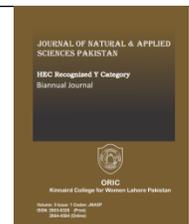




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LACK OF AWARENESS OF CELIAC DISEASE IN PAKISTAN

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Abstract

Celiac disease (CD) is an autoimmune disorder in which an individual's immune system attacks their own intestine upon gluten ingestion. It is inherited so if a person has an affected parent or sibling the chances of them getting celiac would be particularly high. Due to the lack of awareness and misdiagnosis, most of people don't get any proper treatment throughout their life and may suffer from many complications. In Pakistan itself, about 1-3% of the population has celiac disease but 90% of them never get diagnosed throughout their lives. This study explores the level of awareness in population of Pakistan including its incidence rate, misdiagnosis and the facilities provided by the health care system. Primary data of awareness level in the general population was collected via an online survey and the data regarding the availability of facilities was collected through interviews with MBBS doctors. The data was analysed using simple chi-square test in association with demographics, to predict the awareness level of celiac disease. Logistic Regression model was also performed. A total of 283 participants filled the questionnaire and almost 40% of the participants claimed to know CD while 60% didn't, and these findings mimicked a survey conducted in Turkey. Chi-square test was performed between awareness of celiac disease and the various demographic categories, and we obtained significant p-values ($p < 0.05$) for gender and education. The factors that were significantly associated with the awareness of celiac disease included media awareness, information about what is celiac disease, seriousness of gluten intolerance, inheritance of celiac disease, as well as information about the cure of CD. The results of binary logistic regression revealed that awareness through media platforms, knowledge about gluten, treatment of Celiac, and inheritance of celiac disease are significant variables. Doctors admitted that rate of CD is high due to misdiagnosis and can cause serious complications if not treated. They proposed the utilization of social media to increase awareness.

Keywords

Celiac Disease, Chi-Square Test, Lack of awareness, Gluten Free Products



1. Introduction

1 in 100 people have Celiac disease but only 25% of these individuals are ever correctly diagnosed (What is Celiac Disease?). Specifically in Pakistan, 1-3% of the population is celiac patients (Rashid & Khan, 2009) but they often go undiagnosed. However, most studies believe that CD-related data for the Pakistani population is insufficient to conclude actual incidence rates as they are likely under estimations of the true numbers. CD is an autoimmune condition wherein the immune system, in response to gluten ingestion, unleashes antibodies on the immune system, causing inflammation and malabsorption of nutrients. Gluten is found in wheat, rye, barley as well as many commercial products including skin and hair essentials, toothpastes, lip balms, vitamins and supplements.

Although different people are differently affected by CD, the disease generally manifests as diarrhoea, nausea, stomach pain and cramping, bloating, permanent sense of fatigue, anaemia, weight loss, recurring mouth ulcers and even constipation. Disease symptoms also vary depending on whether the affected individual has the classical or non-classical type of CD. Classical CD is heavily characterized with diarrhoea-like symptoms in addition to malabsorption while the non-classical variation is distinguished by anaemia. Silent CD, on the other hand, is an asymptomatic form of the disease.

CD is hereditary and there is no specific age of onset and it can develop whenever the individual is exposed to disease triggers. If left

undiagnosed or untreated, Celiac can lead to several complications including but not limited to infertility and miscarriage, lactose intolerance, neurological anomalies such as ataxia, dementia, migraine, epileptic attacks, CNS and PNS disorders, and vitamin and mineral deficiencies. In Pakistan alone, 90% of CD affected individuals remain undiagnosed (Rashid & Khan, 2009) their entire life, having to suffer in silence. The only effective treatment at present is a lifelong gluten prohibition in the patient's diet.

2. Materials & Methods

This study aimed to assess the level of awareness of celiac disease in the population of Pakistan. The target population comprised of individuals belonging to different age groups and educational levels. Most of the respondents belonged to Lahore but other cities and districts were also covered. Online questionnaires distributed via Google Forms were used. Snowball sampling was used for data collection. The total number of respondents was 283 including both males and females. The tests that were applied on the data were chi-square test and logistic regression models to check the level of awareness of celiac disease. The analysis of data was done using IBM® SPSS 26.0.

