

Assessment of Parents' and Child's Attitude as Barrier to Dietary Compliance in Celiac Disease

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Objective: To assess the attitude of parents and child as a barrier to dietary compliance in celiac disease.

Methods: 100 parents and 100 children were assessed for dietary compliance with the questionnaire based interview. The assessment of psychosocial parameters was done by standard Pediatric Symptom Checklist (PSC). Comparative analysis and assessment of dietary compliant and noncompliant groups were done for factors affecting the dietary compliance. Predictability of all factors was assessed by means of binary logistic regression analysis with backward elimination.

Results: Factors that were significantly related with compliance were age at presentation, mother's education, nuclear families, and knowledge of parents regarding celiac disease. Parents' and child's attitude towards restrictive diet and child's feelings were also important factors associated with compliance.

Conclusions: The results of research will provide health care practitioners with a framework for better dietary instruction to assure maximum adherence to GFD.

Keywords: Celiac disease (CD);barriers to dietary compliance; Gluten free diet (GFD)

I. Introduction

Celiac disease is a systemic disorder(immune-mediated) elicited by related prolamins and glutenin genetically vulnerable individuals. It is characterized by the presence of CD-specific antibodies, variable combination of gluten-dependent medical manifestations, enteropathy and HLA-DQ2 or HLA-DQ8 haplotypes [1]. In recent times, the prevalence of celiac disease across the European countries is 1.5% which is based on people who had positive TTG and biopsy results [2]. In the United States, the occurrence of CD in children up to 5 years of age is 1 in 104 [3]. The disease is quite common in India with rates of 1 in 96 in north India [4]. Lifetime adherence to a gluten-free diet is the basic treatment of celiac disease [5]. A GFD restricts all products containing the proteins from barley, rye and wheat [6]. It is strongly recommended not only to control symptoms but also to decrease the complications and improve quality of life [7]. Strict adherence to gluten-free diet may be more difficult in children and adolescents than in adults. Compliance to GFD differs from 45% to 81% in children according to the reports of the North American Society of Pediatric Gastroenterology, Hepatology, and Nutrition [8].

The major problem is noncompliance which may occur due to temptation or not liking the taste of alternative food grains and gluten-free food [9]. In teenagers, peer pressure, non-availability of gluten-free food and greater reliance of packaged foods have contributed to noncompliance [10]. Low level of knowledge about the diet among the parents leads to noncompliance in children [11]. Many children face psychological reactions like feeling anxious, deprived etc. when they are placed on a restrictive diet which leads to further decrease in compliance [12]. This research evaluates the impact of celiac disease and the gluten-free diet on the well being and lifestyle of children with celiac disease and their families.

II. Material and Methods

The present study was conducted by Department of Pediatrics, S.M.S. Medical College and attached Hospitals, Jaipur, Rajasthan, India. 100 children were enrolled in the study on basis of inclusion and exclusion criteria:

Inclusion criteria were patients aged between 2 to 15 years, children with celiac disease as per Revised ESPGHAN criteria 1990 [13] and those who are on gluten-free diet for more than 6 months. Exclusion criteria includes any child less than 2 years and more than 15 years, those who did not have a documented positive serology and/or biopsy suggestive of celiac disease as per revised ESPGHAN criteria 1990, those on gluten-free

diet for less than 6 months, and those children whose parents are not included in the study. The children were enrolled in the study after getting the requisite clearance from the Institute Research Review Board and were evaluated for dietary compliance which was based on a 5-day dietary recall form. A child who had taken even one food item containing gluten in last 5 days was considered noncompliant and those who are on strictly no gluten diet were considered compliant. The factors that were found associated with compliance were identified. This collected data was analyzed in Microsoft excel 07 and Primer 5.00. Inference was drawn using Mann-Whitney test and Chi-square test to compare compliant and noncompliant groups. Value of <0.05 was considered significant. Software PASW18 (trial version) was used to apply binary logistic regression analysis to assess predictability of all the variables used in the study. The dependent variable was dietary compliance and the factors which affect the dependent variable are factors studied for association with compliance.

Diet recall was done by parents for children up to 5 years of age since they were the only one for children diet and for the children, above 5 years of age; diet recall was done by themselves along with the parents.

