Gluten-Free Diet Nonadherence in Children with Celiac Disease in Bahawalpur

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ABSTRACT

Background: Celiac disease requires lifelong adherence to a strict gluten-free diet (GFD). However, maintaining dietary restrictions during childhood can be challenging because of limited caregiver knowledge, family practices, financial constraints, and restricted availability of gluten-free foods.

Objective: To determine the frequency of GFD nonadherence and identify its reported barriers among children with celiac disease attending a tertiary care hospital in Bahawalpur, Pakistan.

Methods: This descriptive cross-sectional study was conducted at the Department of Pediatrics, Bahawal Victoria Hospital, Bahawalpur, from December 18, 2017, to June 17, 2018. A total of 227 children aged 2–14 years with an established diagnosis of celiac disease were recruited through consecutive nonprobability sampling. Dietary adherence was assessed through caregiver interviews following nutritional counseling and an eight-week follow-up. Nonadherence was defined as consumption of at least one gluten-containing serving per week. Data were analyzed using IBM SPSS Statistics version 10.

Results: The mean age of participants was 7.00 ± 3.09 years, and 133 (58.59%) were boys. Overall, 47 (20.70%) children met the study-defined criterion for dietary nonadherence, while 180 (79.30%) were classified as adherent. Among nonadherent children, limited caregiver knowledge was the most frequently reported barrier (27.66%), followed by family beliefs (23.40%), difficulty affording gluten-free foods (23.40%), limited food availability (19.15%), and child refusal (6.38%). No significant associations were observed between nonadherence and sex, disease duration, father's occupation, or monthly household income ($p>0.05$).

Conclusion: Approximately one-fifth of children demonstrated GFD nonadherence. Strengthening caregiver education, family involvement, and access to affordable gluten-free foods may improve dietary management.

Keywords: Celiac disease; children; gluten-free diet; dietary nonadherence; dietary barriers; Pakistan.

INTRODUCTION

Celiac disease (CD) is a chronic immune-mediated disorder triggered by the ingestion of gluten in genetically susceptible individuals, resulting in intestinal inflammation and varying degrees of mucosal damage.[1] Gluten, a protein complex found in wheat, barley, and rye, initiates an abnormal immune response that primarily affects the small intestine and may impair nutrient absorption.[2] The disease can develop during childhood or adulthood, although pediatric cases frequently present with gastrointestinal symptoms, growth disturbances, nutritional deficiencies, and other extraintestinal manifestations.[3] The clinical presentation varies considerably among affected children, ranging from classical symptoms, including chronic diarrhea, abdominal distension, and weight loss, to less specific manifestations such as anemia, short stature, fatigue, and delayed growth.[4] Because of this heterogeneous presentation, early recognition, appropriate diagnostic evaluation, and long-term disease management are important for preventing complications and improving health outcomes.[5] Currently, a strict lifelong gluten-free diet (GFD) remains the primary treatment for celiac disease.[6] Dietary exclusion of gluten helps reduce intestinal inflammation, promotes mucosal recovery, improves clinical symptoms, and supports normal growth and nutritional status in affected children.[7] However, maintaining a gluten-free diet requires continuous attention to food ingredients, preparation practices, food labeling, and potential cross-contamination during food handling.[8] Even small or inadvertent exposures may occur through processed foods, meals prepared outside the home, or shared cooking utensils.[9] Consequently, dietary management represents a substantial ongoing responsibility for children with celiac disease and their families, particularly in settings where gluten-free alternatives are limited or difficult to identify.[10]

Dietary adherence during childhood is particularly challenging because children frequently depend on parents or other caregivers for food selection, preparation, purchasing, and supervision.[11] Caregiver knowledge regarding gluten-containing ingredients, hidden sources of gluten, food labeling, and cross-contamination is therefore an important component of effective dietary management.[12] Limited awareness or misunderstanding of dietary restrictions may contribute to unintentional gluten

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exposure, while family dietary habits, cultural practices, social gatherings, and eating outside the home may further complicate adherence.[13] In addition, children may experience difficulties accepting unfamiliar foods, restrictions on commonly consumed meals, and feelings of exclusion during school or social activities, potentially affecting their willingness to maintain dietary restrictions.[14] Economic and environmental factors may also influence adherence to a gluten-free diet. Gluten-free products are often more expensive than their conventional counterparts, creating financial challenges for families with limited resources.[15] Restricted availability of suitable gluten-free foods, particularly in areas where specialized products are not widely marketed, may further limit dietary choices.[16] These challenges may be more pronounced in low- and middle-income countries, where awareness of celiac disease, access to specialized nutritional products, and opportunities for dietitian-led counseling may vary considerably.[17] Understanding these barriers is essential for developing culturally appropriate dietary counseling strategies and identifying practical approaches to improve adherence among pediatric patients.

