



Research Article

ISSN : 2277-3657
CODEN(USA) : IJPRPM

Patient Awareness of Extra intestinal Manifestations of Inflammatory Bowel Disease in Riyadh, Saudi Arabia

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ABSTRACT

Background: Insight into extraintestinal manifestations (EIMs) of inflammatory bowel disease (IBD) is important to the patient's quality of life and their coping with the disease.

Objectives: We investigated the awareness and source of information about EIMs among patients with IBD.

Methods: A total of 210 patients [117 (55.7%) males; 93(44.3%) females; age > 18 years] with a diagnosis of IBD were included in this cross-sectional study conducted from July to October 2016 in 3 gastroenterology clinics in Riyadh, Saudi Arabia. Data were collected using a convenience sampling technique and via self-administered questionnaires designed by the investigators. The chi-square test was used for the data analysis.

Results: Most respondents were aware of the relation between IBD and at least 1 EIM (81.9%); however, none could identify all 9 EIMs. Most respondents (57.1%) could identify 2 or less EIMs and the EIM least known to them was venous thromboembolism (4.8%). The most recognized complication was colon cancer (53.8%) followed by oral lesions (42.9%). Less than half of the patients were aware of the relation of arthritis, skin lesions, eye inflammation, and osteoporosis with inflammatory bowel disease. Relatively few participants were aware of the relationship of primary sclerosing cholangitis (14.3%), kidney stones (7.6%), and venous thromboembolism (4.8%) with the disease. Conclusions: Patients had high awareness of the common EIMs and complications but revealed poor knowledge of the rare ones, which may be associated with higher morbidity rates. We suggest that these patients be properly educated not only on EIMs with high incidence but also those with low incidence.

Keywords: *Inflammatory bowel disease, Saudi Arabia, Awareness*

INTRODUCTION

1. Background

Inflammatory bowel disease (IBD) is a chronic condition in which some parts of the gastrointestinal tract are inflamed. This disease has two types, which are ulcerative colitis and Crohn's disease. The etiology of the disease remains unidentified. The symptoms of the disease differ between the two types and range in severity, but they generally include diarrhea with or without blood and mucous, abdominal pain, and weight loss [1]. In some cases, the disease is also associated with extraintestinal manifestations (EIMs), such as dermatological, ophthalmological, musculoskeletal, hepatobiliary, hematological, cardiovascular, pulmonary, and neurological manifestations [2]. Since 1982, when Mokhtar and his colleagues discovered the first 2 cases of IBD among Saudis, research showed that the number of cases has sharply increased overtime in Saudi Arabia and this corresponds to the global worldwide increase

in incidence of IBD [3-5]. A study done in the United States in 2011 reported EIMs in 25%–40% of patients with IBD, whereas in Saudi Arabia it was suggested to be around 10% [6,7].

There are a number of studies assessing patient knowledge in which they address either general information on IBD or awareness of specific factors affecting it, such as smoking, pregnancy and medication [8-14]. However, studies focused on evaluating patient awareness of EIMs with IBD were scarce. In 2012, a study characterized patients' knowledge with regard to each EIM and complication of IBD; Huang V *et al.* found that the majority of patients with IBD attending a tertiary level hospital in Canada were aware of most of the manifestations and complications, with a distinctly high awareness of arthritis and colon cancer. Nevertheless, knowledge of some manifestations, such as venous thromboembolism, primary sclerosing cholangitis, and nephrolithiasis, was markedly low in comparison [15]. IBD carries a potential risk for development of colorectal cancer by 2.2–5 folds and despite that Lopez *et al.* found that only two thirds of the patients were aware of the risk [16].

Whereas some of the EIMs improve with management of IBD, others call for specific focused treatment [17]. Recognizing EIMs is essential for prompt and efficient management to prevent morbidity [18]. Patient knowledge regarding IBD including EIMs might also affect the patient's quality of life and coping with the disease as well as health care costs [19-21].

