Title: What are the experiences of pregnancy for women living with Inflammatory Bowel Disease?

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Abstract

Background

Inflammatory Bowel Disease (IBD) is a long-term condition affecting the digestive tract and is an umbrella term for two main conditions: ulcerative colitis (UC) and Crohn's Disease (CD), which can cause diarrhoea, anaemia, weight loss, rectal bleeding and abdominal pain. Approximately 500,000 people live with IBD in the UK, with half being diagnosed before the age of 35 years (Ferguson, Mahsud-Dornan, and Patterson 2008). IBD increases the risk of pregnancy complications, with symptoms being unpredictable during pregnancy.

Methods

A mixed methods study was undertaken exploring what shaped the experiences of pregnancy for women living with IBD, including an on-line survey and one-to-one interviews.

Data from the interviews were analysed using Interpretative Phenomenological Analysis.

Findings

Expectations, control and care emerged as key themes which shape the experiences of pregnancy. These included expectations about pregnancy and of those providing care during pregnancy, the positive and negative impact of experienced lack of control and the effects of primary care providers during pregnancy.

Conclusion

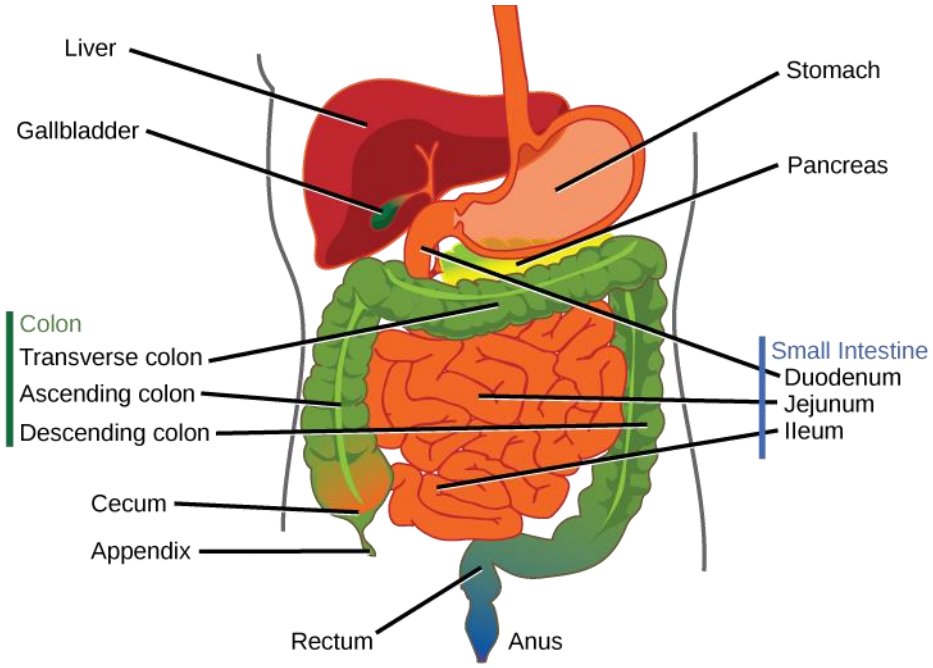
This novel study enabled women living with IBD to share what shaped their experiences of pregnancy and recommendations about midwifery care to be made. Midwives need to be mindful of the additional risks for women and their babies, and ensure care involves multidisciplinary specialists.

Background

Inflammatory Bowel Disease (IBD) is a long-term condition affecting the digestive tract and is an umbrella term for two main conditions: ulcerative colitis (UC) and Crohn's Disease (CD). There are approximately 146,000 people living with Ulcerative Colitis (National Institute for Health and Care Excellence 2019a) and 115,00 people living with Crohn's disease in the United Kingdom (National Institute for Health and Care Excellence 2019b).

The peak incidence of IBD is between 15-30 years of age, however as the aetiology of IBD is still unknown, the reason for this peak age of onset remains unclear. Approximately 50% of people living with IBD are diagnosed before the age of 35 years (Ferguson, Mahsud-Dornan, and Patterson 2008). Crohn's Disease affects the entire digestive tract (figure 1), and symptoms include diarrhoea, loss of appetite, anaemia and weight loss Ulcerative colitis affects the colon and symptoms include diarrhoea, rectal bleeding and abdominal pain. Depending on where the ulceration is within the colon (figure 1), symptoms may vary, with constipation being a symptom if the lower end of the colon is affected and diarrhoea if the colon is more widely affected.

Figure 1 The digestive tract



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Women with IBD have a similar fertility rate to that of the general population unless they 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).

Women living with IBD have an increased risk of pregnancy related complications 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. For this reason, women

living with IBD are considered to have a high risk pregnancy and should have consultant led care including additional surveillance of maternal and fetal wellbeing.