III. Results and Discussions

There are three types of barriers to compliance. Barriers derived from parent's attitude, child's attitude and those by effect of celiac disease on feelings of children suffering from celiac disease.

Table 1 shows results of assessment of child's attitude as a barrier to compliance to GFD. 63.08% of children in complaint group found easy to keep compliance to gluten free diet while 57.14 % of children in non compliant group found it difficult to complaint. In non compliant group, 74.29%, 80% and 62.86% of children found it difficult to maintain gluten free diet at school, at family parties and marriages and with friends respectively. 69.23 % in compliant group and 85.79% in non compliant group found difficulty in complying with diet while travelling. When they were assessed regarding sharing of responsibility in maintaining gluten free diet, 66.15% of compliant children were found to be sharing responsibility of keeping the diet, as compared to 28.57% of non compliant children. 42.86% of non compliant children reported the taste of gluten free food as bad while 66.15% of children in compliant group found it good and only 3.08% of compliant children reported food as bad.

Table 1: Barriers related to child's attitude

Question	Response	Complaint (%)	Non complaint (%)	P value
Finds keeping diet difficult	Difficult	4 (6.15)	8 (22.86)	<0.001
	Fairly difficult	20 (30.77)	20 (57.14)	
	Easy	41 (63.08)	7 (20.00)	
Child shares responsibility	Y	43 (66.15)	10 (28.57)	<0.001
	N	22 (33.85)	25 (71.43)	
Finds taste of gluten free diet	Bad	2 (3.08)	15 (42.86)	<0.001
	Satisfactory	20 (30.77)	16 (45.71)	
	Good	39 (60.00)	3 (8.57)	
	Very good	4 (6.15)	1 (2.86)	
Finds difficult to maintain diet at school	Y	27 (41.54)	26 (74.29)	<0.001
	N	38 (58.46)	9 (25.71)	
Finds difficult to maintain diet at party /marriage	Y	24 (36.92)	28 (80.00)	<0.001
	N	41 (63.08)	7 (20.00)	
Finds difficult to maintain diet while travelling	Y	45 (69.23)	30 (85.71)	0.814
	N	20 (30.77)	5 (14.29)	
Finds difficult to maintain diet with friends	Y	24 (36.92)	22 (62.86)	<0.001
	N	41 (63.08)	13 (37.14)	

In the present study, the questionnaire included questions related to child's attitude in response to the disease and GFD. While 63.08% of children in compliant group found keeping gluten free diet easy; only 20 % of non-compliant children found it easy to maintain a gluten free diet. 57.14% of non-compliant children found it fairly difficult and 22.86 % children found it difficult to maintain the diet. Our study also found that 66.15% of compliant patients were fairly responsible in maintenance of gluten free diet as compared to 28.57 % in non-compliant group. These results show that compliant patients are more involved in maintenance of their diet. Active involvement of child is significantly related ($p = <0.001$) in our study to compliance as in study by Chauhan JC et al in 2010 [9]. In study by Anson et al (1990), 71% of compliant children's mothers and 44% of non complaint children's mothers thought that the children shared responsibility in keeping diet [11].

Barriers related to parental attitude

Table 2 shows 24.62% of parents of children in compliant group hardly felt a burden on their budget. 94.28% and 75.38% of parents with children in non compliant and complaint group respectively

felt a heavy burden on their budget. In compliant group, 72.31% of parents believed that special diet was hardly a burden to the family, whereas in non compliant group 57.14% parents felt it as a burden. 36.92% of parents of children in compliant group were not hesitant to discuss the child's condition and were interacting with other parents of celiac disease in gastrology clinics; these parameters were significantly lower in non compliant group i.e. 14.29%. 64.62% parents of compliant children and 71.73% parents of non compliant children believed that the disease will interfere with their child's marriage. 93.28% and 71.43% of parents of children in non compliant and compliant group respectively felt a financial burden by gluten free diet. 71.43% parents with children in non compliant group cooked more than once for their children as compared to 87.69% of parents with children in compliant group. All these parameters had a significant correlation ($p < 0.001$) with compliance and show that non compliance was most common in parents who consider special diet a burden to budget and family and therefore, they avoided cooking fresh meals for the children. Study by Lee et al in 2007 [17] also shows that financial burden of gluten free food may affect compliance. Anson et al in 1990 [11] also showed that 50% of non compliant group parents considered diet a burden on family's budget. However, this did not significantly affected compliance in their study. In his study, 56% of compliant parents considered special diet a burden however compliant and non compliant parents did not differ significantly with regard to this parameter. In study by Chauhan JC in 2010 (9) 60.7% of compliant parents believed that special diet was hardly a burden. 84.6% in non compliant felt it as a burden. Olsson et al in 2008 (8) and Lee et al in 2007 (17), both have shown that availability of cheap gluten free food was a significant factor affecting compliance. Increase availability of cheap food items is needed for celiac patients.

