Inflammatory bowel disease and pregnancy: Lack of knowledge is associated with negative views

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Pregnancy; Patient knowledge; Attitudes

Abstract

Background: Enabling women with inflammatory bowel diseases (IBD) to have successful pregnancies requires complex decisions. The study aimed to assess patients’ views on IBD and pregnancy and to evaluate any association with subject knowledge.

Methods: General attitudes of females with IBD were assessed on fertility, medication use, delivery mode and pregnancy outcomes. Attitudes regarding personal situation were assessed in participants nulliparous since IBD diagnosis. Knowledge of pregnancy-related issues in IBD was assessed by the Crohn’s and Colitis Pregnancy Knowledge Score ‘CCPKnow’.

Results: Of 145 participants 68% of participants agreed with need for medical therapy for flares during pregnancy, but 24% felt it more important to tolerate symptoms. 36% believed that all IBD medication is harmful to unborn children. Of 96 women nulliparous after IBD diagnosis, 46% were worried about infertility, 75% expressed concern about passing IBD to offspring and 30% considered not having children. Nearly all participants worried about the effects of IBD on pregnancy and the effects of pregnancy on IBD. General attitudes that ‘medication should be stopped prior to conception’ (P < 0.001), ‘pregnant women should avoid all IBD drugs’ (P < 0.001), and ‘put up with symptoms’ (P < 0.001) were associated with significantly lower CCPKnow scores.

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1. Introduction

Many women with inflammatory bowel disease (IBD) are of child-bearing age and therefore addressing any concerns regarding pregnancy is an important part of holistic care. Complex decisions regarding medical therapy are often required to maximize the chance of a successful pregnancy. While medication can pose a potential risk to the unborn child, the importance of both achieving remission prior to conception, and maintaining remission throughout pregnancy, is underscored in a number of international guidelines.1,2 These guidelines are principally based on studies examining fertility, pregnancy outcomes, neonatal abnormalities and drug safety, predominantly in patients under the care of tertiary centres rather than community based cohorts.1,2 Furthermore, the benefits of maintaining medication for IBD may outweigh the potential risk to the foetus, with the notable exception of Methotrexate, which remains absolutely contraindicated.1,2

In contrast, studies examining the patients’ perceptions on pregnancy have been few.3-5 Disease related education aiming to increase patient’s knowledge is a cornerstone of holistic IBD care.6 We have recently published a validated tool to assess disease-related knowledge of pregnancy in IBD and demonstrated that nearly 50% of women surveyed had poor knowledge.7 A study in the USA of 169 women with IBD raised concerns that many participants opted not to have children, when there was no medical reason for them to stay childless.3 Women with Crohn's disease (CD) had a self-reported ‘voluntary childlessness’ rate of 18%, compared to 14% in ulcerative colitis (UC); the corresponding ‘voluntary childlessness’ rate in the general population was only 6% (P = 0.001 for CD, P = 0.08 for UC).3 In contrast ‘involuntary’ childlessness was only marginally raised in IBD versus the general population (5% versus 2.5%, P = ns). The reason for the high rate of voluntary childlessness in IBD is unclear and warrants exploration. Furthermore, many women with IBD also hold negative views on the use of medication for their disease during pregnancy.5 The extent of these negative views, which are contrary to medical evidence, has not been properly examined previously. Perhaps more importantly, any relationship between patients’ views and knowledge of pregnancy-related issues remains unknown.

This study aimed firstly to quantify the extent of negative patient views by assessing the attitudes of women with IBD regarding fertility, medication use in pregnancy and breast feeding, delivery methods and pregnancy outcomes. Secondly, the study aimed to test the hypothesis that poor knowledge (as measured by CCPKnow) is associated with inappropriately negative patient views, when compared to existing evidence on pregnancy in IBD.

2. Methods

2.1. Study cohort

Female patients with IBD, aged 18–45 years, were recruited from two tertiary IBD outpatient clinics (direct invitation) and from outpatient offices (postal invitation) in Sydney, Australia. We have recently developed and validated a questionnaire (CCPKnow) to evaluate knowledge of pregnancy-related issues in IBD. The same cohort was now examined to ascertain patient views and their relation to knowledge. Participants self-reported demographic (age, marital status, employment status, highest educational level and household income) and disease specific data (diagnosis, duration of disease, medication and surgical history). Further information collected included Crohn's Colitis Australia™ (the Australian patient support group) membership status and information on previous pregnancies.

2.2. Attitudes assessment

In the absence of a validated assessment tool and an agreed standard for validation, statements for the assessment of attitudes were developed by a working party of three expert IBD physicians. Patient attitudes were divided into:

1. general attitudes towards pregnancy-related issues in IBD (for example ‘A woman with IBD is less likely to get pregnant’) and
2. personal attitudes towards a statement that directly relates to the patient’s own diagnosis and situation (for example, ‘I am worried that I might not be fertile”).