IBD disease activity can be unpredictable, with symptoms having a remission and relapse cycle, with a worsening of symptoms during relapse, or lessened or no symptoms during periods of remission, and this unpredictability can be the same during pregnancy. Women living with IBD will often be on long term medication with the aim of maintaining remission, or the need to start medication if their disease flares up. There needs to be careful consideration of the risks of the medication to the fetus and the risks to the mother and the fetus associated with increased disease activity.

IBD should not be confused with irritable bowel syndrome (IBS) which is a more common condition affecting the bowel and does not have the pregnancy associated risks of IBD.

Review of the literature

To understand the current evidence and published literature around the experiences of women living with IBD during pregnancy, a systematic review was registered with PROSPERO (CRD42019134856) and completed, which identified the paucity in literature about women's experiences of pregnancy when living with IBD (Janiszewski et al. 2022).

Key words were used to form search terms, which were inputted into selected databases. Data were collected independently by two reviewers. As the topic of interest was the phenomenon of experiences of pregnancy, themes were not predetermined as they could not be assumed and nor would this have been appropriate. Therefore, themes were allowed to emerge with a narrative synthesis undertaken of these emergent themes as they originated from both qualitative and quantitative data (Bryman 2016). Selected articles were critically appraised using the appropriate tools, including risk of bias. After review, five articles were included as outlined in figure 2 using a Prisma Diagram (Liberati et al. 2009), and are outlined in table 1.

Figure 2 Prisma diagram showing article selection

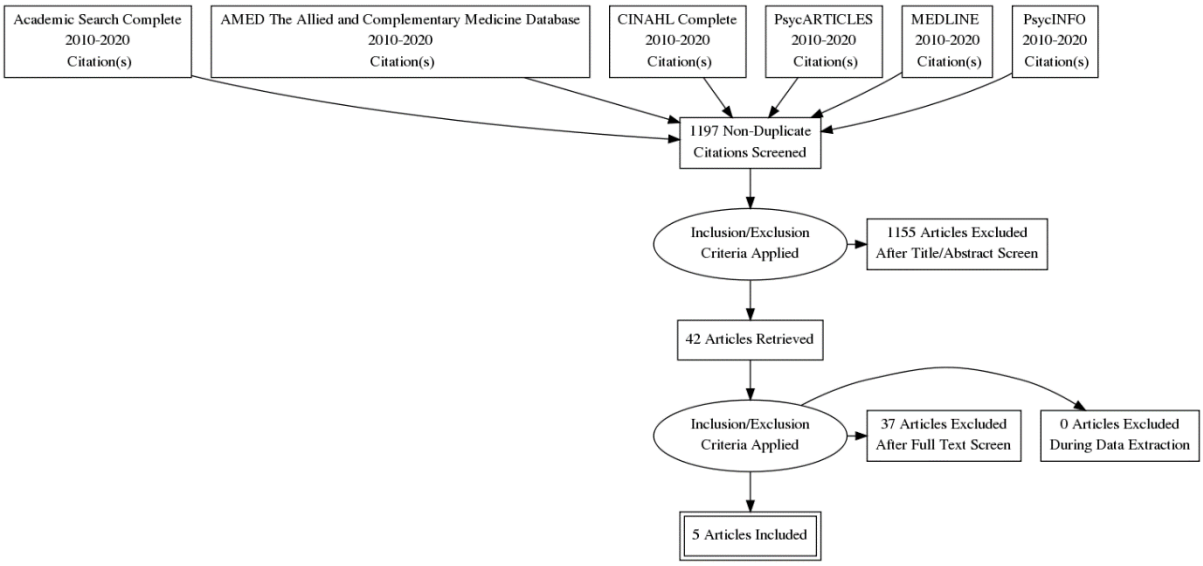


Table 1 included studies

Authors	Title	Year
Mountifield, R.E., Prosser, R., Bampton, P., Muller, K., and Andrews, J.M. (Mountifield et al. 2010)	Pregnancy and IBD Treatment: This Challenging Interplay from a Patients' Perspective	2010
Cooper, J., Collier, J., James, V., and Hawkey, C (Cooper et al. 2011)	Living with Inflammatory Bowel Disease: Diagnosis during Pregnancy	2011
Ellul, P., Zammita, S.C., Katsanos, K.H., Cesarini, M., Allocca, M., Danese, S., Karatzas, P., Moreno, S.C., Kopylov, U., Fiorino, G., Torres, J., Lopez-Sanroman, A., Caruana, M., Zammit, L., and Mantzaris, G. (Ellul et al. 2016)	'Perception of Reproductive Health in Women with Inflammatory Bowel Disease'	2016
Ghorayeb, J., Branney, P., Selinger, C.P., and Madill, A (Ghorayeb et al. 2018)	When Your Pregnancy Echoes Your Illness: Transition to Motherhood With Inflammatory Bowel Disease	2018
Hoekstra, J., Van Roon, A.H.C., Bekkering, F.C., Van Tilburg, A.J.P., and West, R.L. (Hoekstra et al. 2018)	Decision Making and Outcome of Pregnancies in Female Patients with Inflammatory Bowel Disease: Findings from a Community-Based Practice	2018