Even though IBD incidence is on the rise in Saudi Arabia [22], there is still a dearth in studies targeting the awareness of patients with IBD, whether it is on general information about the disease or knowledge about EIMs. It is important to evaluate the IBD population's knowledge regarding EIMs for the previously mentioned impact of that knowledge, to pinpoint the defects, and to bring forth a better educational plan for the patients. In addition, more studies can be conducted based on awareness results to evaluate the cause and effect of the level of awareness [23]. The aim of this study is to identify the knowledge of IBD population about EIM and the impact of this knowledge on medication adherence.

2. SUBJECTS AND METHODS

This is a quantitative observational cross-sectional survey conducted in gastro/IBD outpatient clinics in 3 main governmental hospitals in Riyadh, Saudi Arabia, from September 2016 to January 2017. The hospitals have been chosen to cover different socioeconomic levels and different regions in the city and these hospitals are: King Khalid University Hospital (KKUH), King Fahad Medical City Hospital (KFMC), and Security Forces Hospital. The study population included all patients over 18 years of age with a confirmed diagnosis of IBD (CD, UC, or IBD-unclassified) and who were attending the outpatient clinics in the mentioned hospitals.

Informed consent was obtained from each patient included in the study and the study protocol conforms to the ethical guidelines of the 1975 Declaration of Helsinki. The approval for this study was obtained from the Institutional Review Board, College of Medicine in King Saud University. There was no conflict of interest among the authors of this research paper.

A pilot study was distributed among 35 patients before the intended study to test the validity and reliability of the questionnaire and adjust it accordingly.

Convenience sampling technique was used to collect the data from 210 participants, with 70 participants from each hospital. The new structured, self-administered questionnaire designed by the investigators was used. A three-page questionnaire with close-ended questions was handed to the participants. The questions were incorporated into 3 sections. The first section queried about general and demographic information of the respondents. The second section queried about knowledge regarding EIMs and complications, in which respondents were given a list of conditions to determine whether these are associated with IBD or not. The condition list contained 9 confirmed EIMs associated with IBD (arthritis, colorectal cancer, skin lesions, oral ulcers, kidney stones, uveitis, osteoporosis, liver diseases, and blood clots in the veins), and to assess subjects' background propensity to respond in the affirmative, 3 conditions that are not associated with IBD were added (common cold, migraine, and seasonal allergy). In the third section, the respondents will be queried about their personal experience with EIMs through the same list of conditions provided previously.

The first page of the questionnaire contained a full explanation of the study purpose. All information obtained from the participants was managed with high level of confidentiality. Each participant was informed that he or she is allowed to accept or refuse the chance to participate in the study.

Collected data were entered into an excel sheet for sorting, and then it was analysed by SPSS software (IBM SPSS Statistics, IBM World Trade Corporation, St. Michael, Barbados). Descriptive statistics including percentages, means,

and standard deviations (SD) were computed. Chi-square statistics was used to assess the association between demographic factors and the knowledge of the EIMs.

3. RESULTS

3.1. Characteristics of Respondents

Among the 250 patients who were invited to participate, 210 patients completed the questionnaire (84% response rate). The sociodemographic and disease characteristics of respondents are listed in Table 1. Most of the patients were in the age range of 25–34 (n=73, 34.8%). More than half of the respondents were male (n=117, 55.7%). In terms of IBD diagnosis, 60% of patients had Chron's disease, 42.9% had ulcerative colitis, and 6.1% had an unclassified IBD. With regard to the educational level of respondents, the majority had a college or higher educational level (n=100, 47.6%).

