Chapter 4

Celiac Disease in Pakistan

The scope of celiac disease in Pakistan is not well known. How common the disorder is and how it presents itself clinically remain largely undetermined. Reading review articles on celiac disease one often comes across the statement that celiac disease is common in Pakistan. Also, after interaction and discussions with gastroenterologists and members of the public, it is felt to be a fairly common problem. However, no research study has specifically looked at this question.

Publications on Celiac Disease

Surprisingly, there is not much published on celiac disease from Pakistan. Most of the information in the medical literature is in the form of case reports or small series of patients. After an extensive review of the literature, all available publications were identified. The highlights of these publications are being presented. These studies were discovered thorough various medical literature search engines and it is possible that there are others as well.

The conclusions from various publications are very similar. The major theme that emerges is that celiac disease can prevent in a variety of ways, the awareness of celiac disease is a problem in our country and delays in diagnosis common.

Celiac Disease

Zahra T, Memon AR, Afsar SS. *Pakistan Journal of Medical Sciences* 2005;21(2):225-7

This is a case report from Civil Hospital, Karachi of a 17 year old female presenting with vomiting, weakness and growth retardation. She also had history of leg deformities and protruding chest since age three. On examination she was found to be severely anemic, had short stature and deformity of the chest. Serological testing and intestinal biopsy confirmed celiac disease. The patient had been misdiagnosed as having a skeletal disorder for many years.

COMMENT

This case is an excellent example of a patient with celiac disease who had all the classical and non-classical (atypical) clinical features for a long time and yet the diagnosis was missed.

Celiac Disease in Pakistani Children with Persistent Diarrhea

Aziz, Sina et al. *Journal of Pediatric Gastroenterology & Nutrition* 2005 Oct;41(4):494

This is an abstract of a study from Karachi to document celiac disease in 49 children (age 1-18 yrs) with failure to thrive and persistent diarrhoea. Children with infective causes were excluded. Intestinal biopsy confirmed celiac disease in 61% of cases. The TTG was also positive in these cases. The authors concluded that celiac disease is an existing yet undiagnosed problem in the pediatric population.

COMMENT

Chronic diarrhea and poor growth are classical symptoms of celiac disease in children.

Etiology of Short Stature in Children

Sultan M, Afzal M, Qureshi SM, Aziz S, Lutfullah M, Khan SA, Iqbal M, Maqsood SU, Sadiq N, Farid N.. *Journal of College of Physicians & Surgeons of Pakistan* 2008;18(8):493-7

In this case series from the Combined Military Hospital, Multan the researchers investigated the causes of short stature in children. A total of 214 children (140 boys and 74 girls), ranging from 2 to 15 years presenting with short stature were studied. The five most common etiological factors of short stature in order of frequency were constitutional growth delay, familial short stature, malnutrition, celiac disease and growth hormone deficiency.

COMMENT

As mentioned in the previous chapter, children with celiac disease can present with short stature in the absence of any other symptoms.

Oat: Unique Among the Cereals

Sadiq Butt M, Tahir-Nadeem M, Khan MK, Shabir R, Butt MS. *European Journal of Nutrition* 2008 March;47(2):68-79

This review article on oats is from the Institute of Food Science and Technology, University of Agriculture, Faisalabad. The authors highlight the nutritional value of oats in terms of it being a good source of B complex vitamins, protein, minerals and fiber and its use in celiac disease. The incorporation of oat

grains and oat bran in the food products can provide nutritional benefits.

COMMENT

Pure and uncontaminated oats are safe to consume for most patients with celiac disease. Currently, pure oats are available from limited sources and are quite expensive. Pakistan, with its strong agricultural base, is in a unique position to take the lead in growing pure oats which can be exported to other countries. This will improve food choices for those on a gluten-free diet.

A Case of Celiac Disease in an Adult

Satti SA, Maiken GR, Ahmed A. *Pakistan Armed Forces Medical Journal* 2009 Dec;(5)

This is as case report of a 22 year-old army officer who presented to the medical outpatient department with twelve years history of intermittent diarrhea, oral ulcers and failure to gain adequate weight despite good appetite. He was investigated extensively ever since childhood with repeated blood tests, stool examination, abdominal ultrasound and upper gastrointestinal endoscopy. The latest endoscopic biopsy was carried out three years prior to presentation and had revealed nonspecific gastritis (inflammation of stomach) and non-specific changes in duodenum. On examination, the patient was underweight and had iron deficiency anemia. Serological tests for celiac disease including endomysial antibody (EMA) and anti-gliadin antibodies (AGA) were strongly positive. He was started on a strict gluten free diet and had an excellent response with resolution of symptoms and good weight gain. The authors also provide a brief review of celiac disease.

COMMENT

This case again exhibits typical symptoms of celiac disease. Interestingly, the patient had an endoscopy and duodenal biopsies in the past. The changes were reported as mild and nonspecific. This highlights the need for obtaining and interpreting biopsies appropriately when celiac disease is being considered.

Exploring Celiac Disease and Gluten-free Diet in Pakistan

Rashid M, Khan AG. *Pakistan Journal of Gastroenterology* 2009 Apr;23(1):1-3

In this Editorial the authors highlight some of the key areas of interest in celiac disease for the medical community and suggestions for research in this area.

