Abstract

Inflammatory bowel disease can increase the risk of pregnancy related complications, with severe disease activity during pregnancy further increasing these complications.

This mixed methods study provides original first-hand insights into what women want from their IBD team during pregnancy, with novel themes identified regarding a need for information about what to expect about their disease activity during pregnancy and reassurance about medication use.

Without discussion of this possible disease activity in pregnancy, women may make assumptions based upon 'hearsay', or have expectations, which may not be accurate within the context of their personal experience of disease severity. Women with IBD may also suffer additional, unnecessary negative psychological or physical effects if evidence-based information is not given about medication. Woman may stop taking it, risking increased disease activity, or experience additional anxiety about the perceived effects medication may have on their baby.

The provision of specialist IBD care during pregnancy may vary according to service provider, however the IBD multidisciplinary team can be central to ensuring women receive optimal evidence-based care in a timely manner during pregnancy.

Introduction

Women living with Inflammatory Bowel Disease (IBD) have a similar fertility rate to that of the general population. The exception is those who have had pelvic surgery, which can decrease their rate of conception, or chronic disease activity which has resulted in a malnourished state (Kwan and Mahadevan, 2010). Approximately a quarter of women will become pregnant following their diagnosis of IBD (Ferguson, Mahsud-Dornan and Patterson, 2008).

IBD can increase the risk of pregnancy related complications for women including: maternal gestational diabetes (due to the use of corticosteroids in the treatment and management of IBD) , preterm birth (<37 weeks) both spontaneous and iatrogenic, preterm prelabour caesarean section or induction of labour, low birth weight (< 2.5kg) and caesarean section (Getahun et al. 2014), (Boyd et al. 2015) (Shand et al. 2016) (Bortoli et al. 2011). Severe disease activity during pregnancy further increases the risk of these pregnancy complications, therefore women living with IBD are considered to have a high-risk pregnancy and should have multidisciplinary care with additional surveillance of maternal and fetal wellbeing, even if they are in remission at conception.

Some women will have an established relationship with their IBD team, however this is not universally the case. Pregnancy may be the first time a woman has contact with an IBD team, particularly if diagnosed during pregnancy. An IBD team will usually be multidisciplinary and consist of a gastroenterologist, an IBD specialist nurse and may include a dietician.

Pregnancy care pathways for women living with IBD may vary depending upon the service provision available. In 2021, a cross-sectional survey of 98 IBD units in the UK found that in 86% of units, women their antenatal IBD care was provided by their usual gastroenterologist whilst in only 14% of units did women receive care from a gastroenterologist with expertise in pregnancy. Antenatal clinics with both a gastroenterologist and an obstetrician were offered in 14% of units (Wolloff, Moore, Glanville et al 2021). This highlights the variation in antenatal care provision for women living with IBD.

This study aimed to understand what shaped women's experiences of pregnancy when living with IBD and explore components of maternity care pathways, and this article will focus on what women want from their IBD team during pregnancy. A systematic review was undertaken and findings used to shape questions for the survey and interviews (Janiszewski et al. 2022).

Study design

Full HRA ethical approval (IRAS:256277) was obtained prior to commencing the study, along with university ethical permission.

Methods

An embedded mixed methods study design was used, which included one to one interviews and an anonymous online survey. Women who fulfilled the eligibility criteria (table 1) were invited to participate in a single one to one interview, whilst the anonymous online survey was distributed through social media platforms including Facebook and Twitter. The survey was live for four months.

The survey contained multiple choice questions, agreement scales, open and closed questions and an opportunity to provide additional free text responses to what would have improved their experience of pregnancy or any other comments. Interviews were semi-structured, and included pre-defined prompts and probes where needed.

Data from the interviews were analysed using Interpretative Phenomenological Analysis, whilst qualitative data from the surveys were analysed using thematic analysis. Quantitative data from the surveys were analysed using descriptive statistics.

Data from the systematic review, survey and interviews was then synthesised with the construction of themes and sub-themes.

Table 1: Eligibility criteria

Online survey	One to one interview

Aged 18 years or older at time of completion	Aged 18 years or older at time of participation
Diagnosed with IBD prior to or during pregnancy	Diagnosed with IBD prior to or during pregnancy
Live in the United Kingdom	Received care at the local NHS Trust for either gastroenterology care or maternity care
Experienced pregnancy	Given birth in the last five years

Results and findings

Findings and results from the survey and the interviews were triangulated to provide an in-depth and unique understanding of what shaped experiences of pregnancy and what women want from their IBD team.

