perforation and fistula, and previous studies have found high prevalence rates of anxiety and depression among those diagnosed with IBD (Barberio *et al.*, 2021; Keefer, 2021). Fatigue has also been identified as having a significant impact on people's capacity to perform daily activities (Fourie, Jackson & Aveyard, 2018; Ghorayeb *et al.*, 2018).

Whilst IBD can develop at any age, it is most commonly diagnosed during early adulthood and can result in diagnosis coinciding with significant life events or milestones, such as leaving the parental home, attending university, becoming a parent or pursuing a career. Those with IBD are three times more likely to reduce their activity levels at work and home, when compared to their non-IBD peers (Rogala *et al.*, 2008), which can have opportunity costs for both professional and

family life. Consequently, IBD is considered to have a substantial impact on physical, mental and social wellbeing.

Although the causes of IBD are not fully known or understood, it is believed to involve an interplay between genetic susceptibility, environmental factors, microbiome and gastrointestinal immunity factors (Zhang & Li, 2014). Chronic stress has also been found to further inflame the gut in those with IBD. The brain sends signals to the adrenal glands, releasing chemicals which trigger gut immune cells and block the full development of immature gut neurons (Sidik, 2023).

Inflammatory Bowel Disease in Pregnancy

There is a sizeable body of quantitative research that focuses on IBD during pregnancy. Previous quantitative studies have been instrumental in producing reliable safety data for the majority of IBD medications during pregnancy and breastfeeding. This safety data informs us which medications are safe to take during pregnancy and when breastfeeding. However, there are fewer qualitative studies on this topic, and of those that exist, there is a lack of research exploring the lived experiences of IBD management during pregnancy and the postnatal period. Little is known about how women specifically self-manage IBD during pregnancy and how they negotiate the demands of both pregnancy and IBD.

By conducting this lived experience study, we gained insight into how women adapt to the dual challenges presented by pregnancy and inflammatory bowel disease. Our study reveals priorities which are not always obvious to healthcare providers and has helped us to understand the context in which individuals are implementing management strategies in daily life. This new understanding will assist healthcare professionals who both care for women and provide IBD preconception counselling and pregnancy advice. Currently, only 27.3% of women with IBD are satisfied with the pregnancy guidance and counselling that they receive (Walldorf *et al.*, 2018). Medical care which does not take into account a person's context can make disease and the corresponding treatment management appear more burdensome to the patient (Tran *et al.*, 2015). There remains a significant need in the UK for an informational space focused on maternal IBD. Information also needs to be widely accessible and presented in lay

language, as our researcher found that there is a dearth of suitable resources available.

Women whose IBD is well-controlled and in a state of remission have fertility levels comparable to that of the general population and those without IBD (Crohn's & Colitis UK, 2023). If an individual conceives while experiencing an IBD relapse, then the likelihood of active disease continuing during the pregnancy is increased (Shannahan, Erlich & Peppercorn, 2019; Peppercorn & Mahadevan, 2021). Active IBD during pregnancy can increase the risk of premature delivery and low birth weight babies (Shannahan, Erlich & Peppercorn, 2019). Therefore, continuing to take medications prior to conception and throughout pregnancy is an important factor in maintaining remission. This is supported by previous studies examining pregnancy outcomes and drug safety (Flanagan *et al.*, 2021). The risks from active IBD outweigh the risks from the majority of medications used to keep the disease in remission (Crohn's & Colitis UK, 2023). However, all individuals should discuss their specific medications with their gastroenterologist or IBD specialist. Methotrexate is contraindicated, which means that it should not be taken during pregnancy or breastfeeding. Those taking Sulfasalazine will also require folic acid supplements (Peppercorn & Mahadevan, 2021). At the time of writing, Crohn's and Colitis UK (2023) considered the following medications to have sufficient data to justify continuation during pregnancy or breastfeeding: Corticosteroids, Infliximab, Adalimumab, Golimumab, Ustekinumab, Vedolizumab, 5-ASAs (except Balsalazide), Azathioprine and Mercaptopurine.

Medication remains a source of anxiety and concern for pregnant women with IBD (Flanagan *et al.*, 2021). A lack of reliable health information can lead to concerns about the effects on the unborn baby and an inability to make an informed decision (Ghorayeb *et al.*, 2018). Reassuringly, studies have not found significant increased risk for congenital abnormalities among babies born to mothers with IBD (Mahadevan *et al.*, 2007; Shannahan, Erlich & Peppercorn, 2019). Passing on a genetic susceptibility to IBD is estimated to be between 3-8% for a baby born to a parent with the disease (Peppercorn & Mahadevan, 2021; Crohn's & Colitis UK, 2023).

Long-term condition self-management

At present there is no curative treatment for inflammatory bowel diseases. Disease management involves dietary changes, liaising with specialists, symptom monitoring, and adherence to prescribed medications, such as corticosteroids, immunosuppressants and amino salicylates (Crohn's & Colitis UK, 2019). Individuals are also expected to learn to recognise signs of an imminent relapse in symptoms. Medicines to manage IBD may come in tablet form or be administered via injection or intravenous drip. Some people find diet plans and the avoidance of certain 'trigger' foods useful in managing symptoms. However, there is no specific diet that works for everyone with IBD. Learning to live with, and self-manage, IBD is frequently described as a trial and error process (Palant *et al.*, 2015; Richard *et al.*, 2020).

The rise in the number of people living with a chronic condition has resulted in policy makers emphasising the importance of self-management initiatives, particularly in the UK (Kendall & Rogers, 2007). However, the impact of the disease itself and the effort required to mitigate against symptoms and incorporate self-management into daily life, is often overlooked by healthcare professionals (Tran *et al.*, 2015). There is an inherent workload in self-managing a long-term condition, and this may be experienced differently depending upon the individual's access to resources, the level of support from family and friends, education, housing, and socioeconomic status. The home environment and community is where most of this workload takes place, with those affected by a long term condition spending less than 1% of their time in direct contact with a healthcare professional (Barker *et al.*, 2018).

Report overview

The first chapter of this report details the recruitment strategy used to reach potential study participants, our approach to data collection, and a description of the data analysis process. The second chapter contains an in-depth examination of the study's findings. The third chapter provides a discussion of the report. This discussion outlines how our study contributes to existing research. In our conclusion, we summarise the key messages and recommendations highlighted by our participants, discuss the limitations of the study, and outline opportunities for further research.

The QR code below links to a co-produced information pack. This pack was produced in response to the lack of accessible information on maternal IBD available online. It was developed in conjunction with our study participants and survey feedback from users of an online Breastfeeding and IBD forum. The pack includes links to peer support forums, stoma bag suppliers and questions to ask or discuss with your healthcare provider.





The Study

Methodology

This was a qualitative study that aimed to explore the subjective lived experiences of women with IBD during pregnancy and the postnatal period.¹ Data was collected using semi-structured one-to-one interviews. Interview transcripts were then analysed using the principles of thematic analysis (Braun & Clarke, 2006). This study was a seed project that will form part of a larger workstream focusing on women's health and their experiences living with long-term conditions.

Recruitment

This study aimed to recruit individuals with a self-reported medical diagnosis of IBD, who were over 12 weeks pregnant or had given birth during the last twelve months. During the recruitment stage of the study, we contacted appropriate organisations and stakeholders who either work with or support parents, pregnant people and women affected by IBD. We engaged with community groups, patient partner groups, mother and baby groups, national IBD charities such as Crohn's and Colitis UK, and their associated local networks. The study was also promoted on Healthwatch Essex's social media channels. We engaged with the widest possible cross-section of community groups and national organisations to ensure that we reached those women who were both diagnosed with IBD and caring for babies and/or young children.

We were subsequently contacted by women who were keen to take part in the project, but had given birth up to 6 years before. We therefore decided to extend the 12-month limit on our recruitment specification to ensure that we captured their experiences. Incorporating these participants into our study helped us to assess any developments and continuities in support provided for women with IBD during pregnancy and the postnatal period.

¹ Not all people who experience pregnancy identify as women. Healthwatch Essex uses inclusive language such as pregnant women and pregnant people. However, this report focuses on and refers to women due to the gender identity of our participants.

Qualitative data was collected using one-to-one semi-structured interviews. Interviews were chosen over focus groups due to the sensitive and personal nature of the research area (e.g., bowel function, pregnancy-related concerns etc.) It was felt that individuals would be more likely to share experiences of birth, pregnancy, and bowel disease in a one-to-one setting. An interview guide was prepared in advance with open questions to ensure that participants' experiences were explored in-depth, reflecting the duality of IBD self-management and pregnancy care. This contextualisation is vital for understanding the interaction between individual agency, the environment, and societal influences in the interviewee's daily life (Brinkmann & Kvale, 2015). The interview guide also served to provide useful prompts for both the interviewer and interviewee.

All potential participants were given the option of completing the interview either in-person at a venue of their choosing or remotely via Microsoft Teams. This was to take into consideration the participants' busy schedules. We envisaged that many potential participants would be attending ante-natal appointments and/or providing childcare. Therefore, flexibility on the part of the researcher was essential. All our participants opted for remote interviews. Interviews were conducted from March-May 2023 and lasted from 43 minutes to 1 hour and 8 minutes.

Analysis

All interviews were transcribed verbatim, read through several times to ensure that the researcher felt immersed in the accounts and subjected to thematic analysis. With the research aims in mind, any text describing self-management strategies, and the extent to which self-management was achieved, was highlighted. Factors that limited participants' ability to self-manage IBD whilst pregnant were also highlighted, as well as their descriptions of being under the care of multiple specialities. Highlighted sections of text were then coded and grouped into themes based around contextual factors that influenced the management of IBD while pregnant, the unique experiences of mothers with IBD, and how management of maternal IBD was achieved. Our small sample of interview accounts generated rich, insightful data. Therefore, themes were created based on meaning, as opposed to the frequency with which a phenomenon was described (Braun & Clarke, 2006). Each member of the research team and a small group of

Healthwatch Essex Research Ambassadors read through the anonymised interview transcripts, and final themes were then presented, discussed and agreed upon.

Demographics

Demographic details were collected via survey at the point of consent. This survey data complemented the qualitative accounts and details collected included employment and marital status, dependents at home, ethnicity, religious beliefs, and their IBD type. Given the county of Essex is a mix of urban and rural settings, this was also recorded. These demographics provided an overview of the study sample and are taken into consideration when assessing the study's generalisability. Demographic information is shown on the next page in Figure 1.

Figure 1 – Demographic Survey Results:

IBD Type	Crohn's disease (CD)	3
	Ulcerative colitis (UC)	0
Dependent children	Yes	3
	No	0
Relationship status	Married	3
	Registered in a same-sex civil partnership or marriage	0
	Cohabiting	0
	Divorced	0
	Separated	0
	Single	0
	Widowed	0
Current employment status	Employed full-time	1
	Employed part-time	1
	Self-employed	0
	Retired	0
	Unable to work	0
	Stay at home parent	1
	Unpaid/voluntary work	0
Ethnic group	Arab	0
	Asian/Asian British	0
	Black/African/Caribbean/Black British	0
	Mixed/multiple ethnic groups	0
	Other ethnic group	0
	White	3
Religion	Christian	0
	Buddhist	0
	Hindu	0
	Jewish	0
	Muslim	0
	Sikh	0

	No religion	3
	Other	0
	Did not disclose	0
The area I live in is:	Urban	0
	Rural	3
	Did not disclose	0

Ethics

Ethical approval for this study was granted by Essex County Council in February 2023. High ethical standards were maintained for the duration of this study. All participants were assigned pseudonyms to ensure anonymity and participant details were not shared outside of the Healthwatch Essex research team.