COMMENT

Celiac disease is an untapped area of research in Pakistan. This offers great opportunities to investigators, both in clinical and basic science research.

Sero-Negative Celiac Disease with Dermatitis Herpetiformis: A Case Report

Adhi M, Farooq A, Hamid SA, Hasan R, Mamji S, Baloch AA. *Cases Journal* 2009 May18;(2):7512

This is a case report of a 20-year-old female presented with a skin rash for fifteen years, diarrhea for eight years and spasms of hands with twitching of face for a few months. She had mild anemia, low vitamin D and calcium. Other causes of mal-absorption were ruled out. Total IgA level, tissue trans-glutaminase antibody (TTG), endomysial antibodies (EMA)

and skin biopsy were normal. Intestinal biopsy revealed subtotal villous atrophy. Patient was prescribed a gluten-free diet which alleviated her symptoms.

COMMENT

Serological (antibody) tests are for screening purposes. The definite test for celiac disease is an intestinal biopsy. Although rare, celiac disease can be present in a patient with negative antibody tests.

Celiac Disease in Pakistan: Challenges and Opportunities

Rashid M, Khan AG. *Journal of Ayub Medical College* 2009 July;21(3):1-2

This Editorial discusses the challenges related to celiac disease and gluten-free diet. The need for improving awareness of celiac disease, wider availability of serological testing and better availability of gluten-free diet is stressed.

COMMENT

Better awareness of celiac disease amongst the medical professionals is one of the most important factors for early diagnosis.

Nutritional Status of Children with Celiac Disease

Aurengzeb B, Leach ST, Lemberg DA, Day AS. *Acta Paediatrica* 2010 July;(7):1020-25

This recent study from the Children's Hospital, Pakistan Institute of Medical Sciences, Islamabad investigated the nutritional status of 25 newly diagnosed children with celiac disease and comparing them to healthy children. Relationships

between presentation patterns and nutrition were also examined. Twenty-five children with celiac disease (mean age 8.2 ±4.5 years) and 25 control children were studied. Thirteen (52%) children with celiac disease had gastrointestinal symptoms with 14 having a positive family history. At presentation 8.7% were wasted, 4.2% were stunted and 20.8% overweight. The mean height and weight for age and other nutritional parameters did not differ between the two groups.

COMMENT

This study illustrates that only half of children with celiac disease had gastrointestinal symptoms. About a fifth were overweight. Poor growth is becoming an uncommon presentation of celiac disease in children.

Multiple Autoimmune Syndrome: Hashimoto's Thyroiditis, Coeliac Disease and Systemic Lupus Erythematosus (SLE)

Latif S, Jamal A, Memon I, Yasmeen S, Tresa V, Shaikh S. *Journal of Pakistan Medical Association* 2010 October;60(10):863-865

This case report from Civil Hospital Karachi describes an 11-year old girl with clinical features that led to the diagnosis of hypothyroidism. The patient also developed lupus and then celiac disease confirmed with biopsy. It is uncommon to have several autoimmune diseases in one patient, a phenomenon referred to as known as multiple autoimmune syndrome.

COMMENT

Patients with autoimmune disorders are at higher risk of developing celiac disease. Patients with celiac disease are at higher risk of developing other autoimmune disorders.

Perspectives on Celiac Disease

For this chapter of the book, a select group of gastro-enterologists and patients were invited to share their perspectives and experiences with celiac disease. It is interesting to see that there is so much common in the problems identified by both patients and physicians. It was also amazing to find that the issues raised by all these individuals are very similar to those I had identified while researching for this chapter. Hopefully, the patient narratives presented here will serve as a reminder to everyone regarding the difficulties endured in the diagnosis of celiac disease and treatment with the gluten-free diet.

Physician's Perspective (1)

The Spectrum of Cases

Celiac disease has a worldwide prevalence of approximately 1% and it is expected that in a country like Pakistan with 160 million people, approximately 1.6 million should be suffering from this problem. In the absence of an organized healthcare system, the exact statistics of the people suffering from celiac disease are not available and various direct and indirect studies show a relative higher prevalence in people from central Punjab and certain areas of Khyber PakhtunKhwa province. Though the pediatricians, medical specialists in major teaching hospitals are sensitized to celiac disease the family physicians who constitute the backbone of the healthcare do not often think about this condition. Instead, they have a preoccupation with the infectious etiology of diarrheal diseases resulting in inappropriate prescription of antibiotics.

In addition to the poor awareness of celiac disease, the diagnostic workup poses an extra challenge. The tests like tissue transglutaminase antibodies etc. are expensive and conducted once a month only in one of the reference laboratories of Pakistan. The gold standard test for confirmation of the disease i.e. upper GI endoscopy and duodenal biopsy has problems of its own. This test is available at select centers only and very young kids need anesthesia or conscious sedation. Furthermore, culturally the test is not very well accepted and carries some risk of transmission of infection as well. As majority of the population lives in villages and small towns where this facility is not available, many patients remain undiagnosed for a long period of time. Clinical picture of celiac crisis, seen rarely in the developed world with an organized healthcare system, are seen commonly in Pakistan. Patients are very ill by the time the poor kid or the affected patient travels to the teaching hospitals or major city endoscopy/GI treatment centers where a positive diagnosis is established. Mild to moderate clinical presentations of celiac disease e.g. stunted growth, poor physique, bad dentition, recurrent diarrhoea, iron deficiency anemia etc. may remain undiagnosed for a long time or in some cases for the entire life of the individual.