2.3. General attitudes assessment

General attitudes were assessed in all participants by using 13 statements on fertility, medication use (before conception, during pregnancy and during breast feeding), mode of delivery and pregnancy outcomes (see Table 2). Agreement was rated on 5-point Likert scales from ‘totally disagree’ to ‘totally agree’.

2.4. Personal attitudes assessment

Attitudes and beliefs regarding their personal situation were assessed only in those participants who had not given birth since their diagnosis of IBD. Agreements with statements regarding fertility, passing on IBD to offspring, effects of IBD on the course of pregnancy, ability to breast feed and look after a child were rated on 5-point Likert scales from ‘totally disagree’ to ‘totally agree’ (see Table 3).
2.5. Disease related knowledge

Knowledge of pregnancy-related issues in IBD was assessed by CCPKnow. CCPKnow evaluates and quantifies patients’ knowledge on pregnancy-related issues, using 17 self-administered multiple choice questions.7

2.6. Statistical Analysis

Responses of ‘totally agree’/‘agree’ and ‘totally disagree’/‘disagree’ were grouped together for the purpose of analysis. Any association between patients’ knowledge and general attitudes and between patients’ knowledge and personal attitudes was assessed separately. Statistical analysis was performed by t-test and chi-square using the SPSS software package.

The study was approved by the Concord Repatriation General Hospital Human Research Ethics Committee (HREC/10/CRGH/119). All subjects provided informed consent and were given the opportunity to receive the correct responses to CCPKnow on questionnaire completion.

3. Results

3.1. Study cohort

The study included a cohort of 145 women with IBD, 44 (30%) of whom were recruited from hospital clinics. Postal invitations were mailed out to 361 patients under the care of office-based gastroenterologists and 101 (28%) returned the study questionnaire. The median age was 32 years and the majority of patients were either married or living with a long-term partner. The study cohort demographics and disease-related data are displayed in Table 1. 33.8% of the participants (24 CD, 23 UC, 2 IBD-unclassified) had successfully delivered children after their diagnosis of IBD. Not all participants answered every question (maximum non-response per question= 3%); hence percentages were derived from the total number answering each question.

3.2. General attitudes

34% of participants believed that women with IBD are less likely to get pregnant than the general population. Just over half of women agreed that IBD medication should be continued (51.4%), and that it is important to keep symptoms controlled (63.4%) prior to conception. Over two-thirds agreed that women need medical therapy if they experience a disease flare during pregnancy, but 24.3% felt it more important to tolerate symptoms rather than to have medicines during pregnancy. Concerns about any IBD medication were common; 36.1% of participants believed that any IBD medication is ‘bad’ for unborn children. The majority believed that women with IBD are likely to have a vaginal delivery (87%) and a healthy baby (67.9%), but 36.6% expected a difficult pregnancy. While 87.9% believed that there is no need to avoid breastfeeding when off all medication, 69.5% thought that women on any IBD medication should not breastfeed. Detailed results of the general attitudes assessment are displayed in Table 2.

3.3. Personal attitudes

Of 96 women who were nulliparous since the time IBD diagnosis, nearly all were worried about the effect of IBD on pregnancy (90.1%), the effects of pregnancy on the course of IBD (91.2%), and the chance of experiencing a flare induced by the pregnancy (78.8%). Worries about being infertile were expressed by 45.6%. Concern of inheritability of IBD to offspring was common (74.7%). A significant minority (29.7%) was considering voluntary childlessness because of their IBD and 42.9% were concerned about IBD negatively impacting on their ability to look after their child. Only 46% of women believed that they will have an uncomplicated pregnancy,
Table 2 Agreement with general attitude statements (TDA totally disagree, DA disagree, N neither agree nor disagree, A agree, TA totally agree) and correlation with CCPKnow (scores for TDA/DA and A/TA).