There were five key themes from the systematic review : timing of diagnosis, translation of healthcare practitioner knowledge of IBD and pregnancy into meaningful information (merging of women's knowledge and information given by Health Care Professionals), perceptions about IBD medication, impact of disease activity and concerns about IBD and pregnancy Findings from the systematic review were used to shape the research question and highlighted the need for further research in this area.

Objective

The purpose of the study was to explore what shaped experiences of pregnancy for women living with IBD.

Ethical Considerations

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

Study Design

Methods

An embedded mixed methods study design was used (Cresswell and Plano Clark 2011) and is shown in Figure 3, which included an anonymous online survey, distributed through social media and face to face one to one interviews.

Figure 3 Embedded mixed methods design

Data were collected using an anonymous online survey generated through *Qualtrics©* with participants being free to choose whether to divulge particular information through answering certain questions or not which minimised the risk of an invasion of privacy (Bryman 2016) The online survey was distributed through social media platforms including Facebook and Twitter and was live for four months (21/01/2019-26/05/2019). The survey contained multiple choice questions, agreement scales, open and closed questions and free text response in answer to a question on what would have improved their experience of pregnancy with any other comments.

The interviews were audio recorded, and were semi-structured, with pre-defined prompts and probes where needed. They were then transcribed verbatim.

Data from the one-to-one interviews were analysed using the seven steps of 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 survey and interviews were then synthesised, with themes and subthemes emerging. As two independent studies were undertaken to address the specific aims of the study, the embedded mixed methods approach determined the process for undertaking the study, however the principles of methodological triangulation were required to ensure that the combination of data did not adversely impact on the validity. The primary data were collected through one to one

interviews and were analysed using IPA, with the supplementary data being collected through an anonymous online survey. Different data collection methods were needed to ensure that the objectives of the study were met which ensured the research question could be fully answered.

Mayoh and Onwuegbuzie (2015) provide some guidance about how to specifically integrate data obtained from different methods when one is phenomenological. The quantitative data may inform the phenomenological focus of the study, as in the case of this study, where the findings of the survey were used to identify any themes to be explored through prompts in the interviews.

The data collected from the interviews and analysed using IPA were the primary data, and steps were taken to ensure that the study remained faithful to the principles of IPA. The supplementary data from the online survey was analysed prior to undertaking the one to one to interviews as this ensured that the process of data analysis would not influence the analysis of interviews as it may if done concurrently.

Participants

Women self-selected to complete the online survey, and confirmed they met the eligibility criteria through ticking a series of statements at the beginning of the survey – unless they were all ticked the survey did not progress to questions and women received a statement to thank them for their interest but that they did not meet the eligibility criteria..

Purposive sampling was used for the interviews, as the views and experiences of a unique cohort of the population was being sought (Bowling 2014). Women were recruited through study invitation letters sent by the Biomedical Research Centre. and the specialist Inflammatory Bowel Disease nurses to eligible women, posters in relevant departments (including maternity and gastroenterology), information posted on social media and word of mouth. Women were also recruited though the NIHR Biomedical Research Centre where there is a database of patients who are happy to be contacted about upcoming studies and we will search that for eligible patients. Women were given the option of where to have the interview, and whether to have it as face to face or over the telephone.

The inclusion criteria slightly differed for each study and are outlined in tables 2 and 3.

Table 2 inclusion criteria for survey

Online survey
Aged 18 years or older at time of completion
Diagnosed with IBD prior to or during pregnancy
Live in the United Kingdom
Experienced pregnancy

Table 3 Inclusion criteria for one to one interviews

One to one interview
Aged 18 years or older at time of participation
Diagnosed with IBD prior to or during pregnancy
Received care at the local NHS Trust for either gastroenterology care or maternity care
Given birth in the last five years

A total of 50 women completed the online survey and participant characteristics are shown in table 4.

