

Awareness and cognition of illness in Saudi Arabian patients with Crohn's disease

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Abstract

Background: Crohn's disease (CD) is a progressive illness associated with high morbidity owing to the complications associated with the condition. Patients' awareness and cognition of such complications may carry significant psychological impact. The aim of this study is to assess the illness cognition of Saudi patients diagnosed with CD and to identify clinical associations.

Methods: Adult patients with CD were asked to complete an illness cognition questionnaire (ICQ) between January and December of 2019. Additional data was extracted from the medical records. The ICQ composed of three domains: Helplessness (6 items), acceptance (6 items), and perceived benefits (6 items). Descriptive statistics were used to summarize patient characteristics and a linear regression analysis was used to identify associations with the ICQ score.

Results: A total of 88 patients were included, of which 55.8% were females, 18% were smokers, and 11.5% had undergone CD-related surgery. The mean age was 26.9 ± 7.7 years and the mean duration of disease was 54.7 ± 60.5 months. The mean score was 17.4 ± 3.6 for the helplessness domain, 13.4 ± 3.6 for the acceptance domain, and 13.5 ± 3.5 for the perceived benefits domain. We found associations between abdominal pain and acceptance ($P = 0.048$), extra intestinal manifestations and perceived benefit ($P = 0.001$), and treatment with mesalamine and helplessness ($P = 0.03$). In a linear regression analysis, albumin level was the only factor associated with helplessness (coef = 0.18, $P = 0.048$).

Conclusions: A considerable proportion of Saudi patients diagnosed with CD generally reported a negative perception of their disease. Albumin level was associated with helplessness.

Keywords: Acceptance, Crohn's disease, helplessness, illness cognition, Saudi Arabia

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Submitted: 30-Jun-2020 **Revised:** 30-Aug-2020 **Accepted:** 10-Sep-2020 **Published:** 12-Mar-2021

INTRODUCTION

Crohn's disease (CD) is increasing in prevalence worldwide.^[1] While the etiology is believed to be complex, the most widely accepted hypothesis is that CD is an

immune-mediated condition that commonly occurs in genetically susceptible individuals where disease onset is triggered by environmental factors.^[2] Moreover, patients affected by this disease may experience a wide range of

Access this article online	
Quick Response Code:	Website: www.saudijgastro.com
	DOI: 10.4103/sjg.SJG_371_20

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How to cite this article: Mosli M, Saeedi A, Alnefaie M, Bawahab N, Abdo L, Shobai S, *et al.* Awareness and cognition of illness in Saudi Arabian patients with Crohn's disease. Saudi J Gastroenterol 2021;27:91-6.

symptoms such as diarrhea, abdominal pain, fever, and weight loss. Patients' awareness of the chronic recurrent course and uncertain prognosis of these conditions, particularly the risk of complications, including the need for surgery, stoma formation, the development of cancer, associated hospitalizations, frequent physician visits, and the side effects of treatment or surgery, can lead to a wide range of psychological and interpersonal issues in patients. Patients' cognition about the disease and its treatments are important mediators as they may explain the occurrence of differences in the individuals' adjustment to chronic diseases.^[3]

In 2001, Evers *et al.*^[4] defined acceptance as a cognitive response that reduces the aversive sense of long-term stressors, such as that associated with chronic diseases. Patients who accept their disease and become aware of their ability to control it have lower levels of psychological distress. However, limited research has been conducted to identify the effect of illness perception on disease activity in inflammatory bowel disease (IBD).^[5] Illness cognition can be measured using the illness cognition questionnaire (ICQ) tool.^[4] The ICQ has been found to be a reliable and valid instrument for measuring illness cognition across several chronic conditions.^[5-7] A previously performed study demonstrated an association between bowel symptoms, social function, and emotional health, based on ICQ measurements.^[3] As for correlation between patients' disease cognition and objective measures of inflammation, a significant but relatively modest correlation was found between ICQ and the level of C-reactive protein (CRP) during disease exacerbation and the number, as well as the severity, of relapses of IBD per year.^[8]

Therefore, the aim of this study was to examine the degree of illness cognition of Saudi patients with CD and to look for possible associations with positive or negative cognitions.

