

Assessment of Dietary Compliance to Gluten Free Diet and Psychosocial Problems in Indian Children with Celiac Disease

J.C. Chauhan, Praveen Kumar, A.K. Dutta, Srikanta Basu and Arun Kumar

Division of Gastroenterology, Department of Pediatrics, Lady Hardinge Medical College and Associated Kalawati Saran Children Hospital, New Delhi, India

ABSTRACT

Objective. To assess dietary compliance to Gluten Free Diet (GFD), to identify barriers to compliance and to study the impact of diet on the psychosocial behavior of children with celiac disease.

Methods. Children diagnosed with celiac disease and followed up for more than 6 months, were assessed for dietary compliance. After this assessment, patients were subjected to an interview, consisting of self administered questionnaire, by the investigator who was blinded to initial results of initial assessment. Psychosocial parameters were assessed by standard Pediatric Symptom Checklist (PSC) containing 35 items. Dietary compliant and non-compliant groups were compared for assessed factors affecting the dietary compliance. Cases were also compared to healthy controls for psychosocial parameters.

Results. A total of 70 patients were assessed for dietary compliance: 53(75%) were found to be dietary compliant, 13(18%) dietary non-compliant while 4 had doubtful dietary compliance. Final analysis was done for 64 patients who had complete assessment; 4 patients with doubtful dietary compliance and 2 patients who had incomplete assessment, were excluded. Dietary compliance was higher in younger children (>80%) compared to adolescents (44%); in children with higher maternal education; in parents having better knowledge and understanding of disease. Compliance was better in nuclear families; with less number of siblings (68.3% of compliant had <2 siblings compared to 23% in non-compliant); in families with higher per capita income. Dietary compliance was also better in children who presented with typical symptoms of celiac disease (72% of dietary compliant presented with loose motion as presenting symptom compared to only 15% in non-compliant). Celiac children had problems related to adjustment such as difficulty in maintaining diet at school, restaurants, trips, etc. 45% patients complained that their teachers don't understand the nature of their disease. Pediatric Symptom Checklist (PSC) score was above cut-off in 4 children of dietary non-compliant group. Few individual PSC items such as complaints of aches and pains; is irritable, angry; does not listen to the rules, blames other for mistakes; teases others; refuses to share, were more common in celiac children than control.

Conclusions. Noncompliance to gluten free dietary regimen is seen in 18 % of cases. Dietary noncompliance is more common in the adolescent age group, in joint families and those who have more number of siblings. Dietary restrictions have impact on child's social activities and thus psychosocial parameters (PSC score) are better in the dietary compliant group. [Indian J Pediatr 2010; 77 (6) : 649-654] E-mail : kumardrpraveen@rediffmail.com

Key words: Celiac disease; Gluten free diet; Compliance; Quality of life

Celiac disease (CD), also called gluten sensitive enteropathy, is characterized by permanent intestinal intolerance to gluten, which causes damage to small bowel mucosa by an autoimmune mechanism in genetically susceptible individuals.¹ Celiac disease (CD)

presents with a variety of intestinal and non intestinal symptoms.²⁻⁴ In the last two decades celiac disease has been increasingly reported from various north Indian centers.⁵⁻⁷

At present, the only treatment available is lifelong Gluten Free Diet (GFD).¹ The majority of children with CD show normalization of nutritional and growth parameters after GFD.⁸ Dietary compliance is essential for symptomatic improvement, proper growth and preventing long term complications like osteoporosis, malignancy etc. Noncompliance is a major problem in

Correspondence and Reprint requests : Dr. Praveen Kumar, Professor of Pediatrics, Kalawati Saran Children Hospital, Lady Hardinge Medical College, New Delhi, India.

