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RESEARCH ARTICLE

Colonoscopy in patients with inflammatory bowel disease: self-reported experience, understanding, anxieties and tolerance of the procedure [version 1; peer review: 3 approved with reservations]

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V1 First published: 30 Sep 2015, 4:927
<https://doi.org/10.12688/f1000research.6889.1>
 Latest published: 30 Sep 2015, 4:927
<https://doi.org/10.12688/f1000research.6889.1>

Abstract

Objective: To address Inflammatory Bowel Disease (IBD) patients' attitudes, understanding and tolerance of colonoscopy and assess whether there are specific factors that influence these parameters.
Design: structured questionnaire-based survey. Tolerance of various aspects of colonoscopy procedure graded on a scale 1-5, 5 representing most intolerance/burden (worries/concerns about the procedure/risks, bowel preparation, disruption to life, procedural discomfort and travel concerns).
Setting: London teaching hospital - St Georges Hospital
Patients: Consecutive patients with established IBD attending the specialist IBD clinic
Results: 98 patients responded (46% male). Mean age was 43.2 years. 33 had Ulcerative Colitis (UC), 50 had Crohn's Disease (CD), and 11 were unsure of diagnosis. Mean number of colonoscopies was 3.7. Females were more worried about the procedure than males (3.0 vs 2.1, $p < 0.05$), were less tolerant of bowel preparation (3.5 vs 2.3, $p < 0.05$), experienced more disruption to their lives (2.9 vs 1.9, $p < 0.05$) and were more troubled by travel concerns (2.0 vs 1.4, $p < 0.05$). Patients with the disease for ≥ 5 years experienced significantly more discomfort than patients with the disease for a shorter duration (3.2 vs 2.7 $p < 0.05$). Patients aged ≥ 55 years are significantly less worried about the procedure (2.7 vs 2.0, $p = < 0.05$) and tolerate the bowel preparation better (3.1 vs 2.4, $p = < 0.05$). The majority of the patients felt colonoscopy was 'bearable' (53%) with only 13% describing it as 'very unpleasant'. 55% would have the procedure 'as frequently as required' if their physician felt it appropriate.
Conclusions: Our research highlights a significant difference in the perception of colonoscopy by gender and age. Overall our findings

Open Peer Review

Approval Status ? ? ?

	1	2	3
version 1	?	?	?
30 Sep 2015	view	view	view
1. Vassiliki Tsikitis , Oregon Health & Science University, Portland, USA			
2. Agata Mulak , Wroclaw Medical University, Wroclaw, Poland			
3. Alyssa Parian , Johns Hopkins School of Medicine, Baltimore, USA			

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reveal a preparedness to undergo colonoscopy as required despite an increasing requirement for this test. The differences highlighted should prompt endoscopy units to accommodate and make allowances for these different perceived tolerance in routine clinical activity.

Keywords

Inflammatory bowel disease , Colonoscopy , tolerance

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Competing interests: No competing interests were disclosed.

Grant information: The author(s) declared that no grants were involved in supporting this work.

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How to cite this article: Morgan S, Alexakis C, Medcalf L *et al.* **Colonoscopy in patients with inflammatory bowel disease: self-reported experience, understanding, anxieties and tolerance of the procedure [version 1; peer review: 3 approved with reservations]** F1000Research 2015, 4:927 <https://doi.org/10.12688/f1000research.6889.1>

First published: 30 Sep 2015, 4:927 <https://doi.org/10.12688/f1000research.6889.1>

Introduction

Inflammatory Bowel Disease (IBD), made up primarily of Ulcerative Colitis (UC) and Crohn's Disease (CD), is a chronic relapsing and remitting intestinal condition that affects an estimated 240,000 patients in the UK¹. Medical treatment of IBD may include combinations of steroids, 5-aminosalicylic acids (5-ASAs), immunomodulators and biologic therapies. Failure of medical therapy may lead to surgery. Optimising treatment is dependent on various surrogate markers of inflammation, radiological imaging and direct endoscopic assessment of mucosal inflammation². More recently, the importance of mucosal healing, as determined at colonoscopy, has been underscored as a key indicator of therapeutic success^{2,3}. Mucosal healing is associated with improved health-related quality of life⁴, results in a longer time to relapse in CD⁵, and ultimately in fewer hospital admissions⁶.