3.2. EIM Awareness

Respondents were asked about the association of IBD with 9 EIMs, and most of the respondents were aware of the relation between IBD and at least one EIM (n=172, 81.9%). However, none of the participants were able to identify all the 9 EIMs. Table 2 demonstrates participants' knowledge of each EIM. The complication most recognized by the participants was colon cancer (n=113, 53.8%) followed by oral lesions (n=90, 42.9%). Less than half of the patients were aware of the relation of arthritis, skin lesions, eye inflammation, and osteoporosis to IBD. Comparably, few participants related primary sclerosing cholangitis (n=30, 14.3%), kidney stones (n=16, 7.6%), and venous thromboembolism (n=10, 4.8%) to IBD, and those who did were more prone to mistakenly identify common cold, migraine, and seasonal allergy as EIMs.

3.3. Perceived vs Actual Knowledge

Most of the respondents scaled their knowledge as "Enough to get by" (41%) and "good" (33.3%). Among those who perceived their knowledge as "Enough to get by", 67% of them were only able to identify 2 or less EIMs. More than half of those who indicated that they have a good knowledge about their disease identified 3 or less EIMs. When asked whether the patients want to know more about their disease, 87% of the respondents expressed their interest to know more about their disease.

3.4. Source of information

Figure 1 shows that gastroenterologists were the main source of information for the majority of patients (81.4%), followed by the internet and social media (40.5%), whereas nurses (3.3%) were the least cited source.

Among those who indicated that their gastroenterologist was their main source of information, more than half of them reported that their gastroenterologist discussed EIMs specifically with them. By contrast, only 41% of those who stated their family physician as their primary source of information reported that EIMs were discussed specifically. Family physician as the main source was selected by people who identified no more than 3 EIMs. In contrast, patients who chose gastroenterologists as the main source were able to identify more EIMs. Direct discussion with gastroenterologists (59%) and Internet and social media (44.3%) were proposed by the participants as the most effective modalities to increase awareness of the patient about their disease.

3.5. Factors affecting the knowledge of EIM

Table 3 illustrates the factors associated with EIM awareness. Age, sex, patient diagnosis, and compliance on medication did not show any statistically significant relationship on knowledge of all the EIMs. By contrast, awareness levels of all EIMs were significantly increased in patients who had a personal experience. Interestingly, apart from colon cancer, educational level did not show any statistically significant difference in the level of awareness.

4. DISCUSSION

In this study, we assessed the awareness of patients with IBD regarding EIMs and complications. We believe that this study is the first in Saudi Arabia to use a validated questionnaire to assess the IBD population's awareness of EIMs, the importance of which was shown in multiple studies investigating its effect on patient's coping with the disease and quality of life [19-21].

Our study revealed that none of the participants were aware of all 9 EIMs and complications that were mentioned in the questionnaire. However, a great number of the participants were aware of one of the common EIMs, which is the oral lesion, but even though arthritis is considered the most common EIM, less than half of the patients recognized it as an EIM as opposed to the findings of Huang *et al.*, which showed a markedly high awareness of arthritis in Canadian patients with IBD [24]. Even though the incidence of colon cancer in patients with IBD is relatively low, the majority

of patients identified the risk of colon cancer in IBD, which was shown to be a main concern for patients with IBD. This finding coincides with previous literature regarding colon cancer awareness in IBD [16,25,26]. Despite the serious nature of venous thromboembolism and primary sclerosing cholangitis, very few participants recognized them as IBD complications, which may be due to their low incidence and that reason may also apply to the poor knowledge of renal stones [24]. We also found that 67% of those who perceived their knowledge as “enough to get by” were only able to identify 2 or less EIMs, which may suggest that there is a significant issue in regard to lack of awareness among the Saudi IBD population.

In terms of factors affecting the patient’s knowledge, the results showed that awareness of all EIMs was significantly higher in patients who personally experienced them. Demographic factors had no connection with the patient’s level of knowledge. In comparison with the work of Moradkhani *et al.*, our study did not find any significant relationship between compliance to medications and awareness of EIMs, or between the knowledge and number of exacerbations [20].