Findings

This chapter outlines the findings of our study. Findings have been organised into the following themes: Balancing Acts, Life Interruptions, Relationships and Communication, and the Unique Challenges for Mothers with IBD.

Balancing Acts

A key theme to emerge from the interviews related to the balancing acts that participants had to perform to fulfil their daily routines and self-manage IBD while pregnant. Their time was divided between having to seek out information on IBD in pregnancy, liaising with various clinical specialties, and attending multiple appointments, all while trying to maintain a sense of normalcy in their lives. Previous studies have defined the treatment, management and learning of what alleviates or aggravates symptoms in IBD as 'trial and error'. Project participant Adriana described this process:

I think those, particularly those first few years after diagnosis is very much trial and error. You're trying a load of different drugs, different strategies. You might try different foods, you might try different behaviours, or physical activity. The thing that works for me is the biologic drugs. They don't work for everybody, but for me, they are my lifeline [...] So, I think everyone's got their things and it is trial and error to get there. It takes time, doesn't it?

For Adriana, pregnancy did not lead to the development of any new IBD 'triggers' and so she continued with strategies that had worked pre-pregnancy for managing and preventing her symptoms.

All our participants described spending time searching for information on maternal IBD. They noted that there were no centralised information sources on pregnancy and IBD. Therefore, they had to read about pregnancy and IBD from separate sources, before attempting to mentally amalgamate the information that they had collected. The onus was very much on the individual to search for the information, as one participant highlighted:

I think there is a gap for that long-term condition and pregnancy information.

Adriana also reflected on how some individuals may find it challenging to identify reliable sources of information:

So, I'm used to reading evidence and prioritising it and knowing what the source is. Is it a reliable source or is it just 'Joe Blogs' in his living room? That's familiar territory for me. I'm used to doing that as part of my job. But again, there's a lot of people who probably couldn't do that.

Where there was a lack of specific maternal IBD information, social media groups and online forums appeared to fill this void. Some of our participants found support and reassurance by speaking online to others with IBD who were also pregnant or had recently given birth. Online forums provided a safe space for sharing experiences, as Leah described:

I'm part of a Crohn's forum on Facebook and we've got a big group of friends on there [...] Yeah, so the forum helps you, because you can just say, 'I'm having a really bad day'. And it's just someone saying, 'I know, so am I. Don't worry'.

Another participant, Alison, was diagnosed with Crohn's disease during pregnancy, and described how she had to process the diagnosis first. She therefore had to balance her perceptions about having IBD as well as being pregnant:

I think the Crohn's disease, especially initially, kind of took precedent. It was like, 'I can't even think about being pregnant'. I have this, I don't know, life-changing diagnosis, I guess, and wondering like, 'Oh, what will my life be like now with a baby and with Crohn's and things?'

Being diagnosed in pregnancy meant that Alison had no previous self-management strategies to draw upon. She felt the lack of maternal IBD information acutely and struggled to find information or accounts of others who had been diagnosed during pregnancy:

I guess when you find out you have something, you go into digging mode, don't you? Like, 'I need to know everything about it. And how can I make it better? What will help?'. And also finding out about other people who have been pregnant with Crohn's and what was their [experience]? Which you can't find. Because if you look on the internet, it's, 'Oh, I went to remission

when I was pregnant; and things like that. What's going to happen? It's kind of, you don't know, I guess. So yeah, it'd definitely be better, I guess, for more information to be out there for people that don't go into remission.

Alison had to come to terms with her diagnosis whilst also preparing for motherhood. Despite the shock IBD diagnosis, she said she felt that she had been able to prepare for becoming a mother during the third trimester of her pregnancy:

I felt like I was able to prepare as normal. I don't think Crohn's affected it in that point of view and things like that, which was good.

Our participants spoke of a need for support in pregnancy. This need increased substantially in the immediate postnatal period. Some participants went into remission during pregnancy so were unprepared for the speed with which they experienced a flare after giving birth. Their respective gastroenterology teams had not warned them about the potential for postnatal flare-up. Consequently, they were unable to prepare in advance for managing a flare whilst also caring for a newborn. Participants worked hard to maintain a fine balance between the demands of daily life and management of their IBD during their pregnancies. However, Crohn's disease flare-ups significantly disrupted this balance after childbirth:

As soon as she was born, my body didn't have a clue what it was doing. Went into this flare-up. I think I had no heads-up about that. I think if there was something out there that said you could flare, be ready for that. That could have been helpful. If there was something to read or some resource, that would've been really helpful – Adriana

Leah experienced a real contrast during and after both her pregnancies. Whilst pregnancy provided a respite from her Crohn's symptoms, she experienced flares soon after birth:

[Being pregnant] was amazing. It was like I didn't have it [Crohn's disease]. So I always loved being pregnant [...] They [the gastroenterology team] said you might get a slight different feeling in your symptoms, so might get

more diarrhoea or something after [birth] but they never said there's a risk that you'll have a bad flare-up, so it was a massive shock

The women in our study had to manage Crohn's symptoms, whilst also parenting and providing care for a newborn baby. They were obliged to manage this multitude of new daily tasks whilst experiencing symptoms of a flare. Fatigue was particularly debilitating during the postnatal period and was a source of distress at a time when the women had additional caregiving responsibilities. Leah described the challenge of caring for both a newborn and a toddler while experiencing a Crohn's flare. She reiterated the need to warn pregnant women with IBD about the potential for postnatal IBD relapse:

But the real struggle after, and people need to prepare new mums, is having a flare-up with a new-born and a toddler. You just can't do it, you just can't cope, because I remember taking my daughter to play school and pushing the pram and trying to come home and having to stop every five seconds because I just thought, 'Oh God, I'm going to pass out!'

The women we interviewed found themselves having to liaise between various healthcare professionals in order to access treatment for their postnatal flare-ups. Leah described how her treatment was delayed for several days due to the time it took the GP to successfully contact the gastroenterologist:

So, because the GPs, if you find the GP, they don't want to help. [It's not that] they don't want to help you, they don't want to prescribe or do anything until they've spoken to your consultant. So, then you get left for probably three or four days. If they could have just given me the steroids, and, um, what would they give me, the Metronidazole I was having, because it was obviously an infection. If they're just given that to me straight away, then it would've helped.

The management of IBD symptoms such as fatigue and toilet urgency in the postnatal period are further discussed in the 'Unique Challenges for Mothers with IBD' section of this chapter.

The women interviewed for our study were often having to advocate for themselves. They described this characteristic as a necessity for anyone diagnosed with a long-term condition, particularly when engaging with healthcare professionals. Alison described an incident where the duty medic at an Accident and Emergency department did not respect her lived experience. He accused her of using 'Dr Google' rather than recognising that her assertion was based on her knowledge of her own condition.

By contrast, family members were more likely to respect that the women were experts in managing their IBD and could therefore recognise their symptoms of imminent relapse. Adriana described how her partner deferred to her and followed her lead when it came to Crohn's management:

He knows to take me at my word or whatever it might be. He knows that I've run the show when it comes to the Crohn's [...] If you've had a long-term condition for however many years it is now, 20 odd years, you know it intimately, you know it inside out.

Healthcare practitioners played a vital role in supporting participants' capacity to balance the various responsibilities associated with self-management. Our participants consistently rated their IBD nurses positively. Leah described how her IBD nurse would schedule calls and regularly follow-up:

To be honest, the person that looks after you the most in everything is your IBD nurse [...] And actually I wasn't even phoning them because I felt fine. They were checking in on me, so they'd obviously put it in to call at certain points.

For other participants, however, the support provided by IBD nurses was inconsistent. Whilst Alison largely spoke positively about her IBD nurses, at the time of interview she was yet to receive any follow-ups regarding pain that she was experiencing. Alison was unable to eat solids and her GP was trying to get her an appointment with gastroenterology:

I called the IBD nurses but they usually just leave a voicemail and they say, 'Oh, we'll get back to you in 48 hours.' They sent me a text back saying, 'We

got your call', but it's been like two weeks and I've still not heard anything back from them'

Adriana described how she felt she could contact her IBD nurse if she had a query. Her infusion for her Crohn's medications was booked for 4 weeks postpartum. The infusion was booked in advance, while she was pregnant:

I did have an appointment booked. It was for about four weeks after she was born for my infusion of Crohn's drugs. So, I'd had to come off them during the third trimester. And then once I got back on those drugs, things started to settle again. Took a little bit longer than normal, but...So it was good timing. That was booked in already through the Gastro Team to get back on the drugs [...] That was booked all before she was even born. We'd got that in the diary. So that was good planning.

However, Adriana's Crohn's flared shortly after birth. Rather than contact her IBD nurse when the flare-up started, she decided to wait for the scheduled infusion. She described how this was due to the fact that her priorities had changed; her focus was now on her baby. A routine follow-up call from her IBD nurse would have taken the onus away from Adriana to instigate contact:

I think I came to the bottom of the list. I think because I'd got this baby that needed feeding, changing everything else, that my needs didn't come into it as you know, it didn't matter as much, do you though? Because she was my first priority. In hindsight, I think the world is you have your baby [...] Perhaps [I] should have had a phone call with the gastro teams. Some fabulous nurse specialists there. Perhaps [I] should have a phone call after a week or two with them to say, 'How are you doing? How is your Crohn's?' At that point in time for me, they'd probably put me on some steroids or something, or brought me in for the infusion earlier. But instead, I think, I thought in my head, it's okay. I've got that infusion booked for a few weeks' time and I just waited it out. Yeah. So, on reflection, I think that being early would've been helpful.

These examples demonstrate the variations in care and accessibility provided by gastroenterology/IBD specialist teams to women who are pregnant. They also

highlight how participants' approach to self-management was destabilised following childbirth, as they took on the physical and emotional responsibilities of caring for a newborn child.

The women we interviewed appeared to align their personalities with their approach to IBD self-management. However, it was not clear if their personality traits shaped their approach to self-management, or whether the need to self-manage a long-term condition led to the development of these characteristics. Participants provided examples that supported both these formulations. The women we interviewed used terms such as 'resilience', 'organisation' and 'prioritising'. Leah described well the organisation and proactivity skills required as a mother with a long-term condition:

You're just resilient when you've got a condition like this and you just get on with it [...] I'm a very organised person. So that's how I survived I suppose, because I was always five steps ahead of what was going on in our lives. I'd already prepared everything that when I was unwell, I could just rest because I'd already sorted out all the other stuff that was coming up in the next week. So, it's self-preservation really, it's all about organisation.

The women we interviewed had multiple roles: mother or mother-to-be; partner; employee; and homemaker. They negotiated these roles, and the activities and responsibilities associated with them, whilst also living with a long-term condition. On occasion, the women would have to compromise or make sacrifices to manage the workload associated with IBD treatment. Adriana described how she had to attend an Outpatient appointment for the administration of her biologic infusion. This appointment had been scheduled in advance and the medication was crucial for reducing the symptoms of a flare she was experiencing after giving birth. However, the Outpatients department did not permit children in the waiting area or to accompany their parents who were attending an appointment. As Adriana had no family living nearby, and her partner had returned to work, it was difficult to secure childcare:

This was such a challenge.

Adriana had no choice but to invite an unrelated distant acquaintance to the appointment so that she had someone to look after her baby. She had to compromise her privacy so that she could receive the much-needed infusion:

I know her well enough, but not well enough to invite her along to an infusion with me. But there we go.