Despite the importance of lifelong dietary management, nonadherence remains a concern in children with celiac disease, and its contributing factors may differ according to family knowledge, socioeconomic circumstances, food accessibility, and individual preferences. [18] Assessing dietary nonadherence and identifying the barriers reported by caregivers can provide useful information for clinicians and nutrition professionals to strengthen patient education and follow-up services. Therefore, this study aimed to estimate the frequency of gluten-free diet nonadherence among children with celiac disease attending the pediatric outpatient department of Bahawal Victoria Hospital, Bahawalpur, Pakistan, and to describe the barriers recorded among children who met the study-defined criterion for nonadherence.

METHODOLOGY

A descriptive cross-sectional study was conducted in the Department of Pediatrics at Bahawal Victoria Hospital, Bahawalpur, Pakistan, from December 18, 2017, to June 17, 2018. Children aged 2–14 years with a previously established diagnosis of celiac disease for at least three months were eligible for inclusion. The diagnosis was operationally defined as a positive anti-tissue transglutaminase immunoglobulin A (anti-tTG IgA) level of ≥18 U/mL. Children were recruited through consecutive nonprobability sampling. Patients were excluded if their caregivers declined participation or were unable to provide reliable information regarding the child's gluten intake during the preceding two months. The required sample size of 227 participants was calculated using the World Health Organization (WHO) sample-size calculator, assuming an anticipated dietary nonadherence prevalence of 18%, an absolute precision of 5%, and a 95% confidence level. [3]

Dietary assessment was performed through caregiver interviews conducted by the investigator. At the initial assessment, caregivers received nutritional counseling regarding the principles of a gluten-free diet, including the avoidance of gluten-containing foods. Families were subsequently instructed to return for follow-up after eight weeks. During the follow-up assessment, caregivers were asked to recall the frequency of gluten-containing food consumption by their children over the preceding eight weeks. Dietary nonadherence was operationally defined as an average consumption of at least one gluten-containing serving per week during this period. Children meeting this criterion were classified as nonadherent, whereas those reporting consumption below this threshold were classified as adherent.

Potential barriers to dietary adherence were documented among children classified as nonadherent. Five barrier categories were considered: limited caregiver knowledge, child refusal, family beliefs, affordability, and availability of gluten-free foods. Caregiver knowledge was evaluated using three food-identification questions, with all three correct responses required to demonstrate adequate knowledge. Child refusal was assessed in children older than nine years. Family beliefs were evaluated using information concerning family history and joint-family living arrangements. Affordability was assessed using a monthly household income threshold of less than PKR 25,000. Although limited availability of gluten-free foods was recorded as a separate barrier category, its precise operational definition was not specified in the original study documentation. Similarly, the original documentation did not clarify whether multiple barriers could be recorded for an individual participant.

Data were analyzed using IBM SPSS Statistics, version 10. Continuous variables were summarized as means and standard deviations, while categorical variables were presented as frequencies and percentages. Categorical subgroup comparisons were performed using the chi-square test, with statistical significance defined as a two-sided p-value of less than 0.05. Only subgroup comparisons supported by consistent participant counts and category labels in the original study tables were retained. The analyses were descriptive, and subgroup comparisons were unadjusted; no multivariable modeling was performed.

Ethical approval was obtained from the institutional ethics committee before study commencement, as documented in the original thesis. Written informed consent was obtained from the parents or legal guardians of participating children. The ethics approval number was not available in the original study documentation.

RESULTS

The 227 children had a mean age of 7.00 years (SD 3.09) and a mean disease duration of 6.29 months (SD 1.60). There were 133 boys and 94 girls. Table 1 summarizes child and household characteristics.

Table 1. Child and household characteristics (N = 227)

Characteristic	n (%)
Age 2–8 years	152 (66.96%)
Age 9–14 years	75 (33.04%)
Male	133 (58.59%)
Female	94 (41.41%)
Disease duration 4–6 months	130 (57.27%)
Disease duration >6 months	97 (42.73%)
Monthly household income <10,000	41 (18.06%)
Monthly household income 10,000–50,000	85 (37.44%)
Monthly household income >50,000	101 (44.49%)

Income bands are reproduced as recorded. The results table in the thesis does not specify the currency.

Of the 227 children, 47 (20.70%) met the study's nonadherence criterion and 180 (79.30%) were below the threshold (Figure 1). The denominator of 227 agrees with the two outcome counts and the enrollment total.