Non-invasive surrogate markers of inflammation such as faecal calprotectin may offer an alternative in the assessment of disease activity in IBD but are yet to be fully evaluated as an alternative to direct visualisation of mucosal healing⁷. Colonoscopy therefore currently remains the gold standard test for assessing mucosal healing. This potentially means an increasing burden of endoscopic procedures from the current level for IBD patients in the future⁸. However, colonoscopy is invasive, time consuming and costly, and may be viewed as an unpleasant or intolerable procedure by patients. With this in mind, it is important to assess patients' perception and tolerance of colonoscopy, particularly since it may be performed increasingly more often to assess mucosal healing. We therefore aimed to assess the perceptions of a cohort of IBD patients consecutively recruited through a specialist IBD clinic at a large regional hospital with respect to their understanding, experience and attitudes towards colonoscopy.

Methods

Our study was performed at St George's Hospital (SGH), which is a large 800 bed regional teaching hospital in central London with a catchment area of about 1.3 million patients. The department of gastroenterology runs weekly IBD specialist clinics. The endoscopy unit performs over 5000 procedures per year and is both a regional bowel cancer screening centre and national colonoscopy training centre. Colonoscopies were either performed by a senior clinician or by a trainee under their direct supervision. Consecutive patients with an established diagnosis of IBD attending the weekly specialist IBD clinic were invited to take part in this study by completing a short questionnaire. Data was collected over a 4 month period between September and December 2013. Data was collected anonymously. There was no specific exclusion criteria and the inclusion criteria was a confirmed diagnosis of IBD with a history of at least one colonoscopy. Consent was presumed by patients' willingness to complete the survey. They were informed verbally by the clinic staff, that the data they provided would be used in a study to evaluate patients' perceptions, understanding tolerance and experience of colonoscopy. Ethical approval was sought from the local Health Research Authority, who felt after consideration of the methodology, that specific ethical approval was not required for

this study. The questionnaire comprised of nine questions and was divided into categories described below. A copy of the questionnaire in full is available as [Supplementary materials](#).

Demographics, disease characteristics and understanding of the procedure

Patients were asked to self-report their age and sex and provide details of their IBD subtype and how long they had had their diagnosis as they understood it. They were asked to estimate how many colonoscopies they had undergone since diagnosis. Patients were also asked to demonstrate their understanding of the indications for colonoscopy. They were provided with eight potential indications, four of which are accepted indications and four which were "sham" indications. Choices available - 1) to assess how severe the disease is, 2) to see if you have constipation (sham), 3) to see if your treatment is working, 4) to see if there is another cause for your symptoms, 5) to get samples of the bowel wall (biopsies), 6) to see if you are digesting food properly (sham), 7) to get blood sample (sham), and 8) to check for intestinal worms (sham).

Experience of procedure

The patients were asked to address the burden of various aspects of the procedure using a numerical grading score 1 to 5, where 1 represents least burden and 5 most burden. Parameters evaluated included: worries/concerns about the procedure/risks, bowel preparation, disruption to life, procedural discomfort and travel to and from hospital. They were then given the opportunity to describe the entire colonoscopy experience using one of the following qualitative statements: not unpleasant, neither unpleasant nor pleasant, bearable, unpleasant, and very unpleasant.

Finally, the patients were asked to comment on how often they felt they could tolerate the procedure (once a year, once every 2 years, once every 3 years, once every 5 years, or as often as their doctor felt it appropriate). They were also given a space to add further comments about any aspect of their colonoscopy experience.

Data was collected, stored and analysed on StatView™ 5.0.1 statistics program (Abacus Corporation, Baltimore, Maryland, USA). Where appropriate, comparison of continuous data was performed using the student's *t*-test.

Results

Dataset 1. Table showing raw data collection from questionnaires

<http://dx.doi.org/10.5256/f1000research.6889.d102841>

94/295 patients completed the questionnaire (32% response rate). 46% were male. Mean age was 43.2 years (male 47.1 years; female 39.9 years). [Table 1](#) presents combined demographic, disease and tolerance data on the entire cohort of responders. More than 60% of responders to the questionnaire had their disease for longer than 5 years. The most burdensome aspect of the procedure reported was bowel preparation and procedural discomfort.

Table 1. Perspective on colonoscopy in IBD patients - Whole cohort data.