Table 4 Participant Characteristics for survey

Characteristic	N = 50 (100%)
Type of IBD: ulcerative colitis	28 (56%)
Type of IBD: Crohn's disease	22 (54%)
Age range at time of completion of the survey	29-63 years
Mean age at time of completion	40 years
Age range at time of diagnosis of IBD	6-39 years
Mean age at time of diagnosis of IBD	23 years
Time since last pregnancy in years	0-34 years

Of the 50 women who completed the survey, 48 (96%) were diagnosed with IBD prior to their most recent pregnancy; however nine (18%) had experienced pregnancy prior to their IBD diagnosis and then subsequently experienced another pregnancy following diagnosis. Two (4%) women were diagnosed with IBD during pregnancy.

Participant characteristics were not routinely gathered for the women who were interviewed, and information was gained during the interviews as women chose to disclose and discuss.

Seven women were interviewed, (which is an appropriate number for Interpretative Analysis (Smith, Flowers, and Larkin 2012). Five of the seven women (71%) had been diagnosed with IBD prior to pregnancy, (one diagnosed during first pregnancy, one diagnosed between first and second child). The number of children the women had ranged between one and three. As per the inclusion criteria for the interviews, all women had been diagnosed with IBD prior to or during pregnancy and had given birth to at least one child in the last five years.

For the one to one interviews, names. Names have been changed to preserve anonymity and for the interviews participants are identified by a number.

Findings

Three main themes emerged from the survey and interviews: expectations, control and care with subthemes within the theme of expectations. .

Expectations

One of the three main themes; 'Expectations' is comprised of subthemes: expectations of others and expectations of IBD and pregnancy.

Expectations of others

For the women who responded to the survey, most commonly (21/49) (43%) identified that their lead care provider during pregnancy was a community midwife, however during the interviews women's expectations of their midwives varied, with some women expecting that midwives would not know about IBD, whilst others felt they should know about it and that this lack of knowledge detracted from their experience

"I think it's difficult isn't it I suppose because you wouldn't expect them to know a great deal about it" *Laura*

"erm maybe my community midwife knowing a bit more about erm IBD would have been helpful" *Ellie*

When specifically asked what would have improved their experience of pregnancy, midwifery knowledge about IBD and pregnancy emerged as a theme in the survey responses

A Crohn's trained midwife who didn't just google... I could do that

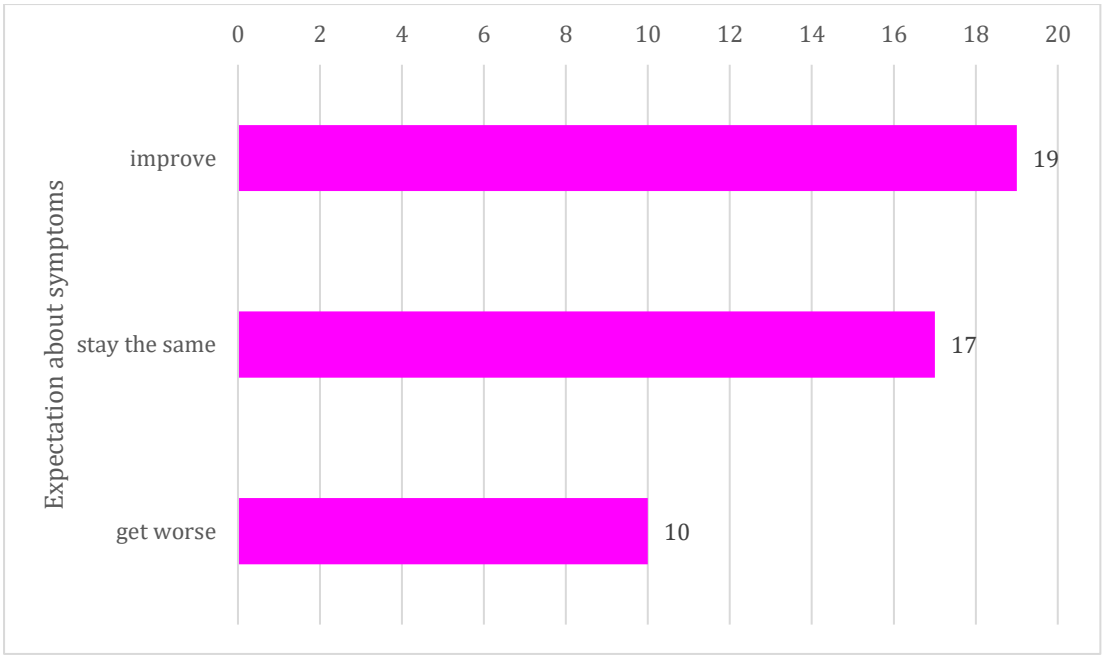
p14

Midwifery services were OK once we knew what was wrong with me but not very knowledgeable *p27*