Table 2: Barriers related to parents' attitude

Question	Response	Compliant (%)	Non compliant (%)	P value
Finds burden on budget	Heavily	12 (18.46)	16 (45.71)	<0.001
	Fairly	37 (56.92)	17 (48.57)	
	Hardly	16 (24.62)	2 (5.71)	
Feels burden on self	Y	18 (27.69)	20 (57.14)	<0.001
	N	47 (72.31)	15 (42.86)	
Cooks food once or more than once	>Once	57 (87.69)	25 (71.43)	<0.001
	Once	8 (12.31)	10 (28.57)	
In contact with other parents of children with celiac disease	Y	24 (36.92)	5 (14.29)	0.012
	N	41 (63.08)	30 (85.71)	
Believe that disease will interfere with Childs marriage	Y	42 (64.62)	25 (71.43)	0.225
	N	23 (35.38)	10 (28.57)	

36.92% of parents of children in compliant group were not hesitant to discuss the condition with others and were able to interact with other parents in the clinic. These rates were 14.29% in non compliant group, which were significantly lower. This shows that efforts are required on part of health care providers to break the stigma among the parents and increase their interaction mutually and with medical faculty to ensure compliance. Rashid M et al (2005) reported compliance rates of 95% in those children whose families were a part of celiac support group, Canadian Celiac Association (CCA). These families regarded CCA as the best source for the information provided to them about their child's disease.

Barriers related to child's feelings

In present study, 47.69% of the compliant children never felt left out of the activities at school while only 22.86% of non compliant children never felt left out of the activities at school. Also, 14.28% of non compliant children and 7.69% of compliant children believed that their teacher and friends didn't understand the disease all or most of the time. 45.72 % of non compliant children and 3.08 % of compliant children felt different from other kids because of disease. 72.31% of children (compliant) do not have any problem in carrying GFD to school, parties while in this was true for 28.57% (non compliant) only, 62.86% felt discomfited to bring gluten free diet at parties. Positive attitude towards his/ her condition is also a significant factor connected with higher degree of compliance. GFD item served at above places was a problem for children in compliant and noncompliant groups. The results indicate the need of availability of gluten-free food and more apparent and clear labeling of gluten-free items is as important as proper counseling.

When they were inquired about their social life and asked to grade it, 9.23% children in compliant group believed that they were left out of activities at school or friends' home due to their disease all or most of the time while 48.57% children in non compliant group believed that they were left out of activities at school or at friends' home all or most of the time. In non compliant group

2.86% felt different from others all the time while 42.86% felt different most of the times as compared to 0% and 3.08% respectively in the compliant group. Due to their disease; feeling of embarrassment of bringing gluten free diet to parties was higher in non compliant group as compared to compliant group i.e. 80% and 27.69% respectively. Feeling of anger for following special diet was also higher in non compliant group as compared to compliant group i.e. 91.43% and 78.46% respectively. 21.54% never felt angry to follow gluten free diet in compliant group while this count is 8.57% in non compliant group who never felt angry to follow gluten free diet. In compliant group, 66.15% of children understood the importance of following a gluten free diet and never felt that they can be healthy without following a special diet while in non-compliant group only 20% understood this. 74.28% children in non-compliant group had problems all or most of the times in identifying the gluten free food stuff as compared to 38.46% in compliant group who had this problem all or most of the time. 72.31% in compliant group believed that their teachers and friends understood the nature of their disease compared to 51.43% in non compliant group. 10.77% in compliant group always or most of the time felt that they were not invited for meals outside because of the disease, while 14.29% in non compliant group believed so all or most of the time. Most these questions showing the perception of the child about the disease and gluten free diet significantly affected compliance ($p < 0.001$). The study results show that dietary restriction has effect on child's feelings and social activities like eating out and travelling. This is the area where the counseling of the doctor is important so that a child can become adjustable in his situation.