Negotiating the balance between work and home commitments was also influenced by employers' working practices and attitudes. Leah described how her previous employer was not understanding when she needed time off to care for her children. Consequently, she felt pressure to work during a flare and this affected her health:

I had worked for a company that were supportive about my disease because they knew that I worked very hard and I really didn't take time off unless I was really bad. But then it was very different because you had times where I had to take days off because my kids were ill, and then I thought, 'right, well, now I've got this [flare]. I'm not very well, but I'm not going to be able to take that time off for me because I've already had a week off because of chickenpox', that kind of thing. So that's really hard. So then you put yourself to the back of all importance and then you just get worse because I should have been resting, but then I'm chasing round, working.

This section has demonstrated how participants had to negotiate multiple responsibilities to successfully balance the self-management of their IBD during their pregnancy and postnatal period. Several factors affected participants' abilities to perform this balancing act. These included healthcare practitioners' varying levels of support and a failure to inform them that they were likely to have a flare-up following childbirth. This lack of information limited participants' capacity to adequately plan for the postnatal period and resulted in them sacrificing their own health for the sake of their newborn children. The compromises and sacrifices that our participants had to make ties in with the next theme discussed in this chapter: life interruptions.



Life Interruptions

As stated in the introduction to this report, IBD is a disease with a relapsing/remitting cycle. Management approaches in IBD and the ongoing maintenance of remission (reducing the inflammation) is not the same for everyone. There is no single diet that works for those diagnosed with IBD. Often individuals will have to keep a food diary to detect 'trigger' foods in a trial-and-error process. Some individuals will require surgery, whilst others will not. Identifying and limiting, where possible, exposure to factors that exacerbate symptoms is a time-consuming process. When coupled with a diagnosis journey that is often quite lengthy, IBD can have implications for the affected individual that result in the interruption of life plans.

The women we interviewed typically experienced first-time symptoms in adolescence or early adulthood. Our participants received a diagnosis from between a year to six years after the onset of initial symptoms. Adriana was 16 years of age at the time of her diagnosis:

I was 16 at the time. That journey to diagnosis was quite lengthy. It's probably about a year in total that started in primary care back and forth. GPs, trying different things to manage the tummy pain and then eventually referred to secondary care.

Diagnosis did not necessarily mean an end to symptoms. Adriana tried different medications and underwent two surgical procedures. Treatments which were initially successful did not result in the long-term relief of symptoms. The turning point for Adriana was when she was given a permanent ileostomy and began to take fortnightly biologic drugs:

So, during the first probably, eight, 10 years in hospital, probably twice a year on IV steroids or I think they call them antispasmodics, to calm down the bowel. So, a variety of drugs. And then I've had two lots of surgeries. The first surgery was a Hemicolectomy, which is where they removed part of your bowel. Well, it was successful for about six months, then deteriorated. And then in 2005 I had a permanent ileostomy, so had a permanent ileostomy since then, although about two years after that, the

Crohn's, which is quite typical, came back in the small bowel. So since about that time I've been on biologic drugs. So that used to be going into the hospital for an infusion every few weeks. Now that's injecting a biologic drug every fortnight.

Alison's journey highlights how Crohn's can be misdiagnosed as irritable bowel syndrome (IBS). The time from the start of symptoms to obtaining a diagnosis and initial treatment can be protracted, crossing from adolescence into adulthood:

It started in sixth form, maybe a couple years before, that I started getting the typical symptoms of Crohn's. But I didn't even know that Crohn's existed at that time. And then going into my twenties I was going to the GP, I was having my (inaud.) and things like that, and I was actually getting really bad constipation and things. And I went to the GP, but they did say, and I quote, 'It's just IBS, and antidepressants can fix that', so did not get diagnosed at that time. Then a few years later I'd gone over to America and I was working over there, and just one day I was at work and I was suddenly getting this really severe pain, and I was vomiting, I couldn't stop going to the toilet, and my stomach felt like it was going to pop. We went to the emergency room and they did a CT scan and that's where they said like, 'Oh, you have Crohn's disease.'

Appropriate investigations and subsequent treatment were delayed in Alison's case, as it was revealed that she was pregnant:

They booked me in for a colonoscopy. I did all the prep work and everything, went in that morning and they do like a pregnancy test, a standard, and then it turned out I was pregnant. I didn't get my colonoscopy after doing the prep. Anyone who's done prep knows that you don't want to do it. That was the story of how found out I had Crohn's and pregnancy.

Here she describes her initial feelings when she found out she was pregnant after taking a pregnancy test in the endoscopy department:

[I was] freaking out. Because it would've been only two weeks since I'd been diagnosed [with Crohn's], finding out I was pregnant. When I went to the ER initially, my period was supposed to start the next day. And they took a pregnancy test at the ER, and obviously it came up negative because it wasn't far along enough, so I was like, 'I can't be. I've been on this medication. Is it safe for pregnancy? I've had a CT scan.' Those worries of these things aren't good for pregnancy. So yeah, definitely not how I was hoping to find out.

Alison was given steroids and discharged home. However, she continued to experience severe pain, constipation, and other symptoms. She returned to the hospital emergency department after several days at home but was incorrectly told her pain was due to kidney stones. Alison's pain intensified and she was unable to open her bowels despite taking laxatives and enemas. This prompted her to visit a different hospital where she finally received an MRI:

And I had, they described it as half a basketball size of abscess fluid in my abdomen. It wasn't like stool; it was abscess fluid. Then I got transferred to another hospital where I could get the abscess then drained. I think they pulled out two litres of fluid then and there and then I had a drain for a few weeks. But I was in hospital for a couple weeks. So yeah, not a good start to my diagnosis.

Alison was under the care of multiple specialties once admitted to hospital, but each had a different perspective when it came to her care:

I then got admitted to hospital – I had a gastroenterologist [GI], a surgeon, an OB [obstetrician] and just a regular hospital doctor. I can't think what they're called – I'm sorry. They'd all come in individually and have their own view of what to do with things. They didn't really communicate with each other. The GI was actually really good, and he was in contact with my new GI who was going to do the colonoscopy. They were conversing back and forth, which was really good, on what to do.

Legislative changes further influenced the care received by some of our participants. The Texas Heartbeat Act (Tuma, 2021) had a direct impact on how

Alison's care was managed. Her colonoscopy was delayed, and the management of her abscess was given much deliberation. The delay in this diagnostic testing also meant that it took longer for Alison to receive IBD treatment. Physicians were hesitant as they did not want to perform any clinical procedure that could potentially affect her pregnancy:

I lived in Texas, and so pregnancy in that state is like, 'Well, we can't do anything. We can't put you at risk in any sort of way'. It was definitely like an elephant in the room being pregnant with Crohn's because they couldn't agree what to do. And they kept saying like, 'Your uterus is really low. You're probably going to miscarry. It doesn't look good'. But then it was also I had all that abscess fluid and I don't know if that had actually just pushed my uterus down, because it was definitely a bit cramped in there. But definitely no one wanted to put hands on me. And even a nurse had said like, 'Oh, you are the pregnant one'.

Alison also felt that her gender impacted the care she received from clinicians. A negative interaction with a doctor when she attended the emergency department for severe pain brought back memories of the way that Alison's GP had dismissed her early symptoms of IBD as a teenager:

I wish I would've said like, 'That was actually rude'. Because I said I'd been told that before by my GP about like, 'Oh, you just have IBS and antidepressants can fix that'. And I just feel like, 'Is it because I'm a woman?' And it stresses me out. I do have severe anxiety, but that isn't to do with it [...] The things I'm feeling are real. I go to therapy for my anxiety and I don't need you to tell me it's... [...] This pain isn't in my head.

Leah also experienced a misdiagnosis of IBS. Her diagnosis journey took seven years in total:

It was a bit of a long process really. I had symptoms from when I was 19, but I had various tests and it never showed up. So, I kept getting flare-ups. So, they didn't know what they were, they thought it was IBS. So, I probably had that going on for about six years – quite bad symptoms and then it just so happened I had quite a bad flare-up and they had booked a

colonoscopy and it tied just in when I was having the flare-up so they could finally see that I had Crohn's. So, it took, I'd say, about seven years to get the diagnosis.

Crohn's disease also interrupted some of our participants' career plans. Alison was no longer able to continue with her job in a veterinary hospital – a role which she had enjoyed greatly. When diagnosed, her employer made it difficult for Alison to stay on in her role:

I was depressed at the time. I wouldn't have been pregnant right now or things if I'd have known I'd had Crohn's, because that was not an ideal situation. So yeah, upset. And then I was working at the time and then when I got really sick and went to the ER, I then didn't go back to work and even my job literally would not let me come back to work. So then it was sad that I couldn't work. I love my job. I worked at a veterinary hospital [...] You're kind of mourning these normal things that you were doing that suddenly you can't do any more. Definitely a dark time.

Leah is currently working full-time as both her children are now in school. However, she described how fatigue has become the most problematic symptom she experiences during a flare:

Since I had the bowel resection, when I have a flare, I don't have that agonising pain and we know now that was because of the fistula. So now, it's the fatigue. That's the main problem. So, I work full-time, and both my kids are at school now. So, during my lunch hour, I go and pick them up but when I get home from that, I could go to sleep. Some days I don't because I just have to get on with it but it is exhausting.

These examples highlight how Crohn's disease interrupted participants' daily routines and long-term plans, including key life milestones like pregnancy and transitioning to becoming a parent.

Conversely, for our participants, pregnancy also interrupted their IBD symptoms. Leah enjoyed both her pregnancies and did not experience any flares whilst pregnant:

It was amazing. It was like I didn't have it. So, I always loved being pregnant. Well, I had morning sickness. Anything to do with Crohn's was perfect. I had other sickness for other things but the whole pregnancy I've never been so well really, with both of them.

Despite this respite, our participants had to negotiate additional considerations and apprehensions regarding their Crohn's disease whilst pregnant. Their peers without IBD did not have to make these considerations. Participants' concerns were generally centred firstly on the impact that Crohn's would have on their pregnancy and baby and secondly, how the pregnancy would affect their Crohn's disease. Adriana, however, was more curious than concerned. She attributed this to both the length of time she had lived with Crohn's and her professional role in healthcare:

I didn't have any particular reservations or concerns. I'm sure there's many people who have gone through Crohn's and pregnancy. I had questions, do I keep taking my medication? Could my Crohn's be affected during pregnancy? So it was more those curious questions as opposed to feeling worried about being pregnant and having Crohn's.

Leah also described her initial feelings upon learning she was pregnant:

I was over the moon, but then I was really panicking because I thought what happens if I am unlucky and I just kept thinking, the fear was, oh, I'm going to lose the baby because I'm going to get really ill and I'm going to miscarry. Because in the whole time that I had Crohn's, I'd never spoken to anybody about pregnancy. I'd never spoken to a specialist about it. So, I should have really. I don't know it's odd because you've only got a small period of time in your appointment and then you are there for a check-up, so you don't really have time to then ask questions about how do I prep myself ready for pregnancy.

Both Leah and Adriana spoke positively of their IBD specialist nurses, describing how pre-emptive management plans and guidance from gastroenterology reduced concerns about their disease during pregnancy. We will expand upon this further in the next section of this report, which explores how effective communication helped to ease participants' potential anxieties.

Their experiences, however, contrasted with Alison's, who was provided with little advice and reassurance during her pregnancy. It is worth noting that both Adriana and Leah experienced remission during pregnancy, which may have served to reduce their anxiety further. Alison, on the other hand, was diagnosed and symptomatic throughout her pregnancy. It is therefore important to consider how individuals with IBD can be best supported during pregnancy, regardless of whether they experience relapse during this period.