Two predominant themes emerged around what women wanted from their IBD team during pregnancy: sharing expectations about what would happen during pregnancy and information and discussions about medication use during pregnancy. A sub theme around additional anxiety and worry emerged within the medication theme.

Participant Characteristics

A total of 50 women completed the survey, who had experienced pregnancy whilst living with a diagnosis of IBD, including women diagnosed with IBD during pregnancy.

Table 2 Participant characteristics for survey

Characteristic	Range in years	Mean age in years including standard deviation
Age at diagnosis	6-39	Mean age 23 (SD 6.617)
Age at completion of survey	29-63	Mean age 40 (SD 6.813)
Years since giving birth	0-34	-

There was no restriction on the length of time since birth for participation, and this was in response to feedback from a previous study (Janiszewski et al 2019) where women who were outside of the eligible timeframe communicated a desire to share their experiences and be included in such studies.

Demographics were not collected from the women who participated in the interviews as the interviews were an opportunity for women to discuss what they considered to be important and therefore only if this was considered important would it be discussed. The inclusion criteria was also more exclusive for the interviews and therefore women had confirmed they had given birth within the last five years.

During the interviews it emerged that one women had experienced pregnancy prior to diagnosis as well as after and one woman was diagnosed with IBD during pregnancy.

Most women were diagnosed with IBD prior to pregnancy, however two were diagnosed during pregnancy and nine women had also experienced pregnancy prior to diagnosis. There was a relatively even split of women living with Crohns disease (22/50) and ulcerative colitis (28/50)

The themes and subthemes emerged following triangulation of the quantitative and qualitative data and will be presented in turn

What should I expect to happen?

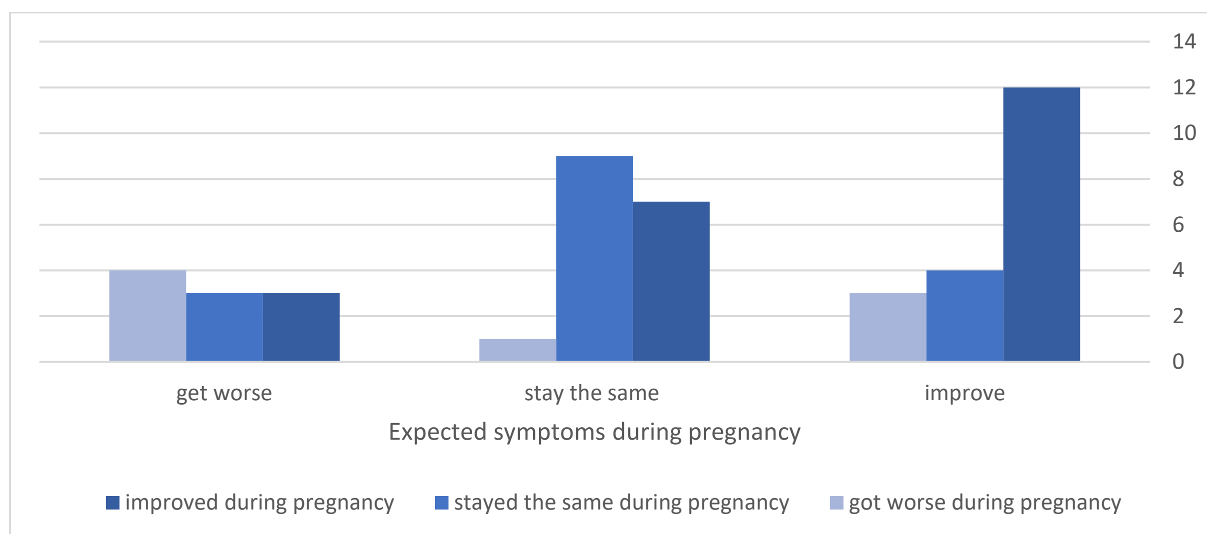
In response to the survey question on whether women received advice from their healthcare provider about how to expect their symptoms to be during pregnancy, 19 women reported having received no advice. Of the women who were given advice, most were told to expect an improvement, with the remaining women being told to expect their symptoms to remain the same or get worse.