Our findings showed that patients chose gastroenterologists as their main source of knowledge regarding IBD, which was consistent with the study findings of Bernstein *et al.* [27]. We found that patients, who chose gastroenterologists as their main source, were able to identify more EIMs, and more than half of them reported that EIMs were specifically discussed. A study conducted in Europe reported that people in Eastern Europe sought their information from the internet, whereas people in Western Europe received their information from nurses [28]. Even though the Internet was the second most chosen source in our study, we found that the Saudi Gastroenterology association website (www.saudigastro.com), which is one of the known internet sources, did not mention EIMs in their IBD online pamphlets; however, they mentioned arthritis, skin lesions and oral lesions but did not include the rest of the EIMs in their educational videos. By contrast, the Ministry of Health website (www.moh.gov.sa) did not include an educational content for IBD. These indicate the lack of valid internet sources about the disease.

4.1. Limitations

The research had several possible limitations that were primarily associated with sampling. Since we gathered our data from gastroenterology clinics in 3 tertiary hospitals, we were at a risk for referral bias, because it was collected in IBD clinics specifically in tertiary hospitals and one of which is an educational hospital, which might have more educational resources. As we followed a convenience sampling technique, there may have been a potential selection bias. Apart from the limitation related to sampling, we also found that patients who chose the rare EIMs and complications were found to be more likely to choose the 3 extra symptoms that were not related to IBD (common cold, migraine, seasonal allergy), which might be due to their tendency to answer in the affirmative. Also, some physicians in the selected centers might have been affected by their previous perception about EIMs, which consequently influenced their choice of specific EIMs discussed with the patient, either because of a higher incidence or because it was thought to be of high importance.

5. CONCLUSION AND RECOMMENDATIONS

In conclusion, the results of this study showed a high awareness of the common EIMs and complications but revealed a poor knowledge of the rare EIMS, which may be associated with higher morbidity rates (24). Even though studies did not show any improvement in morbidity or mortality relating to awareness, they did show better effect on coping and quality of life; hence, the importance of an inclusive education program for patients with IBD. We suggest proper education of patients with IBD regarding not only the EIMs with high incidence, but also those with low incidence. We also recommend that these patients be educated on the preventable EIMs, because we found that participants who recognized more EIMs had personal experiences with them; hence, the role of preventative health education is significant. Since, the majority of the patients preferred gastroenterologists as their main source of information, we encourage gastroenterologists to dedicate time for one-on-one health teaching with patients to raise their level of knowledge regarding EIMs. Despite the finding that the internet was the second source of information, we unfortunately found that the Ministry of Health website did not provide any educational material about IBD. Moreover, the Saudi Gastroenterology association website mentioned some EIMs in their videos but not in their pamphlets. Therefore, we highly suggest that they should improve their websites’ educational content by making it more comprehensive. Finally, we recommend a bigger scale study in the country with a more randomized sample and another study on the physician’s direction in patient education.

ACKNOWLEDGEMENT

The authors would like to thank Dr. Mohannad AlTaib for his help in reviewing the manuscript; Ms. Enam Faden, Ms. Nouf Abo-alsamh, Mr. Nasser Abdulaziz Alqahtani and Mr. Faisal Abdulaziz Alzamel for their assistance in the data collection; and King Fahad Medical City and Security Forces Hospital for giving us the permission to collect the data of the patients.

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Tables

Table 1. Sociodemographic and disease characteristics of survey respondents

| | |
|---------------------------|------------|
| | |
| Age group, years | |
| 18–24 | 41 (19.5) |
| 25–34 | 73 (34.8) |
| 35–44 | 54 (25.7) |
| 45–54 | 21 (10) |
| 55 and above | 21 (10) |
| Sex | |
| Male | 117 (55.7) |
| Female | 93 (44.3) |
| Education | |
| Elementary or less | 14 (6.7) |
| Intermediate | 8 (3.8) |
| Secondary | 47 (22.4) |
| Diploma | 41 (19.5) |
| College or higher | 100 (47.6) |
| Patient diagnosis | |
| Crohn's | 107 (50.9) |
| Ulcerative colitis | 90 (42.9) |
| IBD-unclassified | 13 (6.2) |
| Disease duration | |
| Less than 1 year | 21 (10) |
| 1–5 years | 89 (42.4) |
| 6–10 years | 50 (23.8) |
| More than 10 years | 50 (23.8) |

