Research Article

A clinical study on knowledge assessment in IBD: A glimpse in tertiary care hospital at Coimbatore, South India

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Abstract

Background: Inflammatory bowel disease (IBD) is a chronic relapsing inflammatory disease comprised of ulcerative colitis (UC) and Crohn's disease (CD) with uncertain etiology. There is rising incidence and prevalence of IBD in India topping the Southeast Asian (SEA) countries. Disease related knowledge plays a vital role in facilitating patient's acceptance of their diagnosis and compliance with active participation in the treatment of IBD. **Objective:** The objective of the study is to analyze the disease related factor and to compare the difference in knowledge after educating the patients. **Material and Methods:** It was a prospective interventional study conducted in the outpatient Gastroenterology department of Kovai Medical Center and hospital, Coimbatore with total of 74 patients. Disease related patient knowledge was assessed by validated CCKNOW scale. Once after collecting the baseline information's, patients were counseled for IBD and provided with information leaflets. During the follow up visit after a two month, parameters were reassessed and compared with the baseline visit. **Results**: In 74 IBD patients, 36 (48.6%) UC patients and 38(51.4%) CD patients, the mean CCKNOW score during the baseline visit was 6.56±3.26 and the revisit period of 16.17±2.16 respectively. Knowledge of patients about their disease were insufficient during baseline visit but the result shown slight improvement in patient knowledge with information leaflet in the re visit. **Conclusion**: The study proves that patient education programme is essential for better understanding about the disease and their management with positive outcome.

Keywords: Inflammatory bowel disease (IBD), Ulcerative colitis (UC), Crohn's disease (CD), Crohns and Colitis Knowledge Assessment (CCKNOW)

Introduction

Inflammatory bowel disease (IBD) encompasses of ulcerative colitis (UC) and Crohn's disease (CD), two chronic inflammatory disease of uncertain etiology affecting the gut (Ray, 2016). The Crohn's disease means the inflammation in the lining of the digestive tract, which often spreads from mouth to anus deep into affected tissue. Ulcerative Colitis is the condition in which the entire colon is affected as a continuous pattern, occurs in innermost lining of the intestine. IBD can be debilitating and sometimes leads to life threatening complication (Yoo et al., 2015). The specific etiology of IBD is unknown. A common hypothesis for the cause of IBD is the result of an unregulated intestinal immune response to environmental and bacterial triggers (Nishida et al., 2018).

India is projected to have one of the highest disease burdens of IBD across the globe and recently all the tertiary referral centers of India are diagnosing Inflammatory Bowel Disease (IBD) at an increased rate compared to past years. It is believed that the burden of UC is twice that of CD in Asia as compared to the West. The overall estimated IBD population in India in 2010 came out to be 1.4 million, which was the second highest number after the USA (with 1.64 million). A comparison of incidence and prevalence rates with other countries suggests that among Asian countries the disease burden is highest in India and among the largest across the globe (Kedia and Ahuja, 2017).

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Patients with IBD are at risk for serious complications when their disease is poorly managed. Disease-specific information is increasingly being recognized as important for patients as it improves compliance with therapy and satisfaction with their overall care. Appropriate knowledge and information enable the effective coping of patients before they visit doctors (Casellas et al., 2004). Previous studies have shown that patients who receive information related to their disease are less anxious, more compliance, and more satisfied with their treatment and have a reduced number of physician visits and lower patient cost (Molenaar et al., 2001; Whelan et al., 2004). Patient non-adherence to medical therapy contributes to suboptimal outcomes, but may be modified through improved education. Poorly controlled disease increases the risk for serious and often irreversible negative outcomes including death. Education specific to IBD, its effects, and its management, can potentially increase patient adherence and improve outcomes for these patients (Greenley et al., 2013). Specific areas of interest to IBD patients include: prevention and management of IBD symptoms, complications related to IBD, long term prognosis, risk of cancer and mortality, alternative therapies, risks from pharmacotherapy, potential new therapies, and fertility (Wheat et al., 2016).

Indian Statistics indicates that about 50 lakhs people around the world have IBD with the number of cases exceed 12 lakhs annually. However, there is not much awareness on the seriousness and symptoms of this disease in the country as reported by Indian Medical Association on July 2017. In south India, no more studies have been performed on the knowledge and education demands related to IBD disease. But, with respect to these topics, there were no similar reports for south Indian patients with IBD even though the incidence rate of IBD has been rapidly increased.The purpose of this study was to determine the general characteristics of IBD patients and to compare the difference in knowledge of IBD patients.

