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It is worth the effort: Patient knowledge of reproductive aspects of inflammatory bowel disease improves dramatically after a single group education session

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Received 29 November 2013; accepted 20 December 2013

KEYWORDS

Inflammatory Bowel Disease;
Pregnancy;
Fertility;
Patient knowledge;
Patient education

Abstract

Background: Individuals with Inflammatory Bowel Disease (IBD) have poor knowledge regarding the implications of disease for fertility and pregnancy. Previous studies suggest that this poor knowledge adversely influences reproductive decision making.

Aim: To examine the effect of a single group education session on IBD-specific reproductive knowledge in subjects with IBD.

Method: People with IBD attending an educational event were invited to complete the CCPKnow questionnaire, testing reproductive knowledge in IBD, before and after an evidenced based presentation on this topic delivered by a Gastroenterologist.

Results: Of 248 attendees, 155 participated; 69% female, mean age 40.3 years. CCPKnow scores (maximum 17) were low at baseline and increased significantly post education (mean 5.4 pre vs. 14.5 post education; $p < 0.0001$). A large majority (65.1%) of subjects had “poor” (score < 8) knowledge at baseline, compared with only 1.9% after education ($p < 0.0001$). Whilst all subareas of knowledge improved after education, the most important improvement was in attitudes toward medication use in pregnancy: 33.5% of subjects indicated at baseline that women should avoid all drugs in pregnancy compared with only 1.2% post education ($p < 0.0001$).

Conclusion: A single group-delivered education event focussed on reproductive issues in IBD can dramatically improve patient knowledge. This has the potential to change reproductive behaviour and may reduce voluntary childlessness resulting from misperceptions amongst individuals with IBD. Crown Copyright © 2013 Published by Elsevier B.V. on behalf of European Crohn's and Colitis Organisation. All rights reserved.

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<http://dx.doi.org/10.1016/j.crohns.2013.12.019>

Please cite this article as: Mountifield R, et al, It is worth the effort: Patient knowledge of reproductive aspects of inflammatory bowel disease improves dramatically after a sing..., *J Crohns Colitis* (2014), <http://dx.doi.org/10.1016/j.crohns.2013.12.019>

1. Introduction

As survival is generally normal in Inflammatory Bowel Disease (IBD), quality of life and the opportunity to have a normal work, social and family life is a key aim of management. IBD usually has its onset during the reproductive years, but fortunately both male and female fertility outcomes as well as pregnancy outcomes overall are good amongst individuals with IBD,^{1–3} especially if good disease control is maintained.^{4–6} Most IBD medications are considered safe to continue throughout pregnancy,^{7–10} with the exception of teratogens methotrexate and thalidomide,⁷ whilst sulfasalazine causes reversible infertility in men.¹¹

Data, however, suggest that many IBD subjects have poor knowledge regarding IBD-specific issues relevant to fertility and pregnancy.¹² Moreover, it appears that this knowledge gap contributes to increased rates of voluntary childlessness as a result of misinformation.^{13–15}

Formal education of patients has been shown to be beneficial in improving general IBD knowledge and satisfaction in a Canadian study,¹⁶ but other studies have not demonstrated such a benefit,^{17,18} and it is not known whether such a programme would be effective in improving reproductive knowledge in IBD.

The effect of group education of patients with IBD to address the interaction between disease, medications, fertility and pregnancy has not been previously addressed using a validated knowledge test.

2. Aim

To determine whether IBD-specific reproductive knowledge improves in patients with IBD after a single targeted group education session.

3. Methods and materials

Crohn's and Colitis Australia (CCA) is a patient-run support group, holding regular information evenings in each state in Australia. One such evening was held at Flinders Medical Centre (FMC), a tertiary referral hospital with an active IBD Service, in South Australia in 2013. The evening consisted of a variety of presentations on different topics of interest which had been identified as being important by the members of CCA. The meeting was widely advertised, and was open to all patients and their families, irrespective of CCA membership. One of these presentations focused on the relationship between IBD and reproductive issues such as IBD inheritance, fertility, pregnancy, drug safety and breast feeding.

Upon arrival each attendee was handed a questionnaire which consisted of 2 copies of the "CCPKnow" test,¹² a validated tool assessing knowledge regarding IBD-specific aspects of reproduction. This test consists of 17 multiple choice questions with 5 option answers of which 1 is considered correct, covering subareas of IBD inheritance, fertility, the effects of IBD activity and medications on pregnancy, mode of delivery, perianal disease, pregnancy outcomes and breast feeding. The minimum score is zero and maximum 17, with scores of 0–7 indicating poor knowledge, 8–10 adequate, 11–13 good and 14–17 very good knowledge.¹²

Subjects were also invited to state using free text their main sources of information regarding IBD and fertility and pregnancy.

Each attendee was seated by IBD nursing staff on arrival and invited to complete the first CCPKnow test before the presentations commenced. Time and materials were supplied to enable this. It was stressed that participation was entirely voluntary and anonymous. If participants felt comfortable doing so they were asked to state their gender and age on the front of the questionnaire. The reproductive presentation was then delivered, consisting of 24 slides covering current evidence-based practice regarding the effect of IBD and medications on fertility for men and women, pregnancy, breastfeeding and inheritance, in simple language with visual aids and using repetition for major messages. All information presented was consistent with ECCO guidelines on the management of special situations such as reproduction and IBD.^{19,20}

Directly after the reproductive IBD presentation audience members were invited to complete the second copy of the CCPKnow in their questionnaire booklet without altering responses from their initial questionnaire. Ten to fifteen minutes was allocated for this. The other presentations then proceeded. At the conclusion of the evening all questionnaire booklets were collected and CCPKnow scores calculated for each participant before and after the presentation, with the intention of determining whether improvement in reproductive IBD knowledge had occurred as a result of attendance.

3.1. Ethical considerations

This study was approved by the Flinders Clinical Research Ethics Committee, with informed consent taken to be signified by the return of a completed questionnaire. Attendees wishing not to participate simply handed back their blank booklets.

3.2. Statistics

CCPKnow scores before and after the presentation were compared using a paired t-test, with Mann Whitney U or unpaired t-tests for other comparisons as appropriate, using the SPSS programme. A p value of <0.05 was taken as statistically significant. Contingency tables with Fisher's exact test were used to compare responders and non-responders and also to compare correct and incorrect responses for individual domains pre and post education and to perform comparisons by gender.

4. Results

There were 248 attendees (170 female, 78 male), of whom 155 participated (69% female,) yielding an overall response rate of 62.5%. Mean age of respondents was 40.3 years, similar for females and males (39.0 years versus 41.6 years, $p = 0.55$).

Of a maximum overall CCPKnow score of 17, mean pre education score was 5.4 versus 14.5 after education ($p < 0.0001$) (Table 1 and Fig. 1) Males and females both had low baseline scores, although male scores were significantly

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