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Knowledge of Chronic Inflammatory Bowel Disease Patients about Their Disease in the North Moroccan Region

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Abstract	Original Research Article

Patients' level of knowledge about their disease plays an essential role in therapeutic management, by facilitating patients' acceptance of the diagnosis, their active participation in treatment and improved compliance. Few studies have been conducted in Morocco to assess the level of knowledge of IBD patients. The aim of this study was to assess the level of knowledge of IBD patients in the northern region of Morocco. *Materials and methods*: We conducted a cross-sectional study over a period of 5 months in the hepato-gastroenterology department of the Mohammed VI University Hospital in Tangiers. Our study involved a series of 100 patients with confirmed IBD. A questionnaire was drawn up and given to the patients. *Results*: The main results of our study reveal a considerable lack of knowledge among our patients about their disease, covering all areas of the disease and more specifically the treatment and complications aspect. This lack of knowledge can be attributed in part to the high rate of illiteracy in our setting. *Conclusion*: These results underline the importance of raising patients' awareness of their disease by setting up educational workshops tailored to their level of understanding. These workshops aim to improve patients' knowledge, encourage adherence to treatment and, ultimately, improve their quality of life.
Keywords: Inflammatory bowel diseases, patient knowledge, therapeutic education.

INTRODUCTION

The management of IBD patients is complex and requires a multidisciplinary approach. In this context, patients' knowledge of their disease is essential for optimal management.

Previous studies have shown that patients' knowledge of their disease does not affect their quality of life. However, more recent research has established that the higher the level of knowledge about the disease, the better the patients' QoL. On the other hand, a low level of knowledge about the disease can lead to a more serious deterioration in quality of life [1, 2].

The aim of our work is to report on the state of knowledge of IBD patients in the northern region of Morocco.

MATERIALS AND METHODS

This is a cross-sectional study conducted in the hepato-gastroenterology department of the Mohammed VI University Hospital in Tangiers, over a period of 5 months (June 2022-October 2022). All patients followed for IBD diagnosed on clinical, radiological, endoscopic and/or histological criteria were included. Patients aged less than 16 years, followed for uncontrolled psychiatric disease or refusing to participate were excluded.

All patients were informed of the purpose of the study and their consent was obtained. Our study used a self-administered questionnaire to assess IBD patients' knowledge of their disease. The questionnaire was developed to cover various aspects of the disease and is divided into three distinct parts:

- The first section looks at patients' socio-demographic data and the type of IBD.
- The second part assesses patients' knowledge of their disease, including the name of the disease, the nature and origin of the disease, extradigestive manifestations, diet, and the impact of psychological state, the therapeutic aspect and any complications.

- The third section provides information on the source of patient information and the quality of the doctor-patient relationship.

The questionnaire consists of 35 questions, 26 of which are designed to assess patients' knowledge. These questions are single-choice, and each correct answer is scored with one point, enabling a total score to be calculated for each patient.

Statistical analysis was carried out using SPSS (Statistical Package for the Social Sciences) version 27 software, with the significance threshold set at a p-value of less than 0.05 ($p < 0.05$).

RESULTS

During the study period, 100 patients were included. The median age was 31.5 years [25,44], with extremes of age ranging from 16 to 67 years, and a sex ratio of 0.88. Urban origin was noted in 75% of cases (N=75). Of all the people questioned, the majority had received primary (30%, N=30) or secondary (41%, N=41) education, while 17% had not attended school (N=17) and only 12% of patients had reached university level (N=12). Crohn's disease was diagnosed in 74% of cases (N=74) and UC in 26% (N=26). The median duration of follow-up was 4 years [2,9].

In terms of treatment, 25% of patients are receiving a combination therapy including Azathioprine and Infliximab or Adalimumab, 40% are on Azathioprine, 8% are on 6MP and 8% are on tapering corticosteroids.

The median number of correct answers to the 26 questions on the questionnaire was 9 [7,12]. The general knowledge section had the highest median number of correct answers (6 [4,7]), followed by the treatment section (2 [1,3]) and the complications section (1 [0,3]).

Of our patients, 49% did not know the name of their disease (N=49), and 32% knew that their disease was inflammatory in origin (N=32).

The hereditary risk factor was known by only 19% of our patients (N=19). Ninety-three per cent of patients (N=93) were aware that this was a chronic condition requiring regular monitoring throughout their lives.

Psychological state had an influence on the disease for 57% of patients (N=57), and 22.5% of them thought they could control the disease solely by controlling their psychological state (N=13).

Extradigestive manifestations are part of the disease in 28% of our patients (N=28), and osteoarticular manifestations are the most frequently reported symptoms, followed by ocular involvement.