Patient no.	94
Male:Female (male %)	43:51 (45.7%)
Mean age (yrs)	43.2
UC:CD:unsure	33:50:11
Length of disease	
Less than 1 year	4.3%
1 to 2 years	9.6%
2 to 3 years	7.4%
3 to 5 years	17.0%
5 to 10 years	19.1%
More than 10 years	21.3%
More than 20 years	21.3%
Mean no. colonoscopies	3.7
% questions correct	69.2%
Mean score	
Procedure worry	2.6
Bowel preparation	3.0
Disruption to life	2.4
Discomfort	3.0
Travel to hospital	1.7

All statistics corrected to 1 decimal place

Table 2 shows the intergroup comparison data. Of note, females found all aspects of colonoscopy more burdensome than their male counterparts, with all parameters reaching statistical significance bar procedural discomfort. Of interest, older patients (>55 years) reported less concerns about the procedure and associated risk, and also were less burdened by bowel preparation. Finally, patients with a longer disease duration reported higher burden of procedural discomfort.

Patients demonstrated good knowledge in their understanding of the indications for colonoscopy, with 69.2% answering all four indications correctly. Figure 1 illustrates patient responses to the individual indications for colonoscopy. Figure 2 indicates the qualitative summary statements by IBD patients as to general tolerability of the procedure. The majority of patients thought colonoscopy was bearable (53%), with only a small minority (13%) describing it as very unpleasant. Figure 3 indicates the frequency that respondents would be prepared to tolerate colonoscopy in future. The majority of patients (55%) would have the procedure 'as frequently as required if their physician felt it appropriate'. A very small minority (7%) responded that they would only prepared to have colonoscopy every 5 years.

Discussion

Main findings

Mucosal healing has evolved as a key endpoint in the assessment of therapeutic response to medical therapy in IBD patients. Requests for colonoscopy are therefore likely to continue to increase in this patient group making it particularly important to gain insight into the patients' perceptions of this procedure. A good patient experience in the endoscopy unit is critical in facilitating long term medical management and continued engagement in services in

this cohort. We have found that both women and young patients have a heightened concern about this procedure although actual reported discomfort following the procedure did not differ in these sub-groups from the rest of the cohort. Patients with an IBD disease duration of more than 5 years expressed significantly more procedural discomfort than patients with a shorter duration.

Findings in relation to other studies

Our research highlights a significant difference in the perception of colonoscopy between men and women. Females had a significantly worse perception of colonoscopy in four key areas: concerns about the procedure and associated risks; tolerance of bowel preparation; disruption to life and travel concerns to and from hospital, but not procedural discomfort itself. The results illustrate that women have higher pre-procedural anxiety than men. There are limited studies differentiating between gender and pre-procedure anxiety in patients with IBD, but our findings are supported by other work examining procedural anxiety in a non-IBD population undergoing colonoscopy^{9,10}.

In our cohort, females showed a tendency towards increased procedural discomfort compared with males, approaching statistical significance. The majority of previous work on this subject suggests that females experience more discomfort during colonoscopy¹¹⁻¹³, although this is not a universal finding¹⁴. It has been suggested that performing colonoscopy on females may be more difficult and more uncomfortable because of previous gynaecological surgery or differing colonic and pelvic anatomy¹², and of note in this respect the procedure usually takes longer in women¹⁵.

Bowel preparation in colonoscopy is another important area of patient concern, with one study suggesting it is the most unpleasant part of the whole process¹⁶. This was mirrored in our group of patients with bowel preparation perceived as the most burdensome aspect of the whole episode (joint top with procedural discomfort). In our study, women were significantly less satisfied with bowel preparation compared to men, a finding supported by others¹⁷. The negative symptoms associated with bowel preparation may magnify pre-procedural anxiety in this group of patients¹⁸.

Our results showed significant age-related differences in two measured outcomes. Patients aged 55 years or more were less worried about the procedure and risks. Secondly, this group reported that they found bowel preparation less burdensome than their younger counterparts. In keeping with our findings, a study showed older people expressed less discomfort associated with bowel preparation than younger patients and were overall, more satisfied¹⁷.

However, we did not observe differences in procedural discomfort between the two age groups. The literature in this respect is conflicting. A Finnish retrospective study reported that older patients tolerate the procedure better than younger patients⁹. Conversely, Kim *et al.* reported no significant age-related differences¹⁹. Other studies have indicated older patients may tolerate the procedure less¹². These inconsistencies between studies may reflect differences in the indication for and the underlying pathologies of the respective patient groups studied. Additionally, 'older age' is categorized differently between studies.