We also interviewed around 10 MBBS doctors to check the level of awareness of medical practitioners and to access their perceived level of awareness of the general public. For this purpose, we picked a few questions from the questionnaire in addition to some questions about the misdiagnosis of CD, the available

managerial facilities as well as how we can raise awareness about CD.

We will survey a wide demographic of individuals including people of different age groups, educational levels and social classes of Pakistan about Celiac Disease its incidence, causes, symptoms and the quality of life of CD patients. The data collected will be used to assess:

- The level of awareness in the Pakistani people regarding Celiac Disease
- Incidence rates and statistics of unreported cases of the disease
- Reasons for the lack of awareness in the population regarding CD
- Misdiagnosis of CD
- Comparative analysis of the response from people of different demographic backgrounds
- Treatment and managerial facilities in Pakistan for patient care
- Potential solutions to improve the situation
- We will also strive to raise awareness about CD in the research participants

3. Results

The results of the study are summed up as follows.

3.1 Demographic Characteristics

A total of 283 participants took part in filling the questionnaire. The data was analysed using SPSS software. The Percentage of female participants was 84.1%, Percentage of males was 15.5%, whereas 1 participant preferred not to tell their gender. People from different age groups ranging from 15 years and above, were included in the survey, the highest percentage

about 47.3%, of the participants belonged to the age group 21-25 years. The educational level of participants was Matric/O-level, Intermediate/A-level, Bachelors, M.Phil., PhD, MBBS. About 69% of the participants field of study was related to science. Demographic characteristics of the participants are given in Table 1. People from different cities were included in the survey; responses were collected from 29 cities of Pakistan (Table 2).

Table 1: Demographic Characteristics

Demographic Properties		Percentages
Gender	Male	15.5%
	Female	84.1%
	Prefer not to say	0.4%
Age	15-20	41.3%
	21-25	47.3%
	26-30	6.0%
	31-35	2.1%
	36-40	0.7%
	41-45	0.4%
	46 & Above	2.1%
Educational Level	Matric/O-level	3.9%
	Intermediate/A-level	17.0%
	Bachelors	66.8%
	M.Phil.	5.7%
	PhD	4%
	MBBS	6.4%
Science Majors	Yes	68.9%
	No	31.1%

Table 2: Percentages of Participants in Accordance to Cities

Cities	Percentages
Wazirabad	0.7
Toba-Tek-Singh	2.1
Sialkot	2.5
Sheikhupura	1.8
Shakargarh	1.8
Sargodha	0.7
Sangla hill	0.4

Sahiwal	0.4
Rahim yar khan	0.4
Peshawar	0.4
Okara	3.2
Noorkot	0.4
Muridke	0.4
Multan	1.8
Lahore	64.0
Khanewal	0.4
Kasur	0.7
Karachi	1.4
Kamalia	0.7
Jhang	0.4
Islamabad	0.4
Haroonabad	0.7
Hafizabad	1.8
Gujrat	0.4
Gujranwala	6.7
Faisalabad	1.1
Chishtian	1.4
Bahawalpur	3.2
Bahawalnagar	0.4

3.2 Awareness of Celiac Disease

Out of the total 283 participants who were asked if they have ever heard about celiac disease in the questionnaire approximately 40% of the individuals claimed that they have some awareness about celiac disease whereas about 60% had never heard of it. The results showed similarity to the results of a survey conducted in Turkey where 50.9% of the participants were aware about celiac disease (Taşkin & Savlak, 2020). When asked about the knowledge about gluten, about 64.3% were aware about gluten, 22.3% were unaware and 13.4% answered maybe. When participants were questioned, what do you think Celiac Disease is all about? 14.8 % choose food allergy, 7.4% choose GI tract issue, 69.3 % choose Gluten Intolerance, 8.5% choose Wheat allergy. About 48 % individuals responded that celiac disease is a serious condition. 24.7% of the participants had a

point of view that celiac disease can be permanently cured. Approximately 30% of the participants answered yes, when questioned if celiac disease can be inherited. To check the knowledge about incidence of celiac disease in Pakistan, 66.8% answered 1-3 percent incidence rate, 20.5% answered 50 percent and 12.7 % answered less than 1 percent. When asked about the symptoms of the disease, most people choose diarrhoea, stomach pain, nausea, bloating and weight loss.