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management of celiac disease, specially in children and adolescents which may occur due to several factors like ignorance about the diet, non availability of gluten free foods, social pressure especially, in teenagers, temptation and not liking the taste of foods made of alternative food grains.⁹ Reported strict dietary compliance varies from 32-95% from western countries.¹⁰⁻¹²

Dietary restriction may lead to psychological and social disturbances. Children with celiac disease, who have to follow strict dietary regime, may have problems of adaptation to the social life. These children may also be predisposed to psychological problems such as anxiety, depression, and feeling of isolation *etc.*¹³⁻¹⁴

Our socio-cultural environment including, dietary habits is different from the western countries. In view of scanty data from India on these aspects this study was undertaken to assess the dietary compliance, the knowledge and attitude of Indian celiac children and their parents to gluten free diets

MATERIAL AND METHODS

Kalawati Saran Children's Hospital runs Pediatric Gastroenterology and Nutrition (PGN) clinic, in which children with chronic gastrointestinal disorders including Celiac disease are followed up. CD patients are diagnosed according to modified ESPGHAN criteria (suggestive duodenal biopsy histopathology in form of either partial or total villous atrophy along with increased intraepithelial lymphocytes and or crypt hyperplasia and unequivocal response to GFD and positive celiac serology (anti tissue transglutaminase antibodies or anti-endomysial antibodies).¹⁵⁻¹⁶ At the start of the GFD the parents and the children are explained about the disease and need of GFD. All parents are given a chart containing the list of Gluten Free foods. Seventy consecutive children attending PGN clinic with the following inclusion criteria were enrolled:

1. Those diagnosed with celiac disease and on GFD for more than six months and
2. Both the parents alive and living together

They were evaluated for dietary compliance based on detailed dietary history and clinical evaluation by a senior consultant. After the dietary assessment, children and their parents were subjected to an interview by the investigator who was blinded to the consultants' assessment. Interview consisted of a self administered Questionnaire which had 18 questions related to demographic profile; 5 questions related to the history of illness; 9 questions related to parents' knowledge and understanding of disease; 12 questions related to barriers to compliance and 10 questions related to effect of celiac disease on feeling of children,

eating out and travel. The questionnaire was developed from 4 previously published studies.¹⁷⁻²⁰ The developed questionnaire was pre-tested and validated in 20 children in the pediatric gastroenterology unit of Kalawati Saran Children's Hospital.

To assess the quality of life, standard Pediatric Symptom Checklist containing 35 items was added to the questionnaire. Each PSC items was rated as Never – 0, Sometimes – 1 and Often – 2. Item scores were summed and the total score was recorded into a dichotomous variable. PSC score of 28 or higher for children aged > 6 yr, and 24 or higher in children between 2-6 yr was taken as emotional and psychosocial impairment. The items for which no answer was given were scored 0. If 4 or more items were unanswered, questionnaire was treated as invalid.²⁰

Sixty age and sex matched controls were taken from Pediatric Medicine and surgical OPD and Immunization clinic, fulfilling the following criteria:

1. No chronic illness in the family and
2. Both the parents alive and living together

Psychosocial parameters of these controls were assessed using Pediatric Symptom Checklist (PSC). During the final data analysis, senior consultant's assessment was entered and based on this assessment, the group was subdivided into Group Ia- dietary - compliant and Group Ib-dietary non-compliant.

The statistical analysis was done by using chi-square test and student's t-test to compare the cases and the controls (Group I and II) and the compliant and the non-compliant group (Group Ia and Ib). The groups were compared with respect to demographic, physical and psychological parameters. Group Ia & Ib were also compared regarding the parental knowledge about the celiac disease, child and parental behavior, the PSC scores and items, and effect of celiac disease on social activities. A p value of <0.05 was considered as significant.

RESULTS

A total of 70 patients were evaluated for compliance. Good dietary compliance was observed in 53 children (75%), while 13(18%) were dietary non-compliant and 4 patients had doubtful dietary compliance (dietary history not suggestive but poor clinical correlation). Interview of 64 patients were analyzed (51 dietary compliant and 13 dietary noncompliant). 4 patients with doubtful compliance and 2 who were unable to complete full assessment, were excluded from final analysis.

