

# Disease-related knowledge in inflammatory bowel disease: experience of a tertiary care centre in a developing country in South Asia

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## ABSTRACT

**Introduction:** Disease-related knowledge plays a critical role in facilitating patients' acceptance of their diagnosis and compliance with active participation in the treatment of inflammatory bowel disease (IBD). The aim of this study was to analyse the deficits in knowledge for future health education programmes.

**Methods:** A validated questionnaire was used to assess and analyse disease-related knowledge among patients with ulcerative colitis (UC) and Crohn's disease who attended outpatient gastroenterology clinics of a tertiary care hospital in Sri Lanka.

**Results:** There were 184 patients (83 males) with a mean age of 44.5 (range 20–78) years. 83.2 percent of the patients had UC. The mean duration of IBD was 8.17 (range 1–28) years, and 33.7 percent of the patients had IBD for over ten years. The mean Crohn's and Colitis Knowledge questionnaire score was 6.86. The majority (68.5 percent) of the patients were aware that sulfasalazine can be used to reduce exacerbations. There was no statistical difference in disease-related knowledge between genders, but the level of education showed a significant difference. Only 14.1 percent of patients were aware that prolonged IBD is a risk factor for colorectal cancer and that screening for colorectal cancer is important. 9.2 percent of the study population was aware of restorative proctocolectomy.

**Conclusion:** There is a lack of knowledge regarding colorectal cancer risk and surgical interventions. There was no significant difference in the knowledge scores between genders but there was a significant association with the educational level.

**Keywords:** Crohn's disease, disease-related knowledge, inflammatory bowel disease, ulcerative colitis

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## INTRODUCTION

Ulcerative colitis (UC) and Crohn's disease (CD) are chronic inflammatory conditions that are related to the gastrointestinal tract with an unknown aetiology. They form a group of chronic disorders that are characterised by intestinal inflammation and occasionally, extra-intestinal manifestations associated with periods of remission and unpredictable relapses. The clinical spectrum of inflammatory bowel disease (IBD) is very wide and ranges from an asymptomatic quiescent state to life-threatening severe illness. Although the incidence of IBD is low, ranging from 2–15 per 100,000 for UC and 0.1–14 per 100,000 for CD,<sup>(1-4)</sup> the economic costs to the patient and the state are high. These disorders typically affect people during their economically productive years and may require extensive medical and surgical interventions during the course of the disease.<sup>(5)</sup> The onset in early adult life, the chronic nature of the disease, the need for a visiting clinician, laboratory tests, diagnostic procedures, hospitalisation and surgery all result in high costs for IBD patients with UC and CD as well as for the society.<sup>(6-8)</sup>

IBD also has significant adverse effects on the quality of life of patients suffering from it. The level of knowledge of IBD and quality of life are strongly inter-related, and a lower level of disease-related knowledge leads to more severe impairment of the quality of life.<sup>(9,10)</sup> Although some previous studies have shown that patient knowledge has no effect on Health Related Quality of Life (HRQOL),<sup>(11,12)</sup> currently, there is evidence supporting the fact that the higher the level of disease-related knowledge, the better the HRQOL in IBD.<sup>(13,14)</sup> Chronic diseases such as IBD require patient education in order to achieve adequate control and prevent adverse health outcomes. Disease-related knowledge also plays a critical role in facilitating patients' acceptance of their illness and

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**Table I. Demographic characteristics of the study population (n = 184).**

Variable	No. of patients (%)	Mean score (range)	SD	p-value
Gender				
Male	83 (45.1)	6.99 (1–16)	2.978	p > 0.05
Female	101 (54.9)	6.76 (1–14)	2.906	
Age (yrs)				
20–29	39 (21.2)	7.13 (2–15)	2.830	p < 0.01
30–39	27 (14.7)	8.33 (2–16)	3.397	
40–49	40 (21.7)	6.78 (2–11)	2.224	
50–59	47 (25.5)	7.02 (1–14)	3.186	
60–69	27 (14.7)	5.41 (2–10)	2.241	
70–79	4 (2.2)	3.25 (1–4)	1.500	
Employment status				
Unemployed	48 (26.1)	5.69 (1–15)	2.561	p < 0.01
Employed	136 (73.9)	7.28 (1–16)	2.951	
Education status				
Primary (Grade 1–5)	40 (21.7)	5.23 (1–10)	2.434	p < 0.01
Secondary (Grade 6–13)	118 (64.1)	6.97 (2–15)	2.728	
Higher education (diploma/university)	26 (14.1)	8.88 (4–16)	3.204	

SD: standard deviation

understanding of behavioural changes that are required for active participation in treatment and in developing a better doctor-patient relationship.<sup>(13,15-17)</sup> The incidence of IBD is beginning to stabilise in high incidence areas such as northern Europe and North America but continues to rise in low incidence areas such as Asia and most of the developing world.<sup>(18)</sup>

There have only been a few studies that have assessed disease-related knowledge in IBD, and most of these have been carried out in developed Western communities.<sup>(15,19,20)</sup> There is virtually no published data on this topic from the South Asian region, where there are many developing countries, in spite of evidence indicating that the incidence of IBD in Asia is increasing beyond that in the West.<sup>(18)</sup> Therefore, the main aim of this study was to report on the disease-related knowledge of IBD from a developing Asian country.