Table 3: Questions about Awareness of Celiac Disease

Questions	Responses in Percentage %	
	Yes	No
Have you heard of Celiac Disease before?	Yes	40.3
	No	59.7
Do you know what gluten is?	Yes	64.3
	No	22.3
	Maybe	13.4
What do you think Celiac Disease is all about?	Food allergy	14.8
	GI tract issue	7.4
	Gluten Intolerance	69.3
Do you think it is a serious issue?	Wheat allergy	8.5
	Yes	48.1
	No	2.8
Do you think Celiac Disease can be permanently cured?	Maybe	49.1
	Yes	24.7
	No	19.8
Do you think Celiac can be inherited?	Maybe	55.5
	Yes	29.0
	No	26.1
Predict the incidence rate of Celiac Disease in Pakistan	Maybe	44.9
	1-3%	66.8
	50%	20.5
	Less than 1%	12.7

Relationship between Awareness of celiac disease and demographic factors along with the various factors was tested using Chi-square test. Table 4. Amongst Demographics, gender, educational level was significantly related ($p < 0.05$) to the awareness of celiac disease. The factors that were significantly associated with awareness about celiac disease included, media awareness, information about what is celiac disease, seriousness of gluten intolerance, inheritance of celiac disease, information about cure of celiac.

3.2 Binary Logistic Regression

To predict the awareness of Celiac disease, Logistic Regression was performed through SPSS on the following factors:

- Gender
- Field of study related to science
- Having heard about Celiac Disease in TV shows, newspapers or any seminars
- Knowledge about gluten
- Treatment of celiac disease
- Inheritance of celiac disease

The Pseudo R² values, the variance of awareness of celiac disease (Dependent variable). The Nagelkerke R squared value is 0.450 which indicates that the model is good. The value of Cox & Snell Square indicates that probability of events of awareness of celiac disease is 33.3%

The null hypothesis was evaluated by the Hosmer-Lemeshow test. The insignificant value of Chi-square test at 0.235 indicates that the null hypothesis is incorrect and the data is suitable for the model. The correctly classification cases were 75.3%.

Table 5 shows the results of binary logistic regression. The table indicates that factors: awareness through media platforms, knowledge about gluten, treatment of Celiac, and inheritance of celiac disease are significant. These variables add significantly to the model. The odds of participants not knowing about gluten were 3.104 times higher. Likewise, chances of people knowing that celiac can be permanently cured were 0.383 lower whereas 0.470 odds were higher in people with awareness about the factor that celiac disease can be inherited. The factor about media awareness was positively associated with awareness about celiac disease.

3.3. Awareness about Gluten Free Products

Participants were asked about their awareness and availability of gluten free products for celiac patients. Approximately 34% of the participants responded yes to the question, 'Do you think gluten-free products are widely available?' When participants were asked that, 'Have you ever seen gluten-free dishes on restaurant menus?' Only 19.1% responded yes.

Table 4: Chi-Square Test between Level of Awareness and Significant Factors

Variables	Categories	P-value
Gender	Male Female	0.009
Education level	Matric/O-level Intermediate/A-level Bachelors, MPhil, PhD, MBBS	0.004
Is your field of study is related to science	Yes No	0.001
Have you ever heard about Celiac Disease in TV shows, Newspapers or any seminars, etc.?	Yes No	0.000
What do you think Celiac Disease is all about?	Food Allergy GI Track issues Gluten intolerance Wheat allergy	0.000
Do you think it is a serious issue?	Yes No Maybe	0.000
Do you know what gluten is?	Yes No Maybe	0.000
Have you ever felt abdominal pain, vomiting or diarrhea after eating gluten rich foods?	Yes No Maybe	0.000
How serious do you think Celiac Disease is?	1 2 3 4 5	0.001
Do you think Celiac Disease can be permanently cured?	Yes No Maybe	0.000
Do you have gluten intolerance or do you know someone who does?	Yes No Maybe	0.000
Do you think Celiac can be inherited?	Yes No Maybe	0.000
Have you ever seen gluten-free dishes on restaurant menus?	Yes No Maybe	0.000

