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The relationship between different information sources and disease related patient knowledge and anxiety in patients with inflammatory bowel disease

Running title: information sources in IBD

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Inflammatory Bowel Disease; ulcerative colitis; Crohn's disease; patient knowledge; anxiety; information sources

Abstract

Background: Patient education forms a cornerstone of management of inflammatory bowel disease (IBD). The internet has opened new avenues for information gathering.

Aim: To determine the relationship between different information sources and patient knowledge and anxiety in patients with IBD.

Methods: The use of information sources in patients with IBD was examined via questionnaire. Anxiety was assessed with the hospital anxiety and depression scale and disease-related patient knowledge with the Crohn's and colitis knowledge score questionnaires. Associations between these outcomes and demographics, disease-related factors, and use of different information sources were analysed using linear regression analysis.

Results: Of 307 patients (165 Crohn's disease, 142 ulcerative colitis) 60.6% were female. Participants used the hospital IBD team (82.3%), official leaflets (59.5%), and official websites (53.5%) most frequently in contrast to alternative health websites (9%). University education ($p<0.001$), use of immunosuppressants ($p=0.025$), Crohn's and Colitis UK membership ($p=0.001$), frequent use of the hospital IBD team ($p=0.032$), and frequent use of official information websites ($p=0.005$) were associated with higher disease-related patient knowledge. Female sex ($p=0.004$), clinically active disease ($p<0.001$), frequent use of general practitioners ($p=0.014$), alternative health websites [homeopathy, nutritionists, etc] ($p=0.004$), and random links ($p=0.016$) were independently associated with higher anxiety.

Conclusion: Different patient information sources are associated with better knowledge or worse anxiety levels. Face-to-face education and written information materials remain the first line of patient education. Patients should be guided towards official information websites and warned about the association between the use of alternative health websites or random links and anxiety.

Introduction

Inflammatory bowel disease (IBD) comprising ulcerative colitis (UC), Crohn's disease (CD), and IBD-unclassified (IBD-U) is a chronic inflammatory disorder of the intestine.[1, 2] Most patients affected by IBD require life-long medical follow-up and medical or surgical treatments. Modern management of IBD should be governed by joint decision making with well-informed patients. Disease education is therefore paramount for effective treatment, which has been recognised by the British IBD standards.[3] Traditionally patient education has been delivered through face-to-face encounters with clinicians, official patient information leaflets, and meetings of patient support organisations. The advent of the internet has opened new avenues for directed and self-directed patient education.

Information on the internet is provided through a variety of websites run by health care organisations, patient support organisations, pharmaceutical companies, news organisations, and alternative health providers, as well as individuals contributing to patient experience blogs and discussion forums.[4] The information available on the internet is of variable quality[4] and a systematic review found that in 2007 many website were of poor quality.[5] Although most websites provide adequate information,[6] unsurprisingly, the quality of information provided by alternative health websites may be inferior to that from websites run by health care or patient support organisations.[4] Furthermore the use of patient-friendly language could be increased to improve the poor readability of some websites.[4, 6] Efforts to promote the websites with best quality content are hindered by the fact that these websites often do not feature in the top three for the most commonly used internet search engines.[7]

Patients with IBD are increasingly using the internet to search for information about their condition, as demonstrated by studies in North America[8] and the United Kingdom.[9] In both cohorts more than half of the surveyed patients reported using the internet for health-related issues. Younger patients and those with higher educational achievements were more likely to search for IBD-related information.[8]

While good quality information sources may improve disease-related patient knowledge, it is also conceivable that some (especially unregulated) information available on the internet may cause anxiety. The hypothesis that the use of different information sources is associated with better patient knowledge and/or worse anxiety levels has so far not been rigorously investigated. The aim of this study was therefore to quantify the use of different information sources in a cohort of ambulatory patients with IBD, and examine any potential associations with patient knowledge (primary outcome) and anxiety.

Materials and Methods

Study cohort and participant identification

Care for patients with IBD is almost exclusively provided by National Health Service hospitals in the UK. The ambulatory IBD clinics at Leeds Teaching Hospitals Trust provide secondary care for the population of Leeds (800,000 inhabitants) and tertiary referral care for patients from the surrounding areas. The total clinic cohort consists of approximately 3000 patients with IBD, of which the vast majority are secondary care patients. 774 ambulatory patients with IBD were previously recruited to a cross-sectional observational study conducted at an initial clinic visit. Clinical data were collected at this point. This study was published elsewhere and received approval from the local research ethics committee in November 2012.[10, 11] These participants were sent a single postal invitation to provide additional data via a paper-based questionnaire for this current study.

Inclusion and exclusion criteria

The study recruited adult individuals with ulcerative colitis or Crohn’s disease attending the IBD clinics at our hospitals. Patients were excluded from participation if they did not understand English (self-administered questionnaires), were suffering from IBD-unclassified (no accepted disease activity index) or, had a stoma (inability to calculate the Harvey Bradshaw index).