With regard to diet, 43% of our patients (N=43) were on a special diet, with dairy-free diets predominating. Of these, 37.2% (N=16) followed a residue-free diet during periods of disease flare-up.

With regard to the therapeutic aspect of the questionnaire, 44% of cases (N=44) did not know the name of the medication they were taking and only 59% of patients (N=59) received information before starting their treatment.

Among patients treated with corticosteroids, 82.2% were aware of the limited duration of treatment (N=19). For azathioprine and 6-MP, the frequency of biological monitoring was only recognised by 58% of patients (N=34). Fifteen percent of patients (N=9) were aware of the risks associated with immunosuppressants, the most feared risks being haematological and hepatic complications.

Our results indicate that the majority of our patients (57%) were not informed of the drug contraindicated in the event of a planned pregnancy, while a minority (18%) were aware that methotrexate is strictly prohibited in this context.

Seventy-one percent of patients (N=71) had a poor perception of the use of biotherapy, mistakenly thinking that it was used as a first-line treatment.

Fertility may be affected by the disease in 18% of cases (N=18), and 20% of cases (N=20) think that their disease may affect their sexuality.

All our patients were asked whether their disease might affect a possible pregnancy. The answer was affirmative in 39.6% (N=21).

Half of the cases (52%) feared complications from their disease (N=52), and 78.8% of them (N=41) felt that the disease could degenerate.

Of these patients, 39% (N=16) considered that medical treatment was an effective means of prevention.

The doctor remains the main source of information for 47% of participants (N=47), with the internet increasingly being used as a second source of information (35%, N=35). On the other hand, the media, friends and family and patients are rarely used as sources of information, with only 7% and 11% of patients respectively.

In terms of satisfaction with the information provided, 31% of patients were satisfied with the information they received from their doctor, while 17% said they did not understand it. For the internet, the figures were 25.7% and 20% respectively.

Of the patients who used the internet as a source of information, the majority (91.4%, N=32) used general websites, whereas the use of social networks as a source of information was less widespread (8.57%, N=3).

Thirty-two percent of patients consider their knowledge of their illness to be poor (N=32), while 45% consider it to be average (N=45) and only 23% of patients consider that they know their illness perfectly (N=23).

According to the survey results, the majority of patients (89%) felt that the relationship between doctor and patient was good or excellent, while 11% (N=11) felt that it was poor.

Table 1: Summary table of knowledge for each section of the questionnaire

General knowledge of patients	Correct answers N (%)
Disease name	51 (51%)
Inflammatory nature of the disease	32 (32%)
Hereditary risk factor	19 (19%)
Chronic condition	93 (93%)
Link between illness and psychological state	57 (57%)
Extra-digestive manifestations	28 (28%)
Residue-free diet during outbreaks of the disease	16 (37,2%)
Knowledge of treatment	**Correct answers N (%)**
The name of the drug	56 (56%)
Information received before starting treatment	59 (59%)
Limited duration of treatment (corticosteroids)	19 (82,2%)
Biological monitoring schedule (Azathioprine and 6-MP)	34 (58%)
Risks associated with immunosuppressants	9 (15,5%)
Treatment contraindicated if you are planning to become pregnant	18 (18%)
Use of biotherapy (as first-line treatment)	29 (29%)

Knowledge of the complications of the disease	Correct answers N (%)
IBD and fertility	18 (18%)
IBD and sexuality	19 (19%)
IBD and pregnancy	21 (39,6%)
Disease can be complicated	52 (52%)
Disease can degenerate	41 (41%)
Medical treatment = means of preventing complications.	16 (39%)

Patient information sources	N (%)	Satisfactory N (%)	Moderately satisfactory N (%)	Not included N (%)
GP	47 (47%)	15 (31%)	24 (52%)	8 (17%)
Internet	35 (35%)	9 (25,7%)	19 (54,3%)	7 (20%)
-General websites	32 (91,4%)	-	-	-
-Social networks	3 (8,57%)	-	-	-
Patients / Friends	11 (11%)	1 (9%)	7 (63,6%)	3 (27,4%)
Media	7 (7%)	1 (10%)	2 (30%)	3 (60%)

Patients' perception of their knowledge of their illness	N (%)
- Poor knowledge	32 (32%)
- Average knowledge	45 (45%)
- Good knowledge	23 (23%)

The doctor-patient relationship	
- Good or excellent relationship	89 (89%)
- A poor relationship	11 (11%)

Analytical results

The statistical results of our study show a significant positive relationship between patient age and correct responses. In fact, responses were better when patients were younger (*p=0.001*).

Patients from urban areas had a significantly higher median of correct answers (10 - [8,12]) than patients from rural areas (7.5 - [4,10]) (*p=0.03*).