METHODS

Consecutive patients with confirmed CD seen in the adult outpatient gastroenterology clinic at King Abdulaziz University Hospital (KAUH) were recruited between January and December of 2019. All adult patients diagnosed with CD according to typical clinical, radiological, endoscopic, and histological criteria were included. All patients gave written informed consent prior to participation. Data was collected from interviews with patients and the hospitals' electronic medical records. All patients completed the ICQ, which assesses three main cognitive functions attributable to disease: Helplessness (6 items), acceptance (6 items),

and perceived benefits (6 items).^[4] Each item was scored from 1 to 4 on a Likert scale, with 1 corresponding to "Not at all," and 4 corresponding to "Completely." A total ICQ score varies from 18 to 72, where higher scores in the acceptance and perceived benefits domains reflect better cognition and higher scores in the helplessness domain reflect poorer cognition. King Abdulaziz university ethical committee approval was obtained prior to study commencement (Reference#319-18).

Study outcomes

The primary study endpoint was patients' illness cognition, as measured by each domain of the ICQ. The main secondary study endpoint was to identify associations with ICQ in each domain.

Statistical analysis

The data was analyzed using StataCorp, 2011 (*Stata Statistical Software: Release 12*. College Station, TX: StataCorp LP). Means and standard deviations (SD) were used to summarize continuous variables and frequencies summarized the categorical variables. A Student *t*-test compared the mean scores of each domain against clinical and demographic variables. A multivariate linear regression analysis identified potential associations with the total scores for each domain of the ICQ. The level of significance was set at $P < 0.05$.

RESULTS

Baseline characteristics

A total of 88 patients were surveyed, of which 55.8% were females, 18% were smokers, and 11.5% had previously undergone CD-related surgery. The mean age was 26.9 ± 7.7 years (range, 12–49 years) and the mean duration of disease was 54.7 ± 60.5 months. Perianal disease was reported by 16.1% of the cohort [Table 1].

Illness cognition

Fifty-two percent of the CD patients scored higher on the Likert scale (3 and 4) in the questions related to the helplessness domain and 49% had a high score in the questions related to both acceptance and perceived benefit domains. Table 2 summarizes the response to individual questions related to each domain.

The mean score was 17.4 ± 3.6 for the helplessness domain, 13.4 ± 3.6 for the acceptance domain, 13.5 ± 3.5 for the perceived benefits domain, and 44.3 ± 6.6 for the total score.

Hypothesis testing of the mean scores of each of the illness cognition domains, comparing helplessness,

Table 1: Baseline characteristics of the study cohort (n=88)

Characteristic	Mean±SD or frequency (%)
Mean Age in Years	26.9±7.7
Mean duration of illness in months	54.7±60.5
Female gender	58 (55.8)
Smoker	16 (18)
Disease Location:	
Ileal	22 (33.9)
Colonic	14 (21.6)
Ileo-colonic	29 (44.6)
Upper GI involvement	3 (3.4)
Perianal disease	14 (16)
Previous surgeries	10 (11.5)
Active Symptoms	
Fatigue	19 (21.9)
Abdominal pain	51 (58.6)
Fever	7 (8)
Diarrhea	31 (35.6)
Weight loss	15 (17.2)
Extra Intestinal Manifestations	9 (10.2)
Medications:	
Anti TNF	53 (67.1)
Azathioprine	30 (40)
5ASA	14 (17.5)
Prednisone	12 (15)
Methotrexate	2 (2.5)
Vedolizumab	2 (2.5)
Laboratory Investigations:	
C-Reactive Protein	20.6 (+33.4)
Hemoglobin	11.9 (+2.0)
Albumin	33.7 (+6.6)

acceptance, and perceived benefits against a number of different variables, showed that patients reporting abdominal pain demonstrated higher mean scores in the acceptance domain ($P = 0.048$), patients with extra intestinal manifestations demonstrated lower scores in the perceived benefit domain ($P = 0.001$), patients treated with mesalamine had lower scores in the helplessness

domain ($P = 0.03$), and a trend toward better acceptance was found in relation to treatment with biological therapy ($P = 0.05$) [Table 3].