Collected data

Demographic data included age, sex, ethnicity, marital status, educational level, and tobacco and alcohol use. Type of IBD, disease duration, and clinical phenotype were recorded using the Montreal classification.[12] Current and previous medical and surgical treatments were recorded, and current clinical disease activity was assessed with the simple clinical colitis activity index (for ulcerative colitis patients)[13] and the Harvey-Bradshaw index (for Crohn's disease patients).[14] Anxiety was assessed using the anxiety subscale of the hospital anxiety and depression scale (HADS-A)[15] at the time of disease activity assessment. Laboratory investigations included CRP and faecal calprotectin.

Additional data collection included disease-related patient knowledge, as assessed by the validated 24-point Crohn's and colitis knowledge score (CCKnow)[16]. Participants reported access to the internet, and frequency of accessing the internet generally, and for health-related issues.

The investigators compiled a list of patient information sources on IBD using the existing literature[4, 6] and local patient feedback from an IBD patient panel consisting of expert IBD patients, who regularly advise on service matters and research plans. On the advice of the panel, more specific website examples were added to a list already compiled from the existing literature. The study questionnaire assessed the frequency of use for traditional information sources (general practitioner, hospital IBD team, patient information leaflets (in Leeds leaflets from Crohns and Colitis UK are used exclusively) , local patient organisation meetings), professional internet websites (official websites by patient charity organisations and the National Health Service, news websites, patient-centred pharmaceutical support websites) and unregulated websites (patient discussion forums, alternative health provider websites [homeopathy, nutritionists, etc], random links after web searches). Random links were defined as links appearing on search engines that did not belonging to any of the other categories of interest. For each category of information source we provided several explanatory examples to guide participants (supplementary table S1) Participants rated frequency of use ("I use this service for finding information on IBD" and trust in the source ("I trust the information provided by this service") separately using 5 point Likert scales (always, often, sometimes, rarely, never). Frequent use was defined as at least sometimes.

Sample size calculation

Calculations were made to determine power to answer the primary study hypothesis that patients using official information sources have higher knowledge than those relying on other sources. Based on Eaden *et al.* we assumed that official information source users will have a mean CCKnow score of 12.[16] Sample size calculations were based on the use of a two-tailed t-test for the primary outcome. A sample size of 250 patients would give a 95% percent power to detect a difference of 1.25 in CCKnow (SD 5.5, 5% significance level). We anticipated a response rate of 33%, and hence sent the study questionnaire to all 774 patients.

Analysis plan

Data were first presented descriptively. Factors (disease characteristics, demographics, educational status, medical treatments and use of different information sources) potentially associated with HADS-A and CCKnow (continuous variables) were assessed were assessed by student t-tests and one-way ANOVA. Statistical significance was set at 5% and any significant variables were entered in multiple linear regression analysis. The analysis was performed with SPSS version 22 (SPSS Inc., Chicago, IL, USA).

Ethical approval and consent

The research protocol of the current study was approved by the National Research Ethics Service Committee London - Hampstead (13/LO/1364). Return of the study questionnaire was taken as informed consent.

Results:

Study cohort

The study questionnaire was completed by 307 patients (response rate 39.7%). Of these 188 (60.6%) were female and the mean age was 47.3 years (range 17-88 years, Table 1). The majority of patients were White Caucasian (290, 94.5%) and only 89 (29%) were educated to at least the level of university degree. There was a slight predominance of CD patients (165, 53.7%) over UC patients (142, 46.3%). Further disease characteristics including Montreal classifications, and medical and surgical treatment history are displayed in table 1. Of the patients with UC 70.1% were in clinical remission, while 62.5% of patients with CD were in clinical remission. CRP levels were available for 275 participants (63.8% in normal range) and faecal calprotectin were in the remission range (<250) for 115 of 191 (60.2%) patients who provided stool samples. Responders to the current study did not differ from the full study cohort, apart from a lower exposure to anti-TNF in this study cohort.

The mean HADS-A score was 7.1 (range 0-21) with 67 (21.8%) participants classed as having borderline anxiety levels (HADS-A 8-10) and 68 (22.1%) participants classed as having abnormal anxiety levels (HADS-A >10). The mean CCKnow score was 11.14 (range 0-24). There was no correlation between patient knowledge (CCKnow) and HADS-A (pearson correlation 0.008; p=0.89). Patient organisation membership (Crohn's and Colitis UK) was relatively high with 22.3% indicating current membership and 18% previous membership. 275 patients (89.6%) reported access to the internet and 79.2% used the internet at least daily. Internet use for health-related issues was reported by 74.4%, with 27.7% indicating at least weekly use for health-related purposes.

Use of, and trust in, information sources

Frequent use of information sources by participants included the hospital IBD team (82.3%), official patient information leaflets (59.5%), and official patient information websites (53.5%) (Table 2). General practitioners (33.1%), patient forums (29.9%), and news websites (27.4%) were less frequently used, while Crohn's and Colitis UK meetings (3.3%), pharmaceutical websites (7.9%), alternative health websites (9%), and random links (17.3%) had the lowest rates of use.

