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CELIAC DISEASE

## Going against the grain

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Wheat is among the top eight food allergens, along with soy, peanut, tree nut, dairy, egg, fish and shellfish. Photo: [istock.com/ddsign\\_stock](https://www.istock.com/ddsign_stock)

**A** recent international symposium in New Delhi on wheat-related disorders drew attention to celiac disease, one of the world's most under-diagnosed medical conditions.

AS a person with celiac disease, the exposure that I got at the two-day international symposium on wheat-related disorders held in New Delhi on January 12 and 13 was mind-boggling. The central theme of the symposium, "Beyond Celiac and Beyond the Gut", sought to bring experts and authorities on wheat-related disorders from across the globe onto a single platform. Physicians, gastroenterologists, dermatologists, paediatricians, neurologists, nutritionists and other professionals from the United States, Canada, Italy, New Zealand, Germany and Israel, apart from India, were in attendance to discuss the latest research findings, developments in early diagnosis and treatment of wheat-related

disorders. The aim was to draw the attention of medical professionals, food regulatory authorities, health care service providers and the public at large to one of the world's most prevalent and under-diagnosed medical conditions.

The adage “one man's food is another man's poison” was invoked repeatedly throughout the symposium. Given the wide range of diseases and disorders linked to wheat, the staple diet of the majority of the world's population, the recurrent usage of this maxim seemed justified.

The word celiac is derived from *koiliaks*, a Greek word meaning “suffering of the bowels”. Celiac disease was first recognised by the Greeks in the second century C.E. It is an autoimmune disorder that occurs because of the ingestion of gluten, a protein present in wheat, barley and rye. In patients with this condition, gluten is not digested completely and this leads to damage to the villi, the lining of the small intestine that absorbs food.

An impaired gut leads to a variety of complications such as chronic diarrhoea, gastrointestinal disturbances (abdominal bloating, flatulence, abdominal pain, constipation, nausea, vomiting), anaemia, skin rashes, osteoporosis, stunted growth, and so on.

Celiac disease increases the risk of diabetes, thyroid disorders, liver diseases, asthma and certain types of cancers. The intake of wheat contributes to disabilities such as autism, developmental delay, attention deficit hyperactivity disorder (ADHD), schizophrenia and ataxia. It also contributes to epilepsy, migraine and a variety of skin diseases such as dermatitis herpetiformis, psoriasis and eczema.

## Gluten intolerance

Apart from celiac disease, adverse reactions to wheat—listed among the top eight food allergens along with soy, peanut, tree nut, dairy, egg, fish and shellfish—could be in the form of an allergy, skin rashes or non-celiac gluten intolerance. The most common symptoms for allergies could be asthma, atopic dermatitis, urticaria and anaphylaxis.

The difference between celiac disease and gluten sensitivity is in intestinal permeability and the genes regulating the immune response in the gut. Intestinal permeability is the ability of the mucosal layer of the digestive tract to prevent bacteria, antigens and undigested food proteins from seeping through the gastrointestinal barrier. Although gluten sensitivity is associated with both celiac disease and non-celiac intolerance, the degree of intestinal damage is different in the two settings. There is practically no visible gross or histological structural damage to the mucosa of the intestine in the non-celiac variety. However, both are associated with a leaky gut. This important aspect was repeatedly mentioned in the presentations at the conference.

Dr Alessio Fasano, Director of Paediatric Gastroenterology at the Massachusetts General Hospital for Children, Boston, stated that there were a wide range of diseases and medical conditions associated with the intake of wheat. He claimed that there were around 300 health conditions linked to wheat/gluten intolerance.

It is these new discoveries on other disorders and conditions associated with the ingestion of wheat that were sought to be focussed at the symposium, with a special session devoted to “Wheat Related Disorders: Beyond Celiac, Beyond the Gut.” According to Dr Sarath Gopalan, organising secretary of the conference and senior consultant paediatric gastroenterologist at the Madhukar Rainbow Hospital, New Delhi, wheat-related disorders are not just about gluten alone. “There are other factors associated with wheat which may produce symptoms which are not entirely attributable to gluten. There is an abundance of recent evidence based on research from the West that disorders associated with wheat are not caused from gluten, which is broadly termed as non-celiac gluten intolerance.”

On why a range of specialists from varied disciplines were brought together, Dr Sarath Gopalan said “there is a lot of role for gastroenterologists, dermatologists, hematologists, rheumatologists”, as wheat disorders were not confined to issues with the digestive system.