Associations with different domains in the ICQ score

In a multivariate regression analysis, in the helplessness domain, albumin level was the only significant association with the ICQ score (coef = 0.18, $P = 0.048$). A trend toward significance was observed for duration of the disease in months (coef = -0.01, $P = 0.11$) and for smoking (coef = -2.14, $P = 0.10$) [Table 4]. In the acceptance domain, no associations were identified; however, a trend was found for duration of illness (coef = -0.012, $P = 0.15$), fatigue (coef = 1.51, $P = 0.16$), abdominal pain (coef = -1.78, $P = 0.09$), use of corticosteroids (coef = -1.69, $P = 0.18$), biological therapy (coef = -1.72, $P = 0.08$), and surgery (coef = -1.99, $P = 0.14$). No associations with the perceived benefits domain score were observed, but a trend for duration of illness (coef = -0.015, $P = 0.09$) and extra-intestinal manifestations (coef = 2.78, $P = 0.09$) was noted.

DISCUSSION

CD is one of the most debilitating forms of chronic inflammatory bowel diseases. It is progressive in nature if not promptly managed, and may result in significant bowel damage, including strictures and fistulae formation, and is associated with an increased probability of requiring surgical bowel resection.^[9] This may explain why CD patients are prone to various types of psychological morbidity, including anxiety and depression.^[10,11] Illness cognition is an emerging concept in the psychological

Table 2: Responses to the illness cognition questionnaire (ICQ)

Domain	Scale 1 n (%)	Scale 2 n (%)	Scale 3 n (%)	Scale 4 n (%)
Helplessness				
Q1: Because of my illness I miss the things I like to do most.	34 (38.6)	11 (12.5)	28 (31.8)	15 (17.1)
Q5: My illness controls my life.	25 (28.4)	10 (11.4)	41 (46.6)	12 (13.6)
Q7: My illness makes me feel useless at times	20 (22.7)	14 (15.9)	44 (50)	10 (11.4)
Q9: My illness prevents me from doing what I would really like to do	38 (43.2)	10 (11.4)	17 (19.3)	23 (26.1)
Q12: My illness limits me in everything that is important to me	32 (36.4)	12 (13.6)	26 (29.6)	18 (20.5)
Q15: My illness frequently makes me feel helpless	23 (26.1)	15 (17.1)	32 (36.4)	18 (20.5)
Acceptance				
Q2: I can handle the problems related to my illness	30 (34.1)	22 (25)	6 (6.8)	30 (34.1)
Q3: I have learned to live with my illness	5 (8.3)	18 (30)	19 (31.7)	18 (30)
Q10: I have learned to accept the limitations imposed by my illness	22 (25)	35 (39.8)	2 (2.3)	29 (33)
Q13: I can accept my illness well	26 (29.6)	30 (34.1)	7 (8)	25 (28.4)
Q14: I think I can handle the problems related to my illness, even if the illness	25 (28.4)	15 (17.1)	16 (18.2)	32 (36.4)
Q17: I can cope effectively with my illness	28 (31.8)	24 (27.3)	9 (10.2)	27 (30.7)
Perceived Benefits:				
Q4: Dealing with my illness has made me a stronger person	25 (28.4)	36 (40.9)	14 (15.9)	13 (14.8)
Q6: I have learned a great deal from my illness	17 (19.3)	37 (42.1)	9 (10.2)	25 (28.4)
Q8: My illness has made life more precious to me	21 (23.9)	25 (28.4)	18 (20.5)	24 (27.3)
Q11: Looking back, I can see that my illness has also brought about some positive changes in my life	34 (38.6)	17 (19.3)	23 (26.1)	14 (15.9)
Q16: My illness has helped me realize what's important in life	22 (25)	34 (38.6)	11 (12.5)	21 (23.9)
Q18: My illness has taught me to enjoy the moment more	23 (26.1)	35 (39.8)	13 (1.8)	17 (19.3)