Participants frequently trusted the information provided by the hospital IBD team (92.7%), official patient information leaflets (79.6%), official patient information websites (70.6%), and general practitioners (64.7%). Trust in information provided by news websites (39.7%), patient information forums (34.8%), random links (20.4%), pharmaceutical websites (17%), Crohn’s and Colitis UK meetings (12.9%), alternative health websites (11.8%) was generally lower.

Variables associated with disease related knowledge

Younger patients had better disease-related knowledge (<60 years mean 11.7 vs ≥60 years 9.5; p=0.001), but no associations between sex, marital status, ethnicity, or tobacco or alcohol consumption and CCKnow scores were found (Table 3). Participants with university degree level education had better disease-related knowledge than those without (13.5 vs 10.1; p<0.001). A diagnosis of CD was associated with higher CCKnow scores than a diagnosis of UC (11.9 vs 10.2; p=0.005). Median knowledge score was lower among mesalazine users (users 10.3 vs non-users 12; p=0.004), while patients using immunomodulators had better CCKnow scores than non-users (users 12.5 vs non-users 10.3; p<0.001). Patients with clinically active disease according to Harvey-Bradshaw-Index or simple clinical colitis activity index had better disease-related knowledge than those in clinical remission (remission 10.6 vs active disease 12; p=0.016). There were no differences in disease-related knowledge between patients with normal and abnormal faecal calprotectin levels (Table 3), even when three different thresholds (<50, <100, <250) were applied. Participants with current or past Crohn’s and Colitis UK membership were more knowledgeable than non-members (13 vs 9.9; p<0.001). Daily internet use (11.8 vs less frequent 8.6; p<0.001) and at least weekly internet use for health issues were related with better disease related knowledge (12.8 vs less frequent 10.5; p=0.001).

With the exception of attending the general practitioners and Crohn’s and Colitis UK local meetings, the use of all other information sources was associated with higher CCKnow scores (Table 3; image 1). Multiple linear regression analysis (figure 1) revealed that university degree level education (p<0.001), use of immunosuppressants (p=0.025), Crohn’s and Colitis UK membership (p=0.001), frequent use of the hospital IBD team for information (p=0.032), and frequent use of official patient information websites (p=0.005) were independently associated with higher disease related patient knowledge.

Variables associated with anxiety levels

Younger patients (<60 years HADS-A mean 7.7 vs ≥60 years 5.3; $p<0.001$) and female patients (7.7 vs male 6.1; $p=0.002$) exhibited higher levels of anxiety, but no associations between marital status, ethnicity, tobacco or alcohol consumption, highest educational achievement, disease type, membership of Crohn's and Colitis UK, or exposure to different medications and HADS-A scores were found (Table 4). Patients with clinically active disease had higher anxiety levels than those in clinical remission (8.6 vs 6.3; $p<0.001$). There were no differences in HADS-A scores between patients with normal and abnormal faecal calprotectin levels, even when three different thresholds (<50, <100, <250) were applied (Table 4). Daily internet use (7.5 vs less frequent 5.7; $p=0.004$) and at least weekly internet use for health issues were associated with higher anxiety levels (8.3 vs less frequent 6.5; $p=0.004$). There was no correlation between HADS-A and CCKnow.

With the exception of using the hospital IBD team, local Crohns and Colitis UK meetings and pharmaceutical websites as information sources, the frequent use of all other information sources was associated with higher levels of anxiety (Table 4; image 2). Multiple linear regression analysis (figure 2) revealed that female sex ($p=0.004$), clinically active disease ($p<0.001$), frequent use of general practitioners for information ($p=0.014$), frequent use of alternative health websites ($p=0.004$) and frequent use of random links on search engines ($p=0.016$) were independent predictors of higher anxiety levels.

Discussion:

Patient education is a cornerstone of comprehensive care for patients with IBD.[3] This is the first study to investigate whether the use different information sources is associated with disease-related patient knowledge or anxiety. In this large cohort we have demonstrated that ambulatory patients use their hospital IBD team and official patient information leaflets most often to gather information on IBD. Patients also trust these two sources the most. Patient education therefore should still include face-to-face education during routine clinical encounters and the use of printed information material.

Official web-based information sources provided by healthcare organisation and patient support organisation were also frequently used and trusted. Other web-based information sources were used less frequently and fewer patients trusted them. It appears that many patients display a healthy level of scepticism when assessing non-regulated information on the internet. We chose to report levels of trust for the whole cohort, rather than for just for participants who were regular users of specific information sources, as a perceived low level of trust may explain why some information sources were only used by a small minority of participants. We asked patients about random links as this might reflect non-critical information gathering type behaviour.

Disease-related patient knowledge was associated with a number of factors. More educated patients had better disease-related knowledge and, in line with previous studies, we have demonstrated that membership of a patient organisation is associated with better knowledge.[17] The severity and course of IBD may also influence patient knowledge, as we found that exposure to immunomodulators was independently associated with better knowledge. It is likely that the disease education, provided through membership and counselling for immunomodulator use, positively influences knowledge.