IBD can still cast a shadow over the experiences of those in remission during pregnancy and this speaks to the relapsing/remitting nature of the disease as described by Leah and unpredictability of symptoms:

You're relieved to be in remission, but always in the back of your mind as well I could go into a relapse [...] It is a shock when you go from being so unwell and then when you start feeling normal because then you are also fearful that you're going to lose that, that was the thing with Crohn's. You've always got this fear of what's going to happen around the corner.

Despite the support of the IBD specialist nurses, Leah still felt some anxiety around giving birth. Her gastroenterology team were keen to avoid a caesarean section because of her previous bowel resection:

You're also quite frightened about giving birth because you don't know what that's going to do to your Crohn's. When they said to me, because I thought, oh, maybe I'll have to have a C-section because of all issues with [Crohn's]. But they were no, you mustn't, so it's just a bit overwhelming to be honest and it's a bit frightening.

As mentioned in the previous section, even participants who enjoyed the respite that pregnancy provided were unprepared for the flare-up that they experienced in the in the postnatal period. These symptoms further disrupted an already stressful and overwhelming period. Our participants found themselves having to care for a newborn whilst also managing debilitating Crohn's symptoms. Adriana experienced a flare within days of giving birth:

Within days. I was probably back to my...Well, I was less than my pre-birth weight within two to three weeks, immediately. Obviously lost the baby weight, but then went into probably about a month of diarrhoea, tummy pains

Leah also described her postnatal Crohn's relapse:

After each birth then I'd have a really bad flare-up after. I don't know if it was all the hormones surging, I was breastfeeding and stuff. So yeah, it was brilliant because you'd have a massive high for all those months and then it was a real shock when [the Crohn's] came back.

When it came to labour and the birth of their babies, our participants appeared to develop high pain thresholds due to the abdominal pains they had previously experienced with Crohn's disease. During labour, Leah realised she was further along than she thought because she had assumed that the pain of childbirth would be worse than the pain of Crohn's disease. She suddenly discovered that she was in established labour and needed to get to hospital:

That's what's with Crohn's as well, because you are used to such high levels of pain, I probably should have gone to the hospital way before, but I just thought it was going to be more painful than Crohn's. So, I possibly could have had her at home, which is really dangerous. Yeah, so that's what they need to explain to people as well, like those probably used to severe pain, you probably are further along in labour than you think, so go in.

The postnatal flare-up that our participants experienced shortly after giving birth, also interrupted their breastfeeding journey with their newborn. Our participants were able to breastfeed their babies initially, but then Crohn's symptoms such as fatigue, weight loss, diarrhoea and pain reduced their capacity to breastfeed and consequently they started hybrid feeding or switched to formula feeding. This switch to different kinds of feeding was accompanied by feelings of disappointment, selfishness, and guilt. Some participants felt as though they were putting their own health before the needs of their child.

For Alison who was diagnosed during pregnancy, giving birth did not relieve any of her Crohn's symptoms. Initially after giving birth she had more energy, but fatigue and constipation symptoms soon returned. She was having to care for her baby whilst experiencing both sleep deprivation due to the nighttime feeding and fatigue brought on by Crohn's disease. This fatigue interrupted her breastfeeding journey with her baby. Alison described feeling disappointed as she had wanted to continue:

A few days afterwards I'd gotten so lethargic. It was getting really hard to get out of bed and probably coupled with the lack of sleep, and so my husband was having to take a bigger role in helping feed Thomas. I tried pumping and things like that, but actually one of my breasts just was not having it. It wasn't producing milk, so that also then made it harder. And so eventually we just said we'll just do formula. That will just be easier for everybody and to help. But that was disappointing as well. I wanted to breastfeed Thomas and things. But just getting up every two or three hours, it was too hard on my body. When I say I physically could not get up, I could not get up. It's not even tired. You can't explain fatigue to someone. It's just like you've been zapped of everything.

Adriana's breastfeeding journey was also interrupted. She made the decision to switch to hybrid feeding (a combination of breast and formula feeds) after experiencing significant weight loss and diarrhoea. Hybrid feeding meant that her partner could then help with bottle feeds. Whilst the health visitor had discussed hybrid feeding with Adriana, they had not discussed the practical elements of making up a bottle feed:

It's just really hard trying to introduce a bottle to a baby that had so used to breastfeeding in, and I had no idea what I was doing. I honestly, literally no idea what I was doing. I didn't know how to make a bottle. I still remember being in a shop thinking, what do I buy? I have no idea what formula to buy. And I remember getting more stressed about that and breaking down because I didn't know how to make a flipping bottle than anything else. But eventually got there and I ended up doing that hybrid feeding. And that was good because it took some of the pressure off me so Josh could feed her

sometimes. And then I was able to selfishly keep some of those calories for myself. So, I was able to put weight back on.

Our participants had to navigate the challenges and changes that new parenthood brings, whilst experiencing disease symptoms. At a time when they needed vital energy to care for their babies, they were experiencing weight loss, toilet urgency, intense fatigue, and the unpredictability of when these symptoms could occur. They therefore required increased support over the postnatal period. For Alison, her support needs meant that her long-term plans and family set-up had to change. The COVID-19 pandemic was also underway at the time of her pregnancy and IBD diagnosis. She and her partner took the decision to relocate and live with her parents:

COVID is happening while I'm still pregnant, and we decide to move from Texas to Chicago where my husband's family is from, because we've got [to be] closer to family, have a bit more support. I think, I suppose, I'm due a month before and we drive 20 hours up to Chicago and things. But then it was the whole thing of then needing to find a new doctor and new OB and things at that time. But because of COVID, everything just stopped. And even after I'd given birth to my son, it was still quite hard to then find the care and things, so then we decided to move from Chicago then back home to my parents to the UK, and yeah, here we are.

Our participants' reflections therefore highlighted how IBD had disrupted their lives, in terms of both their daily routines and their long-term plans. Participants' lengthy diagnosis journeys were especially disruptive, particularly given that IBD symptoms typically appeared in their teenage years and were routinely dismissed by doctors. For one participant, their IBD symptoms coupled with an unsupportive employer forced them to give up the job that they loved. Others found that IBD symptoms interrupted how they planned to care for their children. Alison and Adriana both wanted to breastfeed but had to switch to formula and hybrid feeding to ensure their own wellbeing. Participants mourned these interruptions, expressing feelings of disappointment and guilt that they could not fulfil their plans and ambitions. Our participants highlighted the importance of having a support network around them during the postnatal period. However, this also meant that they were obliged to

reorientate their lives to be near supportive family members. The value of support networks will be discussed in more detail in the next section, which focuses on relationships and communication.



Relationships and Communication

All our participants emphasised the importance of receiving support from those around them. Support networks often comprised of marital partners or immediate family such as parents. The locality of family members influenced how much support they were able to offer. As described above, Alison returned to the UK to be with her parents:

I couldn't control when I needed the bathroom, the fatigue and things like that. And all these things are what pushed us to move back, because my husband wasn't able to work because he was having to help me and things like that.

She also highlighted how supportive her partner was:

I am very lucky to have the support of my parents as well as my husband. They understand I need the bathroom. I could go up to like seven times in the morning and things like that, and so they watch [the baby] for me and help.

Leah echoed the importance of parental support. She shared how supportive her mother was during a flare by assisting with the care of her son:

My mum had to come and help me a lot. And if I didn't have her, my husband was working, if I didn't have her, I don't know how I'd have got through that flare-up when I had my son [...] I'm really close with my family and friends. So, I've had lots of help if I needed it. I never really took the offer apart from when I had that flare-up after my son – Leah

Adriana did not have any family who lived locally. This meant that her support network was smaller:

So, I have my husband who's fab support, but he's one person, so we don't have either our families living nearby, so it is literally me and him [...] he had two weeks paternity, and then was back in London 12 hours a day.

In terms of healthcare professionals, those that were specialists in the gastroenterology/IBD field appeared able to offer greater clinical support. Leah

and Adriana highlighted the support that they received from IBD clinical nurse specialists. Both had known their IBD nurses for several years, meaning that they had developed trusting professional relationships. This enhanced the support that they provided the participants during their pregnancies:

I've known the gastro nurse for obviously a long time now, and she knows when she doesn't hear from me, everything's good. I haven't been in touch with them for two years because everything's good. So, she knows that if I do make contact, then there's a really legitimate reason and I'm struggling. I don't go to the outpatient department anymore because I do the injections at home. But same there. I know I could have rung up and said, X, Y, or Z, and someone would've helped me – Adriana

Of all our participants, Leah reported the most examples of good practice. She highlighted one episode in particular that typified the proactive care and communication that she received from her IBD nurse specialist team:

I had to go and have quite a lot of anti-D jabs, and every time I went and had an anti-D jab, obviously it's on my notes, so then the IBD team called me to check I was okay and that my Crohn's wasn't flaring or anything, so they were spot on.²

Leah praised the fact that her maternity and gastroenterology teams communicated well with one another. She even had an in-person appointment where both the Gastroenterology Registrar and Obstetrician were present. This provided additional reassurance during her pregnancy:

Then I was under a consultant in the maternity bit, and then because of the Crohn's, they did extra growth scans as well. But I just think that they were communicated really well between both teams. And one appointment I had, there was the maternity guys and then one of the registrars of the gastro team came to the appointment which was good [...] And that

² Anti-D injections are administered to mothers with rhesus negative blood to reduce the likelihood of the mother's immune system responding to the baby's positive blood type.

happened with both pregnancies, so at least one appointment, someone was representing both teams.

Leah did state, however, that she would have further benefitted from this dual appointment during early pregnancy. She also positively rated her midwife. Although Leah's midwife had not cared for a mother with IBD before, she endeavoured to learn about the condition and educated herself on Crohn's disease by reading research.

While Leah's team were proactive in making prompt contact, working together, and enhancing their knowledge of IBD during pregnancy, Adriana had to reach out if she needed advice or support:

I've known the gastro nurse for obviously a long time now, and she knows when she doesn't hear from me, everything's good.

This limited proactivity extended to Adriana's ileostomy care during pregnancy. Adriana described how she received no warning from her healthcare team that her stoma bag sizing requirements would change throughout her pregnancy and the postnatal period. The onus was then on Adriana to contact stoma bag suppliers directly and arrange to get the items on prescription. She reflected on how this might be difficult for an individual with additional needs or other conditions:

So, you can just ring them up [the suppliers] and say, 'Can I try a sample of X bag?' They'll send you something through [...] As for a prescription...it is a faff because the onus is on the patient. I'm very aware that I am educated. I can read, I will go and do stuff. There's probably people out there who, I don't know, they might have severe mental illness, they might not be able to read, they might not have the awareness of the healthcare system that I have and wouldn't do that, and could struggle. So, whether there is something that could be there to help that cohort of people to say, this is probably going to happen. This is what to do. Here's the phone number for the stoma nurse who can help you. But there wasn't anything there.

Whilst Leah and Adriana could cite several examples of good communication from professionals, they both felt that forewarning of a postnatal IBD flare-up would have been beneficial and helped them to prepare. Neither were warned that flaring after birth could happen. As her due date approached, Leah grew concerned about what would happen if there was an emergency during childbirth. She had been advised not to have a caesarean section due to her previous abdominal surgery. Leah had to seek advice from peers on an online forum and took this feedback to her consultant. However, the interaction with the consultant was insufficient in alleviating her fears:

And then up from what people have told me in the forum, then I asked the consultants and about what would happen if I had to have a C-section. That was quite scary actually, because they said, 'Oh, if we have to, then we need one of the gastro team in the room to check, because it could be quite dangerous'. So that was always terrifying – actually, I didn't mention that before – the thought of having an emergency [...] because then I thought, if I have to have one, then they're just going to knock me out completely because they need to check all the...So that was scary.

