Better disease specific patient knowledge is associated with greater anxiety in inflammatory bowel disease

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Abstract

Background: Inflammatory bowel disease (IBD)-related knowledge not only empowers patients, but may also engender anxiety. The study aimed to identify predictors of anxiety in IBD and examine the interplay between anxiety and disease-related patient knowledge. The effect of anxiety on quality of life was also explored.

Methods: Ambulatory IBD patients provided data on demographics, their IBD and Crohn’s Colitis Association (CCA) membership status. Disease-related knowledge was assessed using the validated Crohn’s and Colitis Knowledge score (CCKnow) and disease related QOL using the short IBD questionnaire (SIBDQ). Anxiety and depression were assessed with the Hospital Anxiety and Depression Scores.

Results: Of the 258 patients 19.4% had a potential anxiety and a further 22.4% had a probable anxiety disorder. Females ($P=0.003$), tertiary care patients ($P=0.014$) and non-Caucasian patients ($P=0.037$) had significantly higher anxiety levels. CCA members had marginally higher levels of anxiety ($P=0.07$). Anxiety was associated with significantly better patient knowledge ($P=0.016$) and increased depression ($P<0.001$). Disease related quality of life was significantly lower in patients with anxiety ($P<0.001$).

Conclusions: This is the first study to demonstrate that better patient knowledge is associated with higher anxiety levels. The reason for this is unclear: educating patients about their disease might trigger anxiety, but, equally, anxious patients might seek out information and hence have...
1. Introduction

As a life-long relapsing remitting disorder, inflammatory bowel disease (IBD) has a significant impact on patients' general and disease-related quality of life. Intestinal inflammation in IBD can lead to many physical symptoms including abdominal pain, diarrhoea and fistulation, all of which have a direct negative influence on quality of life. Physical disease activity has been determined as an important longitudinal predictor of quality of life (QOL). Patients with IBD may require a number of hospitalisations, resective surgery and may have an awareness of an increased risk of developing bowel cancer. Extra-intestinal symptoms such as joint or skin involvement increase the disease burden. National and international guidelines focus largely on medical and surgical management of IBD with, as yet, less attention paid to psychological aspects. The importance of the psychological well being of IBD patients has been increasingly recognised, with evidence arising that anxiety and depression are common in IBD patient cohorts. Patients with IBD have a greater lifetime risk of developing anxiety or depressive disorders than the general population. Anxiety is often worse during times of higher disease activity and could therefore have an additional negative impact on patients quality of life. Causes for and factors associated with anxiety in IBD remain largely unknown and hence little guidance exists on how to treat this problem. Disease-related patient knowledge empowers patients and aids self-management. Educating individuals about IBD also incorporates discussion of IBD associated risks such as surgery, cancer and infertility, which in turn might trigger anxiety. The relation between patient knowledge and anxiety has so far not been studied. The study aimed to identify predictors of anxiety in IBD and investigate the association of anxiety with knowledge and disease-related QOL.

2. Methods

Ambulatory patients with Crohn's disease (CD) and ulcerative colitis (UC) were recruited from two tertiary IBD outpatient clinics (direct invitation) and from outpatient offices (postal invitation) in Sydney, Australia. All participants had a diagnosis of IBD based on internationally accepted endoscopic, radiological and histological standards. Participants self-reported data on demographics (age, marital status, employment status, highest educational level and household income), disease specifics (diagnosis, duration of disease, medication and surgical history) and Crohn’s Colitis Association (the Australian patient support group) membership status. Self report of current steroid treatment was used as a crude proxy indicator of higher disease activity. Disease-related knowledge was assessed using the validated Crohn’s and Colitis Knowledge (CCKnow) score. This 24 item self-administered questionnaire is the most commonly used knowledge assessment tool. Disease related QOL was determined using the short IBD questionnaire (SIBDQ). Anxiety and depression were assessed with the Hospital Anxiety and Depression Scores, which (despite its misnomer) is validated and commonly used for the assessment of ambulatory patients. This 14 item self report questionnaire consists of two subscales for anxiety (HADS-A) and depression (HADS-D) ranging from 0 to 21. Higher scores are associated with increased symptom severity: HADS-D > 10 has been defined as indicative of a probable and HADS 8–10 indicative of a potential disorder. A cut-off of eight was chosen for analysis of predictors and associations as this is a widely validated cut-off capable of identifying individuals with early stages of anxiety or depression.