The frequent use of nearly all information sources was associated with better knowledge on univariate analysis, but after multiple linear regression analysis only the association with frequent use of the hospital IBD team and official websites remained significant. In light of this, patient education efforts should focus on face-to-face education by gastroenterologists and IBD nurses, as well as signposting to official websites providing high quality patient information.

Anxiety levels were higher in women and those patients with active disease. There is a clear interplay with disease activity and anxiety levels,[18] which can be explained both by the direct effects of symptoms on the patients psychological status, as well as the interplay between abnormal pathophysiology and pathopsychology. Psychological stress may be implicated in the development of intestinal inflammation through pro-inflammatory cytokines.[19] A number of information sources were associated with worse levels of anxiety, including the use of general practitioners, alternative health websites, and random unchecked links generated by search engines. Within the constraint of a cross-sectional study, and without the option of longitudinal assessments, we cannot draw any firm conclusions on causality here. It is conceivable the information provided by these sources induces anxiety. However, anxious patients may also seek out information from a wider variety of sources than patients without anxiety. Even in the absence of a clear causal link, patients should be advised to treat alternative information sources with caution. The study did not ask participants to rate the content of alternative health websites they accessed, nor would such data be of much value without in-depth reporting of specific individual websites (unlikely to be reported accurately). As such, we have no means to assess the quality of content. We feel strongly that patients should be advised to apply caution when accessing alternative health websites, as the quality of content is often unknown. Patients may be at risk of increased anxiety, but they may also follow non-evidence based treatment advice and as such put their physical health in jeopardy.

Whether the frequent use of general practitioners relates to more frequent need for reassurance for some patients and therefore is a consequence, rather than the source, of anxiety also remains unclear. In contrast to a previous study we did not find a correlation between knowledge and anxiety in this cohort.[17]

Our data suggest that patients' experience of their disease, and specifically their experience of current symptoms, is significantly associated with knowledge and anxiety. Patients with clinically active disease had better disease-related knowledge (on univariate analysis only) and exhibited higher levels of anxiety. Interestingly, the objective level of intestinal inflammation, as measured by calprotectin, was neither associated with knowledge nor with anxiety. It appears that symptoms rather than inflammation are the main driver of anxiety, and that information gathering is also associated with active symptoms. Our findings are supported by evidence that perceived stress is also associated with symptoms but not with levels of intestinal inflammation.[10, 20]

Membership of a patient support organisation was associated with significantly better knowledge, as also demonstrated consistently in previous studies.[17, 21] Very few patients, however, used local patient support organisation meetings for information gathering. In light of this, efforts to provide patient education to a wider audience should focus on different formats, as the impact of education delivered through local patient support organisation meetings may be limited.

The efforts by the pharmaceutical industry to provide patient education and support through web-based formats have so far (at least in our sample) failed to reach a significant number of patients. Furthermore, patients exhibited a low level of trust in information provided by the pharmaceutical industry, which may relate to healthy scepticism rather than the highly regulated and scrutinised content of the websites. It is therefore questionable whether efforts by the pharmaceutical industry are likely to achieve the objectives of patient education and support.

There are a number of limitations to this study. Firstly, the study cohort comprised patients from a single institution in the UK, and the results may therefore not necessarily be representative of other centres and/or countries. Ideally, the study would have involved a true population-based cohort. The study cohort consisted predominantly of secondary care patients and the disease characteristics of our cohort (high remission rates, relatively low use of immunomodulators and biologics) make it unlikely that significant selection bias towards a highly specialised referral cohort has occurred. Our rate of patients exposed to anti-TNF therapy was comparatively low. There are a number of explanations for this: In the UK, at the time this study commenced, anti-TNF therapies were only approved for use in UC as rescue therapy for acute severe ulcerative colitis. The National Institute for Health and Care Excellence (NICE) has only recently endorsed their use for chronic relapsing and remitting UC. Our centre provides care for approximately 1500 patients with CD, of whom 500 have received anti-TNF since 2000. The proportion of patients with Crohn's disease receiving these therapies in this study is a little lower than in other cohorts and may reflect slightly milder disease. This study consisted of mainly White Caucasian patients, who are representative of our local population. There are, however, significant differences in patient knowledge between ethnicities and countries.[22]

Secondly, the study assessed knowledge and anxiety at a single time point, rather than studying trends over time. While it would be desirable to examine the development of knowledge and anxiety in an inception cohort, this would require a much larger multi-centre approach, with significant financial resources. This study examined traditional and web-based information sources. Patients with IBD also frequent social media and a number of studies have looked at the available information and the use of social media.[7, 23-25] We did not specifically examine the use of social media, such as facebook, twitter, youtube or instagram in this study. However, the social media strategy of the patient support organisation Crohn's and Colitis UK is based on the principle of creating awareness with links to their website for further information. The study should therefore adequately cover this use indirectly. Furthermore we did not ask patients about healthcare utilisation, the frequency of contact with the IBD team or which members of the hospital IBD team they most often approached for information and can therefore not comment on whether different professional background (physician, nurse, dietician, pharmacist) or seniority influence patient knowledge or satisfaction. Data elicited by CCKnow and HADS scores are often not normally distributed, and we also found this to be the case for this study. We chose to analyse the data using t-test and linear regression analysis, as the statistical literature suggests that the use of parametric tests, rather than non-parametric tests, delivers the same results provided the sample size is as large as in our study. [26]