As shown in Fig. 1, dietary compliance was better (>80%) in children aged < 9 yr of age as compared to adolescent age group *i.e.*, 10-17 yr (44%). As depicted in table 1

Assessment of Dietary Compliance to Gluten Free Diet and Psychosocial Problems in Indian Children

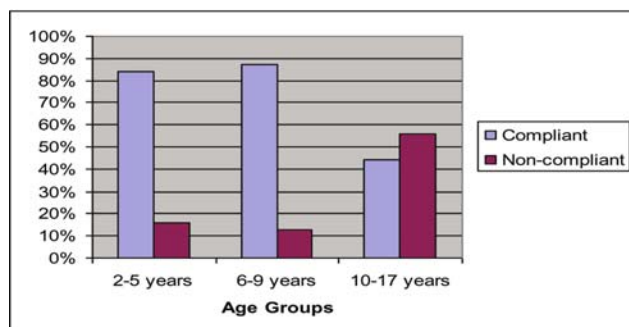


Fig. 1. Compliant and Non-compliant patients in various age groups.

lower maternal education was seen more commonly in non-compliant group (Group Ia had 25.4% graduate mothers compared to 15% in Group Ib). Compliance was better in patients belonging to nuclear family (51% compared to 38.4%), in families with higher per capita income, with less number of siblings (70% of the dietary compliant patients had 1 or no sibling). Differences in all the above parameters were found to be statistically significant.

TABLE 1. Demographic Profile of Children with Celiac Disease

Parameter	Compliant	Non-compliant
Level of education < Class 10th of mother	30 (58.8%)	10 (76.9%)
>10th to non graduate	8 (15.6%)	1 (7.6%)
Type of family		
graduate	13 (25.4%)	2 (15.3%)
Nuclear	26 (51%)	5 (38.4%)
Joint	25 (49%)	8 (61.5%)
Per Capita Income (In Indian rupees)		
<5000	19 (37%)	7 (53%)
5000-10000	23 (45%)	5 (38%)
>10000	9 (18%)	1 (9%)
Number of Siblings		
0-1	35 (68.6%)	3 (23%)
>1	16 (31.3%)	10 (76.8%)

72.3% of the dietary compliant patients presented with the typical symptoms of the Celiac Disease while 53.8% of dietary non-compliant patient presented with atypical symptoms.

As shown in table 2, questions related to parental knowledge and understanding, revealed that parents of compliant group had better knowledge and understanding about the disease. 82.3% of children in Group Ia found it easy to maintain GFD, while 53.8% of Group Ib found it fairly difficult to maintain GFD. Most children in Group-Ib (76.9%) found it difficult to maintain GFD at school; while 69.2% found it difficult to maintain GFD at family parties or marriages. 23% of dietary non-compliant group, graded taste of GFD bad while 83.2% found it very good or good. A statistical significant

difference was observed when all these results were compared. 60.7% parents of Group Ia believed that special diet was hardly a burden to the family whereas, in Group Ib 84.6% felt it as burden. Dietary noncompliance was more common in parents who were hesitant to discuss the child's condition with others and were not interacting with other parents of CD. 84.6% parents of Group Ib felt they will have problem in their child's marriage, while 78.4% of parents in Group Ia felt their children's similar to other children.

As depicted in table 3, 74.5% of children in Group Ia never felt that they were left out of activities at school or social functions due to their disease, while 76.9% in Group Ib felt left out of the activities at school or friend's home. Feeling of resentment for following special diet was also higher in Group Ib (92.3%).

As depicted in fig. 2, mean PSC score of cases was 17.3 (Range – 12 to 32), as compared to 10.6 (Range – 6 to 17) in controls. Mean score for compliant group was 16.1 (Range – 12 to 21) as compared to mean score of 20.3 (Range – 14 to 32) in noncompliant. Thus, celiac children had higher PSC scores than the controls. However, only 4 children had significant score to suggest social, emotional and psychosocial impairment and all of them belonged to dietary non-compliant group.