From being considered a rare disease, a disease of the West, to that of the rich and the super-rich, celiac disease is now recognised as a disorder that cuts across geographical and socio-economic boundaries. Elaborating on this, Carlo Catassi, Head of the Department of Paediatrics, Marche Polytechnic University, Italy, said: “Celiac disease used to be considered a rare disease limited almost exclusively to the region of Europe and the age group of children. However, the first comprehensive tests, launched in the 1980s, revealed a very different reality. Celiac disease is one of the most frequent of all lifelong diseases, affects children and adults in equal measure and is more common in women (the ratio of men-women is 1:1.5-2). In Italy and generally in Europe where a great deal of research on celiac disease has been conducted, there are variations in the rate of prevalence in different countries. This can also be seen in the Americas, where the rate is only 0.2 to 0.6 per cent in Brazil but 1.5-3.5 per cent in Mexico. As the genetic differences between these populations are very small, it can be assumed that these fluctuations in frequency are the result of still relatively unknown environmental factors such as child nutrition, intestinal infections and the typology of intestinal flora (known as ‘microbiome’). Other countries with populations of primarily European descent, such as the United States, Australia and Argentina, have also shown an average frequency of 1 per cent.”

Epidemiological research shows that the frequency of celiac disease continues to be on the rise. In the U.S., for example, the frequency has increased over the last 40 years from two cases per thousand to 10 cases per thousand (1 per cent). Although authentic data are unavailable about its prevalence in India, according to projections, it is estimated that 1-2 per cent of the Indian population suffers from celiac disease. It has gone up by four times since the 1960s.

Environmental factors, as also the spread of ever more “toxic” cereals, have played no small role, a fact underlined by Dr Tom O’Byrne, Adjunct Faculty at the Institute for Functional Medicine in the U.S. Genetically modified (G.M.) wheat and various hybrid varieties that demand the usage of huge quantities of chemical fertilizers and pesticides, combined with environmental pollution, has only added to the problem. Ishi Khosla, nutritionist and president, Celiac Society of India, the organiser of the symposium, said that “the intake of processed foods and toxic chemicals in food and environment are

triggers. Extensive and expanding use of gluten-containing foods has contributed to the rising numbers of patients in India.” Dr Rodney Ford, who used the term “gluten syndrome” to refer to a cluster of symptoms that are experienced in reaction to gluten, said that “gluten-containing products are being added to our food chain in ever-increasing amounts, and our wheat, which is one of the primary sources of gluten, is being genetically engineered to provide an even higher gluten content. This gluten overload is occurring while our communities remain unaware of the harm that it is causing.” (*The Gluten Syndrome*, 2008)

In her book *Is Wheat Killing You?* (Penguin, 2011), Ishi Khosla writes: “Celiac disease is often compared to an iceberg, where the visible tip represents those with the symptomatic ailment. The greater portion of the iceberg represents those with the silent and latent form of the disease. Most escape diagnosis and only a small proportion of celiac individuals are diagnosed on clinical grounds.” The overwhelming majority, or approximately 70-80 per cent of the cases, remains undiagnosed. It is far more serious in countries such as India, where it is estimated to be 97 per cent. Lack of awareness among medical professionals and lack of access to health care are among the prime reasons.

## Dietary patterns

A shift in dietary patterns was one of the reasons given for the increasing prevalence of the disease, especially in south India. According to Dr B.S. Ramakrishna, Director, Institute of Gastroenterology at SRM Institutes for Medical Science, Chennai, celiac disease was uncommon in south India earlier. But a change in diet with increased intake of wheat is increasing its prevalence. Karnataka, he said, is a classic case where an increasing number of people have been diagnosed with celiac disease. He attributed this to the increasing use of wheat in a variety of dishes.

However, he said that the prevalence of celiac disease was more in north India. “In a countrywide study conducted in 2012 of more than 23,000 persons, what we found is the prevalence was the highest around Delhi of 1.2 per cent approximately. This included both symptomatic and potential celiacs. In Assam, it was 0.8 per cent and in Tamil Nadu, 0.1 per cent.”

Dr Ramakrishna pointed out that this has increased in the post-Green Revolution period. Early discontinuation of breastfeeding and introduction of cereals to children before the age of six months has also contributed to the increasing prevalence of celiac disease among children. With more women entering the workforce, this issue gains more importance, he said.

Celiac disease and sensitivity to gluten are commonly unreported in India because of lack of awareness, particularly among the medical fraternity, despite the rise in the number of cases.

Lack of awareness results in addressing the symptoms alone rather than the underlying factor. Ishi Khosla said that “millions of patients suffer with symptoms that neither fit a specific diagnosis nor disappear. Their symptoms are treated, but no underlying cause can be found. They live in a perpetual state of indefinable ill health. Patients undergoing

several courses of antibiotics and steroids are common. Some may even be put on anti-tubercular treatment, as they do not respond to conventional therapies, only to worsen their suffering.”

