

A Regional Survey of Awareness of Inflammatory Bowel Disease among the Saudi Population

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Research article

Keywords: Inflammatory bowel disease, Ulcerative colitis, Crohn's disease

Posted Date: December 10th, 2020

DOI: <https://doi.org/10.21203/rs.3.rs-123583/v1>

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Abstract

Background: Inflammatory bowel disease (IBD) is common among different age groups worldwide, including the gulf region. It is categorized into Crohn's disease and Ulcerative colitis. Early diagnosis and treatment of inflammatory bowel disease can improve patients' outcomes and reduce the incidence of complications. However, early diagnosis is highly dependent on patients' awareness of the disease to seek medical advice. This study aims to survey the awareness IBD in the general population of the western region of Saudi Arabia.

Methods: A self-administered structured questionnaire was translated into Arabic and distributed to the general public above 16 years old. The questionnaire included questions about Crohn's disease and Ulcerative colitis and their treatment, in addition to the respondents' demographic data.

Results: 1304 participants responded to this survey. 29% had not heard or read about Crohn's disease, while 19% of the responders had not heard or read about Ulcerative colitis. The mean awareness level score was 1.72 ± 1.19 , with a minimum score of 0 and a maximum score of 3. Females showed a significantly higher average score compared to males (p -value < 0.001). Also, the age group between 31 to 40 had the highest average score (p value = 0.002). Moreover, responders, who had a Ph.D., showed significantly higher mean scores than the other educational degrees (p value < 0.001). Responders who dealt with Crohn's disease patient or ulcerative colitis patients, showed significantly higher scores than their peers, with p values < 0.001 for both

Conclusion: The general population in Saudi Arabia has an unacceptable level of awareness of inflammatory bowel disease. Males, young adults, highly educated individuals who dealt with patients previously had better awareness compared to the rest of the population. National acts are essential to improve public awareness towards the disease.

Background

Inflammatory bowel disease (IBD) is classified into Crohn's disease (CD) and Ulcerative colitis (UC) [1]. It is defined as a chronic inflammation that affects the gastrointestinal tract. It can also have some systemic manifestations due to the inflammatory process [2]. IBD has shown increased morbidity and reduced quality of life among patients [3, 4]. Some reports demonstrated that the quality of life is more reduced in the case of Crohn's disease due to the need for more interventions as well as a higher risk of complications [3].

A recent systemic review of population-based studies demonstrated that IBD is now a global public health issue with surging incidence that will challenge and burden healthcare systems across the world [5]. The true incidence and prevalence of IBD is unknown in the Kingdom of Saudi Arabia (KSA) due to the lack of population-based studies. However, from regional retrospective studies it is estimated that the incidence of both CD and UC are rising reflecting the global trend [6].

Early diagnosis and management of IBD can reduce the severity of symptoms and the incidence of complications [7]. Nonetheless, delayed diagnosis is well recognized in IBD and is associated with significant complications [8, 9]. Diagnostic delay, which prolongs the disease duration, in addition affects the response to therapy. Patients with shorter disease duration have better response to biologic therapy, the shorter the duration the more significant the response and those with < 1 year of disease have the highest response to therapy [7, 10]

When different aspects of the delay in diagnosis were analyzed, it was noted that patient related factor was considerably prolonging the delay [11]. One of the explanation could possibly be the lack of awareness among patients of the likely IBD symptoms, leading to a delay in seeking medical advice. A public opinion poll survey conducted in Austria highlighted the lack of nation-wide IBD awareness with up to 80% of responders being ignorant about IBD [12].

A study in the Kingdom of Saudi Arabia did find a long delay in diagnosis of IBD in a paediatric population and delay in patient seeking healthcare was a major factor. One of the suggestions of the authors to shorten the delay was to raise awareness of the disease in the general public [7]. However, there is a lack of data in the medical literature about the awareness of the general population towards CD and UC in the KSA Therefore, the objective of this study is to understand the general Saudi population's awareness of inflammatory bowel diseases.