Material and Methods

The study was conducted at Kovai Medical Center and Hospital, a tertiary care hospital in Coimbatore, Tamilnadu and South India. Seventy four consecutive outpatients who presented at the Department of Gastroenterology from January 2018 to August 2018 diagnosed with either CD or UC confirmed by endoscopy, radiography, and/or histological examination of adults aged 20 years and above from both genders were enrolled for the study. People who were pregnant women, Irritable bowel syndrome, pediatric patients, severe physical illness and lack of cooperation were excluded from the study. Initially, Institutional Ethical Committee approval was obtained and all the eligible study subjects, fulfilling the selection criteria were screened by the gastroenterologist during their routine clinical practice. Informed consent was taken from the patients or their legal caretakers before initiation of the study. All the patients included in the study received a standard care of treatment and counseling from the consultant gastroenterologist. Apart from the care of gastro-enterologist, clinical pharmacist counseled all the patients and made them aware about the disease and the benefits of drugs, common ADR's and extra intestinal complication, significance of patient's adherence to treatment, alterations on diet etc. Throughout the patient counseling period, specially designed patient information leaflets in English and Tamil were provided to the patients. A complete baseline investigation was recorded in a predesigned Performa and CCKNOW assessment with the patient education on IBD.

Development of questionnaire and data collection

The 24-item Crohn's and Colitis Knowledge (CCKNOW) score (Eaden et al., 1999) was used by interviewing with the patient. We chose this questionnaire because it examines knowledge from multiple aspects, because of its reliability and validity in assessing disease-related knowledge of IBD patients. The questionnaire assesses four areas of knowledge regarding IBD management, these being general IBD knowledge (11 questions), diet (2 questions), treatment (5 questions), and IBD complications (6 questions). Scoring for CCKNOW is one point for each correct answer, and the maximum possible score is 24. Higher CCKNOW scores indicate better IBD-related knowledge.

Statistical analysis

Statistical analysis was performed using the SPSS 16 of IBM statistical package software. For demonstrating the categorical variables, frequency and percentage were utilized. The mean and standard deviation were used to find the association between demographic character, disease characteristics with knowledge score and significance assessment with chi-square test. Statistical significance was set at the $p < 0.01$ level.

Results

Association of demographic features with their patient Knowledge

In a total of 74 patients, 36 (48.6%) were UC patients and 38(51.4%) were CD patients completed the study. There were equal numbers of males and females patients in which majority of 34 patient's falls within the age group of 20-40 years (45.9%). In the disease pattern 37 male patients of 21(28.38%) were having UC and 16(21.62%) were having CD and in the female patients with 15(20.27%) of UC and

22(29.73%) CD, respectively. Regarding the education status of the patients, majority of them completed 45% of primary education, 42% completed secondary education and 13% completed higher education .On finding the association between demographic features and knowledge on age, gender, education and employment status there was the significance of p<0.01* with education status ((Table 1) . Based on the food habits of the patients, most of them were taking coffee (68.9%) and 62(83.8%) were non vegetarians with few 12(16.2%) vegetarians.

Association of Disease characteristics with Knowledge of IBD

In this study, we have compared demographic characteristic and the CCKNOW score. The results showed that, male patients have the mean CCKNOW score of 1.72±0.69 and female patient with the score of 1.67±0.78. Patients with Ulcerative Colitis (UC) had higher CCKNOW median score 16.63±1.64 compared to patient with Crohns Disease (CD) 15.73±2.50. Duration of IBD was grouped into 4 sub

Table 1. Association of demographic features with their Patient Knowledge

Demographics	No of Patients		Mean± SD	p value
	n=74	%		
Gender				
Male	37	50%	2.97±0.49	0.2
Female	37	50%		
Age				
20-40	34	45.9%	3.17±0.45	
41-60	28	37.8%	2.85±0.35	0.18
61-80	12	16.2%	3.08±0.51	
Education				
Primary	34	45%	16.79±1.70	
Secondary	30	42%	16.11±2.58	***0.01****
Higher	10	13%	15.06±1.56	
Employment				
Employed	29	39%	15.76±0.0123	
Unemployed	31	41%	14.76±1.1232	0.06
Student	14	18%	14.23±1.56	