Being identified as a high-risk pregnancy raised alarm for our participants as they did not feel 'high risk' themselves. There was an interesting contrast between how the maternity professionals appeared to perceive our participants' pregnancy 'risk', compared to how the participants' regarded themselves. Some participants felt the best they ever had during pregnancy, in terms of both overall wellbeing and absence of IBD symptoms.

So certain things put me into that box. Did I myself feel like a high-risk pregnancy? No, I just felt like somebody who was pregnant. I had a really good pregnancy, I didn't feel high risk, but obviously, they have to put me in that box. It did put me a little bit on edge, so on why am I high-risk? And then it does, of course, determine what your birth options are – Adriana

Alison's account of the absence of joined up working between her maternity and gastroenterology teams reiterates the need for services to provide reassurance, compassionate communication, and holistic care. Given that Alison was

diagnosed with Crohn's disease during pregnancy, she had many questions and had to learn about her condition rapidly whilst preparing to become a parent. She illustrated several areas where care and communication could be improved. The multi-disciplinary working and cross-speciality communication appeared limited during her inpatient stay and there was not a single occasion where the specialties came together in-person with Alison:

They all just came individually. I think maybe the GI [gastroenterologist] would come with the general hospital person, but they would never come the OB [obstetrician] with the GI. And I actually saw three different OBs while I was there, because the first two I had seen had been quite elderly gentlemen and they just didn't have an opinion on it [managing an abscess secondary to IBD], so to speak, and so I kept asking for another OB.

Her account highlights the importance of providing person-centred care, with health care professionals actively engaging with and respecting the individual. In Alison's case, several professionals voiced their recommendations from their specialist perspective, but her voice was given little credence. During what was an understandably daunting and worrying time, the healthcare professionals gave Alison little reassurance:

I was getting stressed by them having said all different ideas of what to do because some were saying that, oh, they need to put a drain [to manage the abscess] in a place that I didn't want them to put a drain and things like that, and it's like, 'Are you doing that? Are you not?'

There was a turning point when a new obstetrician took over Alison's care. She instilled confidence, offered more definitive advice and provided some much-needed reassurance:

Eventually I got a younger woman who was [...] on it. She downloaded all my case notes, she got studies. She was a lot more like, 'It's okay. This is what we're going to do.' And she was finally the person to say like, 'This pregnancy will be okay. [Your uterus] is low, but it's fine'. And that was definitely what I needed to hear and to be. It was nice to finally speak to someone who was saying like, 'It's okay'.

Once in the UK, Alison attended the emergency department due to new and worsening pain symptoms. By this stage, she was familiar with Crohn's and how she could manage it. As mentioned in the section above, she shared her previous experience of fistulas with the attending medic. However, her input was disregarded:

I said, 'I'm worried about difficult things like obstruction. I've had fistulas before. Is it possible that it's that?' The doctor was like, 'Oh, have you been Dr. Googling?' And it's like, 'No, I know what happens with Crohn's. It's my disease. Could you just rule those out?'

Alison is now under the care of gastroenterology and the IBD specialist nurses at her local NHS Trust. She spoke positively of her GP and their communication with her IBD nurses. However, she was yet to meet her gastroenterologist and did not feel involved in the plan for her care:

I feel like my GP is very good at listening and trying their best sort of thing. But the GI, said I've not met the new GI yet and I would like to see them and be able to talk to them. Because I feel like maybe, oh, they have a plan that maybe I don't feel involved in [...] It seems like if the IBD nurses say something, the GP will then call to arrange something and schedule things. I'd say that their communication is good.

This section has highlighted how supportive relationships and good communication benefitted our participants during their pregnancy and the postnatal period. Participants praised the support they received from their partners and parents. However, this support was contingent on participants living close to their relatives. Participants highlighted various ways in which healthcare practitioners' communication could be improved. These included acknowledging women's experiences and perspectives, working together across specialities, offering consistent reassurance, and recognising the negative connotations associated with defining a pregnancy as 'high risk'. The challenges our participants shared often aligned. These commonalities will be discussed in the final section of this chapter, which considers the unique challenges for mothers with IBD.



Unique Challenges for Mothers with IBD

Our three participants shared comparable reflections about their experiences of new motherhood as individuals with IBD. As previously highlighted, even though our three participants were all under different care providers and NHS Trusts, none of them were forewarned about the risk of a Crohn's disease flare-up after childbirth. They also shared experiences about caring for a newborn whilst experiencing symptoms such as diarrhoea, constipation, pain, weight loss, intense fatigue and toileting urgency during a Crohn's disease flare. Whilst not all pregnant women with Crohn's disease will necessarily flare during or immediately after giving birth, our participants shared these challenges. Participants recognised that their experiences were not shared by new mothers without IBD. They therefore sought advice from other women with IBD, finding solidarity among IBD forums and their members.

The urgency and unpredictability surrounding when our participants would need the toilet disturbed the time that they spent feeding their baby and affected how comfortable they felt venturing outside the house:

All the hormones made my Crohn's so bad, so I'd be feeding her and then I'd have to rush to the toilet. So, I'd have to take her off, put her down, she'd be screaming, and I'd be running to the toilet – Leah

But then as we went home and then the fatigue started to set back in, and I was going to the toilet a lot. And you have this newborn and it's like, 'I need the bathroom. You are going to have to come with me' – Alison

Our participants also described rapid and significant weight loss due to IBD flare-up during the postnatal period:

I was breastfeeding as well, which probably in hindsight wasn't the best choice for me. Obviously the best choice for Lily, but [...] I don't think it was best for me because it was pulling all of my nutrients on top of diarrhoea. So, I didn't keep anything – Adriana

Our participants had debilitating fatigue on top of the tiredness typically faced by new parents. When participants experienced symptoms during pregnancy, they

reported that the management was generally easier compared to the postnatal period, as they could take rest when needed.

I guess it was I'd say easier during pregnancy than it was post-partum. During pregnancy I could rest a lot and lay down and had access to the toilet, which was all good and things – Alison

This reiterates the importance of providing women with IBD enhanced support during the postnatal period, particularly as flare symptoms can take several weeks to settle. Alison described how she would have welcomed support and talking therapies from services tailored to mothers with long-term conditions, as they would have recognised her experiences of IBD:

I really haven't seen any services or support for people that are pregnant and do have conditions. That's definitely something that I would look at [...] When you just have a disease, you have that disease, you're not having to take care of anybody. But when you have a disease and you're having to take care of someone else, that is just something else that other people then can't empathise with. And so, yeah, definitely we need more things like that.

Alison reiterated that she would prefer a support forum that meets in-person, but she had been unable to find one locally. She attempted to engage with a forum online during the COVID-19 pandemic but found it difficult for practical reasons as she could not hear the audio when her baby was tearful in the background. Her experience serves as a reminder that not all young people want to access remote online forums:

I definitely prefer physical interaction and talking to people. It just feels a bit impersonal when you just talk to people on the computer.

This chapter has highlighted the key findings from our research, as organised into themes that emerged during our data analysis. The rich accounts provided by our participants highlight the unique challenges that IBD posed during their pregnancy and postnatal period. In the following chapter, we will align our findings with

existing research, highlighting how the experiences we recorded both support and expand current understandings of maternal IBD.



Discussion

This study has sought to understand the pregnancy and postnatal experiences of women with IBD. The qualitative approach taken has helped to explore these experiences and illustrate areas where the care of pregnant women with IBD can improve. The women we spoke to shared examples of both positive and negative care. Their accounts underlined the importance of holistic antenatal and postnatal care. In the following discussion, we will explore how the central themes that emerged during analysis of participants' accounts – 'Balancing Acts', 'Life Interruptions', 'Relationships and Communication' and 'Unique Challenges for Mothers with IBD' – both support and expand existing research on the topic of maternal IBD. These themes will be further discussed through the lens of Burden of Treatment theory.

Treatment Burden and Workload

During our analysis of interview data, we explored the workload that participants negotiated when managing their IBD during pregnancy and the postnatal period. One way of conceptualising this workload and the tasks required to maintain remission is examining findings through the lens of Burden of Treatment theory. Burden of Treatment theory focuses on the relationship between workload and patient capacity (May *et al.*, 2014). It is important to consider the interplay between the individual, their support networks, and available healthcare services as an individual navigates the management of their IBD and aims to prevent relapse during pregnancy and after giving birth. In focusing on workload, this study highlights the realities of IBD self-management while pregnant, indicating which elements of the work are amenable to support from healthcare professionals.

Previous studies have found that an accumulation of complex self-management tasks and treatment plans can reduce the likelihood of good outcomes for mothers, particularly if they do not receive an increase in support and capacity (May *et al.*, 2014). For women with IBD, their capacity to manage their condition is reduced after the birth of their child, as they have increased caregiving responsibilities. Their immediate priorities may also change upon becoming a

parent. It is therefore important that services acknowledge the new context in which these mothers are operating when providing care.

The NHS Constitution states that services should be tailored around and reflect the individual's needs (Department of Health & Social Care, 2021). It also states that the patient should be at the heart of NHS services. Participants in our study reported both positive and negative examples of services incorporating their preferences and adapting to their requirements. Our participants said they would have valued healthcare professionals warning them of the potential for a flare or an increase in IBD symptoms after giving birth. This would have given them the chance to prepare and inform their support networks in advance. Leah stated that it would have been helpful for her gastroenterologist to provide her GP with information about how to treat a postnatal flare-up prior to her giving birth. This would have saved time and reduced the number of days where her symptoms went untreated:

What they should have done was have advised the GP that they can prescribe these things rather than...You should have written to them and say, 'If she's got this after the X, Y, and Z, you can give her these drugs'

Our participants highlighted the benefits of proactive communication and precautionary flare pathways that mirrored their own self-management approaches. Planning ahead has been cited as an adaptive strategy in other IBD studies (Sykes, Fletcher & Schneider, 2015; Lovén Wickman et al., 2016). Being forewarned reduces some of the workload following birth, enabling individuals to put their support networks in place earlier and ensure that they have adequate stocks of required medications and analgesics.

Our participants spoke highly of maternal care tailored to them as women with Crohn's disease. Examples of this care included members of the gastroenterology team being present during maternity appointments, IBD nurses who proactively followed-up with participants during their pregnancy and midwives who read literature on Crohn's disease. However, some of these examples were not consistently available and depended upon the proactivity of individual healthcare professionals. A systematic approach to embedding improvements in antenatal

care for women with IBD would ensure consistency. Quantitative studies elsewhere have found that patients report higher levels of trust and confidence in individual healthcare professionals and low levels of trust in managerial and organisational aspects of healthcare (Calnan & Sanford, 2004). Our participants highlighted clear areas for improvement which, if recognised by service providers, would further shape maternal care around the needs of mothers with IBD.

When our participants did not receive pregnancy and postnatal care tailored towards them as an individual with IBD, their workload in maintaining disease remission increased. Without postnatal flare pathways, our participants had to liaise between their GP, gastroenterologist and IBD nurse, adding administrative tasks to their already expansive workload. For some, IBD nurses were instrumental in reducing this administrative burden as they were proactive and communicated directly with the GP and/or gastroenterologist. All new mothers in the UK can expect a 6–8 week postnatal check with their GP and their babies will receive routine care from the health visiting team in the community. Mothers with IBD, however, will also need to accommodate their IBD treatment and associated appointments (Flanagan *et al.*, 2021).