Expectations of IBD and pregnancy

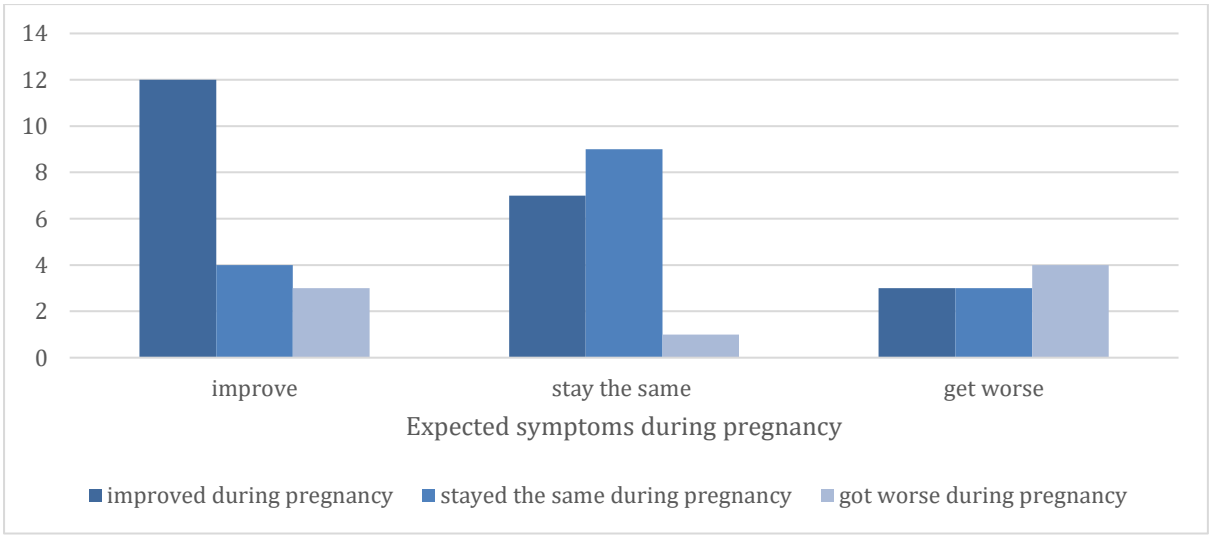
Women who responded to the survey had differing views on what they expected to happen with their IBD during pregnancy as shown in figure 4, with most women expecting their IBD symptoms to either improve or stay the same, and just over a fifth (10/46) (21%) of women expected their symptoms to get worse.

Figure 4 Expectations about symptoms during pregnancy (n=46)



For the women who responded to the survey, expectations were generally well matched to what was experienced as shown in figure 5; however a small number of women (3/19) (16%) expected an improvement but actually experienced a worsening in symptoms. For women who expected their symptoms to stay the same, nearly half (7/17) (41%) experienced an improvement in symptoms, which may have provided some unexpected respite.

Figure 5 Expected symptoms compared to experienced symptoms (n=46)



For the women who were interviewed, they described how they had been advised what their IBD may be like during pregnancy, although were not sure who had advised them:

"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

Control

Being beyond their control was something women described in the interviews as experiencing during their pregnancy, and the impact this had on their life.

Some women described how pregnancy provided respite from IBD symptoms. Although this had a significant, positive impact on the experience of pregnancy, there was a sense that this was something they had no control over and with one women considering herself to be 'lucky' that her disease activity was controlled.

"but yeah I suppose for me I was fairly fairly lucky that it sort of was controlled and settled"

Laura

"I was really quite healthy I was actually healthier in sort of the nine months of being pregnant that had been for the last like four years before"

Ellie

"obviously as soon as I was pregnant my symptoms seem to have been relieved completely with both pregnancies"

Emma

Although beyond their control, some women did have a positive experience with the unexpected change in symptoms during pregnancy, however for some women they described the additional physical or psychological suffering from uncontrolled symptoms due to the combination of IBD and pregnancy.

"I'm heavily pregnant as well and I'm getting up to go to the toilet four to five times a night and can you imagine if you're not eating and drinking"

Olivia

The lack of control women may experience during pregnancy is not limited to physical effects. Most women when asked in the survey reported feeling worried during pregnancy, feelings which are beyond their control, with pregnancy being considered an already anxiety inducing time, and therefore the addition of IBD compounded this

