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Planning to conceive within a year is associated with better pregnancy-specific disease-related patient knowledge and better medication adherence in women of childbearing age with inflammatory bowel disease

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Abstract

Background: Adherence to inflammatory bowel disease (IBD) medication is crucial to maintain remission, especially during pregnancy.

Objective: To examine the influence of family planning and pregnancy-related patient knowledge regarding IBD and pregnancy on adherence.

Design: Cross-sectional survey study

Methods: We surveyed female patients with IBD aged 18–35 years, who at recruitment to the UK IBD BioResource had not had children. We elicited disease and treatment history, demographics and family planning status *via* an online questionnaire. Patient knowledge as assessed by the validated Crohn's and Colitis Pregnancy Knowledge Score (CCPKnow) and adherence by visual analogue scale (VAS).

Results: In 326 responders (13.8% response rate), good adherence (VAS $\geqslant$ 80) was found in only 38.35%. Disease- and treatment-related factors were not significantly associated with good adherence, except for methotrexate (70.0% adherent of 10 exposed patients *versus* 37.2% non-exposed; $p = 0.036$). Patients planning pregnancy for the next year were more often adherent (59.0% *versus* 35.5%; $p = 0.019$) and knowledgeable (median CCPKnow 8 *versus* 7; $p = 0.035$) compared to those in other family planning categories. Pregnancy-related patient knowledge was significantly associated with adherence (Pearson correlation 0.141; $p = 0.015$). Adherent patients had significantly higher CCPKnow scores than non-adherent patients (median 8 *versus* 6; $p = 0.009$). On binary regression analysis, only planning to conceive within 12 months was independently associated with better adherence ($p = 0.016$), but not methotrexate exposure ($p = 0.076$) and CCPKnow ($p = 0.056$).

Conclusions: In a cohort of women of childbearing age with IBD overall medication, adherence was low. Planning to conceive within the next year was associated with better adherence and greater patient knowledge.

Keywords: inflammatory bowel disease, medication adherence, patient knowledge, pregnancy

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Background

Inflammatory bowel diseases (IBDs) are chronic diseases that may cause inflammation, ulceration, fistulation and/or stenoses in the gastrointestinal tract.[1] IBD often presents in early adolescence or young adults and therefore affects women of childbearing age with an increasing prevalence of IBD.[2] Active inflammation during conception and pregnancy can adversely affect pregnancy outcomes in patients with IBD.[3–5] Active inflammation from IBD should be treated with effective medication prior to and during pregnancy including mesalazine, thiopurine and biologics.[5] Strict control of inflammation is associated with better pregnancy outcomes but requires adherence to maintenance medication for IBD. Medication adherence in general is suboptimal in patients with IBD,[6] and a limited number of studies examining adherence during pregnancy have reported levels of non-adherence around 30–40%.[7–9] While the studies examining adherence during pregnancy report slightly better levels than seen outside pregnancy the overall adherence level remains a risk to mother and foetus.[9] Interestingly Watanabe *et al.*[9] found that adherence dropped from the preconception period to the first trimester of pregnancy.

Many women of childbearing age have concerns about potential medication side effects on the unborn child,[10] although most IBD medications are recommended to be continued during pregnancy by international guidelines.[5,11,12] Many women of childbearing age have poor knowledge of IBD and pregnancy-related issues,[13–15] which is associated with views contrary to evidence-based medical guidelines and patient facing treatment guidances.[16] In the general IBD population, poor adherence to medical therapy is also associated with higher healthcare costs.[6] Causes of non-adherence are incompletely understood. A lack of belief in the necessity of medications to maintain disease remission and concerns about potential medication toxicity have been reported by several studies.[17–19] However, disease-related patient knowledge about IBD in general has previously been found to not predict medication adherence.[19,20]