Previous research has found that a lack of coordination between healthcare providers and difficulty planning appointments are structural factors that add to treatment burden (Tran *et al.*, 2015). Healthcare professionals may refer to ‘non-compliance’. This is where individuals are unable to implement and follow all of the strategies that have previously worked to maintain their IBD remission. By defining individuals as ‘non-compliant’, healthcare professionals may disregard the inaccessibility of elements of their service or the disruption that treatment places on that individual’s everyday life (Sinkfield-Morey, 2018). Following the birth of their babies, our participants’ everyday routines changed and their priorities altered.

At times, services may inadvertently create barriers to accessing IBD treatment and this potentially affects how an individual engages in self-management. When the demands of treatment compromise an individual’s capacity, this is referred to as structurally induced non-compliance (May *et al.*, 2014). The strict rules around infants in waiting areas assumes that patients have a close support network or

regular childcare arrangements. This systematic assumption resulted in challenges for Adriana when she attended her infusion appointment, as she had no family living locally. Research has found that men are less likely to miss appointments than women (Kane & Dixon, 2006; Ellis *et al.*, 2017). However, labour divisions persist across gendered lines with women undertaking the majority of domestic work and childcare. Further research is needed to explore the competing priorities of healthcare appointments and caregiving responsibilities.

Balancing Acts

Our participants balanced the demands of new parenthood, IBD management, family life and other commitments. Their capacity to perform this balancing act was influenced by a range of factors. These factors reflected wider determinants of health, including the availability of social support networks, variations in health services, and employment. These factors will now be discussed in further detail.

This study has found that families, and in particular partners, are crucial for IBD self-management during pregnancy and the postnatal period. This reiterates findings from existing studies, whose evidence suggests that partners are the strongest source of support for those with IBD (Plevinsky, Greenley & Fishman, 2016). Whilst research recognises the positive influence of partners in supporting those with chronic conditions, there remains scope to understand the experiences of single parents with IBD during pregnancy and the postnatal period.

Healthcare providers should provide educational resources and service contact details to the partners of those with IBD. The benefits of directly providing partners with service contact details are twofold. First, it removes some of the administrative workload surrounding tasks such as organising appointments. Second, this information helps the partner to advocate for their significant other by informing the IBD nurses of any relapses, particularly during the postnatal period when mothers are prioritising their babies.

An individual's IBD self-management is also informed by the quality of the social support network around them (Plevinsky, Greenley & Fishman, 2016). A social network's quality is typically influenced by the availability of its members. As Adriana's account highlights, when friends or relatives who provide practical and

emotional support are not available, the individual with IBD's workload increases. The availability of support networks is also influenced by employment-related factors. Both Adriana and Alison had partners who worked 11-12 hours per day. Partners employed in the UK are entitled to 1-2 weeks of paternity leave. Previous studies have linked paternity leave to a reduction in maternal depressive symptoms (Seimyr *et al.*, 2004). Researchers have also recorded a general correlation between more generous parental leave schemes and the prevention of maternal mental health problems (Heshmati, Honkaniemi & Juárez, 2023).

Alison and Adriana described the difficulties that they experienced when their partners worked long hours. For Alison, this informed her decision to move back to the UK. Her partner did not receive paid leave in the United States and was having to take unpaid time off to support her. Our participants' accounts highlight the need for extending paid paternity leave, particularly for couples where the mother has a long-term health condition. Practical assistance from family members meant that our participants could rest when experiencing fatigue. Partners shared the childcare and tasks such as cooking and housework. Other studies also cite the importance of having the support of close family members during a period of relapse (Sykes, Fletcher and Schneider, 2015; McMullan *et al.*, 2017; Richard *et al.*, 2020; Radford, Moran and Czuber-Dochan, 2022).

All three of our participants experienced variations in their care. They were each under different NHS trusts and described varying levels of engagement and proactivity from healthcare professionals, including their respective gastroenterology/IBD teams. Their accounts verify an existing nationwide survey which reported variation across IBD antenatal care (Wolloff *et al.*, 2021). Variation across different geographical areas and their corresponding NHS trusts is often termed the 'postcode lottery' (Graley, May & McCoy, 2011). Leah had at least one antenatal appointment where a gastroenterology doctor was present, but this was not the case for our other participants. Despite these discrepancies, all of our participants rated their IBD nurse specialists highly.

By providing rich accounts of their experiences of maternal IBD, our participants highlighted how their lives were influenced by wider determinants of health that

were ultimately beyond their control. Wider determinants in this context include societal gender norms, variation in care delivery in different areas, and the paternity leave policies at partners' places of work. As this study shows, wider determinants of health can disrupt the delicate balancing act that pregnant women and new mothers aim to facilitate in order to manage their IBD.

Life Interruptions

Our study has highlighted how IBD can disrupt or interrupt the course of women's lives. Women diagnosed with IBD prior to pregnancy often experience life interruptions due to lengthy diagnosis journeys and IBD flares with associated symptoms. Our participants developed a sense of a 'new normal' to contend with these interruptions. Participants sense of what was 'normal' was constantly changing; they had to continually mentally reorientate themselves to deal with these changes. Alison had to adapt to the fact that she was pregnant and had Crohn's disease because her diagnosis was made during pregnancy.

This study has also generated qualitative evidence highlighting how pregnancy can bring respite from Crohn's disease. The severe pain of Crohn's disease had become normalised to an extent for our participants. Respite from this pain during pregnancy made our participants realise the extent to which they had come to view their symptoms as 'normal':

I was so used to being unwell that actually when you become well, it's a bit of a shock because you think, oh, is that what it's like to feel normal.

Hearing of other women's experiences whilst pregnant made Leah grateful for her own pregnancy. Those without IBD may take an asymptomatic pregnancy for granted. Leah, however, felt a sense of relief that pregnancy meant her Crohn's went into remission:

Some people's pregnancies were horrific, so I was very lucky.

The sense of shock Adriana and Leah felt when experiencing postnatal IBD relapses shows that they had grown accustomed to being free of Crohn's symptoms during pregnancy. After childbirth, however, they had to quickly readjust. Initially, their Crohn's remission meant that they frequently stayed home

and were restricted by symptoms of fatigue. Leah described how she had to structure her plans around breastfeeding. She would have to predict how much time she had between feeds before she needed to go to the toilet again. She arranged her trips outside within this window.

As our findings demonstrate, none of our participants were warned of the potential for flaring after birth. Consequently, there was no counselling or guidance from healthcare professionals regarding breastfeeding and balancing self-care in the event of an IBD relapse. Increased support for those with IBD who wish to breastfeed their babies could potentially reduce interruptions to their breastfeeding journeys. This reflects findings in other studies on breastfeeding mothers with IBD (Restellini *et al.*, 2020). Breastfeeding benefits both baby and mother (Meyers, 2009). Therefore, an awareness among health visitors of IBD and its relapsing and remitting cycle could inform a more tailored care approach for our mothers and their new babies. Personalised discussions could also support those who wish to continue breastfeeding and assist those who have decided to hybrid or formula feed.

Some of our participants had been affected by career interruptions, a factor highlighted in other studies exploring the impact of IBD on work (Sammut, Scerri & Xuereb, 2015; Restall *et al.*, 2016; Le Berre *et al.*, 2019). As reported in our findings, Alison had to leave a role that she had previously enjoyed due to her employer's failure to make accommodations for her IBD. Adriana was working part-time at the time of her interview. She valued the flexibility offered by her employer when she was experiencing a flare. Other studies have linked the severity and unpredictability of IBD symptoms with underemployment. They highlight how some people are unable to work due to their symptoms. Others have to relinquish promotions or reduce their hours (Sammut, Scerri & Xuereb, 2015; Matini & Ogden, 2016; Radford, Moran & Czuber-Dochan, 2022). Our study highlights how mothers with IBD benefit from their employers being flexible and understanding. It is also important that employers give equal consideration to mothers' IBD and caregiving responsibilities so that they don't have to choose between taking time off to relieve their symptoms or care for their children.

All our participants described undergoing lengthy diagnosis journeys. Diagnostic delays are more commonly reported by those with Crohn's disease compared to those with Ulcerative Colitis (Battat *et al.*, 2019). Alison speculated that her GP's dismissal of her symptoms as IBS was highly gendered. Studies of delayed diagnosis in other long-term health conditions, such as endometriosis, have revealed similar accounts (Ballard, Lowton & Wright, 2006). Some women perceived that their GP was dismissive of their symptoms or did not believe the severity of their pelvic pain.

A previous review has also found that male doctors place more emphasis on the visibility of an individual's symptoms when making clinical judgements regarding pain (Champagne-Langabeer & Hedges, 2021). However, the most debilitating symptoms associated with an IBD flare, such as fatigue and pain, are not externally visible to others. Even once diagnosed, some participants experienced challenges when trying to get clinicians to comprehend their ongoing pain and other complications related to their IBD. Another study has found that female doctors are more patient-centred in their interactions when compared to their male counterparts. This applies to outpatient, inpatient and emergency department settings (Hall, Gulbrandsen & Dahl, 2014). Notably during a hospital admission while pregnant, it was a female physician who provided the most reassurance for Alison and exhibited more decisiveness in supporting her.

Relationships and Communication

Our participants emphasised the importance of relationships in their accounts. They described the positive aspects of their relationships with partners, family members, IBD nurse specialists, and GPs. Often the strength of these relationships was founded on high levels of support and open communication. Individuals with IBD may have smaller social networks compared to their non-IBD peers, but research has found that their familial relationships are stronger (Sewitch *et al.*, 2001). This perspective was consolidated by findings in our study, as support from partners and parents was crucial, particularly when participants were experiencing a postnatal IBD flare.

Participants consistently praised the support and professionalism provided by IBD nurse specialists:

I just think that the IBD nurses don't get enough gratitude for things like this.[...] I was really looked after and I don't think they could have done any better really, to be honest – Leah

The children of our participants also appeared to know about IBD from a young age, as their mothers would tell them about their Crohn's disease. During the early days following birth, the mothers we interviewed often had no choice but to take their infants to the bathroom with them when toilet urgency arose. This mirrors what mothers have described in qualitative studies elsewhere (Flanagan *et al.*, 2021).

In the UK, the delivery of healthcare for people living with long-term conditions is underpinned by the concept of self-management (Wilson, 2001). As a result, individuals with IBD become experts at managing their condition, often learning what works best for them through a trial-and-error process. They will have personal knowledge of which symptoms signal an impending relapse and may have lived experience of complications. However, as highlighted by our participants, this self-knowledge is not always recognised by healthcare practitioners. Whilst at the emergency department with severe pain, Alison shared her previous experience of bowel obstruction and a fistula, which are known complications of Crohn's disease. However, her previous knowledge and concerns were dismissed by the doctor.

Healthcare professionals must respect an individual's lived experiences and experiential knowledge. When an individual feels validated and that their concerns are taken seriously, they are more likely to have trust in the healthcare professional (Crocker *et al.*, 2013). When a healthcare professional disparages or challenges an individual's account of their symptoms, this affects the therapeutic relationship and negatively impacts clinical care (Rogers, 2002). Successful self-management requires the individual to develop self-efficacy. The invalidation of their experiences can affect their confidence and self-belief.

Alison saw different members of the multidisciplinary team when admitted to hospital, but they often failed to collaborate and did not attend at the same time. Communication within the same specialty was good:

The GI was actually really good, and he was in contact with my new GI who was going to do the colonoscopy. They were conversing back and forth, which was really good, on what to do.