Methods

Study design:

This is a cross-sectional observational study that was carried out in the Western region of Saudi Arabia. There are no validated questionnaire addressing the awareness of IBD in the general public, therefore, a questionnaire that was previously used in a Austrian study for similar purpose was used [12]. This questionnaire was translated into Arabic according to WHO criteria. The questions were then reviewed by experts in IBD for accuracy and appropriateness. Following this step, the questions were piloted on lay public persons to test for appropriate comprehension. Participants aging above 16 years old were eligible to participate. On the other hand, participants with a history of inflammatory bowel diseases were excluded. Only participants who filled the survey were included in the analysis.

Data collection:

The above questionnaire was disseminated to members of the public in the Western region, Saudi Arabia through holding awareness stands and stalls at major family gathering places like shopping malls, hospitals and parks and community center like mosques. In addition, internet based monkey survey was done.

The questionnaire collected demographic data, educational level, age group, gender, age, and employment status of the participants. Additionally, general questions about Crohn's disease and

ulcerative colitis were included.(see appendix)

Statistical analyses:

Data were expressed as frequencies and percentages for categorical variables and as means and standard deviations for continuous variables. Every correct response to each question was assigned one point, while wrong answers were assigned zero point which were then added to calculate the total score. One-way ANOVA analysis was applied to compare means among different groups. All P values < 0.05 were considered statistically significant. IBM SPSS (Statistical Package for the Social Science; IBM Corp, Armonk, NY, USA) was used to carry out all statistical analyses, version 26 for Microsoft Windows.

Ethical considerations:

All participants were provided with detailed information about the study, and only those who voluntarily consent were recruited. Confidentiality was maintained, and the patients were identified by research serial number only. Ethical approval was obtained from King Abdullah Medical City, Makkah institutional review board that accredited by Association for the Accreditation of Human Research Protection Program.

Results

Only participants who finished all the questions in the questionnaire were included. One thousand eight hundred and nine from the Western region in Saudi Arabia answered the questionnaire, of these five hundred and five were incomplete and excluded. One thousand three hundred and four participants were hence, included in the final analysis. The demographics of participants and analysis of the questionnaire are shown below.

General Characters of responders:

Out of 1304 participants, age was categorized into six age groups, starting with age below 20 years old, and ending with age above 60 years old, most of the responders (35.4%) were from the age group between 21 and 30 years old, the average age of responders among the whole cohort was 34.19 ± 14.02 . Additionally, 64.2% of the whole cohort were females.

Turning to educational level, only 0.8% of the responders were illiterate, while 54.4% had a bachelor's degree. Also, 41.2% were employed. All Demographic data is shown in detail in Table 1.

Table 1
Socio-demographic data of responders to the questionnaire.

Parameters		Count	Percent
Gender	Male	467	35.8
	Female	837	64.2
Age group	< 20 years	206	15.8
	21 to 30	462	35.4
	31 to 40	229	17.6
	41 to 50	210	16.1
	51 to 60	147	11.3
	> 60 years	50	3.8
Employment status	Employed	537	41.2
	Unemployed	200	15.3
	Retired	68	5.2
	Student	361	27.7
Educational Level	Illiterate	10	0.8
	Primary	15	1.2
	Intermediate	47	3.6
	Secondary	415	31.8
	Bachelor	709	54.4
	Masters	69	5.3
	PhD	39	3.0
*138 (10.6%) responses were present			

Awareness about the Crohn's disease

Participants were asked a set of questions to identify their awareness of Crohn's disease. It has been shown that 29% of the responders did not hear or read about the disease, while 32.4% got some information about Crohn's disease. Moreover, 37.1% of the responders knew that Crohn's disease affects the intestine, while a quarter of the responders (25%) knew that there is a medical treatment for Crohn's disease as shown in Table 2.

Table 2
Responses towards awareness about Crohn's disease.

