# Psychosocial Impacts as Predictors of Compliance in Celiac Disease

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## ABSTRACT

Celiac disease is an immune-mediated disease due to gluten and related prolamins in genetically susceptible individuals. The only option of treatment is lifelong gluten-free diet (GFD). Strict adherence to GFD may be difficult in children and adolescents due to psychosocial factors. A study evaluated the impact of celiac disease and GFD on social interactions of children with celiac disease and their families, in the backdrop of aim to identify predictors of barriers affecting compliance to GFD. Three types of psychosocial impacts as predictors of barriers to compliance were noted - those caused by effect of celiac disease on feelings of children suffering from celiac disease; barriers derived from parent's attitude; and those derived from child's attitude.


**Keywords:** Celiac disease, gluten-free diet, psychosocial impact, barriers, predictors, compliance, adherence

Celiac disease is an immune-mediated disease due to gluten and related prolamins in genetically susceptible individuals and characterized by variable combination of gluten-dependent clinical manifestations, celiac disease-specific antibodies, HLA-DQ2 or HLA-DQ8 haplotypes and enteropathy. Celiac disease is a global disease with continuously increasing incidence, particularly in Western countries. This rise is related to increase of autoimmune diseases (Rheumatic, Endocrinological, Gastrointestinal and Neurological) whose incidences and prevalences are on significant rise over the past 30 years. The frequency of celiac disease in general population is reported to be approximately 1% with regional differences. Higher rate is mentioned in females, concrete ratio is 2:1. Celiac disease is also prevalent in India with rates of 1 in 96 in North India. The patient may initially present with nonspecific symptoms but unpleasant complaints, such as diarrhea, flatulence, cramps, fatigue causing difficulties to patient and sometimes even limiting daily activities may be there. Weight loss, decreased bone density, unexplained iron deficiency and infertility are also noted in celiac disease.

Neuropsychiatric symptoms such as ataxia, neuropathy, headache, epilepsy, depression and anxiety are also frequent in celiac disease. The only option of treatment is lifelong gluten-free diet (GFD). Although a well-planned GFD may provide adequate nutrition, it may be restrictive. Strict adherence to GFD may be more difficult in children and adolescents than in adults due to psychosocial factors. Compliance to GFD varies from 45% to 81% in children as reported by the North American Society of Pediatric Gastroenterology, Hepatology and Nutrition.

Noncompliance is a major problem and the greatest challenge, which the pediatricians face is in predicting the compliance to GFD in children. Noncompliance may occur due to factors like temptation and not liking the taste of GFD and alternative food grains. In adolescents, peer pressure, unclear labeling on ready-to-eat food and nonavailability of GFD at party, marriages and so forth have contributed to noncompliance. An increasingly hectic lifestyle of teenagers has contributed to a greater reliance on packaged foods which often contain gluten, and thus making it inconvenient for them to adhere to restrictive diet.

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According to Urban-Kowalczyk (2015) depression is one of the main psychiatric disorders related with celiac disease (besides anxiety, psychosis and anorexia nervosa). Many children experience psychological reactions to being placed on a restrictive diet (e.g., feeling deprived, depressed, angry and anxious), which have been found to further decrease compliance. This study evaluates the impact of celiac disease and the GFD on social interactions of the children with celiac disease and their families, in the backdrop of aim to identify predictors of barriers affecting compliance to GFD. This study is significant and will contribute to better understand education techniques for dietary instruction as well as provide an insight in the psychosocial effects of the disease.

## MATERIAL AND METHODS

The present study was conducted by Dept. of Pediatrics, SMS Medical College and Attached Hospitals, Jaipur, Rajasthan, India. One hundred fifty children and their parents visiting the gastroenterology superspecialty clinic for growth monitoring and compliance assessment, aged between 2 years and 15 years, diagnosed with celiac disease as per revised European Society of Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) criteria for diagnosis of celiac disease 1990, on GFD for more than 6 months, were enrolled in the study after getting the requisite clearance from the Institute Research Review Board. Children less than 2 years and more than 15 years of age, those who did not have a documented positive serology and/or biopsy suggestive of celiac disease as per revised ESPGHAN criteria 1990, those on GFD for less than 6 months, and those children whose parents refused consent were excluded.