The main stay of the management of patients suffering from celiac disease is strict lifelong avoidance of gluten-containing foods. The strict adherence to the gluten-free diet required to maintain the person in a normal state of health is learnt the hard way by the families. There is emergence of symptoms on the repeat challenge with gluten-containing diets as a gluten-free diet is hard to practice because of presence of gluten cross contamination in diets which consist of naturally gluten-free ingredients. Better understanding about the food contents and improved recipes with permissible foods can help with the dietary compliance.

Next, I would like to share a few cases that I have seen in my clinical practice in Pakistan to illustrate the variety of ways in which patients with celiac disease can present.

Case 1

A young girl of 18 years from southern Punjab presented to me in 1995 with generalized anasarca, anemia and recurrent loose stools ever since her childhood. She was a college student and had a family history of type 2 diabetes. She had dimorphic picture with low ferritin, low iron and increased iron binding capacity. She had low albumin and high anti-gliadin antibodies (IgA as well as IgG). A small intestinal biopsy was done and confirmed the diagnosis of gluten enteropathy (celiac disease). The nature of the problem was explained to patient and her family. She was an intelligent young lady who understood and accepted the dietary restrictions. She recovered from her anemia, anasarca and diarrhea within three months of gluten avoidance. She completed her bachelor's degree and got married. She had two live births and two abortions. The births were normal, full term and the birth weight of the babies was 9 and 10 pounds respectively. She gained a significant weight after the marriage. 1n 2006, she was found to have hepatitis C infection. She had also developed type 2 diabetes and obesity with a BMI of 31. She was treated with a six-month course of interferon therapy and sustained viral response was achieved. She was found to have low bone mineral density and is currently receiving calcium and vitamin D supplements.

Case 2

A 32 year-old married women from Lahore (central Punjab) suffering from aggressive rheumatoid arthritis had presented in 1998 with anemia, anasarca, pleural effusion and ascites. She was grossly emaciated and had a poor functional capacity. On evaluation, she had microcytic anemia, low serum iron, high

total iron binding capacity, low albumin and transudative pleural and peritoneal fluid. Upper GI endoscopy showed few erosions in the distal stomach with flat and sparse valvulae coniventes (mucosal folds of small intestine). Histology was typical for severe celiac disease. She was put on gluten-free diet and despite excellent adherence to the diet, she continues to have low hemoglobin and albumin, recurrent loose stools and aggressive rheumatoid arthritis. She has been extensively investigated for other immunological diseases and small bowel lymphoma. She is currently receiving numerous medications including methotrexate, leflunamide, hydroxychloroquine, salazopyrine and low dose prednisolone along with calcium and vitamin D supplements.

Case 3

A 55 years old male came in 2004 with long standing anemia. The blood test revealed that the hemoglobin was low at7.5 gm/dl with microcytosis. His physical examination was unremarkable. An upper GI endoscopy was performed and he has found to have fine serrations of the duodenal mucosal folds. A biopsy of the mucosa revealed intraepithelial lymphocytes along with villous flattening. He was put on gluten-free diet and his hemoglobin improved in next three months.

Case 4

A 22 year old male from Mansehra, province of Khyber Pakhtunkhawa came in 1996 with long standing intermittent, loose stools. He had been given repeated courses of antibiotics. On examination, he was emaciated, anemic with a distended abdomen and loud bowel sounds. On laboratory investigations, he had microcytic anemia with hemoglobin 6 gm/dl, low ferritin, and albumin and increased liver enzymes. His serology for viral hepatitidis was negative. His anti-gliadin antibodies

(both IgA and IgG) were elevated. Duodenal biopsy confirmed the diagnosis of celiac disease. The diagnosis and its management were explained to the patient. He adhered to the gluten-free diet and his health recovered very quickly. He got married to his first cousin and two out of his four siblings were also diagnosed with celiac disease. Unfortunately, the whole family died in the massive earthquake in 2007.

Case 5

A teenage girl presented in 2005 with recurrent abdominal pain and loose stools since 4 to 5 years of age. She belonged to a poor family and had anemia, emaciation and very poor general health. Duodenal biopsies confirmed the diagnosis of celiac disease. Despite repeated explanations, the girl failed to improve as she could not adhere to the gluten-free diet purely because of economic reasons. There was a significant element of depression as well. Though she gained four or five pounds of weight and had improved hemoglobin, she continues to have recurrent abdominal pain and diarrhoea.

Case 6

A 45 year old lady presented last year with recurrent abdominal pain and recent weight loss. She was a known case of celiac disease since 1989 but had adhered poorly to the gluten-free diet. She acquired hepatitis C infection in 1992 following a blood transfusion at the time of delivery of her second son at one of the community hospitals. She later on developed pulmonary tuberculosis in 1997 treated with anti-tuberculosis therapy for nine months. A CT scan of the abdomen showed thickening of the jejunal wall and a small intestinal endoscopy and biopsy confirmed the diagnosis of lymphoma.

