Original Article

Prevalence of Risk Factors for Non-Compliance in Serologically Diagnosed Celiac Patients

Asad ur Rahman Javed[1], Sahar Gull[1], Ishfaq Hussain[2] and Ahsanullah M. Mirbahar[3]

ABSTRACT

Objective: To investigate the prevalence of risk factors for non-compliance in serologically diagnosed celiac patients.

Study Design: Observational / descriptive study.

Place and Duration of Study: This study was conducted at the Department of Pediatric Medicine, Nishtar hospital, Multan, from March 2016 to February 2017.

Materials and Methods: A total number of three hundred and twenty nine (n=329) patients selected for study. Data was analyzed with the use of SPSS version 23.1. Categorical variables like gender and predictors of non-compliance were calculated and presented as frequencies and percentages and numerical variables like age were presented as mean ± SD. Chi square test was applied to see effect modification. P value ≤ 0.05 was labeled as significant.

Results: A total number of 100% (n=329) patients were included in this study, both genders. Gender distribution showed that there were more males i.e. 55.9% (n=184) and 44.1% (n=145) were females. The mean age of the patients was 7.54 ± 3.22. The main outcome variable of this study was Non-Compliance and it was observed that non-compliance was found 38.3% (n=126) in patients.

Conclusion: This study investigates the frequency of non-compliance in celiac patients and also identified the risk factors associated with non-compliance, finding of this study provide foundation to overcome these factors.

Key Words: Celiac disease, Serology, Non-compliance, Risk factors.

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INTRODUCTION

Celiac disease is a common cause of malabsorption worldwide especially those of European decent making it a most common cause of genetically related malabsorption. Genetic, environmental and immunological factors are the main suspected etiological agents indicating the multifactorial nature of this disease[1]. Celiac sprue is initiated by an environmental factor named gliadin which is a component of gluten and related prolamins. Gluten is found in wheat, barley, rye and oats. Whenever gluten containing substances are ingested by genetically susceptible individuals, an autoimmune response against tissue transglutaminase is commenced leading to progressive flattening of the small intestinal mucosa. Silent, potential, latent or symptomatic celiac disease are the various types of manifestation of celiac disease[2].

[1.] Department of Medicine, Bakhtawar Amin Medical and Dental College, Multan.
[2.] Department of Pediatric Medicine / PHRC Research Center[3], Nishtar Medical College, Multan.

Correspondence: Ahsanullah M. Mirbahar, PHRC Research Center, Nishtar Medical College, Multan.
Contact No: 0300 3180 513
Email: meerbahar@gmail.com

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Gluten is largely indigestible owing to its complex macromolecular structure rich in proline and glutamine. Glutenins and gliadins are the alcohol-water soluble fractions of gluten. Gliadins can be segregated in to its alpha, gamma and omega fractions on the basis of electro density[3]. 90 to 95% specificity and sensitivity of serological tests for detecting celiac disease in symptomatic, minimally symptomatic or even asymptomatic individuals have paved the way for calculating the true prevalence of celiac disease[4]. In North America, high prevalence of celiac disease amounting to almost 1% of the general population was narrated by several screening studies[5,6]. Additionally, a dramatic increase in the prevalence of celiac disease is observed during the past few decades[7,8.] In an epidemiological investigation conducted in Northern Sweden, a prevalence of almost 2% was found by using a combined serological/endoscopic approach in a population of 1000 adults[9]. Chronic diarrhea, weight loss, anorexia, abdominal distension, vomiting, abdominal pain are the typical manifestation of celiac disease in young children and infants. The sole treatment of a patient with celiac disease is lifelong avoidance of gluten ingestion. Though a daily dose of > 10 mg is likely to cause mucosal reaction, wheat, rye, oats, barley and their products should be avoided as completely as possible[10]. A strict gluten-free diet typically resolves gastrointestinal symptoms in a symptomatic patient within a few weeks. Normalization

of hematological and biochemical parameters with improved height and weight follows the adherence to gluten free diet in a patient diagnosed with celiac disease. A study conducted by Margot L on celiac disease patients showed that, out of all patients, at least one negative follow-up serology was seen in 50% of patients and at least one positive follow-up serology was found in 27% of patients. Moreover, only 69%[11] of patients were documented to have good compliance.

This study was done to provide basic literature on the prevalence of risk factors for non-compliance in patients diagnosed with celiac disease and to help respective doctors in devising different strategies in order to minimize non-compliance. To this point, no local study is available on this topic despite the high prevalence of celiac disease.