All children enrolled in the study after signing of the written informed consent form were evaluated for dietary compliance based on a 5-day dietary recall form. A child who had taken even one food article containing gluten in last 5 days was considered noncompliant and those who had strictly taken no gluten in their diet in that period were considered compliant. Diet recall was done by parents for children in preschool age up to 5 years since parents were the only one giving the eatables to these children. Children, above 5 years of age, going to school and interacting with peers, were actively involved in the dietary recall along with the parents. Parents and children in the study group were assessed for dietary compliance followed by a questionnaire based interview. Psychosocial parameters were assessed by standard Pediatric Symptom Checklist (PSC). Dietary compliant and noncompliant groups were compared and assessed for factors affecting the dietary compliance. Predictability of all of these factors was assessed using binary logistic regression analysis with backward elimination to find out the best predictors of compliance.

## RESULTS AND DISCUSSION

Three types of psychosocial impacts as predictors of barriers to compliance were noted- those caused by effect of celiac disease on feelings of children suffering from celiac disease, barriers derived from parent's attitude and those derived from child's attitude. All percentage data are rounded off for purpose of easy understandability.

### Predictors Related to Child's Feelings

In the present study, about 48% of the compliant children never felt left out of the activities at school, while only 23% of noncompliant children never felt left out of the activities at school. Also, 15% of noncompliant children and 8% of compliant children believed that their teacher and friends didn't understand the disease all or most of the time. Forty-six percent of noncompliant children felt different from other kids because of disease as compared to 3% of compliant children; 72% of children in compliant group were not having any problem in bringing GFD to school parties, while in noncompliant group this was true for 28% only; 63% felt embarrassed to bring GFD at parties. While inquired about their social life and asked to grade it, 9% 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% children in noncompliant group believed that they were left out of activities at school or at friends' home. In noncompliant group, 3% felt different from others all the time while 43% felt different most of the times as compared to 0% and 3%, respectively in the compliant group. Due to their disease, feeling of embarrassment of bringing GFD to parties was higher in noncompliant group in comparison to compliant group i.e., 80% and 28%, respectively (Table 1).

Feeling of anger for following special diet was also higher in noncompliant group as compared to compliant group i.e., 91% and 78%, respectively. Twenty-two percent never felt angry to follow GFD in compliant group in comparison to 9% in non-compliant group who never felt angry to follow GFD. In compliant group, 66% of children understood the importance of following a GFD and never felt that they can be healthy without following a special diet while in noncompliant

**Table 1.** Predictors Related to Child's Feelings

| | Compliant Group (%) | | | | | Noncompliant Group (%) | | | | | P value |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | A | B | C | D | E | A | B | C | D | E | |
| Feel left out of activities at school or friends home | 0 (0.00) | 9 (9.23) | 40 (41.54) | 45 (47.69) | 2 (1.500) | 2 (2.86) | 24 (45.71) | 15 (28.57) | 13 (22.86) | 0 (0.00) | <0.001 |
| Felt different from other kids | 0 (0.00) | 3 (3.08) | 36 (36.92) | 58 (60.00) | 0 (0.00) | 2 (2.86) | 22 (42.86) | 16 (28.57) | 13 (25.71) | 0 (0.00) | <0.001 |
| Felt embarrassed to bring gluten-free foods to parties | 2 (1.54) | 10 (9.23) | 14 (16.92) | 70 (72.31) | 0 (0.00) | 5 (8.57) | 22 (42.86) | 6 (11.43) | 15 (28.57) | 6 (8.57) | <0.001 |
| Felt angry about following a special diet | 0 (0.00) | 18 (18.46) | 58 (60.00) | 21 (21.54) | 0 (0.00) | 21 (40.00) | 12 (22.86) | 15 (28.57) | 5 (8.57) | 0 (0.00) | <0.001 |
| Felt their teacher and friends didn't understand the disease | 0 (0.00) | 7 (7.69) | 20 (20.00) | 62 (64.62) | 7 (7.69) | 4 (5.71) | 5 (8.57) | 18 (34.29) | 22 (42.86) | 5 (8.57) | <0.001 |
| Felt that they can be healthy without following a special diet | 2 (1.54) | 2 (1.54) | 35 (30.77) | 66 (66.15) | 0 (0.00) | 10 (17.14) | 12 (22.86) | 21 (40.00) | 111 (20.00) | 0 (0.00) | <0.001 |
| Avoid restaurants | 47 (50.77) | 25 (26.15) | 9 (9.23) | 9 (9.23) | 5 (4.62) | 27 (51.43) | 13 (22.86) | 3 (5.71) | 4 (5.71) | 8 (14.29) | 0.171 |
| Avoid traveling | 33 (35.38) | 49 (50.77) | 12 (12.31) | 2 (1.54) | 0 (0.00) | 34 (57.14) | 7 (14.29) | 5 (8.57) | 8 (20.00) | 0 (0.00) | <0.001 |
| Found difficult to determine which food is gluten-free | 12 (12.31) | 25 (26.15) | 48 (49.23) | 12 (12.31) | 0 (0.00) | 24 (45.71) | 15 (28.57) | 9 (17.14) | 4 (5.71) | 1 (2.86) | <0.001 |
| Felt they were not invited out | 2 (1.54) | 10 (9.23) | 12 (13.85) | 60 (61.54) | 12 (13.85) | 6 (11.43) | 2 (2.86) | 4 (8.57) | 28 (51.43) | 14 (25.71) | 0.002 |