These are few cases that I have picked to highlight the problem of celiac disease in the Pakistani community. The cases seen by

the clinicians are just the tip of the iceberg and there are many more in the community that remain undiagnosed. Many young kids die in their early childhood and many more die as a result of opportunistic infections arising out of poor general health. We need to strive hard to sensitize the public in general and doctors in particular regarding the presence of celiac disease, its early diagnosis and education about the gluten-free diet.

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Physician's Perspective (2)

Diagnostic Dilemmas

The term celiac disease is as yet not well known to most and, of course, not understood in this population with rare exception. I have been practicing in Pakistan for past twenty-eight years. Celiac disease has been considered as a disease of the West or of White people; but considering that our part of the world is a wheat consuming belt, we probably should have and do have some burden of this particular disease. Contrary to teachings and announcements, often early weaning of infants is practiced and that also with wheat-based items.

How prevalent is this entity? This answer is missing due to lack of any population based studies to date. This issue is further confounded when we take into account the fact that unsafe and unclean water, lack of health education, inadequate sanitation, prevalence of malnutrition and infections (mostly enteric) contribute to multiple episodes of diarrhea, being a common manifestation of many disorders. The problem of

diagnosis of celiac disease, besides lack of awareness and common occurrence of other causes of diarrhea, has been further compounded by lack of availability of serological tests. Also, there is absence of endoscopic testing facility in most major cities of the country. Currently, the anti-tissue transglutaminase antibody test is commercially available in most cities but is "costly". Overall, there are only five centers in the entire country of 180 million (with 45% population under 15 years of age) where pediatric age group patients especially young ones get benefit of jejunal biopsies.

The diagnosis of classical cases is probably being made in major centers but not-so-classical (atypical) presentation still defies identification. Short stature and anemia are other features that seem to be now catching the thought process of medics in the field. There is mostly delay of over one to two years and even longer in arriving at a confirmed diagnosis. It is not only cost of tests and endoscopy but also that of physicians, which makes access difficult.

The allergy to wheat is often thought to wean off over some years and then it shall be business as usual....!!! There is often mixing of wheat flour in the preparations of many of our food items that, despite advice, are difficult to avoid due to lack of information about ingredients. Various wheat flour fractions are used in foods and sweets which once again sneak in to the diet of unfortunate patients. Then comes the millet (*bajra*) and *dalya* (oat) which are often confused as being of wheat origin. Lately, specialty stores are carrying gluten-free foods, but their availability is limited for common people, being illiterate and non-affording anyway.

Furthermore, looking for confounding and/or associated conditions is delayed or difficult to pursue due to cost of diagnosis and treatment e.g. growth hormone deficiency. Most patients that have been diagnosed and having adhered to nutritional instructions have shown excellent results in terms of

growth and overall health but often are lost to follow-up. Some of these been seen after a gap have been found to have returned to normal diet with gluten and happy to report that they have outgrown their allergy to gluten!

I have a strong feeling that majority of celiacs are missed due to multiple factors mentioned above. Many a cases with recurrent diarrhea, growth failure, stunting, malnutrition and micronutrient deficiencies including anemia need assessment with celiac disease in mind.

Lots of health education, mostly on media like radio and community groups, is needed for best diagnosis and management. Community support groups with information and resources to tackle and cope with the health issues are certainly required.

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Physician's Perspective (3)

Challenges of Management

Celiac disease or celiac sprue as it is some time called, is a disease present worldwide with various incidence rates ranging from 0.5% to 1.5%. It is thought that celiac disease affects about 1% of the world population. The exact incidence is not known in Pakistan but is estimated to be 0.8%. It is felt that Northern Pakistan has slightly higher prevalence because historically the foreign invaders like Alexander the Great entered the South East through Khyber Pass and some soldiers settled down here and some of population might be their descendants. That is why they have fairer complexion like the

Caucasians, who on the whole have higher incidence than Asians.

With advent of newer and more sensitive test plus more awareness both in physicians and patients, certainly the rate of pickup of celiac disease is rising. Although celiac disease was traditionally considered a childhood disease, most patients are diagnosed in adulthood. Delay in diagnosis, especially in patients who have severe symptoms at presentation, is associated with increased mortality, primarily because of malignancy. In Pakistan we usually see patients with advance stage of presentation.

In children, the presentation with malnutrition is very common in young ones brought to tertiary care hospital. The community physicians usually treat them for abdominal tuberculosis, and it is only when they don't respond and kwashiorkor like symptoms set in the specialist's advice is sought.

In adults, the usual presentation is with bowel symptoms like diarrhea. Malabsorption is not that a common presentation as it is in the West. Another cause of confusion is microcytic anemia. This is usually discovered on routine investigations, carried out on automated analyzers, which pick up micro-cytosis also due disorders like thalasemia trait, a condition prevalent in the Pakistani population.

As far as investigations are concerned, the routine test like full blood count which picks up the anemia is widely available and routinely done. More specific tests like tissue-transglutaminase antibody (TTG) are available in major teaching hospitals but not routinely done because of cost to the patient. Endoscopic biopsy in these hospitals is more widely done and cheaper to carry out because the histology is either done free or at minimal cost.