Pre-pregnancy counselling to address the importance of controlling IBD by continued maintenance medication has been shown to improve patient knowledge and pregnancy outcomes in women with IBD.[21] While this approach works for women actively choosing to start a family, it will fall short in those 45% of pregnancies in the United States and in the United Kingdom that are unplanned.[22,23] There are some variations in unplanned pregnancies around the world, which may alter the potential benefits of pre-pregnancy counselling. It is therefore important to examine adherence in women of childbearing age. We have previously examined medication adherence in women aged 18–45 who were under the care of a specialist IBD clinics in Sydney, Australia.[24] In this pilot study, we found that while adherence was generally high, an association between adherence- and IBD-related pregnancy knowledge was observed on binary analysis Crohn's and Colitis Pregnancy Knowledge Score (CCPKnow: $p = 0.02$) with borderline results on continuous analysis (CCPKnow: $p = 0.08$).[24] Therefore, larger studies in a more general setting representing the wider IBD patient community outside of specialist services were required.

We therefore aimed to examine medication adherence and disease-specific knowledge in women of childbearing age that have mainly not had children yet by examining the UK IBD BioResource cohort.

Methods

Study cohort

The UK IBD BioResource is an open research platform that started prospectively recruiting patients with IBD from over 100 UK hospitals in 2016.[25] By 2019, 25,000 patients had been included and current recruitment stands at over 35,000 patients. Patients provide baseline data on inclusion; disease and treatment characteristics are collected from medical records at baseline and blood sampled for genetic analysis.[25] Patients can also consent to be contacted for further studies nested within the UK IBD BioResource cohort.[26] For this study, we approached 2399 female patients aged 18–35 years, who at recruitment to UK IBD BioResource had not had children. Our survey was targeted to include patients who were yet to have children, but we had no prior update of patients' family status prior to this survey. Those who declared having had children on survey invitation were deemed not eligible, but we did not exclude those who had children but proceeded to give survey responses regardless.

Recruitment and study procedures

Potential participants were contacted by email on up to three occasions and invited to fill in an electronic survey hosted on the secure Research Electronic Data Capture (REDCap) research environment. Study data were collected and managed using REDCap electronic data capture tools hosted at Leeds Teaching Hospitals.[27,28] REDCap is a secure, web-based software platform designed to support data capture for research studies. Participants provided informed consent after reading the online patient information leaflet by continuing to the research questionnaire and answered questions around current relationship status, current reproduction, future reproduction intentions, current disease state and current IBD medication. Medication adherence was assessed by a visual analogue scale (VAS; 0–100), which has been validated for IBD with a cut-off of ⩾80 deemed as adherent.[29] We assessed current psychological state with the Hospital Anxiety and Depression Scale (HADS).[30] Pregnancy-related IBD knowledge was assessed by the CCPKnow, a validated self-assessment tool with score ranging from 0 to 17 and scores ⩾8 deemed adequate.[13] Patients self-rated their disease control during the preceding year on a simple 4-point scale from remission, mild, moderate and severe disease. Demographic and phenotype type data were extracted from the UK IBD BioResource.

Statistical analysis plan

Based on the 74% adherence rate found in a prior UK-based IBD study,[31] a minimum of 296 patients were required to be enrolled in this study to achieve a 95% confidence level and 5% margin of error. Descriptive statistics are reported as mean or proportions. Categorical data were compared between groups using chi-square test, whereas independent samples *t*-test was used for normally distributed continuous variables and Mann–Whitney *U*-test for non-normally distributed continuous variables. We performed a binary regression analysis to determine factors independently associated with medication adherence. Differences were considered statistically significant if $p < 0.05$. IBM SPSS version 25 (IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp) was used for statistical analysis.

