

EDITORIAL

CELIAC DISEASE IN PAKISTAN: CHALLENGES AND OPPORTUNITIES

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Celiac disease is a permanent intolerance to gluten (a protein present in wheat, rye and barley), which causes damage to the small intestinal mucosa by an autoimmune mechanism in genetically susceptible individuals. The villous atrophy that ensues can lead to malabsorption of a variety of macro and micronutrients including iron, calcium, folate and fat soluble vitamins.¹ Celiac disease was thought to be a rare malabsorptive disorder of infancy and childhood. However, it is now considered to be a common, chronic, multi-system disorder that can present at any age when gluten is present in the diet.

Typical symptoms of celiac disease are abdominal pain, diarrhoea and weight loss. However, many individuals present with non-gastrointestinal (atypical) symptoms including anaemia, extreme weakness, short stature, osteoporosis, elevated liver transaminases, neuropathy, menstrual irregularities and infertility. Additional symptoms in children include vomiting, delayed growth and puberty and dental enamel defects. Dermatitis herpetiformis (DH) is 'celiac disease of the skin' and presents with a chronic, severely itchy, blistering rash that is poorly responsive to conventional therapies. A skin biopsy helps confirm the diagnosis of DH.

Celiac disease is a hereditary disorder. Both first and second-degree relatives of the patient with celiac disease have a significant (5–15%) risk of developing the disorder. Other high-risk groups include patients with autoimmune disorders, e.g., type 1 diabetes, thyroiditis, and Down syndrome.

Highly sensitive and specific serological tests are available to screen for celiac disease.^{2,3} The currently recommended tests are the serum IgA-tissue transglutaminase antibody (TTG) and the IgA-endomysial antibody (EMA). These tests have a sensitivity and specificity of greater than 90%. The TTG is currently the test of choice and is widely available worldwide. IgA deficiency is common in celiac disease and hence total serum IgA level must also be measured to avoid a false-negative result. The serological tests are less reliable in children under 3 years of age. Also, the patient must be consuming a normal, gluten-containing diet at the time of testing. A negative test does not rule out celiac disease. Serological screening is recommended for all high-risk individuals. Patients with a positive TTG test should be referred for endoscopic small intestinal

biopsies for confirmation of the diagnosis. Endoscopic biopsies, still remain the gold standard for diagnosis.

Celiac disease can be effectively treated by a strict, life-long adherence to a gluten-free diet. However, a gluten-free diet should not be started before a biopsy is done, as the diet will heal the intestinal lesion and affect the interpretation of the biopsy making confirmation of the diagnosis difficult.

Celiac disease is one of the most common chronic gastrointestinal disorders in the world. The disease occurs in about 1% of the population.¹⁻³ However, it is estimated that 90% of these individuals remain undiagnosed. The prevalence of celiac disease in Pakistan is unknown. However, it is felt to be a very common disorder both in children and adults.

It is well recognised that awareness of celiac disease amongst health professionals is poor and delays in diagnosis are common. Unrecognised or poorly treated celiac disease can lead to a variety of complications including nutritional deficiencies like anaemia and osteoporosis, reproductive disorders, increased risk of developing other autoimmune disorders and intestinal lymphoma. Serological screening of minimally symptomatic patients or those with atypical/non-gastrointestinal complaints can significantly increase the rate of diagnosis of celiac disease.⁴

While the gastrointestinal medical community's main focus is on chronic viral hepatitis and infectious diarrhoeal disorders, celiac disease may not be getting its due attention in Pakistan. Two aspects of this issue need to be addressed:

1. Determining the scope of celiac disease in Pakistan

This is not known and needs to be investigated. How common is this disease and how does it present clinically? To answer these questions, data from various medical institutions across the country should be collected to study the patient characteristics and various clinical presentations and manifestation of celiac disease. This information should be used for improving awareness of celiac disease in the medical community.

With the availability of serological testing, a study to investigate the prevalence of celiac disease in Pakistan should be feasible.

2. Availability of gluten-free foods in Pakistan

Although a gluten-free diet provides effective treatment for celiac disease, this diet is complex, costly and socially restrictive. The problem is further compounded by the fact that wheat is the most affordable and readily available grain in the Pakistani diet. Alternates like rice are expensive and outside the reach of the general population especially for long term use. Maize can provide a less costly alternative but contamination with gluten-containing grains remains a concern in the flour production process.

A gluten-free diet poses several other challenges. Contamination with gluten-containing grains always remains a concern. The patients live in constant fear of this possibility. The problem can be remedied somewhat by accurate labelling of food products. Unfortunately, adequate food labelling laws do not exist in Pakistan. Lobbying with the government to enforce mandatory and accurate labelling laws can get this process moving forward.

Availability of manufactured gluten-free foods in Pakistan is limited. Gluten-free foods imported from foreign countries are very expensive and will never be affordable for masses. North American data shows that gluten-free foods are at least 2.5 times more expensive than their regular counterparts. Therefore, efforts must be made in getting the food producers and suppliers to create gluten-free foods from locally available ingredients. Compliance with a gluten-free diet will improve if it is easily available and affordable.

Patient information and education remains a cornerstone in the management of any disorder. Pakistani Celiac Society is a recently established national, volunteer, non-profit organization whose mission is to provide support and services to

individuals and families with celiac disease through programmes of awareness, advocacy and education. The web site of the Society (www.celiac.com.pk) contains information on various aspects of celiac disease and gluten-free diet both in Urdu and English languages. Printable brochures are also available which can serve as a source of useful information both for the patients and health professionals. Advocacy strategies by the Society include getting the medical profession involved in the process, creating patient forums for sharing information and ideas and liaison with food industry for better and affordable locally manufactured gluten-free products.

In summary, there celiac disease in Pakistan comes with many challenges. However, at the same time there are some exciting opportunities. This is a good time for medical professional organizations to partner with patient support groups in order to improve awareness of celiac disease in the country. These efforts will eventually result in timely diagnoses of celiac disease and better availability of affordable gluten-free food products for patients. The task is uphill but can be accomplished with dedication and commitment.

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