“The thing about celiac [disease],” said Dr Sarath Gopalan, “is if you look for it, you are going to find it. If you don’t look at it, even if it is sitting in front you, it is going to pass by unnoticed.” The world average for diagnosis is around 18 years. It is around the same time that it took for this writer to be diagnosed with the condition, during which period a whole range of doctors were unable to get the prognosis right.

It is in this context that awareness creation ranked topmost of the aims among health care professionals gathered for the two-day symposium. Ishi Khosla said that “lack of awareness is the biggest impediment in prevention and treatment.” The Celiac Society of India accords top priority to generating awareness amongst various stakeholders. Ishi Khosla added: “Unless we are aware of this entity and that your food could be responsible for your ill health there is no way a physician can diagnose the problem.” She rued the fact that “the current medical textbooks mention it briefly as a rare childhood condition with diarrhoea and stunting”.

Dr Sarath Gopalan emphasised that awareness, not just of symptoms and various wheat-related disorders but also of screening tools, “practical issues related to investigation and management mainly from the Indian standpoint”, must be known to the doctors. According to Dr Tom O’Byrne: “Apart from the fact that it can occur at any age and is highly under-diagnosed, celiac disease and gluten insensitivity can impact both physical and mental health. The need of the hour is to increase awareness among people and physicians alike.”

Once diagnosed, a person sensitive to gluten has to stay off gluten for the rest of his/her life. “The cure is in the cause,” said Ishi Khosla. This is easier said than done. The experience of those with celiac disease or gluten sensitivity shows that understanding and procuring safe food is an uphill task. It is not just about not consuming chapatis or bakery items. The fact that semolina (*sooji*) is made from wheat and that extracted gluten is used to provide crispiness to various branded potato chips is not common knowledge. Traces of gluten are found in a number of food items that might otherwise look innocuous. Anything that goes by the name of binding agent, edible starch, modified starch, thickener and vegetable protein may contain gluten. Soya sauce used in most Chinese cuisine contains gluten. Even asafoetida, or *hing*, a spice used commonly in Indian kitchens, contains gluten.

In the absence of support mechanisms, those diagnosed are at their wits’ end. Even while flours of some of the gluten-free grains such as rice, corn, sorghum, chestnut and millets are available freely, one cannot be sure that they have not been contaminated if they have been milled in a facility that also grinds wheat.

And in times when eating out and getting semi-cooked and processed food is becoming a sort of norm in major urban centres, the challenge of staying on a gluten-free diet increases manifold.

Agencies such as the Food Safety and Standards Authority of India (FSSAI) have an important role in regulating the use of gluten in foods. Representing the FSSAI at the symposium, its CEO, Pawan Agarwal, admitted that except for putting a labelling system in place for gluten-free packaged products, nothing much has been done. Pointing out that gluten-free products had a huge market, given the fact that around six to eight million people suffer from gluten-related disorders, he said that apart from reviewing the labelling guidelines, the FSSAI had put out a draft consultation paper on menu labelling for hotels and restaurants. He also said: “The FSSAI can play a role in providing technical guidance to the government with the help of professionals for a more robust response to address issues arising out of wheat-related disorders.”

Even while the FSSAI may put in mechanisms for certifying products as gluten-free, packaged food forms only a minuscule part of the market. Also, with other cereals being costlier compared with wheat, options before the economically marginalised, especially in wheat-consuming regions, are few. “Nutritional food, keeping the patient’s cost preferences in mind, should be made available through the PDS,” said Dr Sarath Gopalan.

Surprisingly, despite the fact of wheat contributing in some measure to conditions such as autism, ADHD, schizophrenia and ataxia, a discussion around these disabling conditions was missing at the conference. The Rights of Persons with Disabilities (RPD) Act, 2016, defines a person with disability as follows: “A person with long-term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others.” Since persons with celiac disease have an impairment, and many disorders and diseases such as Parkinson’s disease, haemophilia, thalassemia and sickle-cell disease find a place in the Schedule of the RPD Act, it would not have been out of place if a discussion on these lines had taken place. Countries such as the U.S. recognise celiac disease as a disabling condition.

Also absent was any debate around the wider question of health policy, especially in the context of the fraudulent claims being made about the “Ayushman Bharat” scheme. This gains added relevance as the conference did debate on the necessity of mass screening for celiac disease in the context of the huge number of undiagnosed cases in the country. Additionally, the National Health Policy 2017 does recommend “periodic disease specific surveys to monitor the impact of public health and disease interventions”.

*Muralidharan is general secretary of the National Platform for the Rights of the Disabled. He was diagnosed with celiac disease at the age of 36, 18 years after the first symptoms appeared.*

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