Based on the findings of this study we recommend the continued use of face-to-face education by IBD doctors and nurses, as well as written patient information material as first-line patient education. The difficulties of delivering face to face education in a busy clinic environment could be overcome by setting up dedicated patient education programs, which have been shown to be successful.[27] Patients should be guided towards official patient information websites from health care organisations and patient support organisations. We did not find any evidence that unregulated websites discussing patient experiences, such as blogs or forums led to significant anxiety, but patients should be warned about the link between anxiety and the use of alternative health websites or random links from search engines.

References:

1. Stange EF, Travis SP, Vermeire S, et al. European evidence-based Consensus on the diagnosis and management of ulcerative colitis: Definitions and diagnosis. J Crohns Colitis. 2008;2(1):1-23.
2. Dignass A, Van Assche G, Lindsay JO, et al. The second European evidence-based Consensus on the diagnosis and management of Crohn's disease: Current management. J Crohns Colitis. 2010;4(1):28-62.
3. Standards, editor. Quality Care Service standards for people who have Inflammatory Bowel Disease (IBD). 2009: The IBD Standards Group.
4. van der Marel S, Duijvestein M, Hardwick JC, et al. Quality of web-based information on inflammatory bowel diseases. Inflamm Bowel Dis. 2009;15(12):1891-6.
5. Bernard A, Langille M, Hughes S, et al. A systematic review of patient inflammatory bowel disease information resources on the World Wide Web. Am J Gastroenterol. 2007;102(9):2070-7.
6. Promislow S, Walker JR, Taheri M, et al. How well does the Internet answer patients' questions about inflammatory bowel disease? Can J Gastroenterol. 2010;24(11):671-7.
7. Fortinsky KJ, Fournier MR, Benchimol EI. Internet and electronic resources for inflammatory bowel disease: a primer for providers and patients. Inflamm Bowel Dis. 2012;18(6):1156-63.
8. Cima RR, Anderson KJ, Larson DW, et al. Internet use by patients in an inflammatory bowel disease specialty clinic. Inflamm Bowel Dis. 2007;13(10):1266-70.
9. Limdi JK, Butcher RO. Information resources and inflammatory bowel disease. Inflamm Bowel Dis. 2011;17(8):E89-90.
10. Gracie DJ, Williams CJM, Sood R, et al. Poor correlation between clinical disease activity and mucosal inflammation, and the role of psychological co-morbidity, in inflammatory bowel disease. Am J Gastroenterol. 2016;111(4):541-51. Epub 2016 Mar 22.
11. Gracie DJ, Williams CJ, Sood R, et al. Negative Effects on Psychological Health and Quality of Life of Genuine Irritable Bowel Syndrome-type Symptoms in Patients With Inflammatory Bowel Disease. Clin Gastroenterol Hepatol. 2016.
12. Satsangi J, Silverberg MS, Vermeire S, et al. The Montreal classification of inflammatory bowel disease: controversies, consensus, and implications. Gut. 2006;55(6):749-53.
13. Walmsley RS, Ayres RC, Pounder RE, et al. A simple clinical colitis activity index. Gut. 1998;43(1):29-32.
14. Harvey RF, Bradshaw JM. A simple index of Crohn's-disease activity. Lancet. 1980;1(8167):514.
15. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand. 1983;67(6):361-70.
16. Eaden JA, Abrams K, Mayberry JF. The Crohn's and Colitis Knowledge Score: a test for measuring patient knowledge in inflammatory bowel disease. Am J Gastroenterol. 1999;94(12):3560-6.
17. Selinger CP, Lal S, Eaden J, et al. Better disease specific patient knowledge is associated with greater anxiety in inflammatory bowel disease. J Crohns Colitis. 2013;7(6):e214-8.