Scale 1: Not at all, scale 2: Somewhat, scale 3: To a large extent, scale 4: Completely

Table 3: Hypothesis testing of the mean scores for various illness cognition domains and clinical and demographic characteristics

Variables	Helplessness		Acceptance		Perceived benefits	
	Mean±SD	P*	Mean±SD	P*	Mean±SD	P*
Age category						
≤26 Years	17.5±3.3	0.82	13.2±3.5	0.67	13.7±3.2	0.70
>26 Years	17.3±3.9		13.5±3.8		13.4±3.9	
Gender						
Male	17.64±3.5	0.59	12.61±3.60	0.09	13.30±3.52	0.61
Female	17.22±3.6		13.93±3.55		13.69±3.60	
Smoking						
Yes	18.43±4.19	0.21	12.81±3.25	0.51	13.31±3.38	0.79
No	17.18±3.41		13.47±3.69		13.57±3.60	
Fatigue						
Yes	18.20±4.05	0.26	12.70±3.37	0.36	12.90±3.39	0.38
No	17.18±3.42		13.54±3.68		13.71±3.59	
Abdominal pain						
Yes	17.12±3.31	0.4	14.00±3.16	0.048**	13.80±3.26	0.4
No	17.81±3.92		12.46±4.03		13.14±3.93	
Fever						
Yes	17.29±2.29	0.93	13.86±3.02	0.70	13.43±4.86	0.94
No	17.42±3.68		13.31±3.67		13.53±3.45	
Diarrhea						
Yes	17.29±3.69	0.82	13.58±3.22	0.67	14.09±3.77	0.27
No	17.47±3.55		13.22±3.83		13.21±3.42	
Weight loss						
Yes	17.00±2.98	0.63	14.800±4.16	0.09	14.800±4.66	0.24
No	17.49±3.70		13.05±3.45		13.26±3.25	
EIMs						
Yes	18.56±4.67	0.31	11.44±3.13	0.09	11.33±1.50	0.001**
No	17.28±3.45		13.57±3.62		13.77±3.63	
Perianal disease						
Yes	17.00±4.23	0.63	14.400±3.78	0.22	12.67±3.78	0.31
No	17.49±3.44		13.14±3.57		13.69±3.50	
UGICD						
Yes	17.00±3.00	0.84	12.00±3.46	0.51	10.33±2.31	0.11
No	17.42±3.61		13.400±3.63		13.64±3.54	
Corticosteroids						
Yes	17.58±2.50	0.81	14.58±3.70	0.21	13.92±3.39	0.68
No	17.38±3.73		13.16±3.59		13.46±3.59	
Mesalamine						
Yes	15.63±3.84	0.03**	12.75±3.91	0.46	12.38±3.69	0.15
No	17.81±3.42		13.49±3.56		13.78±3.49	
Immunomodulators						
Yes	17.97±3.19	0.27	12.91±4.00	0.39	13.25±3.65	0.59
No	17.08±3.77		13.61±3.38		13.68±3.52	
Biological						
Yes	17.51±3.38	0.74	13.893±3.29	0.05	13.55±3.32	0.94
No	17.24±3.98		12.39±3.95		13.48±3.95	
Surgery						
Yes	15.64±3.14	0.08	14.18±4.17	0.38	13.45±3.59	0.91
No	17.66±3.61		13.16±3.50		13.58±3.57	