In terms of treatment, it is extremely difficult for patient to follow a gluten-free diet because wheat is a staple diet. A

gluten-free diet is difficult to access. Our experience in the province of Khyber PhuktunKhawa has been that we are seeing a significant number of cases coming from across the border in Afghanistan. The health services being virtually non-existing due to the continuing war there, all the patient load is being taken by us in Peshawar which is the next major city south of Kabul.

Let me share with you a story of a 3 year-old girl from Khyber Agency, a border area with Afghanistan. As soon as she was weaned from milk, she developed diarrhoea. She saw quite a few doctors and various medication were tried, ranging from anti-helmentics to anti-tuberculosis. The child continued to have diarrhea and developed abdominal distension. It took them four days to reach our hospital. The journey was on foot, horseback and on a bus.

On examination, she had pallor, was malnourished and weighed only 8 kg. Her abdomen was distended but soft. The hemoglobin was low at 8.8 gm/dl. The red blood cell morphology showed a hypochromic-microcyctic picture. The serum albumin was also low at 3.0 gm/dl. Celiac serology revealed the IgA-TTG to be elevated at 93.8U/ml (normal range 0-7U/ml.). An upper GI endoscopy revealed flat dudenal folds and nodular mucosa. Histopathology confirmed celiac disease (Marsh III).

After they were advised to start a gluten-free diet, the family noticed a difference in the child's health within a few weeks. The child also put on weight. The family was really pleased but obviously the follow-up was difficult.

All in all, we as doctors should try our best to increase the awareness of celiac disease in Pakistan.

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Patient's Perspective (1)

A Long Journey

It was all fine until I was about five years of age. At that time, I developed persistent abdominal pain. Because of this, I was sent back from school many times. It was very difficult for me as a child. Along with the increasing frequency of pain, I was getting pale (anemic) and my parents observed a noticeable lag in my growth. Being short compared to kids of my age, I was also very concerned. I was getting weaker. This weakness was one of the concerns the doctors were told about at every visit. The last sign was the development of dark circles around my eyes.

With these signs and symptoms in place, visits to doctors began. Starting from a general physician near our residence, moving on to pediatricians and then to gastroenterologists. My parents, worried that nothing has significantly improved, took me to homeopathic doctors and even to *hakeems*! The interesting part was the spectrum of reasons these individuals gave for my condition. The most common reason given was lack of fiber in my diet which had caused constipation leading to abdominal pain and bloating. Some concluded that it is due to improper diet or indigestion. The gastroenterologists blamed it on stomach bugs. Some pediatricians asked my parents to check if I might be suffering from school phobia and try to eliminate this factor which could be the cause of stomach ache during school hours. The other categories of doctors (homeopathic and *hakeem*) had their own views which somewhat overlapped with the allopathic doctors.

Diagnosis:

Every doctor wanted a test report and each test was different from what had been previously done. Starting from the simple

blood test, the investigations moved to examination of urine and stool. Abdominal ultrasound was repeated, often from each doctor's recommended lab. X-rays were done to check the bone growth. Eventually, after all these examinations each being done at least a couple of times, I went for a biopsy. This changed the picture.

It was the end of 1994 when I had my biopsy. The gastroenterologist that I used to visit performed the biopsy and told us that it was a "life-long allergy to wheat"! The doctor also included oats and rye in the list of forbidden grains. It was the strangest thing my parents had ever heard of as wheat is a staple diet in Pakistan. The only options left were rice and corn. I had no idea about the implications this would have on my lifestyle. I was unable to judge this from the amazement and shock on my parents' face. Unaware of the long list of things made from wheat, I had no idea about my future.

A New Life:

So the real challenge began. It was not easy for my family to absorb the diagnosis of lifetime wheat allergy. A list of prohibited food items started to grow longer and few other options were presented. As a growing, school going child, nutritious wheat-free foods were impossible to find. The diet primarily consisted of rice, corn and gram flour. Fruits and vegetables were included in the diet plan. The meals at school often had to be restricted to some fruits and potatoes cooked in different forms. It was a real challenge for my parents to understand and cope with the situation themselves on one hand and to educate and control me on the other. But I am thankful to them. They educated me and other family members and even my teachers in a way that I never felt alone to fight this problem. It has been a team work. This type of support is as essential as the diet for a patient with celiac disease.

Even after the diagnosis, I still had to visit a number of doctors. They were still confused about the state I was in. One of them boldly asked to challenge myself with wheat and instructed to start a regular diet once again along his some prescribed medicines. It failed badly, affecting what I had achieved during the wheat-free diet period. The doctors' consultations continued and I was fortunate to get the name of the condition Celiac Disease in 1998. I was introduced to the term Gluten in 1999 from the same doctor. It was the moment my diet changed from wheat-free to gluten-free. It was this term 'gluten' that made my diet management easier, as I started to get gluten-free flours from my relatives in USA.

But the diet only changed at home, rest remained the same. The combination now was gluten free-flours and rice along with cereals for breakfast and all other local gluten-free foods possible. After the introduction of gluten-free flour, diet management became easier. As a Pakistani it was helpful to have the conventional bread (*roti)* made from non-wheat sources and it solved many problems. I tried homemade diet plans which were meant to be followed but were not always possible due to my mood swings. School time was still a problem, no bread and nothing could be eaten from what the school offered. It was difficult to adopt fruits as a meal in school. It was so different. Other kids never brought fruit for lunch. It was never a desirable meal. But it went okay. It was helpful that my teachers were told of the condition and I never hesitated to share the "strange" situation with friends at school. I managed to maintain my performance and developed the sense of responsibility that eating something that is prohibited will have a negative effect on my health. But I did have monthly or quarterly emotional outbursts about the situation. These were extinguished by full and unmatched family support on all occasions, events and trips.