## METHODS

This study was conducted at the National Hospital of Sri Lanka, which is a tertiary care hospital. The study was approved by the ethics review committee of the hospital. Patients were prospectively enrolled over a period of ten months. Before their interview, the patients were educated about the study, and informed consent was obtained. All patients who attended the outpatient clinic with an established diagnosis of either UC or CD were included in the study. The exclusion criteria were prior enrolment in other literacy studies, age < 18 years, lack of cooperation, police custody, diagnosed psychiatric illness and being too ill to participate. To reduce selection bias, eligible patients were enrolled sequentially according to the routine waiting list in the clinic.

All IBD patients were interviewed using an independent interviewer-administered questionnaire that consisted of two parts. The first part recorded the personal details of the patients, including their sociodemographic data, disease characteristics, management details and history. Formal education was categorised into three groups, i.e. having completed primary education only, having completed secondary education (more than ten years of formal education) and having a higher education (university/diploma). The second part of the questionnaire included a 24-item Crohn's and Colitis Knowledge (CCKNOW) score.<sup>(15)</sup> The CCKNOW score was selected because it has a valid index of high internal consistency. It also has a high reliability that assesses the disease-related knowledge of IBD patients in four specific knowledge areas with regard to the management of IBD. These include a general understanding of the disease (12 questions), diet (2 questions), treatment (5 questions) and complications (5 questions). One point was awarded for each correct answer and there were no negative marks for incorrect answers, with a maximum possible score of 24 for all questions.<sup>(15)</sup> Each patient in this study was given a knowledge score. The mean CCKNOW scores were calculated for independent or related groups as appropriate and the difference in knowledge was compared using ANOVA on Statistical Package for the Social Sciences version 15 (SPSS Inc, Chicago, IL, USA). The four knowledge areas were also separately analysed for any specific knowledge deficits.

## RESULTS

There were 184 patients (male-to-female ratio 83:101) with a mean age of 44.5 (range 20–78) years. The majority

**Table II. Disease characteristics and mean scores.**

Disease characteristics	No. of patients	Mean score (range)	SD	p-value
Type of IBD				
UC	153	6.64 (1–14)	2.823	p < 0.05
CD	31	7.97 (3–16)	3.250	-
Duration of IBD (yrs)				
1–5	83	6.38 (1–12)	2.743	-
6–10	37	7.46 (2–14)	2.501	-
11–15	31	7.13 (2–15)	3.452	p < 0.05
16–20	19	7.37 (2–16)	3.403	-
21–25	4	10.0 (7–11)	2.00	-
26–30	8	5.5 (3–9)	2.507	-

SD: standard deviation; IBD: inflammatory bowel disease; UC: ulcerative colitis; CD: Crohn's disease

**Table III. Disease-related knowledge areas assessed by responses to the CCKNOW questionnaire in IBD patients.**

Knowledge area	Related question no.	Mean score $\pm$ SD (range)
Diet	1,2	0.59 $\pm$ 0.663 (0–2)
Medications	10–13, 16	1.72 $\pm$ 1.021 (0–4)
General knowledge	3–5, 8, 9, 15, 17–19, 22, 23	3.38 $\pm$ 1.782 (0–8)
Complications	6, 7, 14, 20, 21, 23, 24	1.17 $\pm$ 0.880 (0–5)

CCKNOW: Crohn's and Colitis Knowledge; IBD: inflammatory bowel disease; SD: standard deviation

**Table IV. Mean scores for each knowledge area.**

Knowledge area	Maximum score	Mean score $\pm$ SD		p-value
		UC	CD	
Diet	2	0.55 $\pm$ 0.648	0.81 $\pm$ 0.703	p < 0.05
General knowledge	11	3.29 $\pm$ 1.787	3.84 $\pm$ 1.715	p > 0.05
Treatment	5	1.73 $\pm$ 1.032	1.68 $\pm$ 0.976	p > 0.05
Complications	6	1.07 $\pm$ 0.804	1.65 $\pm$ 1.082	p < 0.01
Total score	24	6.64 $\pm$ 2.823	7.97 $\pm$ 3.250	-

SD: standard deviation; UC: ulcerative colitis; CD: Crohn's disease

(n = 153, 83.2%) had UC. The participation rate was high (184 out of 188 patients, 97.9%). The mean duration of the disease was 8.2 (range 1–28) years, while 33.7% (n = 62) of the patients had IBD for more than ten years. The mean total CCKNOW score was 6.86 (range 1–16). Table I outlines the demographic characteristics of the patients and their relevant mean CCKNOW scores. Table II shows the mean CCKNOW scores in relation to the disease characteristics. The CCKNOW questionnaire assessment of the four knowledge areas in IBD, namely, diet, medication, general IBD knowledge and complications,<sup>(16)</sup> as well as the mean score for each knowledge area in our study population are shown in Tables II, III and IV.