18. Walker JR, Ediger JP, Graff LA, et al. The Manitoba IBD cohort study: a population-based study of the prevalence of lifetime and 12-month anxiety and mood disorders. Am J Gastroenterol. 2008;103(8):1989-97.
19. Mawdsley JE, Rampton DS. Psychological stress in IBD: new insights into pathogenic and therapeutic implications. Gut. 2005;54(10):1481-91.
20. Targownik LE, Sexton KA, Bernstein MT, et al. The Relationship Among Perceived Stress, Symptoms, and Inflammation in Persons With Inflammatory Bowel Disease. Am J Gastroenterol. 2015;110(7):1001-12; quiz 13.
21. Selinger CP, Eaden J, Selby W, et al. Patients' knowledge of pregnancy-related issues in inflammatory bowel disease and validation of a novel assessment tool ('CCPKnow'). Aliment Pharmacol Ther. 2012;36(1):57-63.
22. Leong RW, Lawrance IC, Ching JY, et al. Knowledge, quality of life, and use of complementary and alternative medicine and therapies in inflammatory bowel disease: a comparison of Chinese and Caucasian patients. Dig Dis Sci. 2004;49(10):1672-6.
23. Elkjaer M, Shuhaibar M, Burisch J, et al. E-health empowers patients with ulcerative colitis: a randomised controlled trial of the web-guided 'Constant-care' approach. Gut. 2010;59(12):1652-61.
24. Plevinsky JM, Greenley RN. Exploring health-related quality of life and social functioning in adolescents with inflammatory bowel diseases after attending camp oasis and participating in a Facebook group. Inflamm Bowel Dis. 2014;20(9):1611-7.
25. Mukewar S, Mani P, Wu X, et al. YouTube and inflammatory bowel disease. J Crohns Colitis. 2013;7(5):392-402.
26. Lumley T, Diehr P, Emerson S, et al. The importance of the normality assumption in large public health data sets. Annual review of public health. 2002;23:151-69.
27. Sephton M, Kemp K, Ridgway V, et al. An evaluation study of a pilot group education programme for inflammatory bowel disease. Frontline Gastroenterol 2015;7(2):135-40.

Tables 1-4

Image 1:

Independent factors associated of higher CCKnow scores: beta coefficient

Image 2:

Independent factors associated of higher HADS-A scores: beta coefficient

Sex	Male	121 (39.4%)
	Female	186 (60.6%)
Age	Mean 47.3 years	
	Range 17-88 years	
Marital status	Married / cohabiting	201 (65.7%)
	Divorced / separated	44 (14.4%)
	Never married	28 (9.2%)
	Widowed	20 (6.5%)
	Civil partnership	13 (4.2%)
Ethnicity	White Caucasian	290 (95.1%)
	South Asian	10 (3.3%)
	Other	5 (1.6%)
Highest educational achievement	Secondary School	112 (36.6%)
	Technical college	78 (25.5%)
	University not completed	27 (8.8%)
	University degree	34 (11.1%)
	Postgraduate degree	55 (18%)
Current smoker	Yes	38 (12.4%)
	No	268 (87.6%)
Alcohol use	Yes	203 (66.1%)
	No	104 (33.9%)
Diagnosis	Crohn’s disease	165 (53.7%)
	Ulcerative colitis	142 (46.3%)
Crohn’s phenotype	L1	42 (25.6%)
	L2	40 (24.4%)
	L3	82 (50%)
	L4 present	8 (4.8%)
	B1	109 (80.7%)
	B2	15 (11.1%)
	B3	11 (8.1%)
	Perianal disease present	12 (7.3%)
UC extent	E1	31 (22.1%)
	E2	59 (42.1%)
	E3	50 (35.7%)
Current Medication	5-ASA	159 (51.8%)
	Azathioprine/	67 (21.8%)
	Mercaptopurine	2 (0.7%)
	Methotrexate	3 (1.0%)
	Mycophenalate	23 (7.5%)
	Biologics	7 (2.3%)
	Steroids	46 (15%)
	None	
Clinical remission	CD (Harvey Bradshaw	
	index)	100 (62.5%)
	Yes	60 (37.5%)
	No	
	UC (simple clinical colitis activity index)	101 (70.1%)
		43 (29.9%)

	Yes No	
C-reactive Protein	<5 ≥5	196 (71.3%) 79 (28.7%)
Calprotectin (n=191)	<250 ≥250	76 (39.8%) 115 (60.2%)