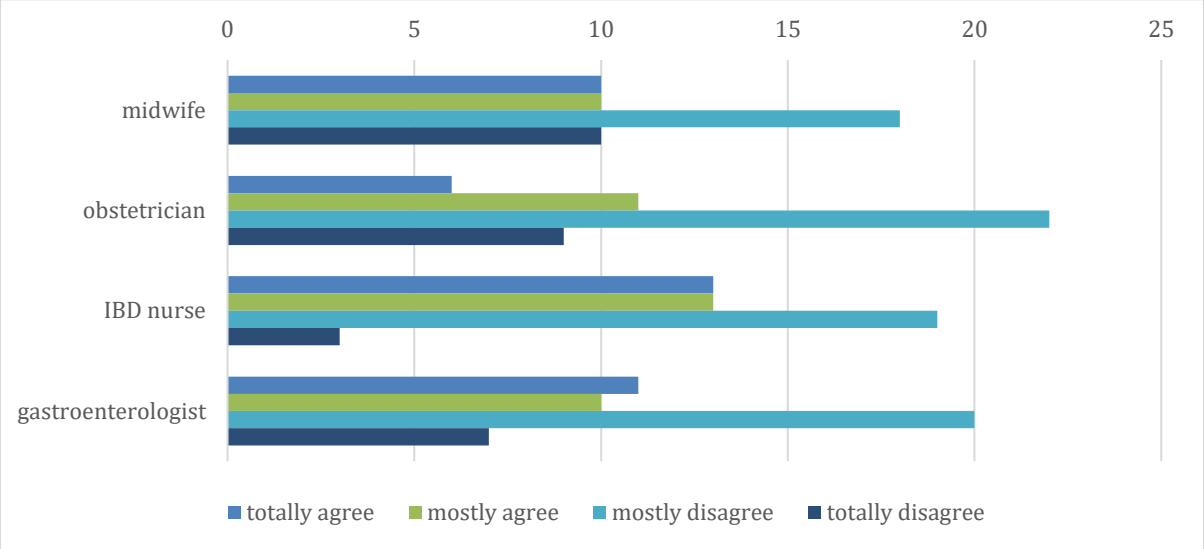
"having a first baby is just can you know be an anxiety inducing time of your life erm so yeah and then add something like that you know can impact how you feel"

Laura

Care

When asked in the survey about their satisfaction with the frequency of interaction with professionals, most women reported being happy with the number of interactions with their midwife (28/48) (58%), obstetrician (31/48) (65%) and gastroenterologist (27/48) (56%), however they would have liked more interactions with their IBD nurse (26/48)(54%) as shown in figure 6.

Figure 6 Satisfaction with frequency of interactions in response to 'I would have liked more interactions with this health professional' (n=48)



As previously described, the survey showed that a community midwife was the lead care provider for most women (21/49) (43%) however a consultant obstetrician would have been the preferred lead carer (figure 7) as they felt that they understood their needs during pregnancy better than their midwife did (figure 8).

Figure 7 Lead care provider and preferred lead care provider during pregnancy (n=49)

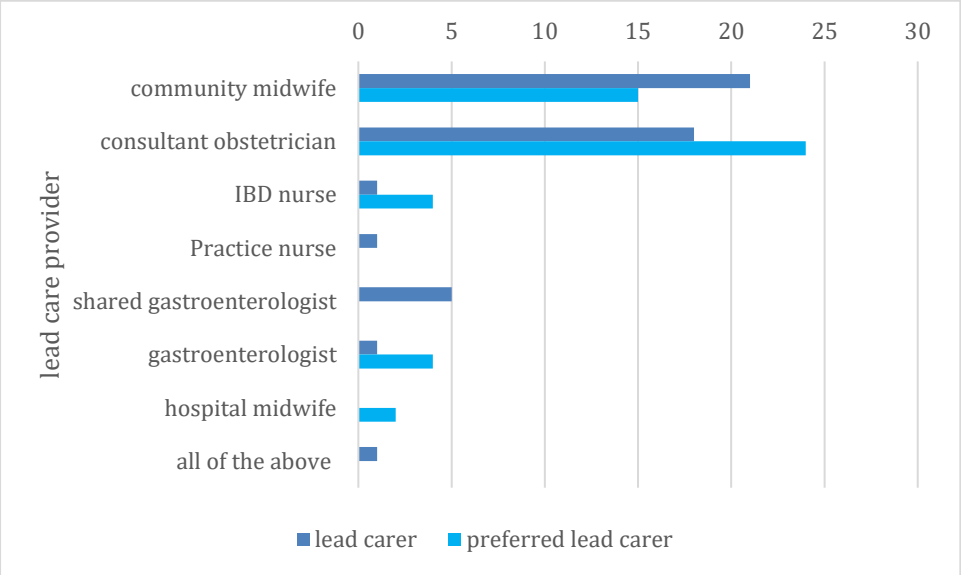
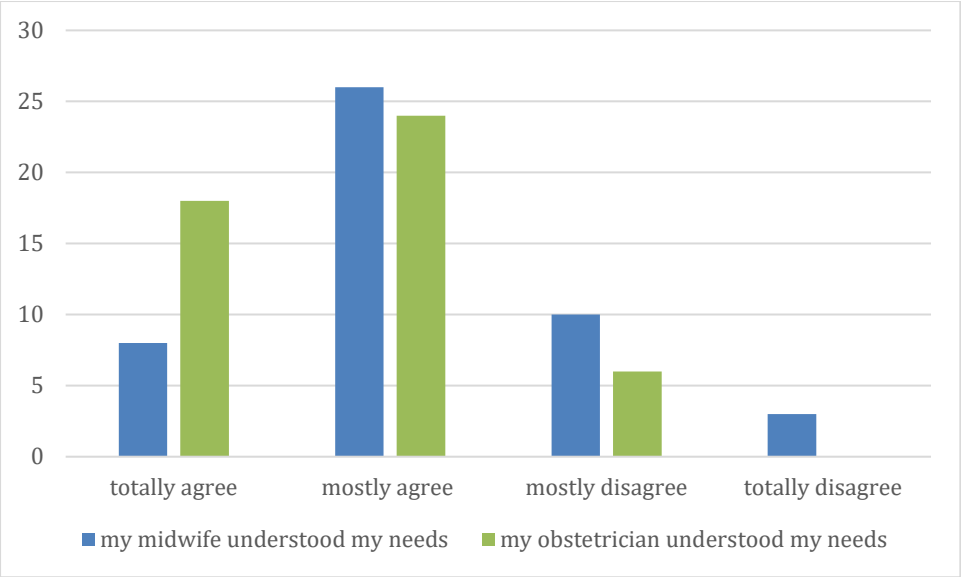