Table 3 Barriers related to child's feelings

	Compliant Group (%)					Non Compliant Group (%)					P
	A	B	C	D	E	A	B	C	D	E	
Feel left out of activities at school or friends home	0 (0.00)	6 (9.23)	27 (41.54)	31 (47.69)	1 (1.54)	1 (2.86)	16 (45.71)	10 (28.57)	8 (22.86)	0 (0.00)	<0.001
Felt different from other Kids	0 (0.00)	2 (3.08)	24 (36.92)	39 (60.00)	0 (0.00)	1 (2.86)	15 (42.86)	10 (28.57)	9 (25.71)	0 (0.00)	<0.001
Felt embarrassed to bring gluten free foods	1 (1.54)	6 (9.23)	11 (16.92)	47 (72.31)	0 (0.00)	3 (8.57)	15 (42.86)	4 (11.43)	10 (28.57)	3 (8.57)	<0.001
Felt angry about following a special diet	0 (0.00)	12 (18.46)	39 (60.00)	14 (21.54)	0 (0.00)	14 (40.00)	8 (22.86)	10 (28.57)	3 (8.57)	0 (0.00)	<0.001
Felt their teacher and friends didn't	0 (0.00)	5 (7.69)	13 (20.00)	42 (64.62)	5 (7.69)	2 (5.71)	3 (8.57)	12 (34.29)	15 (42.86)	3 (8.57)	<0.001
Felt that they can be healthy without following a special diet	1 (1.54)	1 (1.54)	20 (30.77)	43 (66.15)	0 (0.00)	6 (17.14)	8 (22.86)	14 (40.00)	7 (20.00)	0 (0.00)	<0.001
Avoid restaurants	33 (50.77)	17 (26.15)	6 (9.23)	6 (9.23)	3 (4.62)	18 (51.43)	8 (22.86)	2 (5.71)	2 (5.71)	5 (14.29)	0.171
Avoid travelling	23 (35.38)	33 (50.77)	8 (12.31)	1 (1.54)	0 (0.00)	20 (57.14)	5 (14.29)	3 (8.57)	7 (20.00)	0 (0.00)	<0.001
Found difficult to determine which food is gluten free	8 (12.31)	17 (26.15)	32 (49.23)	8 (12.31)	0 (0.00)	16 (45.71)	10 (28.57)	6 (17.14)	2 (5.71)	1 (2.86)	<0.001
Felt they were no invited out	1 (1.54)	6 (9.23)	9 (13.85)	40 (61.54)	9 (13.85)	4 (11.43)	1 (2.86)	3 (8.57)	18 (51.43)	9 (25.71)	0.002

School environment:

Only 41.54% and 74.29% of compliant and non-compliant patients, respectively, found difficulty in maintaining compliance at school. Rashid et al (2005) reported >50% of children felt left out of activities at school and had compliance problems [14]. Olsson et al in 2008 showed that for adolescents, school was the most difficult place to comply with gluten free diet (15). Other children bringing mainly gluten containing foods and peer pressure about taking packed food items containing gluten were responsible for difficulty in maintaining compliance at school.

Family party and marriages:

Non compliant children also found it difficult to maintain gluten free diet at family party/marriages (80%), compared to 36.92 % in the compliant group. Gluten containing food as the main dietary item served at above places was a problem for both compliant and non-compliant groups who had problems in maintaining diet at such places. Anson et al (1990) has also reported non availability of food at party/marriages as barriers to compliance to gluten free diet [11]. These results indicate that these dietary restrictions have significant impact on child's social activities including school and extracurricular events. Non availability of gluten

free items in restaurants and during travel made them to avoid it. The acceptance of diet was better in children in the study by Rashid M et al as compared to those in our study which may be because of support provided by the Canadian Celiac Association (CCA), the celiac support group which makes the children more comfortable with their condition and made them accept the diet better and hence the role of support groups re-emphasized.