IBD: inflammatory bowel disease

Table 2. Correctly identified EIMs by survey respondents

| EIMs | Correctly Identified | Total Number of Answers | % |
|--------------------------------|----------------------|-------------------------|------|
| Arthritis | 85 | 210 | 40.5 |
| Colon cancer | 113 | 210 | 53.8 |
| Skin lesions | 52 | 210 | 24.8 |
| Oral lesions | 90 | 210 | 42.9 |
| Kidney stones | 16 | 210 | 7.6 |
| Inflammation of the eye | 43 | 210 | 20.5 |
| Osteoporosis | 64 | 210 | 30.5 |
| Primary sclerosing cholangitis | 30 | 210 | 14.3 |
| Venous thromboembolism | 10 | 210 | 4.8 |

EIM: extraintestinal manifestation

Table 3. Factors associated with patient awareness of EIMs of IBD

| EIM | Duration of IBD | | | Compliance | | Education Level | | | Awareness | |
|---------------------|-----------------|----------|----------|------------|----------|-------------------|-------------------------|--------------|-----------|-----------|
| | <5 y | 6–10 y | >10 y | Compliant | No | Secondary or less | College and post-second | Post college | Yes | No |
| Arthritis | 36 (33%) | 19 (38%) | 29 (58%) | 59 (40%) | 22 (41%) | 23 (33%) | 57 (44%) | 5 (42%) | 47 (65%) | 38 (28%)* |
| Colon cancer | 52 (47%) | 31 (62%) | 29 (58%) | 77 (53%) | 36 (67%) | 25 (36%)* | 80 (62%)* | 8 (67%)* | 20 (71%) | 93 (51%)* |
| Skin lesions | 25 (23%) | 10 (20%) | 16 (32%) | 36 (25%) | 16 (30%) | 13 (19%) | 33 (26%) | 6 (50%) | 19 (48%) | 33 (19%)* |
| Oral lesions | 46 (42%) | 19 (38%) | 21 (42%) | 57 (39%) | 33 (61%) | 25 (36%) | 61 (47%) | 4 (33%) | 54 (79%) | 36 (25%)* |
| Kidney stone | 4 (4%)* | 3 (6%)* | 8 (16%)* | 10 (7%) | 6 (11%) | 3 (4%) | 11 (9%) | 2 (17%) | 4 (17%)* | 12 (6%)* |
| Eye inflammation | 16 (15%) | 10 (20%) | 17 (34%) | 27 (18%) | 16 (30%) | 12 (17%) | 28 (22%) | 3 (25%) | 23 (56%) | 20 (12%)* |
| Osteoporosis | 24 (22%) | 17 (34%) | 22 (44%) | 44 (30%) | 20 (37%) | 18 (20%) | 43 (33%) | 3 (25%) | 30 (54%) | 34 (22%)* |
| Liver disease (PSC) | 16 (15%) | 5 (10%) | 8 (16%) | 22 (15%) | 8 (15%) | 7 (10%) | 21 (16%) | 2 (17%) | 9 (38%)* | 21 (11%)* |
| Blood clots | 6 (5%) | 2 (4%) | 2 (4%) | 7 (5%) | 3 (6%) | 2 (3%) | 6 (5%) | 2 (17%) | 6 (3%)* | 4 (21%)* |

EIM: extraintestinal manifestation; IBD: inflammatory bowel disease

*P < 0.05

Figure Legend

Figure 1. Patients' Source of information