Responses		Score assigned	Count	Percent
Did you hear, read or deal with Crohn's disease?	I did not hear or read about it	0	378	29.0
	I heard about it somewhere	1	268	20.6
	I got some information about it	1	423	32.4
	I dealt with somebody with the disease	1	95	7.3
	I do not know	0	140	10.7
Chron's disease can affect	Head	0	14	1.1
	Heart	0	5	0.4
	Liver	0	18	1.4
	Intestine	1	484	37.1
	It is an infectious disease	0	285	21.9
	I do not know	0	498	38.2
Is there medical therapy for Chron's disease	Yes	1	326	25.0
	No	0	222	17.0
	I do not know	0	756	58.0
Total score		3		

Awareness about the ulcerative colitis

Like Crohn's disease, participants were asked three questions on ulcerative colitis to evaluate their awareness of the disease as shown in Fig. 1,2 Around 19% of the responders did not hear or read about the condition, while 27.5% heard about it somewhere. Moreover, 73.8% of the responders knew that ulcerative colitis affects the intestine, and 52.5% of the responders did not know if there is a treatment for ulcerative colitis, as shown in Table 3.

Table 3
Responses towards awareness about Ulcerative colitis.

Responses		Score assigned	Count	Percent
Did you hear, read or deal with Ulcerative colitis	I did not hear or read about it	0	248	19.0
	I heard about it somewhere	1	358	27.5
	I got some information about it	1	318	24.4
	I dealt with somebody with the disease	1	165	12.7
	I do not know	0	215	16.5
Ulcerative colitis disease can affect	Head	0	2	0.2
	Liver	0	21	1.6
	Intestine	1	963	73.8
	It is an infectious disease	0	16	1.2
	I do not know	0	302	23.2
Is there medical therapy for Ulcerative colitis	Yes	1	479	36.7
	No	0	141	10.8
	I do not know	0	684	52.5
Total score		3		

Awareness of inflammatory bowel diseases

The total score for correct answers was calculated and compared over different variables; the average score was 1.72 ± 1.19 , with a minimum score of 0 and a maximum score of 3. The comparison revealed a significant difference between males and females, where females showed a significantly higher average score than males (p -value < 0.001). Also, different age groups had a significantly different awareness of inflammatory bowel disease (p value = 0.002), with the age group between 31 to 40 showing the highest average score. Moreover, the awareness level differed significantly over different educational levels. Participants with a Ph.D. showed significantly higher mean scores compared to the other educational degrees (p value < 0.001)

Furthermore, participants who dealt with Crohn's disease patient or ulcerative colitis patients showed significantly higher scores compared to their peers, with p values < 0.001 for both, as shown in Table 4.

Table 4
Awareness level compared over different variables

		Mean	SD	Minimum	Maximum	P-value
Gender	Male	1.47	1.14	0.00	4.00	< 0.001*
	Female	1.87	1.20	0.00	4.00	
Age categories	< 20 years	1.48	1.05	0.00	4.00	0.002*
	21 to 30	1.79	1.22	0.00	4.00	
	31 to 40	1.89	1.24	0.00	4.00	
	41 to 50	1.79	1.24	0.00	4.00	
	51 to 60	1.66	1.20	0.00	4.00	
	> 60 years	1.38	0.92	0.00	4.00	
Employment status	Employed	1.84	1.27	0.00	4.00	0.06
	Unemployed	1.67	1.18	0.00	4.00	
	Retired	1.62	1.12	0.00	4.00	
	Student	1.67	1.10	0.00	4.00	
Educational Level	Illiterate	1.50	1.27	0.00	3.00	< 0.001*
	Primary	1.00	1.13	0.00	4.00	
	Intermediate	1.72	1.19	0.00	4.00	
	Secondary	1.53	1.12	0.00	4.00	
	Bachelor	1.79	1.18	0.00	4.00	
	Masters	1.84	1.37	0.00	4.00	
	PhD	2.77	1.31	0.00	4.00	
Did you hear, read or deal with Crohn's disease	I did not hear or read about it	1.29	1.09	0.00	4.00	< 0.001*
	I heard about it somewhere	1.67	1.08	0.00	4.00	
	I got some information about it	2.08	1.15	0.00	4.00	
	I dealt with somebody with the disease	2.57	1.19	0.00	4.00	
	I do not know	1.36	1.19	0.00	4.00	