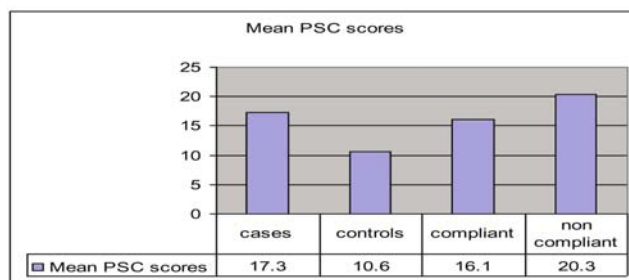


Fig. 2. Assessment of emotional and psychological aspects by Pediatric Symptom Checklist scoring (PSC).

When individual items of PSC were compared, few items like complains of aches and pains; is irritable, angry; does not listen to rules; blames others for his/her mistake; teases others; takes the things that does not belong to him/her; refuse to share, were more common in cases. It was found that dietary non-compliant patients were spending most of the time alone; were tired easily; were less interested in school; were afraid of new situation; felt sad and unhappy and also had trouble in concentration. In these patients school grades were also dropping.

DISCUSSION

Celiac Disease, an immunogenically mediated enteropathy, is emerging as an important cause of chronic diarrhea, particularly in north India.⁵⁻⁷ Lifelong

TABLE 2. Barriers to Dietary Compliance and Parents' behavior and perception

Variable	Response	Compliant (n-51)	Non-compliant (n-13)
Finds keeping diet	Difficult	2 (3.9%)	5 (38.4%)
	Fairly difficult	7 (13.7%)	7 (53.8%)
	Easy	42 (82.3%)	1 (7.6%)
Diet maintenance difficult at school	Not applicable	12 (23.5%)	3 (23%)
	Yes	16 (31.3%)	10 (76.9%)
	No	23 (45%)	0
Diet maintenance difficult at family party/marriage	Not applicable	11 (21.5%)	0
	Yes	6 (11.7%)	9 (69.2%)
	No	34 (66.6%)	4 (30.7%)
Finds taste of GFD	Very good	8 (15.6%)	1 (7.6%)
	Good	35 (68.6%)	1 (7.6%)
	Satisfactory	8 (15.6%)	8 (61.5%)
	Bad	0	3 (23%)
Special diet is a burden to you	Frequently	3 (5.8%)	5 (38.4%)
	Fairly	17 (33.3%)	7 (53.8%)
	Hardly	31 (60.7%)	1 (7.6%)
Discuss the child condition with	Everybody	42 (82.3%)	4 (30.7%)
	Family only	8 (15.6%)	6 (46.1%)
	Don't discuss	1 (1.8%)	3 (23%)
Does the child have problem with marriage	Not answered	9 (17.6%)	0
	Yes	29 (56.8%)	11 (84.6%)
	No	13 (25.4%)	2 (15.3%)

TABLE 3. Effect of Celiac Disease on Child's Feeling, Eating Out and Travel

	Group Ia (%) (Compliant) (n-51)					Group Ib (%) (Non-compliant) (n-13)				
	A	B	C	D	E	A	B	C	D	E
Feel left out of activities at school or friends home	1.9	0	23.5	74.5	0	15.3	38.4	38.4	15.3	0
Felt different from other Kids	3.9	3.9	33.3	58.8	0	7.6	30.7	53.8	7.6	0
Felt embarrassed to bring gluten free foods to parties	1.9	5.8	17.6	13.7	1.9	0	15.3	38.4	15.3	30.7
Felt angry about following a special diet	0	1.9	31.3	66.6	0	7.6	69.2	15.3	7.6	0
Felt their teacher and friends didn't understand the disease	5.8	11.7	27.4	54.9	0	23	23	38.4	0	15.3
Felt that they can be healthy without following a special diet	0	0	17.6	90.4	1.9	7.6	38.4	38.4	15.3	0
Found it difficult to determine if food was gluten free from labels	1.9	7.8	13.7	72.5	3.9	7.6	15.3	38.4	38.4	0
Felt that they were not invited out for meals because of celiac disease	1.9	3.8	7.8	76.4	9.8	0	38.4	30.7	30.7	0

(A = all the time, B = most of the times, C = some of the times, D = never, E = Not answered)

adherence to GFD is the only available treatment at present.¹ Dietary non compliance is very common and effective counseling is the single most important factor for these patients.