Table 2. Association of disease characteristics with their patient Knowledge (CCKNOW score)

Disease Characteristics	No of Patients		Mean ± SD	p value
	n=74	%		
Type of IBD				
UC	36	48.6%	16.63±1.64	*0.04*
CD	38	52.4%	15.73±2.50	
Duration of IBD				
1-6 months	32	43.2%	16.25±1.70	
7-12 months	2	2.7%	14.50±2.12	0.09
>1 years	27	36.5%	16.25±2.58	
IBD related Surgeries				
Yes	26	35.1%	3.2±0.42	
No	48	64.9%	2.91±0.40	0.1
Location of UC				
Proctitis	12	16.2%	16.50±1.50	
Left colon	6	8.1%	17.83±1.32	
Pancolitis	16	21.6%	16.00±1.46	
Location of CD		16.2%		0.442
Ileal	12	27.2%	15.91±1.97	
Ileocolonic	20	10.8%	15.75±2.48	
Colonic	8		16.25±3.61	
IBD related hospitalization				
Yes	6	8.1%	16.50±2.07	
No	38	51.4%	16.23±2.12	0.09
>1	30	40.5%	16.25±2.58	

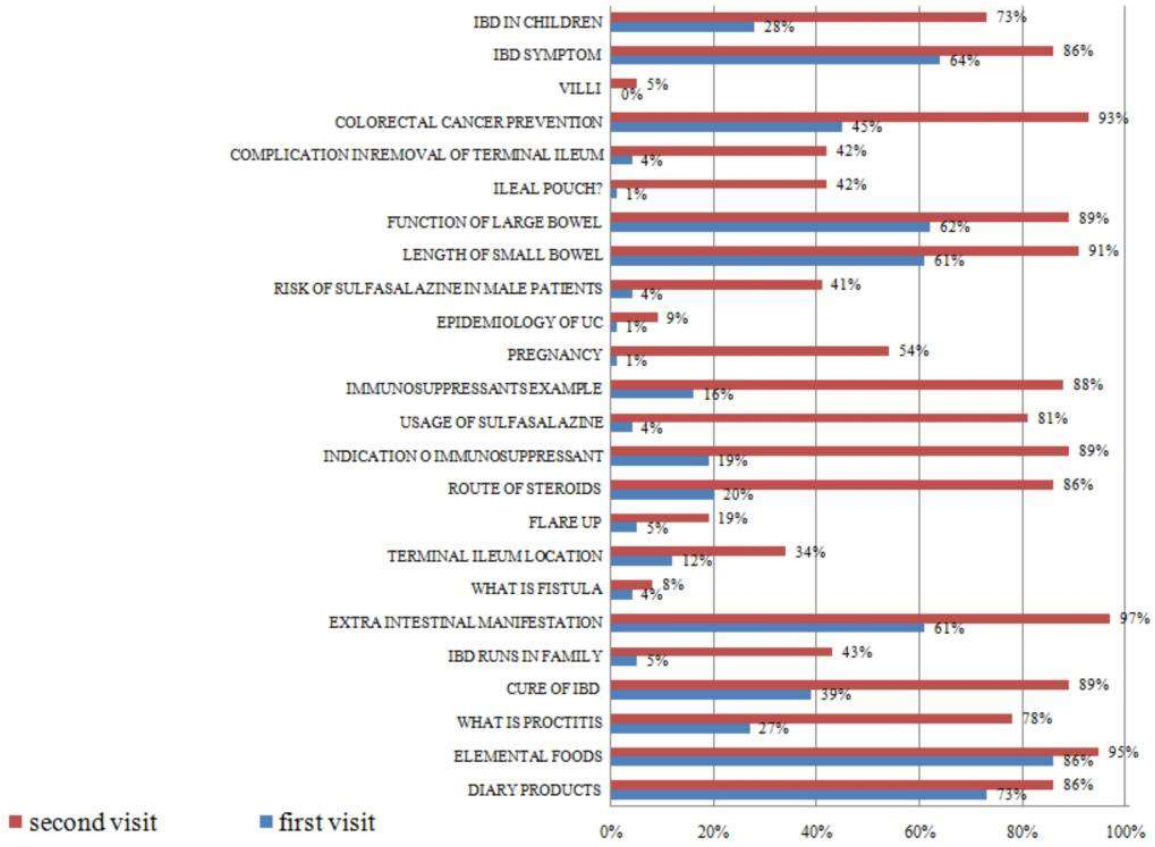

Figure 1. Percentage of Correct Answers for CCKNOW questionnaire for First visits and Second visit (Revisit)