*Student *t*-test. *P*<0.05

literature that measures patient perception, thoughts, and understanding of disease, whether negative or positive.^[12] It has been shown to be important in mediating between illness and psychological adjustments and coping with illness.^[4] In patients with IBD, the perception of IBD and its natural history has been found to be the most important predictor of adjustment to IBD.^[13] The prevalence of psychological morbidity has been correlated with negative illness cognitions and perception,^[10] and the positive cognitions have been associated with better disease outcomes.^[14]

The cognitive perception of IBD varies between individuals. Some patients may develop a negative perception of its manifestations, such as a feeling of helplessness, which may lead to lack of adherence to the treatment strategy and failure of medical care. Others may cope with their illnesses with more acceptance of their status, culminating in adaptation and self-adjustment.^[15] Another category of individuals may have a more positive attitude toward achieving perceived benefits from their illnesses. The helplessness domain represents negative components of illness cognition, while the acceptance and perceived benefits domain represent positive components.

Table 4: Multivariate linear regression analysis for associations with various cognitive domains

Helplessness domain	B coefficient	95% confidence interval for B		P
		Lower	Upper	
Age (years)	0.086	-0.051	0.223	0.21
Duration of illness (months)	-0.014	-0.032	0.004	0.11
Hemoglobin (g/dL)	-0.192	-0.794	0.4111	0.53
Albumin (g/L)	0.176	0.001	0.351	0.048*
Gender	-0.136	-2.33	2.058	0.90
Smoking	-2.138	-4.721	0.444	0.10
Fatigue	-0.976	-3.387	1.435	0.42
Abdominal pain	0.379	-2.009	2.768	0.75
Fever	1.331	-2.771	5.434	0.52
Diarrhea	-0.700	-3.082	1.682	0.56
Weight loss	-1.372	-4.062	1.318	0.31
Perianal disease	1.371	-1.576	4.319	0.36
Extra intestinal manifestations	-1.812	-5.138	1.514	0.28
Corticosteroids	0.450	-2.345	3.244	0.75
Immunomodulators	-1.393	-3.584	0.799	0.21
Biological	0.107	-2.026	2.240	0.92
Surgery	1.928	-1.099	4.955	0.21
Acceptance domain				
Age (years)	0.089	-0.032	0.211	0.15
Duration of illness (months)	-0.012	-0.028	0.004	0.15
Hemoglobin (g/dL)	-0.102	-0.637	0.433	0.70
Albumin (g/L)	-0.024	-0.179	0.132	0.76
Gender	0.575	-1.373	2.524	0.56
Smoking	-0.248	-2.542	2.046	0.83
Fatigue	1.507	-0.634	3.649	0.16
Abdominal pain	-1.782	-3.903	0.340	0.09
Fever	-0.567	-4.212	3.077	0.76
Diarrhea	0.773	-1.342	2.889	0.47
Weight loss	-0.811	-3.200	1.578	0.49
Perianal disease	-0.463	-3.081	2.155	0.72
Extra intestinal manifestations	1.046	-1.909	4.000	0.48
Corticosteroids	-1.689	-4.172	0.794	0.18
Immunomodulators	0.292	-1.655	2.238	0.77
Biological	-1.715	-3.610	0.180	0.08
Surgery	-1.990	-4.679	0.699	0.14
Perceived benefits domain				
Age (years)	0.003	-0.128	0.134	0.96
Duration of illness (months)	-0.015	-0.032	0.002	0.09
Hemoglobin (g/dl)	0.205	-0.372	0.782	0.48
Albumin (g/L)	0.016	-0.151	0.184	0.85
Gender	-0.461	-2.563	1.641	0.66
Smoking	0.099	-2.376	2.575	0.94
Fatigue	-0.542	-2.853	1.768	0.64
Abdominal pain	-0.103	-2.393	2.186	0.93
Fever	0.367	-3.565	4.300	0.85
Diarrhea	0.634	-1.649	2.917	0.58
Weight loss	-1.598	-4.176	0.980	0.22
Perianal disease	-0.097	-2.922	2.728	0.95
Extra intestinal manifestations	2.778	-0.410	5.966	0.09
Corticosteroids	0.008	-2.670	2.687	0.99
Immunomodulators	1.076	-1.024	3.177	0.31
Biological	0.071	-1.974	2.115	0.95
Surgery	-0.283	-3.185	2.618	0.85