In the present study, 75% of the cases were found to

be dietary compliant and 18% were found to be dietary non-compliant. Reported strict dietary compliance varies from 32-81% in several European studies and 95% in a recently published Canadian study by Rashid *et al.*^{9-11, 17}

Assessment of Dietary Compliance to Gluten Free Diet and Psychosocial Problems in Indian Children

The present study found decreased dietary compliance during 10-17 yr of age (44%, compared to >80% in <9yr age group). These results are similar to Ljungman *et al*, who also reported compliance rates of 93% at 12 years of age decreasing to 76% in 15-17 yr age group.¹⁸ Various reasons which may be responsible for non-compliance with increasing age include, child remaining asymptomatic on GFD, increasing peer group pressure, increased outdoor activities, availability of money, increased risk taking behavior, conflicts with parents *etc*.

In the present study, non-compliance was more common in female patients *i.e.*, 61.8%. Higher dietary non-compliance in female patients may be explained by several socio-cultural factors common in north India: family pressure as they grow and approach marriage age; and gender bias.

This study also found maternal education as a significant factor affecting the compliance (Table 1). Results of study by Anson *et al* in 1990 also show that maternal education is important factor affecting compliance, which may be because mother is responsible for preparation of food items and providing GFD.¹⁹

Results of the present study showed that non-compliance was higher in Joint families and when numbers of siblings were more. Anson *et al* study could not find significant difference in compliance in relation to number of siblings.¹⁹

When dietary compliant and dietary non-compliant patients were compared, it was found 93.6% of dietary compliant children presented with loose motion as one of the main presenting symptom, where as 53.8% of the dietary non-compliant children presented with complaints such as progressive pallor, lethargy, constipation, poor height gain *etc*. These findings are probably because patients presenting with loose motion feel visible improvement in their symptoms. Fabiani *et al* also reported higher compliance in symptomatic patients as compared to asymptomatic screen detected patients.²¹

Parents of the dietary compliant groups had better understanding of Celiac disease than those of non-compliant group. Butterworth *et al* have reported lower compliance in south Asian migrants to UK, who were less satisfied with the explanation by the physician.²² Anson *et al* study also showed similar correlation of parental knowledge and dietary compliance.¹⁹ Thus, results of present study shows that compliance is higher when parents have better knowledge about celiac disease, understand value of gluten free diet and are able to handle the menu better. These results highlight importance of proper counseling and reinforcement during subsequent visits.

Difficulty in maintaining dietary compliance at school and at family party/marriage, was higher in

dietary non-compliant group compared to the dietary compliant. Gluten containing food as main dietary item, served at above places, was a problem for both dietary compliant and non-compliant group. Rashid *et al* also reported that more than 50 % of children felt left out of activities at school and had problems related to compliance.¹⁷ Anson *et al* have reported similar barriers to compliance in relation to child's behavior.¹⁹

Present study findings show that dietary non-compliance is more common when preparing gluten free food items is considered a financial burden. Similar finding also have been reported from Anson *et al*.¹⁹ As more and more patients are being diagnosed from lower socio-economic status, counseling regarding cheap food items and easily prepared GF food items will probably help this group.

Present study results showed that dietary restriction has effect on child's emotions and social activities like eating out and traveling. Canadian Celiac study also had similar results.¹⁷ These results indicate that dietary restrictions have impact on child's social activities. It affects their participation in school parties and enjoyable social activities such a birthday parties. Non availability of GF items in restaurants and during travel compels the patients, to avoid it.

On analysis of individual PSC items, it was found that anger, irritability, behavioral problem, tiredness, decreasing school performance, unhappiness *etc* were higher in celiac patients. Ciacci *et al* in their study have also reported that anger is the predominant emotion which induced patients to transgress.¹¹ Fera *et al* in their study also reported higher score for bodily pain in celiac patients as compared to healthy patients.²³ Addolarto *et al* have shown that anxiety is present in celiac disease subjects as a reactive form which decreases with GFD; however depressive symptoms still persist in treated patients. These results highlight the need for psychological support to these patients when they are put on GFD.¹³

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