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

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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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Conclusion: Over a third of patients considered IBD medication harmful to unborn children. Fear of infertility and concerns about inheritance may explain high rates of voluntary childlessness. Attitudes contrary to medical evidence were associated with significantly lower knowledge. Young women with IBD, particularly those with poor knowledge, should be offered education and counselling about pregnancy-related issues.

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).[3] 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.[7] 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).