Women's expectations about their symptoms during pregnancy generally aligned to the advice they were given, however of the women who received no advice they most commonly expected

symptoms to remain the same, with seven women expected a worsening of symptoms and a small number expected an improvement,

Women were also asked about their experienced symptoms and how this compared to their expectations. Experiences reported generally matched expectations, with the exception of women who expected a worsening of symptoms. Of the 10 women who expected their symptoms to get worse, this was realised in only four, with the remainder experiencing either an improvement or symptoms remaining the same.

Figure 1 Expected symptoms compared to experienced symptoms (n=46)



Women who were interviewed (n=7) recalled being given advice that their IBD symptoms would improve during pregnancy, and this then generally aligned to their experience, however were unable to specifically recall who gave them this information. Pseudonyms are used for the following quotes from the interviews

> *"I was actually better than I was before I was pregnant which I knew I thought someone had told me that was a possibility"*

Jenny

"I don't know if this is true or just a myth but I hear that you don't tend to have flare up's of IBD whilst you're pregnant" *Sarah*

"I remember her saying how well she'd been and apparently she'd heard and this is the sort of story they were telling you that when you were pregnant you become well and it was almost a broad brush of that's what happens"

Olivia

"someone said that often you can be quite a lot better during pregnancy and then have suddenly have a flare up again afterwards"

Ellie

Talk to me about medication

Medication emerged as a theme within the study, with most women who responded to the survey taking medication prior to pregnancy. Of the 46 women who responded to this question 74% were receiving treatment.

Women took either one medication (67%) or two medications (33%). Thiopurines were the most common group of medication taken by women with (48%) women taking them either alone or in conjunction with other medications, closely followed by 5-aminosalicylates with (42%) of women taking these.

Discussions about IBD medication use during pregnancy took place for 71% of women who were taking IBD medication, whereas for 29% of women such discussions did not take place.

For the 29/41 women (71%) who had a discussion about IBD medication, 59% (n=17) responded that they were told to continue taking their medication, 14% (n=4) reported having changes made to their medication due to their pregnancy and 21% (n=6) reported being told to stop taking their medication.

Additional worry and anxiety

Additional worry and anxiety emerged as a sub theme – with lack of information and reassurance detracting from experiences and caused additional worry and anxiety for some women, especially around medication use.

When asked in the survey what would have improved their experience of pregnancy, women commented about the lack of reassurance they received about the risk of harm to their baby from the medications, and the need for more information, whilst women who were interviewed discussed this more directly.

"I was terrified my first baby would be affected by azathioprine and couldn't enjoy my pregnancy. Medical staff (GP, midwife, obstetrician) could only say it will PROBABLY be ok, as not enough research but the manufacturer's website says NOT to take when pregnant" P22

"so then I just stopped taking it because I said to my consultant look I feel really well I don't want to take something unnecessarily" *Emma*

"…..and because I knew I wasn't going to start any medication or start treatment…."

Jenny

"I avoided going into hospital or really seeking any medical advice because I didn't know what they were going to do…." Rosie

"I'd had a miscarriage previously as well so you worry about everything just in terrible anxiety about losing the baby and even these procedures and taking medication whilst I was pregnant you know frightened me" Laura

Discussion

This novel study heard first hand from women living with IBD about what they expect from their IBD team during pregnancy.

Timing of diagnosis was important, as some women were diagnosed with IBD during childhood and therefore would have been under the care of a gastroenterologist or IBD team through adolescence and when they potentially could become pregnant either intentionally or unintentionally. This then leads to consideration around when conversations about pregnancy and pre-natal care should happen.

Women in the study placed importance on being given information about what may happen during pregnancy with regards to their IBD activity. The evidence that disease activity at time of conception influences risks in pregnancy, suggests advanced conversations regarding timing of pregnancy according to disease activity may be advantageous. However, it cannot be assumed that just because a woman may be able to get pregnant that she plans to. The choice not to have children (often referred to as 'voluntary childlessness') can be complex and highly personal but concerns about the impact of disease in pregnancy may be an additional part of that decision making for women with IBD (Janiszewski & Sawyer, 2021). This is where evidence based counselling can better inform decisions about timing of trying to conceive or the use of contraception. This highlights the

need for truly personalised care, which includes a trusted relationship between women and their IBD team where potentially sensitive conversations can take place.

A number of women also experienced pregnancy prior to their diagnosis of IBD and so had previous lived experience of pregnancy but without IBD. Careful review of timing of diagnosis when pregnancy is confirmed should be made to prevent assumptions of prior knowledge of self-management in pregnancy, and again, continuity of a familiar IBD team are ideally placed to support this.