		Mean	SD	Minimum	Maximum	P-value
Did you hear, read or deal with Ulcerative colitis	I did not hear or read about it	1.07	1.02	0.00	4.00	< 0.001*
	I heard about it somewhere	1.78	1.09	0.00	4.00	
	I got some information about it	2.37	1.00	0.00	4.00	
	I dealt with somebody with the disease	2.43	0.97	0.00	4.00	
	I do not know	0.89	1.06	0.00	4.00	
*P value at level of significance < 0.05						
#138 (10.6%) responses were present						

Discussion

Since the incidence of IBD is rising world-wide with cure in sight, it is imperative to recognize and diagnose the disease at a early stage to ensure effective control of the disease and avoid complication. In this context, it is important to know the awareness of the lay public about IBD and identify any ignorance that may help to implement appropriate education plan. This in order may enlighten the lay person to seek prompt healthcare assistance for early diagnosis. Hence, the present study aimed to assess the awareness of the general population in Saudi Arabia towards inflammatory bowel diseases (CD and UC). The study demonstrated that the average score of our population was 1.72 ± 1.19 , with a minimum score of 0 and a maximum score of 3.

There was a significant difference between males and females, were females showed a significantly higher average score compared to males (p-value < 0.001) and, different age groups had a significantly different awareness of inflammatory bowel disease (p value = 0.002), with the age group between 31 to 40 showing the highest average score.

Moreover, the awareness level differed significantly over different educational levels. Participants with a Ph.D. showed significantly higher mean scores compared to the other educational degrees (p value < 0.001),. Furthermore, participants who dealt with CDr or UC patients, showed significantly higher scores than their peers, with p values < 0.001 for both.

Disease specific knowledge of IBD patients has been widely studied in different countries using a validated questionnaire of Chrons and Colitis Knowledge score [13]. The knowledge of IBD, in addition has been evaluated in specific setting like primary health care. Alharbi et al noted that the knowledge level of 200 primary care physicians in the western region of KSA was low (Leong Knowledge mean 5.53)

and through education of IBD the awareness improved (mean 6.62) significantly ($p = 0.002$). IBD specific education did translate into better management, by making physicians more comfortable at using specific IBD therapy like steroids and immunomodulators (OR = 8.25 and 6.03, respectively). Moreover, physicians with higher qualification were much more comfortable in prescribing medicines for IBD [14]. However, in another study by Tan et al carried out in Australia showed that the Leong knowledge score among 409 PHC physicians was higher with median scores of 9, even without being educated on IBD specific knowledge [15]. These difference could be due to various reasons. PHC physician in Australia usually look after stable chronic disease patients like IBD, this is not the case in KSA. The lower prevalence of IBD, minimal availability of information in Arabic language and patient supportive organizations may be the other reasons.

However, there is scarcity of literature evaluating the awareness of inflammatory bowel disease in the general public. We identified only a couple of studies that did evaluate awareness of the public about IBD. Groshek et al carried out a national on-line survey of 1200 participants in United States of America on the awareness of IBD and demonstrated that the lay public scored a mean of 5.5 (SD 2.7) on “familiarity” scale of 10 and was considered to be a low score. In addition, low awareness was associated with high stigmatization of IBD, that was worse than other diseases like alcoholism and HIV. Furthermore, the level of knowledge was tested on 12 questions of causes, symptoms and cures of IBD and only 55% (mean 6.58/12) responded correctly with 86% responding inappropriately to nearly 8 of the 12 questions. Though those with higher education had statistically better score. [16]. Our study showed a similar level of knowledge among the public ($1.73/3 = 57\%$), that was significantly better in people with higher qualification.