Of the two questions related to dietary knowledge in IBD, only 9.8% (n = 18) of the patients answered both questions correctly, 39.7% (n = 73) answered at least one question correctly and 50.5% (n = 93) answered both questions wrongly. Out of the 11 questions that assess general IBD knowledge (anatomy related to the disease and investigations), only 26.1% (n = 48) of the patients answered five or more of the questions correctly. In the final analysis, a significant association was observed in relation to education level and employment status (p < 0.01). Patients with CD obtained a higher mean score (7.97 vs. 6.64) than patients with UC (p < 0.05). There was also no significant difference in the CCKNOW scores between the genders.

## DISCUSSION

In our study, the mean overall CCKNOW score was 6.64 (range 1–16). For UC, the mean score was 6.64 (range 1–14) and for Crohn's disease, it was 7.97 (range 3–16). Using the 24-item CCKNOW, Eaden et al obtained a mean score of 12.4 and 12.6 in 96 UC and 86 CD patients, respectively.<sup>(15)</sup> These patients were members of a patient self-help group (the National Association of Crohn's and Colitis [NACC]) in Britain. In addition, they studied another group of IBD patients who did not belong to the NACC and obtained a score of 7.9 for UC (n = 104) and 7.8 for CD (n = 68).<sup>(15)</sup> In comparison to the NACC patients, our patients' overall knowledge score was lower (6.64 for UC and 7.97 for CD). The knowledge scores of our patients were closer to those of the non-NACC patients in that study (UC: 6.64 vs. 7.9, CD: 7.97 vs. 7.8).

General knowledge of IBD (including anatomy) and medication components seemed to fare better among our patients than knowledge of diet and IBD complications, although the scores for both were lower than the knowledge of the patients in the two published Western studies.<sup>(15,19)</sup> For example, only 14.1% (n = 26) of our patients were aware that those with prolonged IBD are at risk of cancer and were therefore alerted to the importance of proper colorectal cancer screening. This figure was lower compared to the findings of Eaden et al (23%)<sup>(15)</sup> and Quan et al (17.8%).<sup>(19)</sup> However, a much lower value

**Table V. The percentage of correct answers for each question in the 24-item CCKNOW questionnaire and comparison with the studies conducted by Quan et al<sup>(19)</sup> and Rezailashkajani et al.<sup>(21)</sup>**

Knowledge area and question no.	Percentage of correct answers		
	Present study	Rezailashkajani et al <sup>(21)</sup>	Quan et al <sup>(19)</sup>
<b>General IBD knowledge (11 questions)</b>			
Q3. Proctitis is a form of colitis that affects the rectum or back passage only.	13.6	6	41
Q4. Being symptom-free for three years does not mean IBD is cured.	73.9	26	82.5
Q5. IBD runs in families.	32.1	35	66.6
Q8. The terminal ileum is a section of the bowel just before the anus.	41.8	7	54.2
Q9. During a flare-up of IBD, the platelet count in the blood rises.	14.7	5	11.7
Q15. Ulcerative colitis is common in Europeans and North Americans.	42.9	19	34.9
Q17. The length of the small bowel is approximately 6 m.	28.8	23	39.6
Q18. The function of the large bowel is to absorb water.	33.2	28	46.8
Q19. Another name for an ileorectal anastomosis operation with formation of a reservoir is pouch.	9.2	3	38.8
Q22. There are millions of tiny "hairs" in the small bowel to increase the absorptive surface, which are called villi.	3.3	5	61.2
Q23. Headache is not a common symptom of IBD.	45.1	38	63.1
<b>Diet (2 questions)</b>			
Q1. Patients are allowed to eat dairy products.	35.9	64	89.4
Q2. Elemental feeds are very easy to digest.	23.4	4	40
<b>Treatments (5 questions)</b>			
Q10. Steroids can be given in the form of an enema into the back passage.	10.3	16	36.7
Q11. Immunosuppressive drugs are given to IBD patients to reduce inflammation in the bowel.	50.5	39	50.9
Q12. Sulfasalazine is used to reduce the frequency of flare-ups.	68.5	37	59.6
Q13. Azathioprine is an immunosuppressive drug.	27.7	25	20.9
Q16. Male patients who take sulfasalazine have reduced fertility levels that are reversible.	14.7	5	18
<b>IBD complications (6 questions)</b>			
Q6. Inflammation can occur in other parts of the body as well as the bowel.	63.6	36	63.8
Q7. A fistula is an abnormal track between two pieces of bowel or between the bowel and skin.	4.3	16	61.5
Q14. A woman with Crohn's disease may find it more difficult to become pregnant.	1.6	8	21.9
Q20. If terminal ileum is removed during surgery, the patient will have impaired absorption of vitamin B <sub>12</sub> .	17.4	8	39.9
Q21. Patients with IBD which has lasted for 8–10 years need to be screened for cancer of the colon.	14.1	5	17.8
Q24. A child who has IBD probably will not be as tall as his or her friends.	16.8	6	48.9