MATERIALS AND METHODS

This descriptive study was conducted in department of Pediatric Medicine, Nishtar hospital, Multan, from March 2016 to March 2017. After approval from ethical committee of Nishtar hospital, Multan. Informed consent was taken from patient's guardian before including patient's data in research and they were ensured about the confidentiality of this information. Patient's addresses and telephonic contacts were taken. All aseptic measures were taken in order to collect and transport blood in BD Vacutainer for serology. Risk factors for non-compliance (medical illness, economical burden, religious norms, and unavailability of gluten free diet) were noted on follow up by researcher himself. All the collected data was entered on a Performa for every patient. Patients with complaint of abdominal pain, chronic diarrhea and positive serological test were labeled as celiac patient. Medical illness (hypertension, diabetes etc.), patient's behavior (economic burden, prolong treatment etc.), religious norms and unavailability of gluten free diet which make the patients difficult to follow prescription were labeled as risk factors for non-compliance. Patients whose parents were not willing to give permission and those with age of <2 years or > 14 years were excluded from our study. SPSS version 10 was the computer software used for entering and analyzing all the collected data. Mean and standard deviation was calculated and presented for quantitative variables like age. Frequency and percentage was calculated and presented for qualitative variables like gender and risk factors (Medical illness, patient's behavior, religious norms, unavailability of gluten free diet). Effect modifier like gender was controlled by stratification of data. Post stratification chi square test was applied to see effect modification. A p value <0.05 was considered statistically significant.

RESULTS

A total number of 100% (n=329) patients were included in this study, both genders. Gender distribution showed that there were more females i.e. 55.9% (n=184) and 44.1% (n=145) were males. The mean age of the patients was 7.54 ± 3.22 (Table-1).

The main outcome variable of this study was Non-Compliance. Out of 100% (n=329) patients, in our study, it was observed that non-compliance was found 38.3% (n=126) in patients. It was also noted that out of 100% (n=329) patients, 16.7% (n=55) were having background of medical illness and 83.3% (n=274) patients presented without any medical illness. In these patients 31.6% (n=104) patients were non-compliant due to their behavior. A major reason of non-compliance in our study was religious norms, 40.4% (n=133) patients were non-compliant because of religious norms and 70.8% (n=233) were because of unavailability of gluten free diet (Table-2).

When patients were grouped into different age categories, it was noted that a majority of patients i.e. 51.7% (n=170) were aged from 2 to 7 years of age and 48.3% (n=159) were aged from 8 to 14 years of age. When Chi-Square was applied to check the effect modification, it was noted that gender, medical illness, patients behavior, religious norms, unavailability of gluten free diet and stratified age were significantly associated with non-compliance with P-values 0.000, 0.000, 0.000, 0.001, 0.007 and 0.025 respectively (Table-3).

A total number of 100% (n=329) patients were included in this study, both genders. Gender distribution showed that there were more males i.e. 55.9% (n=184) and 44.1% (n=145) were females. The mean age of the patients was 7.54 ± 3.22 (Table-1).

The main outcome variable of this study was Non-Compliance. Out of 100% (n=329) patients, in our study, it was observed that non-compliance was found 38.3% (n=126) in patients. It was also noted that out of 100% (n=126) patients, 15.1% (n=19) were having background of medical illness and 84.9% (n=107) patients were presented without any medical illness. In the Non-Compliance patients, 31% (n=39) patients were non-compliant due to their behavior. A main reason of non-compliance in our study was religious norms also, 30.2% (n=38) patients were non-compliant because of religious norms and 23.8% (n=30) were because of unavailability of gluten free diet (Table-2).

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Table No. 1: Demographic Variables

Characteristics	Frequency n=329	Percentage (%)
Gender		
Male	184	55.9
Female	145	41.1
Age groups		
2-7 years	170	51.7
8-14 Years	159	48.3

Table No.2: Frequency (Percentages %) of non-compliance and its factors

Characteristics	Frequency n=126	Percentage (%)
Non Compliance		
Yes	126	38.3
No	203	61.7
Medical illness		
Yes	19	15.1
No	107	84.9
Patient Behavior		
Yes	39	31.0
No	87	69.0
Religious Norms		
Yes	38	30.2
No	88	69.8
Unavailability of Gluten free diet		
Yes	30	23.8
No	96	76.2

Table No.3: Association of non-compliance and its factors

Gender	Non Compliance		P Value
	No	Yes	
Male	88	96	0.000
Female	115	30	
Medical illness			
Yes	NIL	19	0.000
No	203	107	
Patient Behavior			
Yes	NIL	39	0.000
No	203	87	
Unavailability of Gluten free diet			
Yes	NIL	30	0.000
No	203	96	
Religious norms			
Yes	NIL	38	0.000
No	203	88	
Age Groups			
2-7 years	95	75	0.024
8-14 Years	108	51	

When Chi-Square was applied to check the effect modification, it was noted that gender, medical illness, patients behavior, religious norms, unavailability of gluten free diet and stratified age were significantly associated with non-compliance with P-values 0.000, 0.000, 0.000, 0.000, 0.024 and 0.000 respectively (Table-3).