Another study, a nation-wide survey by Angelberger et al. evaluated the public awareness towards IBD in 1001 individuals from the Austria and concluding that the knowledge of the population was poor [12]. 69% and 80% had not heard or didn't know about CD and UC respectively, similarly 64% and 73% did not know the organ affected by CD and UC, respectively. In contrast, only 40% and 36% of our study population had not heard or didn't know about CD or UC, respectively, and only about a third did not know the organ affected in CD or UC. These difference may be a reflection of a high proportional of females and younger participants in our study who were more knowledgeable. In addition, the survey in Austria was exclusively in person, whereas our study used a combination of personal and on-line survey.

Though our questionnaire used to test public awareness has not been externally validated, it nevertheless does capture the basic knowledge that might be accepted of a lay person and has been previously used. In addition, the questionnaire lacked a clear cut-off score to identify appropriate level of awareness. This is a challenge that questionnaire based studies like these face [13]. Nevertheless, this study may inspire further such research with refinement leading to more accurate questionnaires.

Conclusion

This is the first study to evaluate the awareness of the Saudi population towards inflammatory bowel disease and showed a low level of awareness among different community sectors. Males, young adults, highly educated individuals who dealt with patients previously had better awareness compared to the rest of the population.

These findings reveal the basic awareness of IBD among the public in KSA and should be considered by decision-makers and societies to organize campaigns for the general public to improve their awareness of the disease, which will have positive implications on the early diagnosis and treatment of the disease and reduce health care costs.

List Of Abbreviations

IBD	Inflammatory bowel disease
KSA	Kingdom of Saudi Arabia
UC	Ulcerative colitis
CD	Crohn's disease

Declarations

Ethical approval and consent to participate

Ethical approval was obtained from King Abdullah Medical City, Makkah institutional review board that accredited by Association for the Accreditation of Human Research Protection Program. The consent taken was verbal from the participant and approved by ethics

Consent for publication

Consent for publication was obtained from King Abdullah Medical City, Makkah institutional review board.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding Sources

There was no financial support.

Authors' contributions

YM participated in sequence alignment, coordination, data collection, wrote the paper and finalized the final draft of manuscript. AA, MM, YQ, MA, AT, ME, AN, GA participated in data collection and wrote the paper. MK participated in analysis sequence alignment, coordination and reviewed the final draft of manuscript All authors read and approved the final manuscript.