CCKNOW: Crohn's and colitis knowledge; IBD: inflammatory bowel disease

(5%) was found in a study conducted in Iran for the same component.<sup>(21)</sup> Thus, our patients' knowledge of IBD was better than that reported in the study by Rezailashkajani et al,<sup>(21)</sup> but worse than that of the Western population. A lack of knowledge of IBD complications may have disastrous consequences such as an underestimation of the importance of colorectal cancer screening. None of our patients developed colorectal cancer as a result of IBD. This could be due to the fact that the majority (65.2%) of our patients had the disease for less than ten years.

It has been suggested that the urban diet is associated with the induction and/or exacerbation of IBD.<sup>(22)</sup> 48

(26.1%) of our patients were living in urban communities. However, dietary knowledge was not satisfactory among our patients (mean score for UC: 0.55 out of 2, for CD: 0.8) (Table IV).

Knowledge of gastrointestinal anatomy is important in ensuring patients' decision-making abilities when considering different surgical treatment modalities. 41.3% (n = 76) of our patients knew the location of the terminal ileum, compared to 54.2% (n = 402) and 35% (n = 18) of the patients in the studies conducted by Quan et al<sup>(19)</sup> and Eaden et al,<sup>(20)</sup> respectively. These figures are similar to our findings, and far better than the 7% in an Iranian

study conducted by Rezailashkajani et al.<sup>(21)</sup> Out of our 184 patients, only 9.2% (n = 17) were aware of what is done during restorative proctocolectomy, compared to 3% (n = 3)<sup>(21)</sup> and 38.8% (n = 288)<sup>(19)</sup> of patients in other studies. Thus, there is clearly a need for our patients to be more informed regarding this issue. Quan et al studied the effect of workshops on the knowledge levels of IBD patients and their relatives in the USA using a 30-item CCKNOW score, and found a mean score of 18 (out of 30) for 59 IBD patients and their close relatives before they attended patient education workshops.<sup>(19)</sup> Unlike the above study, our study used a 24-item questionnaire, which produced a mean score of 6.86 for IBD (UC and CD). Another difference is that both IBD patients and their relatives were included in Quan et al's study, while our study involved only patients with IBD.

Table V compares the number of correct answers to each question among our patients with the results of the studies conducted by Quan et al<sup>(19)</sup> and Rezailashkajani et al.<sup>(21)</sup> There were 31 patients with CD in our study sample, but out of these, only one (3.2%) patient was aware that a woman with CD may find it more difficult to conceive. This may have social and marital implications and therefore, patient education is essential in order to improve knowledge in this area. In Eaden et al's study conducted on 42 patients with colorectal cancer complicating UC and 44 age and gender-matched IBD patients without colorectal cancer using the 24-item CCKNOW questionnaire, a mean score of 8.2 and 8.3 was found for the two groups, respectively.<sup>(20)</sup> In the Iranian study by Rezailashkajani et al,<sup>(21)</sup> which was similar to our sample size, the mean and median CCKNOW scores of the patients were 4.65 and 4.0 (24-item questionnaire), respectively. Our patients' knowledge was thus better than that of the Iranian study population, when considering the similarities of the study population. The patient scores in the Western study were significantly higher than those in the Iranian study.<sup>(19,20)</sup> Quan et al attributes it to the better quality of health services, the established role of specialised nurses as patient educators, greater access to web-based material in the patients' native languages, the effect of patient self-help groups and the wider availability of published material in developed countries.<sup>(19)</sup> The situation in our country is more similar to that of other developing countries, but the disease-related knowledge of our IBD patients was higher in most of the knowledge areas than that of patients in other developing countries.

It has been shown that patient education programmes exert their effect through patient "learning"<sup>(23,24)</sup> and therefore, the knowledge that was assessed in our study will help in planning patient education programmes

in the future. These educational activities will seek to educate patients on their disease process and the related complications, as well as emphasise the importance of regular follow-up to prevent the development of carcinoma. Taking these facts into consideration, we have already begun a patient education programme by distributing Patient Education Booklets and educating patients about their disease on their first visit to the clinic. We believe that this is a stepping stone to a country-wide educational programme that can be planned for the future.

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