Learning about Gluten-Free Diet:

Along with the gluten-free flour, I started getting reading material. I was fortunate to get books and brochures on celiac disease, gluten-free diet and recipes. The recipes were of no use as most of them required ingredients that were not available locally. It was good that I had started reading labels for every product in order to develop the basic knowledge required for identifying what is safe and what is not. It revolutionized the way I looked and dealt with my condition. On the regular checkups, the doctors told me that I was one of the most privileged celiac patients to get gluten-free diet and the knowledge of disease management that most others did not. My health improved with gluten-free diet.

Both at college and university I shared my condition with friends so they also aware of this disease. Everyone was and is still astonished. Teaching others has helped me. Once I was eating an ice-cream which I considered to be safe while a friend indicated to me that it had bread crumbs. This was an addition to my knowledge. With increasing availability of internet in Pakistan, I had more access to information on gluten-free diet. More products and different brands coming from USA and UK helped a lot. It was hard to get anything from local market. Most shopkeepers here have never heard the word gluten and no one can imagine making products that will be wheat-free.

At the end of 2007, I started blogging about the status of availability of gluten-free foods in Pakistan. It has helped me share my experiences and opinions on various local and foreign products. With increasing responses and queries, I have realized that celiac disease is present all over Pakistan and that diagnosis has improved over time.

(A male student age 23 years, Lahore)

Patient's Perspective (2)

The Dietary Dilemma

I had been a small guy from the start, growing a little late compared to others in my age group. At the age of 15, I suddenly started to put on weight, in fact, more than normal. I must say that I was showing signs of obesity, but that all changed. It was May 2004 and I had just turned 17 at that time, when I had my first episode of vomiting. At first, it was simply blamed on the bad food, but it was clear that it was not a normal case of food poisoning when the vomiting never ceased. This condition continued for three month, during which I had seen six different doctors. Some just prescribed medications like Motilium, while others ordered some blood and urine tests. Some weird medicine was also given, which made my lips swell up and had other side effects. The fifth and sixth doctor concentrated more on multi-vitamin tablets and calcium supplements as I had become quite weak by then. At that time my weight was down at 35 kg from 47 kg in three months.

Finally, I went to a gastroenterologist who at first took some fresh blood and urine tests. It showed nothing specific other than the fact that I was weak and suffering from malnutrition. I then had an upper gastrointestinal endoscopy and multiple small bowel biopsies were taken for histology. The result for that was, "*Small bowel biopsy – chronic non-specific inflammation with partial villous change".* At that point, the doctor introduced me to gluten-free diet, but he wanted to be sure so he wrote another blood test to confirm. These were two test named *"anti-transglutaminase-IgA & anti-transglutaminase-IgG".* The result of that was *"IgA-TTG normal value: 0-7 U/ml and my result was 16.9 U/ml"*. So it was now clear what I had.

Starting the Gluten-Free Diet:

From that moment on, I started my gluten-free diet. The positive effect of the diet was that I finally got a break from throwing up, but the negative was that I had nothing to eat in this roti- (bread) centric culture. At first, it seemed as if I was the odd man out, as no one had even heard of such a problem. Although it was hard, my family was beside me, helping me finding ways to blend into the diet.

Ending the Gluten-Free Diet:

However, after 1½ year of diet, I decided to let it go. Without the permission of the doctor (as I knew he would not recommend it), I started to take a normal gluten-containing diet, one small bite at a time.

The reasons for which I left the diet are quiet mixed. It was harder on my parents than on me, as I only had to eat while my mom had to make special arrangements while cooking. Also, keeping track of gluten-containing product was difficult. This limited my outdoor meals, because even a teaspoon of gluten-containing ingredient in a food product is enough to cause problems. When I started to make the list, it shocked me that wheat (and gluten) was used in so many other products. For instance, even Corn Flakes are not gluten-free. Another problem I faced was that there were no options for snacks. I used to get hungry a lot and there were no options except for boiled or baked corn which, after a period of time, became annoying.

Now after almost 3-4 years of gluten-containing diet, I don't get any symptoms. However, one thing is still unchanged and that is my BMI (body mass index) which is still 17.3 and is considered underweight.

(A male patient age 23 years, Karachi)

Patient's Perspective (3)

Tolerating the Intolerance

Being a patient with celiac disease requires nothing but patience. A deep understanding of what food is in front of you and what you can take is required. In a developing country like Pakistan this can be more challenging as compared to living in some other parts of the world. The awareness about the disorder, diagnosis, availability of options, and last but not the least, food regulations including labeling of the products is not as good as it should be.

In many European and North American countries, special focus is given to celiac disease and availability of food for the convenience of patients. Gluten-free foods and restaurants that serve gluten-free meals are easily available in those countries.