Table 1: Participants characteristics

Information source	Frequency of use	N= (%)	Level of Trust	N= (%)
General practitioner	Always	15 (5%)	Always	62 (23%)
	Often	11 (3.7%)	Often	60 (20.3%)
	Sometimes	73 (23.8%)	Sometimes	52 (19.3%)
	Rarely	112 (36.5%)	Rarely	40 (14.9%)
	Never	88 (29.4%)	Never	55 (20.4%)
Hospital IBD team	Always	75 (25%)	Always	185 (64.5%)
	Often	86 (28.7%)	Often	53 (18.5%)
	Sometimes	86 (28.7%)	Sometimes	28 (9.8%)
	Rarely	26 (8.7%)	Rarely	7 (2.4%)
	Never	27 (9%)	Never	14 (4.9%)
Official patient information leaflets	Always	21 (7%)	Always	110 (40.1%)
	Often	51 (17.1%)	Often	66 (24.1%)
	Sometimes	106 (35.5%)	Sometimes	42 (15.3%)
	Rarely	63 (21.1%)	Rarely	18 (6.6%)
	Never	58 (19.4%)	Never	28 (13.9%)
Crohns and Colitis UK local meetings	Always	2 (0.7%)	Always	17 (7.1%)
	Often	2 (0.7%)	Often	4 (1.7%)
	Sometimes	6 (2%)	Sometimes	10 (4.1%)
	Rarely	18 (6%)	Rarely	0
	Never	272 (90.7%)	Never	210 (87.1%)
Official patient information websites (National Health Service, Crohns and Colitis UK, charities, etc)	Always	35 (12.8%)	Always	63 (23.2%)
	Often	83 (30.4%)	Often	82 (30.1%)
	Sometimes	62 (22.7%)	Sometimes	47 (17.3%)
	Rarely	19 (7%)	Rarely	8 (2.9%)
	Never	74 (27.1%)	Never	72 (26.5%)
News websites (British Broadcasting Corporation, newspapers, etc)	Always	2 (0.7%)	Always	13 (5%)
	Often	22 (7.3%)	Often	22 (8.4%)
	Sometimes	59 (19.5%)	Sometimes	69 (26.3%)
	Rarely	70 (23.1%)	Rarely	37 (14.1%)
	Never	150 (49.5%)	Never	121 (46.2%)
Patient centred websites by pharmaceutical companies	Always	1 (0.3%)	Always	3 (1.2%)
	Often	4 (1.3%)	Often	15 (6.2%)
	Sometimes	19 (6.2%)	Sometimes	23 (9.5%)
	Rarely	39 (12.7%)	Rarely	20 (8.3%)
	Never	239 (79.1%)	Never	180 (74.7%)
Patient forums and blogs centred on exchange about patient experiences	Always	3 (1.0%)	Always	9 (3.5%)
	Often	26 (8.5%)	Often	22 (8.6%)
	Sometimes	61 (20.3%)	Sometimes	58 (22.7%)
	Rarely	45 (15%)	Rarely	38 (14.8%)
	Never	166 (55.1%)	Never	129 (50.4%)
Alternative health provider websites providing advice not in line with medical guidelines	Always	0	Always	3 (1.2%)
	Often	5 (1.7%)	Often	1 (0.4%)
	Sometimes	22 (7.3%)	Sometimes	25 (10.2%)
	Rarely	41 (13.6%)	Rarely	33 (13.5%)
	Never	233 (77.4%)	Never	183 (74.7%)

(homeopathy, nutritionists, etc)				
Random links from search engines	Always	2 (0.7%)	Always	2 (0.8%)
	Often	11 (3.8%)	Often	1 (0.4%)
	Sometimes	39 (13%)	Sometimes	3 (1.2%)
	Rarely	58 (19.4%)	Rarely	36 (14.4%)
	Never	189 (63.1)	Never	163 (65.2%)

Table 2: Use of different information sources and trust in different information sources in patients with IBD

Variable	Variable group	CCK now score mean	Standard deviation	Univariate analysis (t-test)	Multiple linear regression analysis (beta coefficient)	significance
Age	<60 years ≥ 60 years	11.7 9.5	5.9 4.8	p=0.001	0.019 (+/- 0.02)	p=0.35
Sex	Male Female	10.4 11.6	5.1 5.2	p=0.065	N/A	
Marital status	Married Not married	11.3 10.7	5.4 4.7	p=0.29	N/A	
Smoking	No Yes	11.3 9.9	5.2 5.2	p=0.13	N/A	
Ethnicity	Caucasian Non-caucasian	11.2 10	4.3 5.2	P=0.38	N/A	
University degree education	Yes No	13.5 10.1	4.9 5.1	p<0.0001	2.342 (+/- 0.615)	p<0.001
Disease type	CD UC	11.9 10.2	4.9 5.4	p=0.005	-0.116 (+/- 0.67)	p=0.86
5-ASA use	Yes No	10.3 12	5.2 5.1	p=0.004	-0.767 (+/- 0.66)	p=0.24
Immuno-modulator use	Yes No	12.5 10.3	4.7 5.3	p<0.001	1.264 (+/- 0.559)	p=0.025
Biologic use	Yes No	12.2 10.9	4.3 5.3	p=0.089	N/A	
Clinical remission	Yes No	10.6 12	5.3 4.9	p=0.016	-0.264 (+/- 0.56)	p=0.64
Calprotectin	<50 ≥50 <100 ≥100 <250 ≥250	10.5 11.1 11 10.9 10.9 10.9	4.9 5.4 5.2 5.3 5.0 5.5	p=0.54 p=0.81 p=0.99	N/A	
Crohns and Colitis UK membership	Ever member Non-member	13 9.9	4.6 5.3	p<0.001	1.919 (+/- 0.566)	p=0.001
Internet use	At least daily Less frequent	11.8 8.6	4.8 5.7	p<0.001	0.210 (+/- 0.851)	p=0.81
Health related internet use (≥weekly)	At least weekly Less frequent	12.8 10.5	4.4 5.3	p=0.001	0.043 (+/- 0.660)	p=0.95