P < 0.01

In our study, higher scores in the Likert scale were found in 53% of patients for the helplessness domain, 49% of patients for each of the acceptance and perceived benefits domains. The only association we found between helplessness scores and demographic or clinical variables was with treatment with mesalamine ($P = 0.03$), where patients treated with mesalamine had lower scores in

helplessness domain; this might be reflective of how 5ASA does not provide any additional therapeutic benefit for CD. The mean score in the helplessness domain of our study was 17.4 ± 3.6 , which is higher than that reported by Gurkova and Soosova^[3] for 51 European patients with CD and which had a helplessness mean score of 11.67 ± 3.34 , and higher than Han *et al.*^[16] which reported a mean helplessness score of 13.70 ± 4.24 in Chinese women diagnosed with breast cancer.^[16]

Along the same lines, a mean acceptance score in our study of 13.4 ± 3.6 was lower than the mean score of 17.10 ± 3.15 reported for CD patients^[3] and the mean score of 16.86 ± 4.30 reported for patients with breast cancer.^[16] In addition, we found a lower mean score in perceived benefits (13.5 ± 3.5) compared to the mean score reported in a study of CD patients (16.24 ± 3.37) and a study on women with breast cancer (17.93 ± 3.86).^[3,16] Our cohort of patients with CD showed a higher mean of negative cognitions and a lower mean of positive cognitions compared to European patients with CD or Chinese women with breast cancer.^[3,16] These findings may be explained by cultural factors, or may reflect the poor prognosis of this specific cohort of patients or the social or ethnic group that they may represent.

It is not yet fully clear which clinical and demographic characteristics are associated with illness cognition in patients with IBD. A study by Verhoof *et al.*^[7] of children with chronic illnesses found that a stable course of illness correlates with more acceptance and less helplessness, the use of medications correlates with more helplessness and less acceptance, tiredness is associated with more helplessness and benefits and less acceptance, having problems with sitting is associated with more helplessness and less acceptance, and patients with perceptible disability reported greater degrees of helplessness. Palgi *et al.*^[17] have found higher acceptance in older patients with gastric cancer than younger patients. In addition, disease duration was associated with higher acceptance in breast cancer women.^[16] Our study showed an association between treatment with mesalamine and higher helplessness scores, an association between abdominal pain and higher acceptance scores, and an association between extra-intestinal manifestations and lower perceived benefits scores. We also found that albumin level was the only factor significantly associated with helplessness cognition.

The above results may indicate the lack of patients' adjustment to CD but could also reflect some misconceptions by patients about IBD. Therefore, it is important to identify patients at risk of low degrees of

illness cognition early, and to activate a multi-disciplinary approach to help them achieve positive cognitions and minimize negative cognitions through patient education, counseling, engagement, and monitoring. Early referral to a psychologist for counseling and cognitive behavioral therapy may be of value in this respect.^[18] The study is limited by its cross-sectional design; a prospective design could detect dynamic changes of cognitions. In addition, the lack of a comparative group of illnesses, which may give greater insight into, and a point of comparison with, the level of disease cognition in patients with CD, is acknowledged.

CONCLUSION

A considerable proportion of Saudi patients diagnosed with CD report a negative perception of their disease. Albumin level was found to be associated with helplessness. Patient education and counseling may help improve patients' positive cognition of the disease.

Acknowledgements:

We would like to thank Dr. Trevor Rawbone, Cardiff, UK for kindly reviewing and editing the manuscript.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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