Travelling:

While travelling majority number of children in both compliant group (69.23%) and non compliant group (85.71%) face problems with maintaining special diet. This shows the need of easily available packed gluten free diet and properly labeled as being gluten free for on-the-go consumption.

Taste of gluten free diet:

In response to question related taste of gluten free food, 66.15 % of compliant patients graded taste of gluten free diet to be very good or good, while only 11.43 % in non compliant group graded it to be good or very good. Child's liking taste of gluten free diet is significantly associated with compliance ($p < 0.001$). Butterworth et al (2004) have also reported better compliance in patients who were frequently explained and educated by dietitians regarding selection and preparation of gluten free meals to improve the taste of the meals [16]. These results highlight importance of counseling and education of parents and children in selecting and preparing gluten free foods. Parents should be taught about preparing palatable, easily available gluten free food for their children.

In our study 18.46% of complaint and 62.86% of non complaint children felt angry about having to follow a special diet all or most of the time. 66.15% of compliant and only 20 % of non-compliant children never believed that they can be healthy without following a special diet. We also found that majority of both compliant children(86.15%) and non-compliant children (71.43%) avoided travelling because of the fact that gluten free diet is not easily available. Rashid Metal (2005) also studied the effect of child's feeling on compliance to gluten free diet. In their study 13% of compliant children felt left out of school activities due to their disease and 11 % of compliant children felt that their teacher did not understand their disease. While 18% children felt themselves different from other kids, 23% were embarrassed to bring gluten free food to parties. In his study 23% children felt angry about having to follow a special diet [14].

IV. Conclusions

The results show that there is low level of adherence to GFD in children suffering with CD. Effective counseling is the most important factor to assure the required restriction in the diet among the patients. This study enumerates various factors which are associated with GFD compliance. One must have proper understanding of the compliance predictors that will help the clinician to know the problem areas and assure utmost compliance among children. CD is a widespread problem in most parts of world. For many years, clinicians have focused on the diagnosis of celiac disease while scarce attention is given to the well being and care of the patient. Persons with CD should be monitored regularly for new or existing symptoms, and adherence to gluten-free diet as per the ACG. Monitoring of adherence to gluten-free diet must be based on a combination of serology and history [6].

Hence, monitoring of compliance to the diet should promote a favorable attitude and positive feelings for GFD. Children should get support by school health teams and support groups. The easy availability of cheap, socially acceptable and palatable gluten-free food and better labeling of food may increase compliance to gluten-free diet. The results indicate that if the child lives in a joint family, he/she needs more follow-up visits to ensure compliance as he is more likely to resist the diet. Also, since age at presentation predicts compliance, it is the responsibility of the medical fraternity to put the child on gluten-free diet at an age when the child inculcates the dietary habits required of him and is less affected by the peers. In India, many celiac support groups can be established wherein the NGOs, volunteering individuals and doctors should work together to provide required psychological support to the parents and the children of varied options and forthcoming treatments. A routine assessment can be done for any psychosocial impairment to all the children, specifically for those who are above 9 years.

The education and knowledge of mother is found as important factor in the compliance. This might be because the mother is only responsible for preparation of food items for child and she is able to identify gluten free food stuff. PSC scores increase as the age increases, more in noncompliant children. Maximum score was seen in children >9 years of age as this is the age when children interact with people other than their parents and develop a experimentation need and psychological need.

The present study has undertaken research regarding the significant factors that play a major role in compliance to GFD. Nevertheless, there were few limitations of this study. First, compliance was not in confirmation with parallelserological and/or histological assessment. On the other hand, it is unclear if biopsy provides a better evaluation of long-term compliance over nutritional assessment. While serological and histological relapse has been used to evaluate compliance, a more noninvasive approach has been used in some studies to assess the compliance subjectively.

Bidirectionality of evidence is also a limitation in the present study. Though, the results of this study indicate number of areas that may be targets for interventions which are aimed at improving dietary adherence in individuals.

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