The study was approved by the Concord Hospital Research Ethics committee (HREC/10/CRGH/150) and all participants provided informed consent. Statistical analysis was performed using SPSS 16.0. Student’s t-test and ANOVA were used for continuous data analysis.

3. Results

Of 258 participants, 66 (26%) consecutive patients were directly recruited from two tertiary care hospital outpatient clinics in Sydney, Australia. Postal invites were sent out to a further 575 patients with IBD under the care of five local office based gastroenterologists and 192 (33%) patients returned the completed study questionnaire. Full details on demographic and disease related factors are displayed in Table 1.

Abnormal levels of anxiety were found in 41.8% of participants. ‘Significant’ anxiety (HADS-A > 10) was present in 50 patients (19.4%), whilst a further 58 (22.4%) had ‘probable’ anxiety (HADS-A 8–10). ‘Significant’ depression (HADS-A > 10) was present in 11 patients (4.3%), whilst a further 25 (9.7%) had ‘probable’ depression (HADS-D > 10). Higher anxiety levels were associated with a number of predictive factors, with female and non-Caucasian patients having higher HADS-A scores (Table 1). Patient source was also predictive of anxiety levels: outpatients attending tertiary hospital clinics were more anxious than patients under the care of office based gastroenterologists. Membership in the Crohn’s and Colitis Australia patient advocacy organisation was associated with marginally higher levels of anxiety. Marital status, highest level of education, employment status, household income, diagnosis...
(Crohn’s versus UC) and duration of disease were all not associated with higher anxiety levels. Patients on current steroid treatment (n=47) as a crude proxy indicator of higher disease activity did not have higher anxiety levels (6.4 versus 6.8; \(P=0.6\)). Multiple stepwise linear regression analysis of all studied variables demonstrated that female gender and attending a hospital clinic were independent predictors of higher anxiety levels (Table 2).

Disease related patient knowledge as assessed by CCKnow ranged from 0 to 23 with a mean score of 10 and a median score of 9.5. Females had significantly better knowledge than male patients (CCKnow 11.3 versus 8.4; \(P<0.001\)), but diagnosis (Crohn’s 10.9 versus UC 9.8; \(P=0.08\)) or ethnicity (Caucasians 10.1 versus non-Caucasians 9.5; \(P=0.52\)) were not associated with knowledge. A positive correlation between disease related patient knowledge and anxiety was detected (Pearson correlation= 0.13, \(P=0.039\)). Patients with anxiety (HADS-A \(\geq 8\)) had significantly better disease related knowledge than those without anxiety (CCKnow 10.8 versus 9.3, \(P=0.016\)).

Anxiety was also associated with significantly worse depression scores (HADS-D 5.6 versus 2.4, \(P<0.001\)). Furthermore disease related quality of life was significantly lower in patients with anxiety (SIBDQ 44.0 versus 57.4, \(P<0.001\)).