Table 2. Intergroup comparison of demographics, disease characteristics and reported procedural burden in patients with IBD who have undergone ileocolonoscopy.

	Disease type		Sex		Age		Length of disease		No. of colonoscopies	
	UC	CD	Male	Female	< 55 years	≥ 55 years	Disease < 5 years	Disease ≥ 5 years	< 4 colons	≥ 4 colons
Patient no.	33	50	43	51	76	18	36	58	54	40
UC:CD:unsure	N/A	N/A	13:24:6	20:26:5	26:41:9	7:9:2	16:14:6	17:36:5	20:25:9	13:25:2
Male:Female (male %)	13:20 (39.4%)	24:26 (48.0%)	N/A	N/A	31:45 (40.8%)	12:6 (66.7%)	16:20 (44.4%)	27:31 (46.6%)	36:18 (66.7%)	20:20 (50.0%)
Age (yrs)	44.8	42.7	47.1	39.9*	N/A	N/A	39.2	46.3*	39.8	47.9*
Length of disease										
Less than 1 year	2 (6.1%)	1 (2.0%)	1 (2.3%)	3 (5.9%)	4 (5.3%)	0 (0.0%)			4 (7.4%)	0 (0.0%)
1 to 2 years	4 (12.2%)	2 (4.0%)	4 (9.3%)	5 (9.8%)	8 (10.5%)	1 (5.6%)			8 (14.8%)	1 (2.5%)
2 to 3 years	4 (12.2%)	2 (4.0%)	3 (7.0%)	4 (7.8%)	6 (7.9%)	1 (5.6%)	N/A	N/A	6 (11.1%)	1 (2.5%)
3 to 5 years	6 (18.2%)	9 (18.0%)	8 (18.6%)	8 (15.7%)	14 (18.4%)	2 (11.1%)			12 (22.2%)	4 (10.0%)
5 to 10 years	7 (21.2%)	9 (18.0%)	4 (9.3%)	14 (27.5%)	15 (19.7%)	3 (16.7%)			11 (20.4%)	7 (17.5%)
More than 10 years	4 (12.2%)	14 (28.0%)	11 (25.6%)	9 (17.6%)	17 (22.4%)	3 (16.7%)			11 (20.4%)	9 (22.5%)
More than 20 years	6 (18.2%)	13 (26%)	12 (27.9%)	8 (15.7%)	12 (15.8%)	8 (44.4%)			2 (3.7%)	18 (45.0%)
Mean no. colonoscopies	3.8	3.9	3.9	3.6	3.5	4.7	2.3	4.6*	N/A	N/A
% questions correct	68.2%	70.0%	69.8%	68.6%	69.1%	69.5%	70.8%	68.0%	67.1%	71.9%
Mean score										
Procedure worry	2.6	2.5	2.1	3.0*	2.7	2.0*	2.8	2.5	2.6	2.6
Bowel preparation	3.0	3.0	2.3	3.5*	3.1	2.4*	3.0	2.9	3.0	3.0
Disruption to life	2.7	2.3	1.9	2.9*	2.5	2.2	2.4	2.5	2.6	2.3
Discomfort	2.9	3.1	2.8	3.1	3.1	2.7	2.7	3.2*	3.1	2.9
Travel to hospital	0.8	1.7*	1.4	2.0*	1.8	1.5	1.8	1.7	1.7	1.8

All statistics shown to 1 DP. UC - ulcerative colitis CD - Crohn's disease *p<0.05

1: to assess disease severity. 2: to see if you have constipation. 3: to see if your treatment is working. 4: to see if there is another cause for your symptoms. 5: to get biopsies. 6: to see if you are digesting properly. 7: to get blood samples. 8: to check for intestinal worms. The blue bars represent the correct indication; white bars are incorrect

Figure 1. Proportion of patients correctly and incorrectly choosing indications for ileocolonoscopy.

Figure 2. Summary statements on experience of colonoscopy in patients with IBD.

Figure 3. Frequency that respondents would tolerate colonoscopy.