DISCUSSION

Celiac disease is a multi-factorial disease whose only treatment is the restriction of gluten containing edible products. Parents of children suffering from celiac disease have a laborious duty to their children for maintaining their dietary compliance with gluten free die. Noncompliance to GFD in children with celiac disease is a global problem leading to increased morbidity and mortality associated with complications of untreated celiac disease. Effective counseling is the only way to ensure the required adherence. In our study, 329 patients were included with a little female predominance. Non-compliance was found only in 38.3% of patients while the remaining 61.9% of patients were compliant. This compliance rate was similar to the findings of various studies done both in and outside the India.

Our study results were in close approximation to the findings of Chauhan et al who narrated a compliance rate of 75% in 2–17 years of age group[12]. Similarly, a study done by Hill et al showed a variation of strict dietary compliance within the range of 45% to 81%[13]. Only a Canadian study done by Rashid et al had showed an exceptionally high compliance rate of 95%[14]. In our study, an overlapping trend was observed in various causes of non-compliance. Out of all the non-compliant patients, 70.8% were non-compliant because of unavailability of gluten free diet. Religious norms and behavior were the underlying causes of non-compliance in 40.4% and 31.6% of patients respectively. 16.7% of patients had a background medical illness as an excuse. Gender, medical illness, patient's behavior, religious norms, unavailability of gluten free diet and stratified age were significantly associated with non-compliance on applying chi square chart.

Age had an inverse relation with the compliance of GFD in our study. Same trend was observed in a study done by Ljungman and Myrdal[15]. Increased social interaction, outdoor activities, peer group pressure and need for experimentation are the factors responsible for increasing noncompliance in adolescence. Compliance is also related to the gender of the child in our study which is in total contrast to the finding of a study by Errichiello et al[16]. High degree of compliance is seen in children possessing positive attitude and behavior towards their condition. Dietary noncompliant group had greater difficulty in controlling the urge to violate dietary restriction at school and family party than that of dietary compliant group. Most of the food served at these places contains gluten posing a constant threat to the adherence in both dietary compliant and noncompliant groups. These findings emphasize the

need of widespread availability of gluten-free diet and its proper labeling.

A study conducted by Anson et al[17] showed a direct relation between parental knowledge and dietary compliance owing to the fact that the better informed parents were more likely to identify gluten free food. The same idea is also supported by another study. Parents' positive attitude towards the child's condition and financial status is associated with higher degree of compliance. Anson et al. had also reported similar findings[17]. Therefore, counseling with the sole purpose of increasing awareness of parents regarding disease, various cheap and acceptable food alternatives, and delicious GFD recipes is likely to result in good compliance.

No doubt that the child's feelings and social activities like eating out and travelling are affected by this dietary restriction. Rashid et al[14] and Anson et al[17] have studied the effect of personal feeling of children on the degree of non-compliance. A feeling of being left out was reported in more than 50% of children by Rashid et al.[4] These negative feelings are also one of the main reason for noncompliance in these patients. A study by Addolorato et al. have shown a decreased level of anxiety compared to the persistence of depressive symptoms on the use of GFD[18]. Anger was the predominant emotion reported in celiac patients by Ciacci et al. Chauhan JC et al. reported a statistically significant association of nuclear family to the good compliance[12]. On the other hand, Joint family with all its temptation leads to poor compliance.

Our study was limited due to the fact that we were not able to study the effect of family type, parent's income, education level and child's emotion on the compliance of celiac patient. Moreover, histological and/or serological evaluation was not used in the confirmation of compliance assessed subjectively on the basis of dietary recall. However, the role of biopsy in a better assessment of long-term compliance compared to nutritional evaluation is uncertain. Only a modest correlation of histology was found with assessed dietary compliance in several previous studies. Visual analogue scale was used to calculate long-term adherence to the gluten-free diet in a study conducted by Mustalahti in 2002[19]. Jadrešin et al. used 7-day recall of patient's intake to define compliance with GFD into strict, semi strict and not on gluten-free diet[20]. Similarly, a 4-day dietary record was used by Spatola in his study for evaluation of compliance[21,22]. Therefore, dietary recall of 5 days was used to assess compliance in our study. All subjects were interviewed repeatedly in order to uncover minor dietary lapses and hidden transgressions in their follow up visits.

However, our study results point to both obvious and obscure factors leading to non-compliance, putting them on the hit list of interventions for improving dietary adherence in celiac patients.

CONCLUSION

This study investigates the frequency of non-compliance in celiac patients and also identified the risk factors associated with non-compliance, finding of this study provide foundation to overcome these factors.

Conflict of Interest: The study has no conflict of interest to declare by any author.

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