A = All the time; B = Most of the time; C = Some of the time; D = Never; E = Not answered.

group only 20% understood this. Seventy-four percent children in noncompliant group had problems all or most of the times in identifying the gluten-free food stuff as compared to 38% in compliant group who had this problem all or most of the time. Seventy-two percent in compliant group believed that their teachers and friends understood the nature of their disease compared to 51% in noncompliant group. Eleven percent in compliant group always or most of the time felt that they were not invited in parties because of the disease, while 14% in noncompliant group believed so all or most of the time. Most questions depicted perception of the child about the disease and GFD significantly affected compliance ($p \leq 0.001$).

## Psychological Impacts of School Environment

Only 42% of compliant patients found it difficult to maintain compliance at school in contrast to 74% of noncompliant patients. Olsson et al in 2008 showed that for adolescents, school was the most difficult place to comply with GFD. 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.

## Psychological Impacts of Family Party and Marriages

Noncompliant children also found it more difficult to maintain GFD 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 noncompliant groups who had problems in maintaining diet at such places. Greater negative impact of celiac disease on patients was perceived in social activities. This effect was more apparent among women - more women said that they have avoided some social situation (such as eating in a restaurant. Rose and Howard (2014) describe social anxiety that comes from the violation of social rules of decency - patients are afraid that others will negatively perceive their non-conformist behavior. People that are


**IJCP SUTRA 508:** To calm the mind and relax the muscles, try meditation, deep breathing or progressive muscle relaxation.

nervous about eating outside of the home are changing their strategy towards lowering their social activities. Strategies of avoiding eating in restaurants or traveling are also described in other studies.

### Psychological Impact Related to Taste of Gluten-free Diet

In response to question related to taste of GFD, 66% of compliant patients graded taste of GFD to be very good or good, while only 11% in noncompliant group graded it good or very good. Taste liking of GFD is significantly associated with compliance ($p \leq 0.001$). Butterworth et al (2004) have also reported better compliance in patients who were frequently explained and educated by dieticians regarding selection and preparation of gluten-free meals to improve the taste of the meals. These results highlight importance of counseling and education of parents and children in selecting and preparing gluten-free foods. Parents should be taught palatable, easily available gluten-free food preparations for their children.

In our study, 18% compliant and 63% noncompliant children felt angry about having to follow a special diet all or most of the time. Sixty-six percent of compliant and only 20% of noncompliant children never believed that they can be healthy without following a special diet. We noted that majority of both compliant (86%) and noncompliant children (71%) avoided traveling because of difficulty in availability of GFD. Rashid et al (2005) also studied the effect of child's feeling on compliance to GFD. 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 their study, 23% children felt angry about having to follow a special diet.

These results indicate that these dietary restrictions have significant impact on child's social activities including school and extracurricular events. It affects their participation in school, parties and enjoyable social activities such as birthday parties. Nonavailability of gluten-free items in restaurants and during travel is further disastrous.

### Psychosocial Problem Related to Noncompliance

In our study, the mean score increased as the age increased in the children suffering from celiac disease in both compliant and noncompliant patients. Hence, an older child is at more risk of noncompliance.