Figure 8 Understanding needs (n=47)



Women who were interviewed described the reassurance they felt from being cared for by a consultant obstetrician and additional care that this pathway brought

"we were consultant led care through the hospital and that was quite reassuring as it meant that we had quite regular check ups and things"

Ellie

"you know during that times the scans are very reassuring you know having regular scans knowing that you are being looked after"

Laura

Discussion

This study is the first study to actively explore first hand lived experiences of pregnancy whilst living with IBD. Whilst previous studies, although limited, explored knowledge and perceptions around pregnancy and IBD predominantly around medication use, and healthcare provider knowledge about IBD and pregnancy (Janiszewski et al. 2019)(Janiszewski et al. 2022) there is a paucity in literature about lived experiences.

This study heard the voices of 57 women, who either shared their experiences via an online survey or an interview.

The study discovered the importance of understanding expectations women may have about pregnancy and their IBD. Expectations were found to shape the experiences of pregnancy, both positively and negatively. Optimism bias may play a part in the expectation's women had about their symptoms. Optimism bias is when there is a belief that things will be get better regardless of the advice given and expectations that positive things will happen are overestimated as opposed to an underestimation of expected negative events and can reduce the effects of a poor outcome prediction (Barlow et al. 2016)

Women should be appropriately counselled by a professional knowledgeable about IBD about how their IBD may change during pregnancy as a lack of knowledge from the healthcare provider about IBD and pregnancy may detract from experiences of pregnancy. Ellul et al. (2016)) suggests the gastroenterologist is well placed to give this information.

The additional physical or psychological suffering women may experience should also be recognised. The unpredictable nature of IBD may mean women become unwell during their pregnancy and endure debilitating symptoms which when combined with pregnancy leads to a further decline in physical and psychological wellbeing. For the women who anticipated an improvement but experienced a worsening of symptoms this may be even more distressing. For some women pregnancy can result in a lack of control over daily activities and combined with the uncontrolled worsening of symptoms of IBD this is additionally challenging

Women may also have additional worries and anxieties due to additional risks for their pregnancy such as having their baby early or their baby being small together with considerations for their own health. The lack of midwifery knowledge about IBD identified in this study, and supported by Cooper et al. (2011) and Ghorayeb et al. (2018), many contribute to this additional worry as women may seek advice or reassurance from their midwife but find their midwife is not informed enough to provide this. It is important to remember that women have different perceptions of what their midwife should know about IBD and pregnancy, however this may not detract from the effect this has on women's experiences.

In most high income countries, such as the one where this study was undertaken, women are often assigned lead health care providers in line with local or national guidance, and women are usually not involved in such decision making. For women living with IBD, their pregnancy is considered to be high risk and therefore should be led by an obstetrician, however this was not the experience of women in this study. The women whose care was led by an obstetrician found the additional surveillance reassuring and women reported that their needs were met better by their obstetrician than their midwife. The lack of midwifery knowledge about IBD was reported to detract from experiences and this may have influenced women's preference over who was their lead care provider. Women reported wanting to see their IBD nurse more during pregnancy, and this may be due to the trusted relationship they already have with them, however not all women have access to an IBD nurse and this is an inequity is care. A survey in 2021 found that only 14% of units provided IBD antenatal care by a gastroenterologist with expertise in pregnancy and combined clinics with a gastroenterologist and obstetrician at the same consultation were only available in 14% of units (Wolloff et al. 2021). It is important to recognise that for women who do not have access to medical maternity care or medical care for recognition or management of long term conditions, pregnancy may have more risks to the mother and baby than for women who are able to routinely access this care.