### 4. Discussion

This is the first study to demonstrate that patients with higher levels of anxiety also have higher IBD subject knowledge scores. As in previous studies,\(^6,7,19\) a significant proportion of patients evaluated in this study suffered from anxiety, with abnormal anxiety levels (HADS-A \(\geq 8\)) found in 41.8%. Patients with IBD suffer from anxiety significantly more commonly than the general population and patients with chronic liver disease or colon cancer.\(^19\)–\(^21\) Anxiety is also closely linked to depression in many patients and a negative perception of the future might exacerbate anxiety symptoms. Causes of anxiety in patients with IBD have so far remained largely unclear and any association with knowledge base has not previously been evaluated.
The reason why patients with higher anxiety scores also had better subject knowledge is not clear but warrants exploration. On the one hand, knowledge of the long-term risks associated with IBD (e.g. the possible need for surgery or hospitalisation, or the increased risk of colorectal cancer) might trigger anxiety; indeed, our finding that anxiety levels were associated with disease-related knowledge but not with the level of general education would support this. Patients uninformed of the risks associated with their disease might thus be less anxious than those more informed. On the other hand, knowledge could be a consequence rather than a cause of anxiety: patients with pre-existing anxiety might seek out more information about their disease and thereby become more knowledgeable than patients without anxiety. Further work is needed to disentangle this association between anxiety and better knowledge, so patients with poorer knowledge can be educated without increasing their anxiety about their disease and patients with higher anxiety can have their concerns allayed through appropriate counselling. A Cochrane review of educational programmes for patients with IBD has found that educational programmes did not influence QOL and depression levels at 12 months, but data on anxiety were limited due to the small number of studies with only few patients enrolled. The ultimate goal is to develop targeted interventions that will improve an individual's knowledge and simultaneously reduce anxiety.

Identifying individuals with significant anxiety is a difficult, but important, task for clinicians caring for IBD patients. Predictors of anxiety can be of assistance here, especially as few IBD clinicians are trained in assessing for psychological and psychiatric disorders. Our study has demonstrated that women with IBD have greater anxiety levels than men, a finding supported by a Canadian study but in contrast to other studies on anxiety in IBD cohorts. Furthermore, our study detected, in accordance with a Dutch study, a strong trend that patients with anxiety were younger than those without. Patient source was an important predictor of anxiety as hospital outpatients were significantly more anxious than patients under the care of office based gastroenterologists. This could simply represent the fact that most hospital patients had been referred to tertiary care clinics, often from the same office based gastroenterologists, and may therefore have been expected to have more complex disease. Attendants of tertiary care clinics for other gastroenterological disorders have been found to have higher levels of psychopathology. Furthermore patients with coexisting anxiety can also be more difficult to manage and may therefore be referred to tertiary clinics more often. There are, however, other differences in the setup between hospitals and offices, which could account for some of the difference detected in anxiety levels. The attendance at a hospital can be intimidating and in itself could lead to anxiety. Patients looked after by office based gastroenterologists are more likely to have received care from the same physician throughout their illness and so develop a stable and perhaps more reassuring relationship with their healthcare providers, whilst patients attending hospital clinics are more likely to encounter a variety of physicians which would include consultants and junior staff. Non-Caucasian ethnicity also predicted higher anxiety levels and it is notable that this finding was independent of patient disease-related knowledge. Differences in cultural aspects of dealing with long-term illness could be at play and migration itself has been associated with increased anxiety.

Examining the associations with anxiety is not only useful to identify predictors aiding the detection of affected patients, but can also shed light on the consequences of suffering from anxiety. More anxious patients with IBD had higher depression scores as well. The negative effects of anxiety and depression were, predictably, also associated with a lower disease-related quality of life in our cohort of patients, as also evidenced in a recent Canadian study. Anxiety may also be associated with an increase in functional gastrointestinal symptoms, which in turn can lead to a diminished quality of life.

There are a couple of limitations to this study. Firstly anxiety may vary over time (especially with varying disease activity) but longitudinal observations were outside the scope of this cross-sectional study. Furthermore disease activity was unfortunately not formally assessed and steroid co-prescription can only be used as a rather crude proxy. Whilst numerical differences in CCP know score were not large, they were clearly statistically significant. As disease related knowledge was better rather than worse (as many clinicians might expect) in patients with anxiety, this result appears robust.

In summary this study has demonstrated that anxiety in patients with IBD is associated with better rather than poorer disease specific patient knowledge. It remains unclear whether disease specific knowledge causes anxiety, or is itself caused by anxiety. Anxiety has a significant impact on patients as it is associated with reduced quality of life and increased levels of depression. In the absence of evidence for IBD specific psychological interventions, physicians should aim to achieve clinical remission and where appropriate refer patients to general psychological support services.

Conflict of interest

The authors have no conflicts of interest to declare.

References