Figure 1. Dietary nonadherence classification among 227 children.



The study threshold was an average of at least one gluten-containing serving per week over eight weeks.

Barriers recorded among children with nonadherence

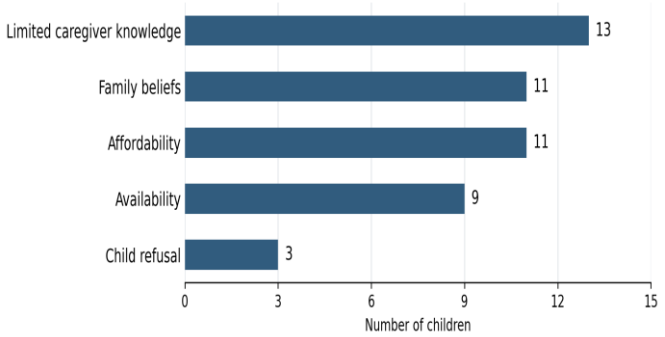
Limited caregiver knowledge was the most frequently recorded barrier. Family beliefs and affordability were tied for the next highest frequency. Table 2 and Figure 2 summarize the five categories among the 47 children who met the nonadherence criterion.

Table 2. Recorded barriers among children with nonadherence (n = 47)

Barrier	n (%)
Limited caregiver knowledge	13 (27.66%)
Family beliefs	11 (23.40%)
Difficulty affording gluten-free food	11 (23.40%)
Limited availability of gluten-free food	9 (19.15%)
Child refusal	3 (6.38%)

Figure 2. Frequency of recorded barriers among 47 children with nonadherence

Percentages use 47 as the denominator. Categories are presented as tabulated in the thesis.



Exploratory subgroup comparisons

Table 3 shows the four subgroup comparisons with internally consistent category labels and counts. None reached the thesis's nominal 0.05 threshold. Reported p values agree with Pearson chi-square tests calculated from these tables.

Table 3. Nonadherence by selected participant and household characteristics

Characteristic	Category	Group n	Nonadherent n (%)	p value
Sex	Male	133	28 (21.05%)	0.878
	Female	94	19 (20.21%)	
Disease duration	4–6 months	130	23 (17.69%)	0.195
	>6 months	97	24 (24.74%)	
Father's occupation	Not employed	60	10 (16.67%)	0.655
	Self-employed	79	18 (22.78%)	
	Employed	88	19 (21.59%)	
Monthly income	<10,000	41	8 (19.51%)	0.977
	10,000–50,000	85	18 (21.18%)	
	>50,000	101	21 (20.79%)	

Percentages are calculated within each category. Each p value applies to the characteristic as a whole.

Discrepancies in the source tables

The age cross-tabulation reports 57 cases of nonadherence, whereas the overall results report 47. It also labels the older group 9–15 years, whereas the eligibility criteria and descriptive table give an upper age of 14 years. The parental education cross-tabulations have category totals that match the opposite parent's descriptive column. In the maternal occupation cross-tabulation, the self-employed and employed totals are reversed relative to the descriptive table. These comparisons require verification against the original data before interpretation.

DISCUSSION

In this outpatient population, approximately one-fifth of children with celiac disease (20.70%) met the study-defined criterion for gluten-free diet (GFD) nonadherence despite receiving nutritional counseling. This finding is relatively consistent with the 18% nonadherence frequency reported by Chauhan and colleagues in a pediatric population from India. [3], [19], However, differences in study populations, dietary assessment methods, and operational definitions of adherence may limit direct comparisons between these findings. Previous studies have reported variations in dietary adherence among children with celiac disease, highlighting the influence of assessment approaches and differences in dietary management practices. [19] These findings emphasize that maintaining a strict gluten-free diet remains a considerable challenge in pediatric populations and requires continued nutritional guidance and follow-up.

Limited caregiver knowledge was the most frequently recorded barrier to dietary adherence, accounting for 27.66% of nonadherence cases. This finding highlights the importance of caregiver awareness regarding gluten-containing ingredients, food labeling, and potential sources of inadvertent gluten exposure. Since children depend largely on their caregivers for food selection and preparation, inadequate nutritional knowledge may complicate the implementation of dietary restrictions. Previous pediatric studies have also examined the influence of caregiver knowledge and attitudes on dietary adherence in children with celiac disease. [3,4,20,21] Accordingly, repeated nutritional counseling should emphasize practical food identification, interpretation of food labels, and prevention of cross-contamination.