Diagnosis:

In Pakistan, the diagnosis of celiac disease is troublesome. I was diagnosed at the age of 23 years but had symptoms since childhood. The last four years consisted of intense experimentation through medications by the doctors who confused the illness with irritable bowel syndrome (IBS), psychological problem, and even tuberculosis. One of the doctors recommended the antibody test for celiac disease at the age 15 but, unfortunately, the testing was not available at that time. It took seven more years to get to the root cause of my health problems. Although the antibody testing facility is now available, it is only in a few laboratories and requires a lot of money. It ranges from Rupees 3,000 to 4,000 in Peshawar (rates vary in different cities) and the only reliable lab is at a medical university in Karachi.

After the diagnosis, diet became a big issue. I was only told that I am not supposed to take wheat for the rest of my life.

However, I was not given any information about other grains that also contain gluten like barley, oats etc. My only option was to collect information from the internet but the names of many local grains in English are difficult to recognize and adjustment to the gluten-free life style took a long time.

Since my diagnosis, I have visited many doctors in Peshawar and Islamabad including gastroenterologists, general physicians, Ear, Nose, Throat (ENT) specialists, dentists and gynecologist. It is distressing to know that apart from the gastroenterologist and a few physicians, doctors related to other fields are unaware of celiac disease. They get the idea only after you give them some explanation. It was also observed that the majority of doctors still consider celiac disease to be a childhood phenomenon. The number of nutritionist (dietitians) available in Pakistan is also very low.

The situation with celiac disease remains serious. After the diagnosis and getting a grip on the issue, a little research in the province of Khyber Pukhtoonkhawa (formerly, NWFP province) gave a better picture of the issue. During the last three years of my gluten-free life, I have come across eight patients diagnosed with celiac disease from different regions. The majority of them got diagnosed through an intestinal biopsy which shows that testing with antibodies is still not very common among the masses.

People still die of celiac disease. I personally know of two such cases, a 35 year old man who got diagnosed at a very late stage where it had already turned into cancer and a family who lost their elder son at the age of 5 years from complications of this disorder. The youngest child, having the same symptoms was fortunately diagnosed in time and is on a gluten-free diet. But again, my interaction with them revealed that although the child has been diagnosed, the family lacks the very basic understanding of the disease and the gluten free life style. In many rural areas when the children are diagnosed with celiac

disease they are put on a gluten-free diet but as soon as they recover, the consumption of wheat starts again. It is again linked to the problem of lack of information, education and awareness.

Another contributing factor to the problem of diagnosis is lack of proper medical facilities in Pakistan. The situation is worse in rural areas where the local people have to access the city hospitals for treatment. On the other hand the city hospitals owned by the public sector are limited in numbers and not enough to cater the need of all. Private hospitals are expensive even for the people living in the cities.

Under such conditions, diagnosing the patients, monitoring them after the diagnosis and giving them guidance seems to be a far reaching goal. The only option left for the patients is to get the information themselves, usually through internet. Unfortunately, the literacy rate is quite low and majority of the population does not have access to computers and internet facilities especially in suburban and rural areas.

Availability of Gluten-Free Foods:

There are many pros and cons of getting diagnosed with celiac disease in a developing country. Being an agriculture-based economy people have access to all kinds of fruits and vegetables. Wheat can be replaced through meat, dairy or fruits and vegetables. Corn or maize flour is a locally produced grain. It is less expensive and easily available in a variety of forms. Therefore, food that is routinely consumed by patients with celiac disease in Pakistan consists mostly of fruits, vegetables, meat, rice, dairy products and corn flour. However, the composition of food consumed also depends on the social status, income levels and awareness about nutritional needs by the patients.

Adults may handle the gluten-free diet, but it is very difficult when it comes to children. Unfortunately, no gluten-

free products are available for children and the parents have to either import them or find them rarely at very expensive shopping marts in big cities. My recent search on gluten- free products for children under the age of five revealed that almost all kinds of flavored milk and cereals contain gluten. In our capital city of Islamabad, I came across one cereal product which was gluten-free but too expensive to be bought.

The children are commonly exposed to gluten when outside their homes. The school system in most regions is not good enough to give special attention to children with celiac disease. It is also very difficult for a common person to understand what contains gluten and what does not.

Other than the naturally gluten-free foods, access to manufactured gluten-free products is a luxury in Pakistan. Locally made gluten-free flours are not available and the imported ones are very expensive. As far as I know, there is only one store each in Islamabad and Lahore that carry a limited supply of gluten-free flour. A half kilogram of flour costs as much as Rupees 1,300 which, for most people, is just too expensive to be bought on a regular basis. Similarly, few other items available include gluten free biscuits, pasta and noodles, all ranging between Rupees 700-800 per pack. A few items like rice noodles, or rice paper imported from Thailand and Malaysia can be bought at a slightly less expensive rate.

Attitude towards Celiac Disease:

Celiac disease is all about a complete abstinence from gluten in any form or quantity, small or large. But that is what only the patient knows. It gets very complicated when it comes to traveling or being outside home. The gravity of the problem is realized when you observe that people around you do not understand the sensitivity of the issue. Wherever I go, I have to take my food with me. This usually consists of maize flour. During a two month teachers training in Islamabad, I had to

stay at a guest house. Managing my gluten-free diet was certainly a major concern. I realized that even after giving a detail lecture to the chef on celiac disease and the care that must be taken with the diet, he still did not take the issue seriously. I came to know after a few days that contamination with wheat was taking place on a regular basis. The only solution was to start cooking myself for the rest of the time period. This is what happens when you are outside your home. Whether you are at relatives, some far off place or during travel, management of diet is a major challenge.