Our study showed that patients who had IBD for more than 5 years expressed significantly more discomfort than patients having the disease for less than 5 years. This finding may relate to underlying disease factors, such as inflammation, stricturing or reduced intestinal compliance resulting in increased technical difficulty and reduced patient tolerance. One large study reported that higher doses of sedation are required amongst IBD patients with active disease²⁰. An alternative explanation is that endoscopists now administer lower doses than historically in response to tighter monitoring and auditing of sedation practices. In a single centre study from the UK of sedation practices over a 10 year period sedation rates for outpatient diagnostic upper endoscopy reduced by 54%²¹. Certainly, in light of the 2004 NECPOD report ‘Scoping our Practice’²², sedation in all patient groups, particularly the elderly, has come under close scrutiny, and inevitably has influenced recent practice in endoscopic sedation. Kale *et al.* suggested endoscopy sedation should be individualised to the specific need of the IBD patient, particularly those that have active disease²⁰ and this is clearly pertinent to the vulnerable subgroups we have identified, namely women and young patients.

The majority of our patients were prepared to undergo colonoscopy as frequently as their physician felt it appropriate. Similarly the majority also found colonoscopy ‘bearable’. These findings support the evidence that colonoscopy is generally associated with high levels of patient satisfaction and willingness to return²³. This is a particularly important factor in patients with IBD, given that they are likely to undergo repeated procedures, especially when they enter into colorectal cancer surveillance programs. Our data suggests a high level of understanding of the indications of the procedure, which may further explain why most are prepared to undergo colonoscopy as frequently as needed.

Strengths and limitations

This study has some limitations, particularly since responses were obtained retrospectively which opens it up to recall bias. If the most recent colonoscopy was a negative experience, irrespective of previous positive experiences, this may have impacted adversely. In one study, a fifth of patients reported that colonoscopy was more uncomfortable than they had expected²⁴ and a previous experience of pain during colonoscopy was found to influence the perceived experience of pain during a subsequent procedure⁹. We sought to evaluate the patients’ qualitative perception of colonoscopy but a more objective and validated verification of discomfort during colonoscopy (or immediately following) might have led to different conclusions. We did not assess the patients’ requirement for sedation and analgesia, which may also have later influenced patients’ perception given the recognised retrograde-amnesic effect of benzodiazepines but we feel our study design best reflects the patient experience in routine clinical practise. Finally, our questionnaire did not include questions relating to ‘procedural embarrassment’, which has been significantly linked to non-compliance in endoscopic screening programs²⁵.

Implications and future work

Providing patients with a positive experience is clearly important in maintaining continued engagement with medical services. Our findings indicate steps need to be taken to address the particular concerns of women and young patients with IBD in advance of their procedure. How might we ameliorate perceived pre-procedural patient concerns better? Consultation prior to colonoscopy with a clinician is associated with increased patient satisfaction²⁶. This should form part of the consent process that is ideally performed before the day of procedure and after the clinic consult, as is the practice for the national bowel cancer screening programme. However, this may not always be logistically feasible. Music during the procedure has been shown to improve procedural experience and reduce anxiety amongst women and increases wellbeing amongst men, as well as significantly reducing discomfort^{27,28}. Similarly, continuity of endoscopist for each procedure also lowers anxiety in females²⁹, although this approach may be difficult to adopt in NHS endoscopy units that usually have pooled waiting lists and endoscopic trainees. Reviewing previous sedation requirements and recorded pain scores should be routine endoscopic practice to individualise the sedation plan. The analgesic adjunct of inhaled Nitrous oxide, a quick acting potent analgesic and anxiolytic, may also be helpful reducing excessive intravenous sedation³⁰. By taking all these factors into account the global patient experience can be improved.

In conclusion, our research highlights a significant difference in the perception of colonoscopy dependent on gender, age of the patient and disease duration. These results should prompt endoscopy units to improve the experience of colonoscopy particularly amongst these subgroups of patients with IBD. In the future surrogate markers such as faecal calprotectin may reduce the burden of colonoscopy. In the meantime, further research is required to develop simple clinical tools to better identify and improve the experience of vulnerable patients that would otherwise tolerate the colonoscopic experience poorly.

Data availability

F1000Research: Dataset 1. Table showing raw data collection from questionnaires, [10.5256/f1000research.6889.d102841](https://doi.org/10.5256/f1000research.6889.d102841)³¹

Author contributions

SM: Article write up and data collection; CA: Article write up and data collection; LM: Data collection; VC: Data collection; PN: Data collection; AP: Data collection; RP: Article write up and data collection.