The median of correct responses showed a positive relationship with educational level, with patients with a university education scoring significantly higher

(11-[10,13]) than those with a secondary education (10 - [8, 11.5]), the latter in turn scoring higher than patients with a primary education (9 - [5.5, 12.5]), as well as patients with no education (7 - [4, 9.25]) (*p = 0.004*).

Patients who received information before starting their treatment had a significantly higher median

of correct answers in the treatment component than those who did not receive information (*p = 0.014*).

In our series, patients who used the Internet as a source of information had a significantly higher median of correct answers in all three parts of the questionnaire than those who relied on their doctor as a source of information, with a *p* value < *0.001*.

Table 2: Summary table of analytical results

	General knowledge	Treatment	Complications	Total
Age:				
P-value	*0,097*	*0,033*	*0,11*	*0,01*
Gender :				
Male	5 [3,6]	2 [1,4]	1 [0,3]	9 [6,14]
Female	5 [4.5, 7]	2 [1,3]	2 [0.5, 3]	9 [8, 12.5]
P-value	*0,151*	*0,846*	*0,067*	*0,209*
Origin:				
Urban	6 [4,7]	2 [1, 3.25]	2 [0.75, 3]	10 [8,12]
Rural	4.5 [3,6]	1 [1,3]	1 [0, 1.75]	7.5 [4,10]
P-value	*0,103*	*0,195*	*0,017*	*0,03*
Marital status :				
Single	6 [4,7]	2 [1,4]	1 [0,3]	10 [7.5 ,12]
Married	5 [3, 6.25]	1 [1,3]	1 [0, 2.25]	8.5 [4,11]
P-value	*0,216*	*0,109*	*0,589*	*0,124*
School level :				
University	6.5 [5, 7.75]	2 [1.25, 3.75]	2 [1,4]	11 [10,13]
Secondary	6 [5,7]	2 [1,4]	1 [1,3]	10 [8, 11.5]
Primary	5 [3.5, 6]	2 [1, 2.5]	1 [0,3]	9 [5.5, 12.5]
Not enrolled	4 [3,6]	1 [0, 2.25]	1 [0,3]	7 [4, 9.25]
P-value	*0,03*	*0,035*	*0,184*	*0,004*
Family history of IBD :				
No	6 [4,7]	2 [1,3]	1 [0,3]	9 [7,11]
Yes	6 [4.4, 7.5]	1 [0, 2.5]	2 [1,4]	11 [7.5, 12]
P-value	*0,011*	*0,532*	*0,95*	*0,087*
Type of disease :				
MC	6 [5,7]	2 [1,4]	2 [1,3]	10 [8,12]
RCH	5 [3,7]	1 [1,2]	1 [0, 1.5]	8 [4,10]
P-value	*0,36*	*0,09*	*0,002*	*0,008*
Length of illness :				
P-value	*0,131*	*0,659*	*0,934*	*0,301*
No. of flare-ups in the last year :				
P-value	*0,656*	*0,319*	*0,245*	*0,854*
Information received prior to treatment:				
No	5 [3,7]	1 [1,2]	1 [0,3]	4 [9,11]
Yes	6 [5,7]	2 [1,3]	1 [0,3]	10 [8,12]
P-value	*0,267*	*0,014*	*0,481*	*0,074*
Sources of information :				
Internet	6 [5,8]	3 [1,4]	3 [1,4]	11 [9,14]
GP	4 [3, 6]	1 [0,2]	1 [0,3]	7 [4,10]
P-value	*<0,001*	*<0,001*	*<0,001*	*<0,001*

DISCUSSION

Studies have shown that high levels of knowledge in IBD patients can reduce treatment costs and the likelihood of using biologics and corticosteroids. However [3, 4], the lack of knowledge about their disease and how it will progress under treatment only increases anxiety in these patients.

Few studies have been carried out in Morocco to assess the level of knowledge of IBD patients about their disease. Our study revealed a real knowledge deficit among these patients, covering all aspects of the disease. Several studies have been carried out with this in mind, using specific questionnaires such as [the Crohn's and Colitis Knowledge (CCKNOW) score, developed in the

UK of 24 items [5], the Inflammatory Bowel Disease Knowledge (IBDKNOW) questionnaire, developed in Korea with 24 items [6], the French IBD-INFO questionnaire, consisting of 65 items [7] and the 30-item Understanding IBD questionnaire (U-IBDQ) was used in Tel Aviv in 2020 [1]. All these studies have reached similar conclusions, confirming patients' lack of knowledge about their disease.

In our study, the average number of correct answers on the 26 questions of the questionnaire was 9.19 (2-18). According to a study conducted in the United States to assess the level of knowledge of IBD patients prior to an educational workshop, the average score on a 30-item questionnaire (CCKNOW) was 18 points [8]. This was higher than a study in Korea, where the subjects' level of knowledge was below average,10 out of a maximum score of 24 [9]. The CCKNOW scores of two other studies conducted in developing countries were also lower, with an overall mean score of 6.64 in a study conducted in South Asia and a mean of 4.65 (out of 24) in a study conducted in Iran [10, 11].