It is also important to recognise that although women living with IBD should have consultant led care, some women may choose not to, and want their pregnancy care to be led by a midwife. In such instances, the midwife again should seek support with the pregnancy care from the relevant healthcare professionals. Consistency in care is essential, to ensure all women living with IBD receive the same standard of care regardless of location or IBD service provision.

Whilst there were themes around what shaped experiences of pregnancy care, individual perceptions, beliefs and previous experiences will also contribute to these, and therefore pregnancy care should be personalised to ensure each women's individual needs are met.

Currently, Midwives receive no formal training about IBD either pre or post registration and therefore this lack of knowledge is not unexpected. However, midwives do have an opportunity to explain to women about their lack of knowledge and ensure they are cared for a multidisciplinary team with appropriate knowledge. Midwives need to be able to recognise that IBD potentially makes a pregnancy high risk (depending upon disease activity) and therefore should be referred to the appropriate care pathway. Failure to recognise the significance of IBD, or confusing IBD with IBS may mean women or their babies are exposed to harm through lack of surveillance or care.

This study provided an opportunity for all women who have experienced pregnancy with a diagnosis of IBD to share their experience, a study which has not been done before. The elapsed times between last pregnancy and completion of the survey demonstrates women's desire to share their experience and the importance of this topic. It is recognised that due to the way in which the survey was distributed, women without access to the internet would not be able to participate and therefore this is considered a limitation. Whilst the study was relatively small and it did not aim to make generalisable conclusions, it does offer a novel insight into women's experiences of pregnancy whilst living with IBD which can be used to make recommendations about maternity care.

Limitations

The recruitment strategy for the study is recognised as being a limitation, with restrictions placed on the inclusion criteria, predominantly for the one to one interviews. The requirement to have received care from the identified NHS organisations maternity or gastroenterology services is identified as a limitation, however this was deemed necessary due to the timescales of the study and also because the recruitment strategy utilised the NIHR Biomedical Research Centre. The limitation for the interviews of given birth within the five years could also be considered a limitation of the study, however this was used to reduce the risk of recall bias and also ensured women had received current care.

Key conclusions

IBD is different to IBS and it is essential that this is recognised by healthcare professionals including midwives to ensure women are assigned the correct care pathway for their pregnancy. IBD is unpredictable, and whilst some women may experience a welcomed relief from symptoms, some may experience an unexpected worsening in symptoms, which may have a significant impact on their physical and/or psychological wellbeing. Midwives lack of knowledge about IBD and the implications of IBD for pregnancy detracted from women's experiences and therefore any lack of knowledge should be acknowledged and appropriate support sought from the multidisciplinary team which may include a gastroenterologist, an obstetrician, an IBD nurse, and a dietician.

Whilst this study was undertaken in the UK and focussed on IBD and pregnancy, it could be argued that the findings may be translatable to women living with other long term conditions which makes their pregnancy medically complex, and relevant to any country where pregnancy care involves midwives.

Implications for practice

Lack of midwifery knowledge about IBD in general and the interactions with pregnancy detracted from women's experiences of pregnancy and may also have implications for pregnancy care. An online learning module has been developed for midwives about IBD and pregnancy hosted by Royal College of Midwives I-learn. It is available in the United Kingdom for members of the RCM.

Midwives should remain mindful of the unpredictability of IBD, and how quickly symptoms may develop or worsen and that this may be different to previous pregnancies. The additional worry women living with IBD may also experience during pregnancy should be recognised, and additional surveillance and support should be provided.

Although the midwife may often be the lead healthcare professional, it is important to ensure that other members of the multidisciplinary team are involved in care from an early stage as required, and that women feel confident that their care is being managed collaboratively.

Highlights

85 words max (5 bullet points)

- IBD and IBS are not the same and midwives must recognise the implications of IBD on pregnancy
- Women living with IBD should have multidisciplinary care, which the midwife is well placed to coordinate
- Experiences of pregnancy are shaped by a multitude of factors, and these should be acknowledged and discussed
- Women may experience a worsening or improvement in symptoms during pregnancy which may have a significant impact on their life

Keywords

Pregnancy

Inflammatory Bowel Disease

Experiences

Crohn's Disease

Ulcerative colitis

Funding

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