Competing interests

No competing interests were disclosed.

Grant information

The author(s) declared that no grants were involved in supporting this work.

Supplementary material

Questionnaire: 'Patients with IBD: survey of attitudes to colonoscopy'.

[Click here to access the data.](#)

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Open Peer Review

Current Peer Review Status: ? ? ?

Version 1

Reviewer Report 10 October 2016

<https://doi.org/10.5256/f1000research.7416.r16816>

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This is a retrospective review of 94 IBD patients at a single center evaluating the IBD patient experience of colonoscopy. The importance of colonoscopy and mucosal healing requires more frequent colonoscopic exams and determining how to make the experience as pleasant as possible can improve patient satisfaction and patient compliance with recommended colonoscopy intervals. However, there are several missing components which are essential for determining how we can improve the patient's experience with colonoscopy. Overall, these findings don't provide any tangible items for the institution change in order to improve patient experience and more data should be included in this study which should be easily gleaned from the chart.

1. The type of bowel prep used plays a role in patients satisfaction and tolerance of the bowel preparation. Smaller volume bowel preps have shown to have increased patient satisfaction and patient compliance. It should be reported if there is a standard bowel prep at the institution and evaluate which bowel prep was best tolerated amongst patients.
2. The type of anesthesia also contributes to the overall patient experience and tolerance of the procedure. Is it typical in this center to use conscious sedation with narcotics/benzodiazepams or propofol sedation? Were both used and a comparison can be made as to which was better tolerated?
3. The disease activity could also influence the patients perception of the procedure. Was disease activity assessed and reported as this can confound the results.
4. The small size of the population studied limits full evaluation of additional factors that may contribute to IBD patient experience of colonoscopy.

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of

expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 21 March 2016

<https://doi.org/10.5256/f1000research.7416.r12490>

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This is a single-center study assessing self-reported experience, understanding, anxiety and tolerance of colonoscopy in 94 patients with inflammatory bowel disease (IBD). The study addresses important issues and has potential practical implications as understanding patients' experience of the procedure is crucial for service improvement, particularly in IBD patients undergoing repetitive colonoscopies in the course of their diseases. The manuscript is written in a comprehensive way. However, there are some methodological shortcomings of the study affecting the reliability of the conclusions.

Major comments:

1. In the Methods section it should be described what kind of sedation (if any) is used in the Center and what is the proportion of colonoscopies involving sedation or anesthesia. This is an important factor affecting patients' experience.
2. Was the bowel preparation procedure the same in all examined patients?
3. The comparison between two age groups: younger patients (<55 years) vs older subjects (≥ 55 years) is not quite representative. Firstly, due to the different number of patients in each group (76 vs 18 subjects). Secondly, female patients were significantly younger than male patients (39.9 vs 47.1 years, respectively; $p < 0.05$). Therefore sex could be a confounding factor in the comparison between these two groups.
4. Were there any differences in patients' experience between subjects with ulcerative colitis and Crohn's disease?
5. It has been previously reported that female patients' preference for the same sex endoscopists may significantly affect the level of pre-procedural anxiety and overall experience in female patients. It was not addressed in the questionnaire.

Additional comments:

1. Please verify the number of patients given in the abstract, because according to the text and Table 1 it should be 94 instead of 98.
2. A written informed consent is usually required in this kind of study.

3. It is said that colonoscopies were performed either by a senior clinician or by a trainee (under supervision). In fact, the endoscopists' skill and experience could importantly determine patients' discomfort during colonoscopy.

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 27 January 2016

<https://doi.org/10.5256/f1000research.7416.r11540>

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Vassiliki Tsikitis

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In the article "Colonoscopy in patients with inflammatory bowel disease: self-reported experience, understanding, anxieties and tolerance of the procedure," the authors comment that the perception of colonoscopy significantly differs by gender and age of this unique patient population, where colonoscopy is required in frequent intervals. Females had a significantly worse perception of colonoscopy and a higher pre-procedural anxiety overall. Patients over the age of 55 were less worried about the procedure, and patients with prolonged duration of IBD expressed more discomfort with it. The survey is only based on a single hospital-institution and included 98 patients, of whom 46% were male. Although there are significant limitations in the study, it brings up an important point about how we physicians prepare our patient for an upcoming procedure.

Overall good article, but the population examined was too small to make any significant findings.

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

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