In our series, the general knowledge component showed the highest median of correct responses, followed by the treatment and complications component. These results are consistent with other studies, where patients were found to have better knowledge of general information about IBD in relation to diet, complications and treatment [12]. On the other hand, in Iran, knowledge in the areas of diet and medication appeared to be slightly better than general knowledge and complication [10]. In South Asia, general knowledge of IBD, including anatomy and treatment, appeared to be better mastered by patients than knowledge of diet and complications of IBD [11].

The therapeutic management of inflammatory bowel disease often involves several therapeutic classes and sub-classes, making drug treatment complex. However, patients often have limited knowledge about their treatment and the side effects associated with the drugs they are prescribed, while doctors' perceptions are often overestimated [13]. Studies show that not only do patients have insufficient knowledge of the side effects of their medicines, but they are also often unaware of the identity of the medicines they are taking [4, 5, 13]. This lack of knowledge is a contributing factor to non-compliance with treatment, as well as to the use of alternative remedies.

The risk of colorectal cancer (CRC) is the main concern for IBD patients, particularly those with UC. According to the Eaden *et al.*, study, patients who have a good understanding of their disease and its cancer risk are more likely to manage their disease adequately by undergoing regular surveillance colonoscopies and taking their medication. This may lead to earlier detection of colorectal cancer, which may reduce the risk of mortality associated with this complication [14].

With this in mind, we asked our patients if they were aware of the risk of degeneration of their disease, and 43% answered positively, a higher rate than that reported in studies carried out in developing countries [10, 11] and close to that found in the Marrakech study by Elhidaoui *et al.*, (44%). However, this result is lower than that reported in a French study by Benjamin *et al.*, on IBD patients' knowledge and fears about their risk of colorectal cancer. In this study, two-thirds of IBD patients were aware of their risk of colorectal cancer and a quarter of patients were aware of the potential role of salicylates in CRC prevention, as observed in our study [15].

According to a recent study by Ostromohov and colleagues [10] patients with IBD diagnosed at a young age had the highest knowledge scores. This observation is consistent with the results of previous research [9, 16, 17] as well as the results of our study, which showed that younger patients had better responses. This could be explained by the fact that younger age groups have higher information needs due to their engagement in active social activities, which leads them to seek more information to better manage their disease in a positive way [6].

Ostromohov's study also showed that the duration and activity of the disease were not associated with understanding of the disease, which is similar to our study where we found that there was no significant correlation between correct answers and the duration either of the disease or the number of relapses in the last year. These results contradict previous reports according to which the shorter the duration of the disease, the lower the level of knowledge perhaps due to patients' level of education, their ability to understand and assimilate information, and limited access to modern media platforms [9, 11].

In our study, we observed a positive correlation between educational level and the number of correct answers, with patients with a university degree obtaining significantly higher scores. These results are consistent with those of other studies, which have also shown that people with a university degree have higher knowledge scores. In addition, a study conducted in Korea found that university graduates also had higher knowledge requirements than high school graduates [9]. This trend can be explained by their strong motivation to actively manage their disease and to actively participate in treatment decisions due to their higher level of education [9, 12]. Therefore, when designing health education approaches, it is important to take into account the individual characteristics and needs of patients.

Several studies have shown that the doctor is generally considered the main source of information for IBD patients [6, 7]. In our study, 47% of patients confirmed that their doctor was their source of

information. However, 17% of patients reported that the information provided was insufficient or poorly understood, although the doctor-patient relationship was rated as excellent or good in 89% of cases.

Our study revealed that patients who used the Internet as a source of information obtained a significantly higher median of correct answers. However, these results contrast with other studies that have shown that information acquired from the Internet was not associated with a high knowledge score [6].

The results of our study highlight the importance of therapeutic education for IBD patients. Indeed, we observed that patients who had received information prior to their treatment had a significantly higher median of correct responses in the treatment component than those who had not.

CONCLUSION

Our study showed a knowledge deficit among our patients concerning their disease, which highlights the need to review our methods of informing patients in order to improve their health and well-being. Acquiring more in-depth knowledge about inflammatory bowel disease could help to reduce medical acceleration in patients with this condition. With this in mind, the introduction of structured education programmes tailored to the needs and educational level of patients could help to improve their understanding of their disease, encourage adherence to treatment and reduce medical complications. It is important to stress that the lack of knowledge observed in our patients could be linked to their lower educational and socio-economic levels. Consequently, raising patients' awareness of their disease through well-adapted programmes could help improve their quality of life and prevent potential long-term complications.

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