Sixty-three percent of children in compliant group found it easy to keep compliance to GFD. Fifty-seven percent of children in noncompliant group found it fairly difficult to maintain GFD. In noncompliant group, 74% children found it difficult to maintain GFD at school; 80% found it difficult to maintain GFD at family parties and marriages; 63% found it difficult to comply to diet when with friends. Sixty-nine percent in compliant group compared to 86% in noncompliant group found difficulty in complying with diet while traveling.

When they were assessed regarding sharing of responsibility in maintaining GFD, 66% of compliant children were found to be sharing responsibility of keeping the diet, in contrast to 29% of noncompliant children who shared responsibility of keeping the diet. Forty-three percent of noncompliant children reported the taste of gluten-free food as bad while 66% of children in compliant group found it very good or good and only 3% of compliant children reported food as bad. A statistically significant difference was observed in these results. In the present study, the questionnaire included questions related to child's attitude in response to the disease and GFD. While 63% of children in compliant group found maintaining GFD easy, only 20% of noncompliant children found it easy to maintain a GFD. Fifty-seven percent of noncompliant children found it fairly difficult and 23% children found it difficult to maintain the diet. Our study also found that 66% of compliant patients were fairly responsible in maintenance of GFD as compared to 29% in noncompliant group. Active involvement of child is significantly related ($p \leq 0.001$) to compliance in our study; as in study by Chauhan et al in 2010. In the study by Anson et al (1990), 71% of compliant children's mothers and 44% of noncompliant children's mothers thought that the children shared responsibility in keeping diet.

Celiac disease patients usually experience relief after diagnosis. Experienced relief decreases with time; however, the acceptance of diet itself gradually increases. Experiencing most of the negative emotions also decreases with time, for example, those who live with GFD for more than 5 years experience difficulties and negative emotions less often. However, frustration and feeling of isolation that most people suffering from celiac disease experience often persist even several years after diagnosis. In first months after diagnosis, the same is true – women experience negative feelings more than men.

### Psychosocial Impact on Parents

Twenty-five percent of parents of children in compliant group hardly felt a burden on their budget; 94% of parents with children in noncompliant group felt a fairly heavy or heavy burden on their budget and 75% of parents with children in compliant group felt a fairly heavy or heavy burden on their budget. Eighty-eight percent of parents of children in compliant group cooked more than once for their children as compared to 71% of parents of children in noncompliant group. In compliant group, 72% of parents believed that special diet was hardly a burden to the family, whereas in noncompliant group 57% parents felt it as a burden. Thirty-seven percent of parents of children in compliant group were not hesitant to discuss the child's condition and were interacting with other parents; these parameters were significantly lower in noncompliant group i.e., 14%. Sixty-five percent parents of compliant children and 72% parents of noncompliant children believed that the disease will interfere with their child's marriage.

Ninety-four percent of parents of children in noncompliant group and 75% of parents of children in compliant group also felt a financial burden by GFD. Seventy-one percent parents with children in noncompliant group cooked more than once for their children as compared to 88% of parents with children in compliant group. All these parameters had a significant correlation ($p \leq 0.001$) with compliance and show that noncompliance was most common in parents who consider special diet a burden to budget and family and hence they avoided cooking fresh meals for the children. Hence, cheap and easy to cook food will help these disease bearing families.

A study by Lee et al in 2007 also shows that financial burden of gluten-free food may affect compliance. Anson et al in 1990 also showed that 50% of noncompliant group parents considered diet a burden on family's budget. However, this did not significantly affected compliance in their study. In the study, 56% of compliant parents considered special diet a burden; however, compliant and noncompliant parents did not differ significantly with regard to this parameter. In study by Chauhan et al in 2010, 60.7% of compliant parents believed that special diet was hardly a burden; 84.6% in noncompliant group felt it as a burden. Olsson et al in 2008 and Lee et al in 2007, both have shown that availability of cheap gluten-free food was a significant factor affecting compliance. Increased availability of food items is needed for celiac patients.

Thirty-seven percent 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. This was significantly lower (14%) in noncompliant group. Rashid 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.

## CONCLUSIONS

These results will contribute to the current body of research by providing healthcare practitioners with a framework for better dietary instruction to ensure maximum adherence to GFD as well as psychosocial impact of celiac disease on parents and children suffering from celiac disease. Psychosocial aspects of celiac disease are not well-studied. Knowledge of psychological aspects and interventions can improve the acceptance and compliance concerning GFD.

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