However, communication across different specialties remained a challenge. Pregnant women with IBD are often under the care of multiple specialties. Therefore, communication across clinical disciplines needs to improve. Schrepel et al. (2002) highlight challenges in cross-specialty communication between emergency and internal medicine doctors. They found that cross-specialty communication approaches are often shaped by a will to exert greater agency and perceived differences between the professional specialties.

Relationships can also take the form of peer support. Leah was able to access online forums and groups, finding solidarity among those with the same condition. She asked forum members questions about their births, finding comfort sharing when a day had been difficult, and knowing that she was not alone:

Having a safe space with peers reduces feelings of isolation, provides an outlet to vent frustrations, and generates opportunities to problem solve together (Haines et al., 2023). Our project confirmed the need for solidarity and connection among women with IBD.

Unique Challenges for Mothers with IBD

Our participants' IBD symptoms generated unique challenges during their pregnancies and postnatal period. These challenges were not shared by their pregnant peers who did not have IBD. These challenges included coping with symptoms of fatigue, the frequent urge to go to the toilet, chronic diarrhoea or constipation, significant weight loss and adapting to a changing stoma size during pregnancy.

All the women we spoke to struggled to find resources that combined information on IBD and pregnancy. This lack of information has been reported in studies on

mothers with other health conditions (Haines *et al.*, 2023). There is clearly an identified need for an informational space applicable to mothers with long-term conditions that recognises the lived experiences and self-knowledge of women who have previously been pregnant. Women with long-term conditions who have experience of pregnancy and new motherhood have intrinsic knowledge which they can utilise to both support themselves and others (Haines *et al.*, 2023).

Our participants' reflections on the challenges they had faced underpinned and informed their recommendations for how women with IBD could be better supported during pregnancy and the postnatal period. These recommendations are outlined in detail in the conclusion of this report. All our participants expressed a deep desire to help women in a similar situation to their own. Alison was particularly passionate about participating in the project so that anybody diagnosed with IBD during pregnancy would feel less isolated and alone. Adriana, Alison and Leah shared their stories to raise awareness and improve care for pregnant women and new mothers with IBD, both now and in the future.



Conclusion

This study has added to the limited knowledge of how women with IBD manage their condition during pregnancy and the postnatal period. It has explored the challenges and complexities of their experiences, as told through their own words. The following section highlights key recommendations, drawing on participants' reflections on how women with IBD can be best supported during pregnancy and the postnatal period. It subsequently discusses the limitations of this study, along with opportunities for future research.

Recommendations

Whilst findings from a qualitative study with a small sample are not generalisable on a population level, our participants provided highly valuable reflections on how their experiences could have been improved. These insights are summarised in the following recommendations.

- 1) **Pre-conception and early pregnancy counselling should be available to all prospective mothers with IBD.** Pre-conception counselling plays a crucial role in dispelling misinformation around taking medications during pregnancy. Tailored counselling should also be available to women with IBD early on in their pregnancy journey to raise awareness about the tests and medications that are safe during pregnancy and breastfeeding, stoma care, birth plans, the management of fatigue, and planning for flare-ups after childbirth.
- 2) **Midwives, health visitors, and IBD nurse specialists should be well-informed about the impact of IBD on pregnancy and the postnatal period.** Prospective mothers who are used to the intense pain of IBD symptoms will have a different comprehension of the pain associated with childbirth to those without IBD. This should be acknowledged by practitioners when communicating the nature of pain during childbirth to pregnant women with IBD. Midwives and health visitors' awareness of IBD's relapsing and remitting cycle could also help them to create more tailored care approaches for mothers and their new babies.

- 3) **Healthcare practitioners should consistently adopt reassuring language when engaging with pregnant women with IBD.** It is important to maintain a balance between positivity and informative discussion about the risk of flaring during pregnancy and after childbirth. Receiving a diagnosis of a high-risk pregnancy can be anxiety-inducing, particularly for women who do not define themselves as 'high-risk'. Practitioners should therefore offer reassurance when discussing the risks associated with maternal IBD.
- 4) **Healthcare practitioners should recognise and respect the knowledge and expertise that people with IBD develop as a result of self-managing their condition.** These perspectives should be incorporated into any plans for their care.
- 5) **Gastroenterology and maternity teams should seek to hold collaborative appointments at multiple stages of pregnancy.** These appointments encourage communication between teams and provide reassurance to women who are obliged to negotiate multiple specialties across the course of their pregnancy.
- 6) **More information should be provided to women and pregnant people who use stoma bags at the start of their pregnancy journey.** It is vital that IBD nurses inform individuals with stoma bags that the sizing of their bag will change as their pregnancy progresses. Stoma bags of varying sizes should be easily accessible. Onus should not be placed on the individual to research suppliers and order the stoma bags themselves.
- 7) **Gastroenterologists should forewarn pregnant women with IBD that they may experience a flare after giving birth.** This information helps pregnant women with IBD to prepare for a flare before childbirth by arranging necessary support and ensuring that they have adequate stocks of medication. Gastroenterologists should provide this information to all those responsible for the individual's care, including their GP. This ensures the timely treatment of postnatal flare-ups.

- 8) **Health visitors and community midwives should provide additional support to breastfeeding women who are experiencing a post-natal flare. Hybrid and formula feeding options should also be discussed.** Detailing feeding options in an informative and non-judgemental manner would help to dispel the guilt and frustration that some women feel when they are obliged to stop breastfeeding to help preserve their health and wellbeing.
- 9) **Individuals with IBD and their partners or close family members should be provided with contact details for IBD clinical nurse specialists and stoma nurses (if applicable).** This makes it easier for women to reach out for support, particularly during postnatal relapses. This information helps the partner to advocate for their significant other by informing the IBD nurses of any relapses, particularly during the postnatal period when mothers are prioritising their babies. This helps to alleviate some of the administrative workload involved in seeking support and arranging appointments.
- 10) **Outpatient appointments should be made more accessible to new mothers with childcare responsibilities.** Foundation Trusts should revisit rules stipulating that children are not allowed in outpatient settings and acknowledge that some new parents will not be able to attend appointments if they are unable to bring their child. Allowing children to attend these appointments with their parents would help to alleviate the administrative burden that comes with having to arrange childcare, particularly for individuals who do not have easily accessible support networks nearby.
- 11) **It is important that information on maternal IBD is available in a centralised and publicly accessible format.** Current information on this topic is typically produced in academic literature, which is often behind a paywall. We have developed an informational resource in response to this lack of information. Details on how to access the resource are featured in the 'Further Information' section below.

Limitations

We recruited a small sample of women with IBD who had young children. They reflected upon and retrospectively described their pregnancy experiences. We therefore acknowledge that there may be some recall bias. All the women in our sample had Crohn's disease. Findings from this study will be generalisable to individuals with similar demographics to our participants. Unfortunately, our sample underrepresented those from minority backgrounds. Our final sample size was small, in part because this is a seed project for a larger body of work focusing on women with multiple long-term conditions. Despite the size of our sample, we were able to capture a range of experiences including Crohn's disease diagnosis during pregnancy and experiences of remission during pregnancy. This study has also been able to explore an international perspective, with accounts of care from the USA and UK. Both countries utilise self-management approaches to care for long-term conditions. Two of our participants were in remission at the time of interview and one was still experiencing symptoms. However, those in remission may be more likely to engage in research due to the unpredictability of symptoms during relapse.

Researcher Reflexivity

During the course of this project, the lead researcher had a close family member diagnosed with Crohn's disease. The researcher was also pregnant at the time of developing the project proposal and was in the postnatal period during interviews. These personal experiences contributed to the researcher's feelings of empathy for the participants, and enhanced their understanding of antenatal pathways and terminology used in antenatal care.

Future Research

There are several areas for further research regarding pregnancy and postnatal experiences of women with IBD. Further lived experience research is needed to understand the pregnancy experiences of those with IBD from minority groups. The single parent perspective of pregnancy and postpartum IBD also needs greater exploration. It is important to understand the experiences of those across social

class strata, insecure or temporary work and those who reside in urban areas. Further qualitative enquiry is also required to capture the experiences of individuals diagnosed with IBD during pregnancy, as there is limited research in this area. Our study contributes to this emerging field owing to the experiences shared by one of our study participants and provides a foundation for future research to build on.

A retrospective study design with purposive sampling may be more likely to reach those with the relevant experience. Over the course of this study, we have learnt valuable lessons which will inform our future workstream on women's experiences of multiple long-term conditions. These lessons include skills in compiling an adaptable interview guide that responds to the varying experiences of women with long-term conditions, engaging with and recruiting mothers, and the value of lived experience working groups. We have been able to engage with various IBD stakeholders and forums, and will continue to build on these professional connections as our research on women and long-term conditions develops.

Further Information

In response to a lack of information for pregnant women with IBD, we have created an informational resource which can be accessed here:





References

- Ballard, K., Lowton, K. and Wright, J. (2006) 'What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis', *Fertility and Sterility*, 86(5), pp. 1296–1301. doi: 10.1016/J.FERTNSTERT.2006.04.054.
- Barberio, B. *et al.* (2021) 'Prevalence of symptoms of anxiety and depression in patients with inflammatory bowel disease: a systematic review and meta-analysis', *The lancet. Gastroenterology & hepatology*, 6(5), pp. 359–370. doi: 10.1016/S2468-1253(21)00014-5.
- Barker, I. *et al.* (2018) 'Self-management capability in patients with long-term conditions is associated with reduced healthcare utilisation across a whole health economy: cross-sectional analysis of electronic health records', *BMJ Quality & Safety*, 27(12), pp. 989–999. doi: 10.1136/bmjqs-2017-007635.
- Battat, R. *et al.* (2019) 'P030 DELAYED DIAGNOSIS OF CROHN'S DISEASE IS COMMON AND ASSOCIATED WITH AN INCREASED RISK OF DISEASE COMPLICATIONS', *Inflammatory Bowel Diseases*, 25(Supplement_1), pp. S14–S15. doi: 10.1093/IBD/IZY393.035.
- Le Berre, C. *et al.* (2019) 'Impact of inflammatory bowel diseases on working life: A French nationwide survey', *Digestive and liver disease: official journal of the Italian Society of Gastroenterology and the Italian Association for the Study of the Liver*, 51(7), pp. 961–966. doi: 10.1016/J.DLD.2019.01.024.
- Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3, pp. 77–101. doi: 10.1191/1478088706qp063oa.
- Brinkmann, S. and Kvale, S. (2015) *Interviews: Learning the Craft of Qualitative Research Interviewing*. 3rd edn. SAGE Publications.
- Burisch, J. *et al.* (2013) 'The burden of inflammatory bowel disease in Europe', *Journal of Crohn's & colitis*, 7(4), pp. 322–337. doi: 10.1016/J.CROHNS.2013.01.010.
- Calnan, M. and Sanford, E. (2004) 'Public trust in health care: the system or the doctor?', *Quality and Safety in Health Care*, 13, pp. 92–97. doi: 10.1136/qshc.2003.009001.
- Champagne-Langabeer, T. and Hedges, A. L. (2021) 'Physician gender as a source of implicit bias affecting clinical decision-making processes: a scoping review',

BMC Medical Education, 21(1), pp. 1–9. doi: 10.1186/S12909-021-02601-2/TABLES/1.

Crohn's and Colitis UK (2019) *All about Crohn's and Colitis*. Available at: <https://crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis/all-information-about-crohns-and-colitis/understanding-crohns-and-colitis/all-about-crohns-and-colitis> (Accessed: 15 June 2023).