Women's expectations around symptoms in pregnancy aligned to what they were told to expect by their healthcare provider, however what influenced this advice is not known. It is often suggested that a third of women living with IBD will experience and improvement in their symptoms, a third will stay the same and third will experience a worsening (Tresca 2019). However, disease activity at conception may be a more accurate predictor of disease activity during pregnancy (Abhyankar, Ham and Moss 2013). The IBD team will be in an ideal position to discuss this personalised risk as they are aware of the current and previous disease activity, and can initiate conversations with the wider multidisciplinary team providing pregnancy care. For the women who were not given any advice, over a third expected their symptoms to get worse, with nearly half expecting them to stay the same and the remainder expecting an improvement. This suggests that without advice, women may have a pessimistic outlook for their pregnancy in terms of their IBD, which may increase anxiety.

The women who were told them their symptoms would improve during pregnancy, could not recall who told them this information, yet they accepted the suggestion and would appear of significance as was freely recalled in interviews.

In consideration of what may have influenced this, the positive impact of expectations on self-efficacy were considered. Being told that their IBD would improve in pregnancy, may have positively influenced their self-efficacy, as although verbal persuasion is considered to be weaker than other

influences, it is still considered to be useful as outlined by Bandura (1977:198) who first described the concept.

It is possible that the way information is shared, and care is experienced, could also positively influence self-efficacy and optimism which could then translate into the perception of experienced symptoms. This may have positive implications for maternity care when caring for women living with IBD. It may be that through shaping an expectation well, an improved experience of IBD symptoms and a reduction in physical discomfort and anxiety may be achieved. However, this novel finding requires further exploration before conclusions can be drawn.

Medication is used for both maintaining remission in IBD and also for managing active disease. Most women who participated in the study were taking IBD medication at conception, and most women reported having a discussion with their healthcare provider about IBD medication and pregnancy. Women voiced their concerns about taking medication whilst being pregnant, and the lack of information or reassurance increased anxiety or increased physical suffering. Timing of pregnancy and IBD team review is also important. There would ideally be opportunity to discuss medication safety prior to conception (or as soon as is confirmed), not just around what may be unsafe, but reassurance about which medications are safe to continue, and also the risks associated with increased disease activity if the medication is stopped. Increased anxiety and worry emerged as a sub-theme for the women who were interviewed, which was predominantly attributed to the uncertainty about the perceived risk of harm from IBD medications and the internal conflict felt about whether to take the medications. The conflicts described were whether to risk the potential harm the medication may cause to either the baby or themselves or not take the medication and risk the possible harm disease activity may cause. These concerns were echoed by a small proportion of women in the survey, with women reporting that they raised concerns about their medication in pregnancy to their healthcare provider, and that they sought reassurance about the risk of harm of such medications. Continual assessment of mental health and wellbeing during pregnancy is

required from all healthcare professionals involved, which includes their IBD team, as pregnancy alone increases the risk of developing anxiety or depression and there is evidence to suggest that diagnosis of a high risk pregnancy (which IBD is) further increases this risk (Zadeh et al. 2012).

In this study that explored lived experience, women considered information about symptoms during pregnancy to be important, and illustrated that without it women make assumptions and not know what to expect, increasing worry if they experience a worsening in symptoms. IBD teams are well placed to have meaningful discussions with women diagnosed with IBD both prior to and during pregnancy. Ideally this will be an established relationship where plans about conception and pregnancy can be raised with signposting or giving personalised and evidence-based information about symptoms and medication use during pregnancy, offering reassurance to reduce additional worry.

Conclusion

The IBD team is a key component of optimal pregnancy care for women living with IBD, and it is recommended that teams are involved in pregnancy care, in conjunction with an obstetrician and midwife. Women expect evidence-based information and personalised discussion on likely changes in disease activity, safe medication use and how these are best managed for safe pregnancy outcomes.

Recommendations

Advice about symptoms however should be based on the current clinical picture and not using the anecdotal ‘a third will get better, a third will get worse and a third will stay the same’.

The IBD team should remain vigilant for any changes in women’s mental health during pregnancy, and signpost to specialist services if concerned – the IBD team will usually have known the woman prior to pregnancy and therefore may be able to identify any changes more quickly than healthcare professionals who have only been involved during pregnancy.

International and national maternity care standards for women living with IBD will ensure pregnancy care is evidence based and structured, and will provide a resource for all healthcare professionals involved in providing care to women living with IBD during pregnancy.

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