Results

Cohort composition, disease and treatment characteristics

We invited a total of 2399 UK IBD BioResource participants, 73 of whom declined and 112 were found to be ineligible. We received 316 (13.8%) responses with sufficient data for analysis. Respondents were aged 18–34 years and predominantly of white British ethnicity (Table 1). Disease phenotype, surgical history and current treatment are displayed in Table 2. Medication exposure included current use of mesalazine in 90 (28.5%), thiopurines in 94 (29.7%), methotrexate in 10 (3.2%), anti-Tumour Necrosis Factor-antagonists in 103 (32.6%), vedolizumab in 38 (12.0%), ustekinumab in 30 (9.5%) and tofacitinib in five cases (1.6%). Steroid exposure occurred in 77 (24.4%) in preceding year, whereas 38 (12.2%; Table 2) required a hospital admission in the preceding year. Current self-rated disease activity was remission in 96 (30.8%), mild in 121 (38.8%), moderate in 74 (23.7%) and severe in 21 (6.7%) of participants.

Mental health, knowledge and adherence

Results for HADS, CCPKnow and VAS were not normally distributed and hence analysed with non-parametric tests. HADS was separately analysed for anxiety (HADSA) and depression (HADSD). Median anxiety score (HADSA) was 9 [interquartile range (IQR) 6–12], 52.9% had a score ⩾9 (possibly abnormal), whereas 24.9% had an abnormal score of ⩾12. Median depression score (HADSD) was 4 (IQR 2–7), 10.1% had a score ⩾9 (possibly abnormal), whereas 2.0% had an abnormal score of ⩾12. Median disease-related pregnancy knowledge score (CCPKnow) was 7 (IQR 4–10), with at least adequate knowledge (⩾8) found in 44.5%. Median adherence score (VAS) was 51 (IQR 51–100) with good adherence (⩾80) found in 38.35%.

Factors associated with good adherence

Age, ethnicity, household income, level of education, employment status, relationship status, sexual orientation, self-rated disease activity, type of IBD diagnosis, IBD phenotype, having a stoma, IBD-related surgery, having extra-intestinal, manifestations, hospital admission within 12 months, steroid exposure within 12 months, having discussed family planning with a healthcare professional were all not associated with good adherence

Table 1. Patient demographics and social background.

Parameter	*N*	%
Age		
18–24	73	23.4
25–29	172	55.1
30–34	67	21.5
Ethnicity		
White or White British	274	91.3
Asian or British Asian	13	4.3
Mixed	13	4.3
Sexual orientation		
Straight/heterosexual	255	82.8
Lesbian/homosexual	3	1.0
Bisexual	39	12.7
Other	11	3.6
Relationship status		
Single, not currently dating	78	24.7
Currently dating (<3 months)	12	3.8
In relationship (>3 months) but not living together	64	20.3
Living with partner unmarried	120	38.0
Married	42	13.3
Family planning status		
Already given birth to a child	14	4.5
Pregnant or currently aiming to conceive	19	6.2
Planning to conceive within 12 months	39	12.6
Contemplating conception in distant future	168	54.4
Not planning to have children	69	22.3
Household income		
<£10,000	13	5.0
£10,000–£20,000	34	13.0
£20,001–£30,000	52	19.9
£30,001–£50,000	82	31.4
>£50,000	80	30.7
Highest educational achievement		
Secondary school	28	8.9
Apprentice/National Vocational Qualification 2 or 3	92	29.1
Bachelor	139	44.0
Masters/PhD	57	18.0
Employment		
Working full time	227	71.8
Working part time	39	12.3
Full time education	32	10.1
Unemployed	15	4.7
House person	3	0.9

(all chi-square tests $p > 0.05$). Exposure to different types of IBD medication was not significant when assessed for binary adherence outcomes except for methotrexate. Patients exposed to methotrexate were more likely to be adherent than those not exposed (70.0% adherent *versus* 37.2%; $p = 0.036$); however, this was in a very small sample ($n = 10$). Current family planning intentions were associated with significant differences in adherence status. Those planning for a pregnancy in the next year were significantly more likely to be adherent (59.0%) compared to those who had actively aimed for a pregnancy (previous pregnancy, currently pregnant and currently aiming to conceive; 33.3%), those planning for children in the more distant future (38.7%) and those not planning to have children (29.0%; $p = 0.019$). Patients planning to conceive had significantly

Table 2. Disease phenotype and treatment.