Family beliefs and difficulty affording gluten-free foods were the next most frequently reported barriers, each accounting for 23.40% of cases. Family attitudes and household dietary practices may influence children's ability to maintain dietary restrictions, particularly when meals are prepared collectively or several family members participate in food-related decisions.[22,23] In addition, the financial burden associated with specialized gluten-free products may restrict food choices among economically disadvantaged households.[24,25] Although household income was not significantly associated with nonadherence in the present study (p = 0.977), this finding does not exclude the possibility that individual families experience difficulties purchasing suitable foods. The reported affordability barrier reflects caregivers' experiences among nonadherent children and should be distinguished from the statistical comparison of income categories across the overall study population.

Limited availability of gluten-free foods was reported in 19.15% of children with nonadherence. Restricted access to appropriate dietary alternatives may create additional challenges, particularly in settings where specialized gluten-free products are not readily available. [26,27] Therefore, nutritional guidance should consider locally accessible and naturally gluten-free food alternatives, including rice, maize, potatoes, pulses, fruits, and vegetables. Child refusal was the least frequently recorded barrier (6.38%).

Nevertheless, food preferences, acceptance of dietary restrictions, and difficulties associated with eating outside the home may influence children's dietary behavior. Previous research has highlighted the psychosocial and quality-of-life challenges associated with maintaining a gluten-free diet during childhood. [28,29] Age-appropriate nutritional education and family involvement may help children better understand and accept dietary recommendations.

The practical implications of these findings extend beyond individual dietary counseling. Regular assessment of caregiver knowledge, family dietary practices, and food accessibility may help healthcare professionals identify barriers that require additional support. Collaboration between pediatricians and nutrition professionals, together with family-centered educational interventions, may strengthen long-term dietary management. [30] Importantly, the present findings support the need for individualized nutritional guidance that considers both the dietary requirements of children and the practical circumstances of their households.

Several limitations should be considered when interpreting these findings. The single-center design limits the generalizability of the results to other populations. Dietary intake was based on caregiver-reported recall, which may have introduced recall and social desirability biases. Furthermore, the study-defined nonadherence threshold of at least one gluten-containing serving per week may not capture all clinically relevant gluten exposure. The assessment of certain barriers, particularly food availability and family beliefs, was not supported by clearly documented operational definitions. The possibility of overlapping barriers was also not specified. Finally, the relatively small number of nonadherent children limited the statistical power of subgroup comparisons. Despite these limitations, this study provides useful local evidence regarding the frequency of dietary nonadherence and the practical barriers reported among children with celiac disease in Bahawalpur.

In conclusion, approximately one-fifth of children met the study-defined criterion for GFD nonadherence. Limited caregiver knowledge, family beliefs, affordability, and restricted food availability were the principal reported barriers. These findings highlight the importance of sustained nutritional education, family involvement, and improved access to affordable gluten-free food alternatives. Further multicenter studies using standardized dietary assessment methods and objective indicators of gluten exposure are warranted to better understand dietary adherence among children with celiac disease in Pakistan.

Limitations

Consecutive recruitment from one outpatient department limits generalizability. Caregiver recall may have missed some exposures, and the serving-based threshold does not capture all intermittent or inadvertent gluten intake. There was no reported baseline adherence measure or comparison group, so the effect of counseling cannot be estimated. The unclear availability definition, uncertain handling of overlapping barriers, and subgroup table inconsistencies further limit interpretation.

CONCLUSION

Nonadherence was recorded in 47 of 227 children with celiac disease. Limited caregiver knowledge was the most frequently reported barrier, followed by family beliefs and affordability. These findings identify practical topics to discuss with families during follow-up.

Ethical Approval

Ethical approval for this study was obtained (Ref: BVH-1400-059-CH) from the Institutional Ethical Review Committee of Bahawal Victoria Hospital, Bahawalpur, Pakistan, before the commencement of data collection.

Data Availability

The data analyzed in this study are available from the corresponding author upon reasonable request.

Author Contributions

Conceptualization: Dr. Sumaira Abbasi, Dr. Ayesha Moin
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Writing – Review & Editing: Dr. Noor Akbar, Dr. Hafsa Liaqat, Arooj Liaquat, Dr. Shahbaz Akhtar
All authors reviewed and approved the final version of the manuscript and agree to be accountable for all aspects of the work, ensuring that questions related to the accuracy or integrity of any part of the study are appropriately investigated and resolved.

Informed Consent

Written informed consent was obtained from the parents or legal guardians of all participating children before data collection.

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No.

Conflict of Interest

No.

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Declaration of AI-Assisted Language Editing

An AI-assisted language editing tool was used solely to improve the language, grammar, and clarity of the manuscript. The authors reviewed and approved all revisions and take full responsibility for the final content.

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