In a society where the gender issues persist, it becomes even more difficult for women who are diagnosed with celiac disease. Even if people around are properly educated, celiac disease is still considered to be a form of illness and especially the fact that this is a genetic disorder. It gets very challenging when it comes to the marital issues for girls. Girls who get diagnosed in childhood or before marriage, celiac disease becomes a stigma for them. For those who got diagnosed after marriage, they still face certain issues when it comes to the social acceptance of the disorder. There are certain misconceptions when a female is diagnosed with this disorder and this requires adequate information and awareness to be created in the society.

Gluten-free life style is not easy. It is a lifelong commitment and can be very stressful at times. It is especially difficult in a country like ours where bread *(roti)* is consumed as a routine and wheat is the most commonly used grain in most food items. The patients need counseling and support from the family members, relatives and friends. They need to be encouraged to stay gluten-free and people around them also need to cooperate with them when it comes to their convenience.

It is very important to take some steps to create awareness about celiac disease by giving proper information to doctors,

patients and the community at large. Only improved awareness can reduce the gravity of the situation.
(A female patient age 26 years, Peshawar)

Issues Requiring Attention in Pakistan

Celiac disease seems to be a relatively neglected disorder amongst the medical profession and the society in Pakistan. The following aspects of this disease require attention.

Determining the Prevalence of Celiac Disease

It is essential to determine how common celiac disease is in Pakistan. Without this type of data it is very difficult to engage the government or food industry. For instance, when a food manufacturer or a retail business is approached regarding making or stocking gluten-free products, they ask for the potential number of customers to decide whether it is worthwhile for them to get involved in this area.

With availability of serological testing, a large scale population-based study to investigate prevalence of celiac disease in Pakistan is feasible and should be considered. Such studies have been performed by some of our neighboring countries like Iran and India.

Improving Awareness of Celiac Disease

There is a need to improve awareness of celiac disease at various levels including the medical community and society at large. Better awareness will lead to timely diagnoses. There should be a systematic collection of data on clinical presentations of celiac disease from hospitals in all four provinces. This information would provide a framework for developing educational strategies for improving awareness of celiac disease among primary care physicians and specialists.

Celiac disease is still being taught as a malabsorptive disorder in the medical curriculum. This needs to be revisited, given the changing clinical spectrum of this disorder. Celiac disease needs to be taught as a multisystem autoimmune disorder.

Wider Availability of Serological Testing

When adequately performed, serological testing is a powerful tool to screen patients for celiac disease. Currently the recommended test is IgA-tissue transglutaminase antibody (TTG). This test is not routinely available except in a few select laboratories. Efforts should be made to have it more readily available to physicians at all levels of health care delivery. Although small intestinal biopsy remains the definitive test for diagnosing celiac disease, access to endoscopy may not be available to many patients in our country due to cost and limited resources.

Availability of Gastroenterologists

Celiac disease is best handled by gastroenterologists, both for diagnosis and management. Given the massive population of about 180 million people, there is a serious lack of gastroenterologists in Pakistan. This problem is much more critical in paediatric gastroenterology. Almost half of the population of our country is less than 18 years of age. This issue can only be resolved by creating more training programmes in gastroenterology, both adult and paediatrics.

Lack of Professional Dietitians

A gluten-free diet provides effective treatment for celiac disease. However, this diet poses several challenges and is complicated to follow. The counseling of a gluten-free diet is best done by a registered dietitian with expertise in this area.

Such trained dietitians are not readily available in our country. There is little doubt that number of cases of celiac disease will increase over time and these patients will require professional nutritional counseling.

Better Availability of Gluten-Free Foods

Wheat is ubiquitous in our diet. *Roti* (pita bread) is a readily available food item and is affordable largely due to government subsidies on wheat. Alternates like rice are expensive and outside the reach of the general population, especially for long term use. Corn/maize (*makai*) provides a less costly alternative but contamination with gluten-containing grains like wheat remains a strong possibility especially in the production of corn flour. Imported gluten-free products are too expensive and will never be affordable for general consumption. Therefore, gluten-free foods prepared locally from home-grown ingredients offer the only practical long term solution.

Improving Labeling Laws

Packaged food products can provide convenience to those on a gluten-free if ingredients are listed on the package. However, this requires that the listing be absolutely accurate. Adequate food labeling laws do not exist in our country, further compounding the challenges for patients who worry about gluten contamination. The government should enact laws to enforce mandatory and accurate labeling of ingredients in packaged food products. The food industry should also be a partner in this important issue and provide adequate labeling for patient safety.

Role of Professional Medical Organizations

Professional organizations like the Pakistan Society of Gastroenterology and GI Endoscopy can play a key role in

improving awareness of celiac disease amongst the medical profession. Including presentations on celiac disease at the annual Congress of the Society and encouraging postgraduate trainees to get involved in celiac disease research are two avenues that should be explored. The medical community can also lobby the government at various levels for better availability of serological testing, easier access to endoscopy and enforcement of accurate labeling laws for packaged food products.