Parameter	*N*	%
Diagnosis		
CD	175	55.4
UC	123	38.9
IBD-U	13	4.1
Other	5	1.6
Crohn's extent		
Oesophageal-gastric	3	1.7
Duodenal	5	2.9
Jejunal	9	5.1
Ileal	119	68.0
Colonic	108	62.0
Rectal	28	16.0
Crohn's behaviour		
Inflammatory	122	69.7
Stricturing	26	14.9
Penetrating	16	9.1
Crohn's perianal disease		
Ever present	49	28.0
Surgery		
In patients with CD	49	28.0
Stoma present	13	7.4
UC/IBD-U extent		
E1 proctitis	18	13.2
E2 left-sided disease	45	33.0
E3 extensive colitis	48	35.3
UC/IBD-U surgery		
Colectomy	13	9.6
Pouch formed	6	4.4
Extra intestinal manifestations		
None	210	66.5
Primary sclerosing cholangitis	4	
Enteropathic arthropathy	12	
Erythema nodosum	12	
Iritis	3	
Orofacial granulomatosis	7	
Psoriasis	15	
Ankylosing Spondylitis	0	
Current self-reported disease activity		
Remission	96	30.8
Mild	121	38.8
Moderate	74	23.7
Severe	21	6.7
IBD-related hospital admission in last 12 months		
Yes	38	12.2
Current medical treatment		
Mesalazine	90	28.5
Thiopurines	94	29.7
Methotrexate	10	3.2
Anti-TNF	103	32.6
Vedolizumab	38	12.0
Ustekinumab	30	95.0
Tofacitinib	5	1.6
Steroid exposure in last 12 months	77	24.4

Percentages are calculated for the whole cohort for diagnosis and medical treatment. For phenotype, surgery and stoma data, the percentages are calculated for the CD and the UC/IBD-U cohort separately. Where data do not add for the total cohort, we omitted missing data.
CD, Crohn's Disease; IBD-U, Inflammatory Bowel Disease-Unclassified; UC, ulcerative colitis.

higher CCPKnow scores than those meeting criteria for the other family planning categories (median 8 *versus* 7; $p = 0.035$).

Disease-related patient knowledge (CCPKnow) was significantly associated with adherence [Pearson correlation 0.141 (weak correlation);