Acknowledgement

Not applicable

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Figures

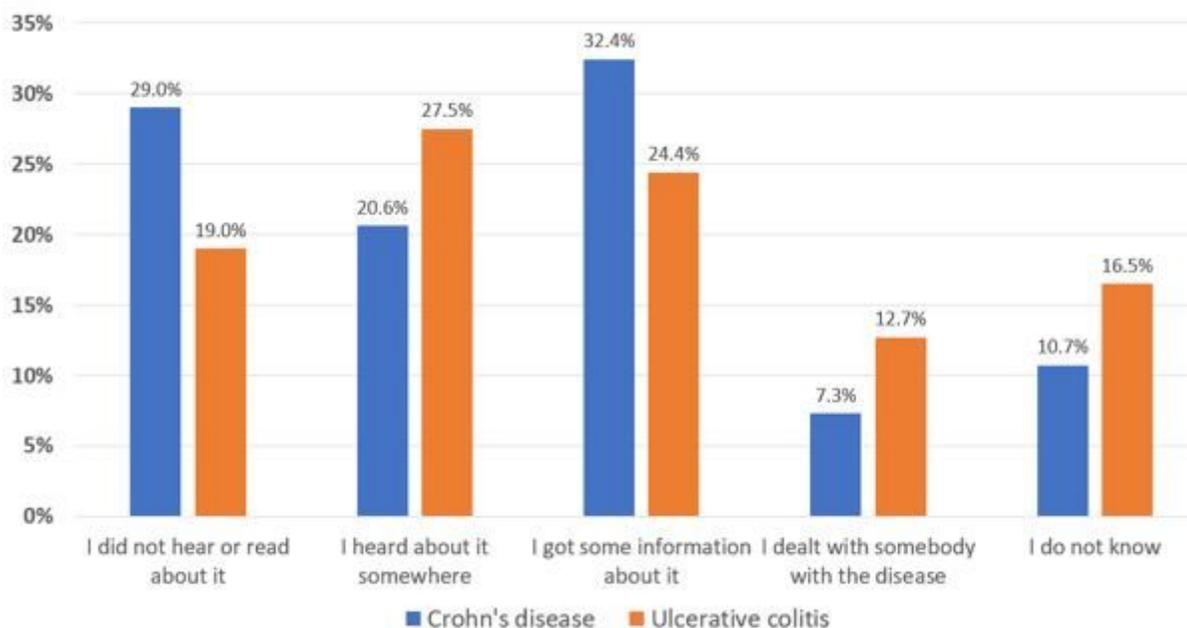


Figure 1

Did you hear, read or deal with Crohn's disease/ Ulcerative colitis

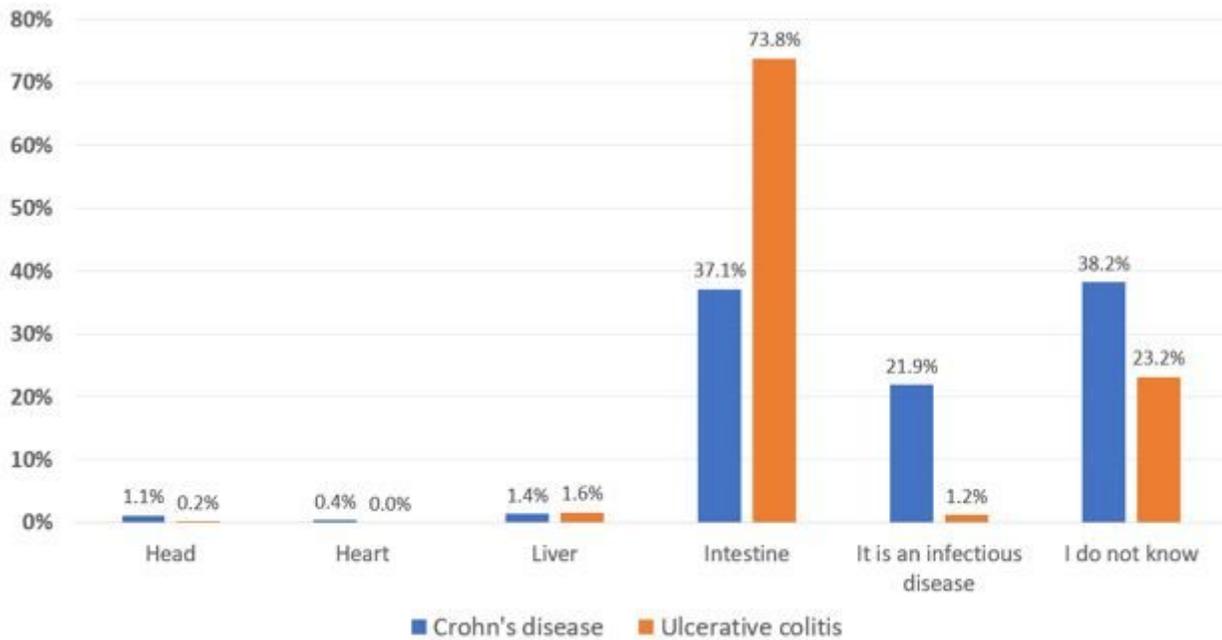


Figure 2

What does Crohn's disease/ Ulcerative colitis affect?

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [appendixIBD.docx](#)