Crohn's and Colitis UK (2022) *New research shows over 1 in 123 people in UK living with Crohn's or Colitis*. Available at: <https://crohnsandcolitis.org.uk/news-stories/news-items/new-research-shows-over-1-in-123-people-in-uk-living-with-crohn-s-or-colitis> (Accessed: 15 June 2023).

Crohn's and Colitis UK (2023) *Pregnancy and breastfeeding with Crohn's Disease or Ulcerative Colitis (IBD)*. Available at: <https://crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis/all-information-about-crohns-and-colitis/living-with-crohns-or-colitis/pregnancy-and-breastfeeding> (Accessed: 22 June 2023).

Crocker, J. E. *et al.* (2013) 'Factors affecting patients' trust and confidence in GPs: evidence from the English national GP patient survey', *BMJ Open*, 3(5), p. e002762. doi: 10.1136/BMJOPEN-2013-002762.

Department of Health and Social Care (2021) *The NHS Constitution for England*. Available at: <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england> (Accessed: 27 July 2023).

Ellis, D. A. *et al.* (2017) 'Demographic and practice factors predicting repeated non-attendance in primary care: a national retrospective cohort analysis', *The Lancet Public Health*, 2(12), pp. e551–e559. doi: 10.1016/S2468-2667(17)30217-7.

Flanagan, E. K. *et al.* (2021) 'Addressing pregnancy-related concerns in women with inflammatory bowel disease: Insights from the patient's perspective', *Journal of Gastroenterology and Hepatology Open Access*, 5(1), pp. 28–33. doi: 10.1002/JGH3.12442.

Fourie, S., Jackson, D. and Aveyard, H. (2018) 'Living with Inflammatory Bowel Disease: A review of qualitative research studies', *International Journal of Nursing Studies*, 87, pp. 149–156. doi: 10.1016/J.IJNURSTU.2018.07.017.

Ghorayeb, J. *et al.* (2018) 'When Your Pregnancy Echoes Your Illness: Transition to Motherhood With Inflammatory Bowel Disease', *Qualitative health research*, 28(8),

pp. 1283–1294. doi: 10.1177/1049732318763114.

Graley, C. E. M., May, K. F. and McCoy, D. C. (2011) 'Postcode lotteries in public health – The NHS health checks programme in North West London', *BMC Public Health*, 11(738), pp. 1–8. doi: 10.1186/1471-2458-11-738/TABLES/7.

Haines, A. J. *et al.* (2023) 'Occupations and balance during the transition to motherhood with a lifetime chronic illness: A scoping review examining cystic fibrosis, asthma, and Type-1 diabetes', *Australian Occupational Therapy Journal*, pp. 1–15. doi: 10.1111/1440-1630.12899.

Hall, J. A., Gulbrandsen, P. and Dahl, F. A. (2014) 'Physician gender, physician patient-centered behavior, and patient satisfaction: A study in three practice settings within a hospital', *Patient Education and Counseling*, 95(3), pp. 313–318. doi: 10.1016/J.PEC.2014.03.015.

Heshmati, A., Honkaniemi, H. and Juárez, S. P. (2023) 'The effect of parental leave on parents' mental health: a systematic review', *The Lancet Public Health*, 8(1), pp. 57–75. doi: 10.1016/S2468-2667(22)00311-5.

Kane, S. and Dixon, L. (2006) 'Adherence rates with infliximab therapy in Crohn's disease', *Alimentary Pharmacology & Therapeutics*, 24(7), pp. 1099–1103. doi: 10.1111/J.1365-2036.2006.03092.X.

Keefer, L. (2021) 'What can we do to tackle anxiety and depression in patients with inflammatory bowel disease?', *The Lancet Gastroenterology and Hepatology*, 6(5), pp. 337–338. doi: 10.1016/S2468-1253(21)00066-2.

Kendall, E. and Rogers, A. (2007) 'Extinguishing the social?: state sponsored self-care policy and the Chronic Disease Self-management Programme', *Disability and Society*, 22(2), pp. 129–143. doi: 10.1080/09687590601141535.

Li, K. *et al.* (2022) 'Trends in Worldwide Research in Inflammatory Bowel Disease Over the Period 2012–2021: A Bibliometric Study', *Frontiers in Medicine*, 9. doi: 10.3389/FMED.2022.880553/BIBTEX.

Lovén Wickman, U. *et al.* (2016) 'Self-Care Among Patients With Inflammatory Bowel Disease: An Interview Study', *Gastroenterology nursing: the official journal of the Society of Gastroenterology Nurses and Associates*, 39(2), pp. 121–128. doi: 10.1097/SGA.000000000000120.

- Mahadevan, U. *et al.* (2007) 'Pregnancy outcomes in women with inflammatory bowel disease: a large community-based study from Northern California', *Gastroenterology*, 133(4), pp. 1106–1112. doi: 10.1053/J.GASTRO.2007.07.019.
- Matini, L. and Ogden, J. (2016) 'A qualitative study of patients' experience of living with inflammatory bowel disease: A preliminary focus on the notion of adaptation', *Journal of health psychology*, 21(11), pp. 2493–2502. doi: 10.1177/1359105315580463.
- May, C. R. *et al.* (2014) 'Rethinking the patient: Using Burden of Treatment Theory to understand the changing dynamics of illness', *BMC Health Services Research*, 14(1), pp. 1–11. doi: 10.1186/1472-6963-14-281/FIGURES/5.
- McMullan, C. *et al.* (2017) 'Adapting to ulcerative colitis to try to live a "normal" life: a qualitative study of patients' experiences in the Midlands region of England', *BMJ open*, 7(8). doi: 10.1136/BMJOPEN-2017-017544.
- Meyers, D. (2009) 'Breastfeeding and Health Outcomes', *Breastfeeding Medicine*, 4(Suppl 1), pp. 13–15. doi: 10.1089/BFM.2009.0066.
- Palant, A. *et al.* (2015) "'And then you start to lose it because you think about Nutella": The significance of food for people with inflammatory bowel disease – a qualitative study.', *BMC gastroenterology*, 15(93). doi: 10.1186/s12876-015-0322-2.
- Peppercorn, M. and Mahadevan, U. (2021) *Patient education: Inflammatory bowel disease and pregnancy (Beyond the Basics) - UpToDate*. Available at: <https://www.uptodate.com/contents/inflammatory-bowel-disease-and-pregnancy-beyond-the-basics> (Accessed: 22 June 2023).
- Plevinsky, J. M., Greenley, R. N. and Fishman, L. N. (2016) 'Self-management in patients with inflammatory bowel disease: Strategies, outcomes, and integration into clinical care', *Clinical and Experimental Gastroenterology*, 9, pp. 259–267. doi: 10.2147/CEG.S106302.
- Radford, S. J., Moran, G. W. and Czuber-Dochan, W. (2022) 'The impact of Inflammatory Bowel Disease related fatigue on Health-Related Quality of Life: a qualitative semi-structured interview study', *Journal of Research in Nursing*, 27(8), pp. 685–702. doi: 10.1177/17449871211061048.
- Restall, G. J. *et al.* (2016) 'Understanding Work Experiences of People with Inflammatory Bowel Disease', *Inflammatory Bowel Diseases*, 22(7), pp. 1688–1697. doi: 10.1097/MIB.0000000000000826.

- Restellini, S. *et al.* (2020) 'Update on the Management of Inflammatory Bowel Disease during Pregnancy and Breastfeeding', *Digestion*, 101(Suppl. 1), pp. 27–42. doi: 10.1159/000502886.
- Richard, L. *et al.* (2020) 'Patients' accounts of living with and managing inflammatory bowel disease in rural Southern New Zealand: a qualitative study', *BMJ Open*, 10(11), p. doi:10.1136/bmjopen-2020-041789. doi: 10.1136/BMJOPEN-2020-041789.
- Rogala, L. *et al.* (2008) 'Population-based controlled study of social support, self-perceived stress, activity and work issues, and access to health care in inflammatory bowel disease', *Inflammatory Bowel Diseases*, 14(4), pp. 526–535. doi: 10.1002/IBD.20353.
- Rogers, W. A. (2002) 'Is there a moral duty for doctors to trust patients?', *Journal of Medical Ethics*, 28(2), pp. 77–80. doi: 10.1136/JME.28.2.77.
- Sammut, J., Scerri, J. and Xuereb, R. B. (2015) 'The lived experience of adults with ulcerative colitis', *Journal of Clinical Nursing*, 24(17–18), pp. 2659–2667. doi: 10.1111/JOCN.12892.
- Seimyr, L. *et al.* (2004) 'In the shadow of maternal depressed mood: experiences of parenthood during the first year after childbirth', *Journal of psychosomatic obstetrics and gynaecology*, 25(1), pp. 23–34. doi: 10.1080/01674820410001737414.
- Sewitch, M. J. *et al.* (2001) 'Psychological distress, social support, and disease activity in patients with inflammatory bowel disease', *The American journal of gastroenterology*, 96(5), pp. 1470–1479. doi: 10.1111/J.1572-0241.2001.03800.X.
- Shannahan, S. E., Erlich, J. M. and Peppercorn, M. A. (2019) 'Insights into the treatment of inflammatory bowel disease in pregnancy', *Therapeutic Advances in Gastroenterology*, 12. doi: 10.1177/1756284819852231.
- Sidik, S. (2023) 'Chronic stress can inflame the gut - now scientists know why.', *Nature*, 618, pp. 221–222. doi: 10.1038/D41586-023-01700-Y.
- Sinkfield-Morey, T. (2018) 'How using the term "non-compliant" keeps providers from partnering with patients', *Creative Nursing*, 24(3), pp. 178–185. doi: 10.1891/1946-6560.24.3.178/ASSET/IMAGES/10.1891_1946-6560.24.3.178-IMG1.PNG.
- Sykes, D. N., Fletcher, P. C. and Schneider, M. A. (2015) 'Balancing my disease:

women's perspectives of living with inflammatory bowel disease', *Journal of Clinical Nursing*, 24(15–16), pp. 2133–2142. doi: 10.1111/JOCN.12785.

Tran, V. T. *et al.* (2015) 'Taxonomy of the burden of treatment: a multi-country web-based qualitative study of patients with chronic conditions', *BMC Medicine*, 13(115). doi: 10.1186/s12916-015-0356-x.

Tuma, M. (2021) *Most extreme abortion law in US takes effect in Texas*, *The Guardian*. Available at: <https://www.theguardian.com/us-news/2021/sep/01/texas-abortion-law-supreme-court> (Accessed: 3 August 2023).

Walldorf, J. *et al.* (2018) 'Family planning in inflammatory bowel disease: childlessness and disease-related concerns among female patients', *European journal of gastroenterology & hepatology*, 30(3), pp. 310–315. doi: 10.1097/MEG.0000000000001037.

Wilson, P. M. (2001) 'A policy analysis of the Expert Patient in the United Kingdom: self-care as an expression of pastoral power?', *Health & social care in the community*, 9(3), pp. 134–142. doi: 10.1046/J.1365-2524.2001.00289.X.

Wolloff, S. *et al.* (2021) 'Provision of care for pregnant women with IBD in the UK: the current landscape', *Frontline Gastroenterology*, 12(6), pp. 487–492. doi: 10.1136/flgastro-2020-101546.

Zhang, Y. Z. and Li, Y. Y. (2014) 'Inflammatory bowel disease: Pathogenesis', *World Journal of Gastroenterology*, 20(1), pp. 91–99. doi: 10.3748/WJG.V20.II.91.

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