Table 5: Binary Logistic Regression Analysis for Awareness of Celiac Disease

VARIABLES	BETA	P VALUE	ODDS RATIO
Have you ever heard about celiac disease in tv shows, newspapers or any seminars, etc.?	-2.983	0.000	0.051
Do you know what gluten is?	1.133	0.49	3.104

Do you think celiac disease can be permanently cured?	-0.961	0.16	0.383
Do you think celiac can be inherited?	-0.756	0.040	0.470

Table 6: Questions about Awareness of Gluten-Free Foods

Questions	Response in percentage (%)	
Do you think gluten-free products are widely available?	Yes	33.6
	No	35.0
	Maybe	31.4
Have you ever seen gluten-free dishes on restaurant menus	Yes	19.1
	No	53.0
	Maybe	27.9

3.4 Doctors' Responses

The doctors that we interviewed were generally aware of Celiac disease. However, they admitted that the misdiagnosis rate of the disease is very high due to the fact that its symptoms are very similar to other GI-associated diseases. Also, most doctors believed that the disease is quite serious if complications occur. Nevertheless, most doctors were unaware of the fact that Celiac can be inherited. Furthermore, they said that gluten free products are not very widely available and even if they are, they are quite expensive. There are no specific managerial facilities available to celiac patients. The majority declared social media as an effective medium for creating awareness. Additionally, most doctors were of the opinion that awareness should be raised in educational institutes as well if we want to efficiently tackle the lack of

awareness.

4. Discussion

We aimed to check the level of awareness of Celiac Disease in the general Pakistani population as well as medical practitioners. The findings revealed some interesting facts. While most respondents claimed to know about Celiac disease, their responses said otherwise. Around 64 percent of respondents claimed to know what gluten was but many of them could not correctly identify the gluten rich foods. However, a majority of these respondents had not been exposed to Celiac patients. Almost half of the participants believed they could not live without gluten at all. Surprisingly, of all the respondents, MBBS students said that they hadn't heard of the disease even though it is more relevant to their field of study.

From the doctors that we interviewed, we

gathered that they had a general idea of the disease and its symptoms but most of the interviewees did not really know a lot about the different types of CD as well as asymptomatic individuals. When asked, one of the doctors revealed that the types of CD were not really focused upon during their education. Similar to a study from the United States, most of the physicians we identified diarrhoea as the main symptom but not abdominal pain, fatigue and depression (Robert & Zipser, 2005).

Moreover, only a few doctors were aware of the genetic predisposition of CD. They also admitted that the misdiagnosis rates were extremely high and there were no particular managerial facilities available for CD. And while there is no treatment or cure for Celiac disease, the enzyme and protein cocktail DPP IV (dipeptidyl peptidase IV) can be used to alleviate symptoms in case of occasional exposures (Sumaira, 2017) but the physicians were not aware of this.

Studies in the past have identified the need for increased awareness regarding Celiac, such that medical practitioners should be able to recognize the variable clinical presentations of the disease because it is a widespread public health problem for developing countries (Francesco, 2007), especially one like Pakistan whose staple diet includes high levels of gluten. The doctors in this study proposed to raise awareness in educational institutes and through social media channels. Overall, both the doctors as well as the

general public agreed that gluten free food options are not widely available in Pakistan. Previous studies have also indicated that there is no regulation of food labels in Pakistan and the general public does not fully know how to read labels which is also a problem when looking for gluten free food options (Sumaira, 2017).

5. Conclusion

Celiac disease is a serious autoimmune disorder that can cause immune response to gluten in result of which inflammation and mal absorption of nutrients occurs. It is common but often misdiagnosed in Pakistan. Most of Pakistani population is unaware of celiac disease but the doctors are largely aware with basic knowledge of CD. There should be more seminars, conferences, TV shows and news articles related to CD to create awareness in the general public regarding Celiac Disease. Moreover, this would also be helpful to prevent misdiagnosis.

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