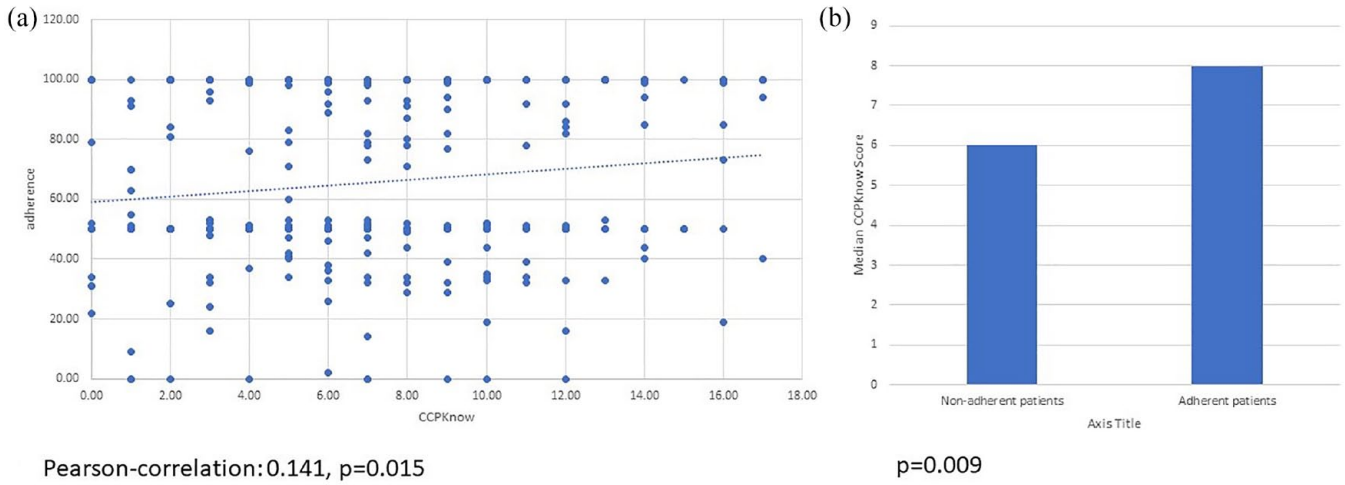

Figure 1. Relation between adherence and CCPKnow. (a) Correlation analysis and (b) categorical analysis.
CCPKnow, Crohn's and Colitis Pregnancy Knowledge Score.

Table 3. Factors associated with good adherence.

Factor	Univariate analysis *p*-value	Binary regression odds ratio with 95% confidence interval	Binary regression analysis *p*-value
Methotrexate exposed	$p=0.036$	3.507 (0.876–14.044)	$p=0.076$
Planning to conceive within 1 year	$p=0.019$	2.363 (1.177–4.478)	$p=0.016$
CCPKnow $\geqslant 8$	$p=0.009$	1.600 (0.987–2.593)	$p=0.056$

CCPKnow, Crohn's and Colitis Pregnancy Knowledge Score.

$p=0.015$; Figure 1(a)]. Adherent patients had significantly higher CCPKnow scores than non-adherent patients [median 8 (IQR 5–12) *versus* 6 (IQR 3–10); $p=0.009$; Figure 1(b)]. HADSA and HADSD were not significantly associated with adherence.

Binary regression analysis (mode: enter) revealed that planning to conceive within 12 months was independently associated with better adherence [odds ratio (OR) 2.363 95% confidence interval (CI) 1.177–4.478; $p=0.016$; Table 3], whereas methotrexate exposure (OR 3.507 95% CI 0.876–14.044; $p=0.076$) and CCPKnow (OR 1.600 95% CI 0.987–2.593; $p=0.056$) did not meet significance criteria.

Discussion

We examined medication adherence in a large cohort of women of childbearing age who had not had children and found low adherence rates of only 38.4%. Based on our pilot work,[24] we aimed to confirm whether patient knowledge of IBD and pregnancy is associated with good adherence to IBD maintenance medication in women of childbearing age. We identified that future family plans, especially the wish to conceive within the next year, was associated with better adherence and better patient knowledge of IBD- and pregnancy-related issues.

Adherence levels in our study (38.4%) were considerably lower than those seen in other cohorts of women with IBD of childbearing age. In 2016, we found that good adherence as measured by the medicine adherence rating scale (MARS)[32] was 74.4% in 1324 women, who were members of the UK IBD patient support charity.[31] Our pilot study of women under the specialist Sydney IBD clinic found again high adherence rate of 84% using MARS.[24] During pregnancy,

adherence rates vary widely with some studies reporting excellent adherence,[33] some suboptimal adherence[7,8] and in one study nearly 50% became non-adherent.[20] Our current study population differs significantly from those cohort as we did not aim to include patients who already have children. Furthermore, patient support charity membership is associated with better adherence, and we expect that membership will be low in our cohort as seen in most cohort studies.[19] The Sydney cohort was under a single specialist clinic, which will have likely also increased adherence.[24] In addition, we used a different adherence measure. Although VAS is fully validated against thiopurine metabolite levels in IBD with good correlation with MARS too, there are obvious differences in the way adherence was measured.[29]