division, in which period of >1yr had the higher mean score of 16.25±1.70. However type of IBD, related surgeries, localization of disease and extra intestinal manifestation was not significantly associated with CCKNOW score (Table 2). The mean CCKNOW score during the baseline visit 6.56±3.26 and the revisit period were 6.17±2.16 respectively. The mean CCKNOW scores were statistically significant during revisit from baseline visit ($p < 000^{**}$). According to the questions, during the baseline visit the percentage of IBD knowledge varies from 0% to 86 % with less than 50% correct answers for 18 out of 24 questions. The knowledge level was reassessed after educating the patients and it ranged from 5% to 97%, among all the questions only 9 questions got less than 50% of correct answers during revisit period (Figure 1).

Discussion

In India there is a rapid increase in the occurrence of IBD but only few reported on this disease rather than western countries with the research on IBD related knowledge and education demands related to IBD disease. In our study gender distribution of patients showed a high preponderance of CD in female and UC in male that reveals the same as the study conducted by (Sumant and Talha, 2015). In our study female patients had high CCKNOW score than males it may be due to their interest in getting the knowledge of disease related factors especially in their childbearing age by taking into consideration about the harmful effects of the disease during their pregnancy and childbirth periods (Ma-osa et al., 2013) similar to our study with the correct answer during revisit of 54%. Majority of the patients in this study comes from age group of 20-40 year with the mean age of 3.17±0.45.In this study CD was more common (52.4%) than UC (48.6%) which shows the vast geographic changes in the frequency of CD to UC ratio among Asian countries and even among different within a country (Yi-Zhen and Yong-Yu, 2014). Patients in the young age groups had higher CCKNOW score as they require more information, regarding effective management of disease, than the other ones since they are active participants in social activities. Duration of disease, IBD related surgeries, extra intestinal manifestations were not significantly associated with CCKNOW scores. In the study population there were only 12(16.2%) patients have appendicitis that was similar to the study (Anaa et al., 2012) and the result shows that appendectomy seems positively associated with the development of Crohns Disease, so appendectomy should be avoided in order to avoid the worsening on prognosis of IBD.

From this study, we found out that there was deficit in the knowledge of patients with more severe deficit regarding

the knowledge about complications of IBD. Lack of knowledge about IBD complications can lead to untoward consequences, patient needs to be informed about the significance of cancer screening, only 45% patients knew that prolonged IBD can increase the risk of colorectal cancer but the reports were higher than the results by Eaden *et al* (23%). The removal of terminal ileum caused impaired absorption of vitamin B12 among 12% of patients. Regarding the treatment related questions, majority of the patients (89%) knew about the aim of immunosuppressant's. General knowledge of IBD and medications was better than the knowledge about complications, majority of the patients knew about common IBD symptoms (86%) and extra intestinal manifestations (61%). During revisit, questionnaire was reassessed and percentage of correct answers increased for each questions. This shows improved knowledge level with positive impact on IBD related education in patients, after providing necessary counseling to the patients with information leaflets.

Limitations

Strength of the study was the first study in South India and only very few studies have been performed by clinical pharmacist in this disease .The main limitation of this study was duration and follow up of the patient. As IBD incidence and prevalence is less and awareness about the disease is rare, population enrolment is minimal with short span of time and to have the medication adherence, long term follow up of study is mandatory.

Conclusion

Education regarding IBD is a crucial step and requires a health care team to provide the patient care in which the pharmacist can play a key role. This study highlight, the disease related knowledge may bring about major changes in the knowledge of patient about the disease and medications. As knowledge of patients were insufficient during baseline visit but after educating the patient with patient information leaflet, there was significant improvement in patient knowledge during revisit resulting in better health care of the patients. Disease-specific information is increasingly being recognized as important for patients as it improves compliance with therapy and satisfaction with their overall care. This study proves that patient education may exert their effect through patient learning and therefore, the knowledge that was assessed 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 initiates the importance of regular follow-up to prevent the development of carcinoma.

Conflicts of interest: Not declared.

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