Information sources	**Frequent use (≥ sometimes)**					
General practitioner	Frequent Non-frequent	10.7 11.4	4.9 5.8	p=0.23	N/A	
Hospital IBD team	Frequent Non-frequent	11.8 8.4	5.0 5.1	p<0.001	2.104 (+/-0.978)	p=0.032
Official leaflets	Frequent Non-frequent	12.1 9.9	5.1 5.0	p<0.001	-0.230 (=/-0.74)	p=0.75
Crohns and colitis meetings	Frequent Non-frequent	13.8 11.1	4.9 5.2	p=0.11	N/A	
Official websites	Frequent Non-frequent	12.8 9.4	4.9 4.5	p<0.001	2.160 (+/-0.771)	p=0.005
News websites	Frequent Non-frequent	12.7 10.7	4.6 5.1	P=0.002	1.271 (+/-0.652)	p=0.052
Forums	Frequent Non-frequent	12.6 10.7	4.5 5.2	P=0.002	-0.002 (+/-0.715)	p=0.99
Pharmaceutical websites	Frequent Non-frequent	14.4 10.9	5.1 5.0	p=0.001	1.875 (+/-1.009)	p=0.064
Alternative health websites	Frequent Non-frequent	12.5 10.7	4.7 5.3	p=0.013	-0.857 (+/-0.722)	p=0.24
Random links	Frequent Non-frequent	13.3 10.8	4.7 5.2	P=0.001	0.474 (+/-0.631)	p=0.45

Table 3: Variables (clinical, demographic, and information sources) associated with better disease related patient knowledge (CCKnow) of IBD

Variable	Variable group	Mean HADS-A score	Standard deviation	Univariate analysis (t-test)	Multiple linear regression analysis (beta coefficient)	significance
Age	<60 years ≥ 60 years	7.7 5.3	4.5 4.1	P<0.001	-0.009 (+/- 0.018)	p=0.62
Sex	Male Female	6.1 7.7	4.3 4.6	p=0.002	1.516 (+/- 0.52)	p=0.004
Marital status	Married Not married	6.9 7.5	4.3 5.1	p=0.3	N/A	
Smoking	No Yes	7.3 7	4.6 4.6	p=0.73	N/A	
Ethnicity	Caucasian Non-caucasian	7.1 6.6	4.9 4.6	p=0.69	N/A	
University degree education	Yes No	6.8 7.2	4.1 4.7	p=0.41	N/A	
Disease type	CD UC	7 7.1	4.5 4.7	p=0.85	N/A	
5-ASA use	Yes No	7.1 7.1	4.5 4.6	p=0.94	N/A	
Immunomodulator use	Yes No	7.3 7	4.5 4.6	p=0.55	N/A	
Biologic use	Yes No	6.6 7.2	4.7 4.5	p=0.34	N/A	
Clinical remission	Yes No	6.3 8.6	4.4 4.5	p<0.001	-1.949 (+/- 0.515)	p<0.001
Calprotectin	<50 ≥50 <100 ≥100 <250 ≥250	6.9 7.1 6.6 7.4 7.1 7	4.2 4.5 4.2 4.5 4.7 3.9	p=0.73 p=0.24 p=0.85	N/A	
Crohns and Colitis UK membership	Ever member Non-member	7.4 6.9	4.1 4.9	p=0.32	N/A	

Daily internet use	Frequent Non-frequent	7.5 5.7	4.5 4.5	p=0.004	0.663 (+/-0.751)	p=0.38
Health related internet use (≥weekly)	Frequent Non-frequent	8.3 6.5	4.9 4.4	p=0.004	0.126 (+/-0.626)	p=0.84
Information sources	**Frequent use (≥ sometimes)**					
General practitioner	Frequent Non-frequent	7.6 6.1	4.5 4.6	p=0.008	1.349 (+/-0.543)	p=0.014
Hospital IBD team	Frequent Non-frequent	7.3 5.7	4.5 5.1	p=0.056	N/A	
Official leaflets	Frequent Non-frequent	6.4 6	4.5 4.5	p=0.029	0.122 (+/-0.642)	p=0.85
Crohns and colitis meetings	Frequent Non-frequent	9.9 6.9	4.8 4.5	p=0.264		
Official websites	Frequent Non-frequent	7.8 6.4	4.6 4.3	p=0.01	-0.707 (+/-0.716)	p=0.33
News websites	Frequent Non-frequent	7.8 6.4	4.7 4.3	p=0.002	0.06* (+/-0.610)	p=0.91
Forums	Frequent Non-frequent	8.4 6.6	4.6 4.4	P=0.002	-0.002 (+/-0.669)	p=0.99
Pharmaceutical websites	Frequent Non-frequent	7.6 7.1	4.5 4.5	p=0.57	N/A	
Alternative health websites	Frequent Non-frequent	10.4 6.8	5.0 4.3	p<0.001	1.955 (+/-0.669)	p=0.004
Random links	Frequent Non-frequent	9 6.7	4.6 4.3	p<0.001	1.447 (+/-0.597)	p=0.016

Table 4: Variables (clinical, demographic, and information sources) associated with higher anxiety levels (HADS-A) in patients with IBD