<table>
<thead>
<tr>
<th>Attitude Statement</th>
<th>TDA (%)</th>
<th>DA (%)</th>
<th>N (%)</th>
<th>A (%)</th>
<th>TA (%)</th>
<th>TDA + DA</th>
<th>DA + A</th>
<th>CCPKnow</th>
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<tbody>
<tr>
<td>A woman with inflammatory bowel disease is less likely to get pregnant.</td>
<td>29.17</td>
<td>19.44</td>
<td>17.36</td>
<td>31.25</td>
<td>2.78</td>
<td>9.3</td>
<td>9.1</td>
<td>P = 0.247</td>
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<td>A woman with inflammatory bowel disease should try to stop all medicines when she is trying to conceive.</td>
<td>18.75</td>
<td>32.64</td>
<td>11.81</td>
<td>26.39</td>
<td>10.42</td>
<td>9.8</td>
<td>7</td>
<td>P &lt; 0.001</td>
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<td>If a woman has symptoms from her IBD when she is trying to conceive, it is important to use medication to control her symptoms.</td>
<td>0.00</td>
<td>9.03</td>
<td>12.50</td>
<td>52.08</td>
<td>26.39</td>
<td>5.8</td>
<td>9</td>
<td>P = 0.003</td>
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<td>A pregnant woman should avoid all prescribed medicines for her IBD.</td>
<td>28.47</td>
<td>29.17</td>
<td>22.92</td>
<td>16.67</td>
<td>2.78</td>
<td>9.6</td>
<td>6.2</td>
<td>P &lt; 0.001</td>
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<td>All prescribed medications for IBD are bad for the unborn child to some degree.</td>
<td>12.68</td>
<td>26.76</td>
<td>16.90</td>
<td>33.10</td>
<td>10.56</td>
<td>10.1</td>
<td>7.1</td>
<td>P &lt; 0.001</td>
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<td>It is important to put up with symptoms to protect the unborn child from medicines.</td>
<td>22.22</td>
<td>34.03</td>
<td>19.44</td>
<td>18.06</td>
<td>6.25</td>
<td>9.9</td>
<td>6.2</td>
<td>P &lt; 0.001</td>
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<td>If a woman has symptoms from her IBD when she is pregnant, it is important to use medication to control her symptoms.</td>
<td>0.71</td>
<td>11.35</td>
<td>20.57</td>
<td>45.39</td>
<td>21.99</td>
<td>5.8</td>
<td>9.6</td>
<td>P &lt; 0.001</td>
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<td>Medication that keeps symptoms under control should be continued during pregnancy.</td>
<td>0.70</td>
<td>19.01</td>
<td>16.90</td>
<td>49.30</td>
<td>14.08</td>
<td>6.5</td>
<td>9.3</td>
<td>P &lt; 0.001</td>
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<td>Most women with inflammatory bowel disease can have a vaginal delivery.</td>
<td>1.41</td>
<td>2.82</td>
<td>19.72</td>
<td>34.51</td>
<td>41.55</td>
<td>9.5</td>
<td>8.6</td>
<td>P = 0.574</td>
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<td>Breast feeding should be avoided by mothers with inflammatory bowel disease even if she is on no medication.</td>
<td>64.29</td>
<td>23.57</td>
<td>7.86</td>
<td>0.71</td>
<td>3.57</td>
<td>8.6</td>
<td>8</td>
<td>P = 0.67</td>
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<tr>
<td>Breast feeding should be avoided by mothers with inflammatory bowel disease, if she is on certain types of medication.</td>
<td>5.67</td>
<td>10.64</td>
<td>14.18</td>
<td>43.26</td>
<td>26.24</td>
<td>8.7</td>
<td>8.7</td>
<td>P = 0.93</td>
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(continued on next page)
and only 73.6% expected to have a healthy baby. Detailed results of the personal attitudes assessment are displayed in Table 3.

3.4. Correlation of attitudes and knowledge

General Attitudes regarding medication use during pregnancy were associated with patients’ CCPKnow score (Table 2). For example, patients with lower knowledge scores believed that all medication should be stopped prior to conception ($P<0.001$), pregnant women should avoid all IBD drugs ($P<0.001$), and/or that it is important to put up with symptoms rather than take medication ($P<0.001$). However, attitudes towards fertility, medication use while breastfeeding and the likelihood of a healthy newborn were not associated with knowledge.

Most Personal attitudes were not associated with knowledge, but women who believed that their IBD medication would prohibit breast feeding had significantly lower knowledge than those who disagreed with this statement (CCPKnow 7.1 versus 10, $P=0.006$). Also women who considered not having children had lower CCPKnow scores (6.8 versus 8.4), but this result did not reach statistical significance ($P=0.08$).

Membership in the patient organisation was associated with better knowledge ($P<0.001$) and subsequently less adverse views (putting up with symptoms $P=0.01$, belief in uncomplicated pregnancy $P=0.047$, belief in ability to breast feed on medication $P=0.01$). Women exposed to immunomodulators and/or biological drugs had better knowledge ($P<0.001$), but believed less that they would be able to look after a newborn ($P=0.01$) and were more often concerned about the effect of IBD on their pregnancy ($P=0.007$).

4. Discussion

This is the first study to describe the views of women with IBD on pregnancy-related issues and their association with disease related subject knowledge. As we have previously demonstrated, patient knowledge of pregnancy related issues in IBD is poor in nearly 50% of women. The current study demonstrated fear of infertility, reluctance to use medication during pregnancy and/or breast feeding and this may, in turn, lead to adverse pregnancy and/or disease outcomes.