Following on from our pilot study, we confirmed the association of better disease-related pregnancy knowledge and adherence, both on binary and correlation analyses. Through regression analysis, we established that the main effect on adherence is driven by the wish to conceive in the next year, which in turn is associated with better knowledge and better adherence. Patients may have accessed pre-pregnancy counselling, which may have helped them in increasing their knowledge and subsequently adherence, as seen in the two Danish adherence studies examining pregnant IBD cohorts.[7,8] It appears that wishing to conceive may influence women to potentially educate themselves and increased adherence. This hypothesis will be tested in the longitudinal follow-up of this cohort that we plan to conduct over the next few years to determine trajectories of patient knowledge and adherence as women's family planning decisions evolve. We have seen a numerical lower rate of adherence in those patients trying to currently conceive, but as numbers are small this may be a random non-significant finding.

In our very selected cohort of women most disease-related factors including perceived disease severity, need for hospital admission in the last year and need for steroids in the last year were not associated with adherence. Interestingly, we found that apart from methotrexate, exposure to different medications was not associated with adherence, in contrast to studies in more general IBD populations where adherence was better on biologics.[6,19] As our aim was to examine the aspects around family planning on adherence, we did not examine for wider measures around adherence including belief of necessity and potential medication concerns. We found however that psychological symptoms of anxiety and depression were not associated with adherence.

The main strength of our study lies in the examination of a well-defined multi-centre cohort of women with IBD, for whom family planning decisions are most relevant as we focussed on those yet to start a family. By using the UK IBD BioResource, we have avoided influence from single centres or clinicians on adherence and knowledge, thereby examining a less select cohort. We used validated tools to assess adherence, anxiety and depression and knowledge. There are a number of limitations to our work. Firstly, we used a survey design with a relatively low response rate, which may in turn reflect that UK IBD BioResource participants get offered participation for several studies per year. Secondly, we used VAS to measure adherence, which while fully validated for IBD, is less often used than other adherence measures. This could potentially lead to differences in absolute levels of adherence but is unlikely to affect associations with adherence. Thirdly, we did not examine for necessity belief and medication concerns as due to the nature of our study the questionnaires were already relatively long. Fourthly, our sample size calculation was based on a presumed adherence rate of 74% and as our adherence rate was lower at 38%, this could have affected the statistical power to detect some associations of adherence. It would have been interesting to compare the adherence between all family planning subgroup, but our sample size was too small to allow meaningful analysis on this aspect.

In conclusion, we have demonstrated that women wishing to conceive within the next year had better adherence to IBD maintenance medication and better pregnancy-specific disease-related knowledge. Clinical teams should focus efforts on improving pre-conception knowledge as the pre-conception group demonstrated better adherence. Longitudinal follow-up of this cohort will examine whether adherence and patient knowledge changes as individual family planning decisions evolve.

Declarations

Ethics approval and consent to participate

The UK IBD BioResource has been reviewed and approved by Cambridge Central Research Ethics Committee (ref 15/EE/0286). All patients provided written informed consent at initial recruitment. For this nested phase 2 study within in the UK IBD BioResource, Human Research Ethics Committee approval was granted by London – Stanmore Research Ethics Committee (Ref 19/LO/1891). Participants in this study provided consent by progressing from the patient information leaflet to the questionnaire.

Consent for publication

Not applicable.

Author contributions

Christian P. Selinger: Conceptualization; Formal analysis; Investigation; Methodology; Writing – original draft.

Robyn Laube: Data curation; Formal analysis; Methodology; Writing – review & editing.

Helen Steed: Investigation; Methodology; Writing – review & editing.

Matthew Brookes: Conceptualization; Methodology; Writing – review & editing.

NIHR BioResource: Conceptualization; Data curation; Writing – review & editing.

Rupert W. L. Leong: Conceptualization; Investigation; Methodology; Writing – review & editing.

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Competing interests

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Availability of data and materials

Summary data are available on reasonable request. Owing to ethics/consent for this study primary data are not available openly.

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Supplemental material

Supplemental material for this article is available online.

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