The low postal return rate of 28% in this study indicates that the study cohort may be more select than the wider community. As general IBD knowledge was, however, rather high in comparison to other studies, any selection bias should lead to an under- rather than over-representation of poor knowledge and subsequent adverse views. The extent to which patients proactively sought pregnancy advice was not recorded, but it is anticipated that any informal education would influence knowledge and attitudes alike.

Concerns over possible medication side effects have a clear negative impact on adherence rates in non-pregnant patients with IBD. Two population-based Danish studies reported IBD medication adherence rates of 72% for CD and 60% for UC prior to and during pregnancy, with concerns regarding the possible teratogenic effects of medications cited as the reason for non-adherence by 50% of participants. While these results are similar to those of other studies on non-pregnant populations, they may underestimate non-adherence due to recall bias. Results from the present study suggest, for the first time, that poor subject knowledge leading to unfounded concerns may play a significant role in non-adherence to medication by pregnant patients.

Our findings confirm those of other studies reporting that a significant proportion of women harbour excessive fears about infertility over and above the actual infertility rate of IBD patients. The present study also demonstrates that the majority of women worry about passing IBD on to their offspring. Such concerns can lead many women to consider voluntary childlessness, which is significantly more common in patients with IBD than the general population. Reassurance through education regarding fertility and hereditary rates in the IBD patient population should lead to reduced rates of voluntary childlessness, in circumstances where this is based on unnecessary and uninformed misconception.

General attitudes (for example, whether any women with IBD should use medication during pregnancy and breast feeding) were significantly associated with disease related patient knowledge. In contrast, personal concerns pertaining directly to an individual’s situation were not influenced by subject knowledge; thus, concerns relating to the risk of infertility, passing on IBD to offspring and the effects on the course of pregnancy were not related to poor knowledge. It is conceivable that such personal attitudes and concerns are formed by personal experience, general personality type and emotions.
rather than rationale and subject knowledge. While women might know that in general females with IBD are likely to conceive, they may still harbour their own personal fears of infertility despite adequate knowledge. Anxiety is overall increased in IBD patients, and this may, of course, negatively influence women who face difficult decisions regarding possible pregnancies.

The attitudes assessment naturally covered topics, which are also part of the knowledge assessment tool CCPKnow. The correlation between knowledge and attitudes could be interpreted as a result of this overlap. The investigators, however, aimed to separate attitude and knowledge assessment. Firstly participants were asked to give (to their knowledge) correct answers for CCPKnow, while the attitude...
assessment asked for their personal agreement with statements. The discrepancy between knowledge and attitudes was exemplified by divergent responses regarding knowledge of medication continuation during pregnancy (CCPKnow Question 5) versus corresponding attitudes of the same topic. More than 30% of respondents demonstrated discordance with high knowledge yet adverse attitudes in that field. Secondly the medication questions included in CCPKnow test for specific knowledge of drug treatments, while the attitude questionnaire aims to measure general patient views about drug treatments. Furthermore as only 30% (5 of 17) questions in CCPKnow concern drug treatments, CCPKnow assesses much wider knowledge of pregnancy related issues. The correlation between knowledge and attitudes towards medication use during pregnancy appears therefore strong.

The results of this study highlight the association between poor subject knowledge and views that may be detrimental to the successful delivery of a healthy child by patients with IBD. Improved education programmes relating to the impact of IBD on pregnancy are vital, not just when considering conception, but for all young women early after disease diagnosis, to allow patients to make informed decisions about having children. Identification of patients with poor knowledge, using tools such as CCPKnow, will allow the targeted education and counselling of women at particular risk, which may in turn improve clinical outcomes for both mothers and babies.

Conflict of interest statement

All authors report no conflict of interest.

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Christian P Selinger designed the study, collected the data, analysed the data, interpreted the results and wrote the draft manuscript.

Jayne Eaden contributed to the design of the study, interpretation of the study results and critically revised the manuscript.

Warwick Selby contributed to the data collection interpretation of the study results and critically revised the manuscript.

D Brian Jones contributed to the data collection interpretation of the study results and critically revised the manuscript.

Peter Katelaris contributed to the data collection interpretation of the study results and critically revised the manuscript.

Grace Chapman contributed to the data collection interpretation of the study results and critically revised the manuscript.

Charles McDonald contributed to the data collection interpretation of the study results and critically revised the manuscript.

John McLaughlin contributed to the design of the study, interpretation of the study results and critically revised the manuscript.

Rupert WL Leong contributed to the design of the study, data collection and analysis interpretation of the study results and critically revised the manuscript.

Simon Lal designed the study and contributed to the interpretation of the study results and critically revised the manuscript.

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