Psychological Dimensions of Celiac Disease in India

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ABSTRACT

An epidemic of celiac disease is being witnessed in India as well as several other parts of the world. Awareness is important for early diagnosis and treatment so as to avoid long-term morbidity as well as irreversible complications. However, the key for resolution of the disease is good compliance to a gluten-free diet. Unfortunately, the current scenario in India is that either gluten free foods are not easily available or are expensive and often not tested. This is especially true in schools and colleges and smaller towns. In addition, the stigma attached to gluten-free food makes it socially undesirable, and this is made worse by the lack of knowledge among peers, family members, advisors, and even health care providers. We need to make a strong pitch to overcome the confusion regarding the disease as well as the diet to avoid psychological and medical complications.

Key words: Attitudes, celiac disease, peer pressure, psychology

Let food be thy medicine and medicine by thy food: Hippocrates

Celiac disease (CD) is an autoimmune disorder that occurs in genetically predisposed individuals on ingestion of gluten.[1] Gluten is a protein found in wheat, barley, rye, and oats or anything that is made or contaminated by them. It can start at any age and develop after even several years of consuming any one of these grains.

Dietary change is the only known treatment for this condition.[2] This translates to removing all food items containing gluten including many everyday items such as roti, parantha, and bread a staple for most Indians.

The diagnosis of CD brings about relief to some families as it is a culmination to an illness that has probably been on-going for some time and in some cases, many years. For others, it is a “heartbreak” and understandably so. After all, the condition, as we know today, requires lifelong strict diet control and the key to good health for a celiac is and only is compliance to gluten-free diet (GFD). An absolute “no” to gluten ingestion each time and every time is critical and paramount even if it is a bite of a birthday cake.

For most individuals and families, as the symptoms improve of the patient, the initial shock gives way to acceptance and the cause-effect relationship, i.e., elimination of gluten ingestion and improvement...
of symptoms is firmly established, and even the most skeptical of this treatment plan mellow down. However, on occasion, after a few weeks of GFD, anger, sadness, blame, depression, and outright rejection of the treatment plan set in the patient or her family.

The primary reason for this is that with the restricted diet many standard food products are out of bounds. In a nascent gluten-free market like ours, gluten free is largely unheard of, substitutes of packaged food items and popularly eaten snack items are either not easily available, are very expensive or are untested. Basically, lack of availability of alternate products often results in an immediate sense of loss and deprivation in parents and children alike. The “losses” cannot thus be easily and quickly replaced unlike in Western countries where one can find information and substitute products relatively easily almost immediately after diagnosis. For example, getting a gluten-free samosa outside the home would be virtually impossible. In fact the likelihood of getting “glutened” is quite high if eating food outside the home.

Lack of awareness of this condition does not help. The social life gets affected and even curbed, further accentuating these emotions. The need to belong to “their” group is clearly endangered with these restrictions. This has much more ramification for teenagers where the need to belong to their peer group is much higher and is a critical psychological input at that age. Teasing, bullying, and exclusion from group activities, for example, movie with dinner or a day-night camping trip are some unpleasant but realistic possibilities unless you remain hungry carry food from home, eat fruits, or cook yourself!

This lacunae often leads to looking out for “alternatives” essentially where the treatment is either not so harsh or even some medication with which gluten can be safely consumed! Other families and people who had been appropriately diagnosed with CD earlier and are now consuming wheat without “obvious” problems suddenly become role models even though this does not mean that their body is not getting damaged, and they may land up with complications later on in life.

Educating people, especially friends, family, health care providers, and food industry about the disease and its treatment is, therefore, critical. Since the diagnosis today happens mostly in children, the efforts need to be focused toward improving their quality of life but also of the college student and the workforce who have long office hours or travel.

The interventions have to be at multiple levels with a variety of experts having the sole aim of being able to provide through the length and breadth of the nation easily available gluten-free food which is cheap and safe and tasty. This will help empower the child who must ultimately take the lead and become the brand ambassador! The initial team consists of the doctor and a nutritionist experienced in managing CD patients and soon thereafter the parents play the most important role along with teachers, friends, and family with continuous dialogue and guidance from the specialists. Some facets of these are described below:

- The initial conversation with the child has to focus on an age appropriate simple clear explanations denial, lies, and false hopes do not help. Focus on the “benefit” to her health derived from this “deprivation.” Focus on the food items which are allowed and help minimize the sense of loss. Fortunately, Indian cuisine has many food items which can be consumed without much change on this diet. This perception that gluten-free is expensive and difficult needs to be corrected immediately
- There is always a sense of relief in numbers-explaining that many children and adults are affected worldwide with this condition helps. Informing her how this diet has helped many other children will help her understand the need for compliance better. For a child, it is useful to draw pictures or show animation films of healthy versus the ill intestine!
- To understand and be able to overcome the challenges the child faces in different situations is important. One of the key ones is acceptance by the child’s peer group can resolve many adjustment concerns. Simple actions like organizing get-togethers for the child’s friends with simple gluten-free meals (e.g., rajma rice or jowar roti cooked at home using appropriate ingredients and taking all precautions of preventing cross contamination) would sensitize them and dispel their notions about gluten-free food. Planning activities, outings, gluten-free camp outs, and holidays with friends (that do not revolve around food) would help too
- Fostering healthy self-esteem in their child is important for every parent and more so for a parent of a celiac child. The feelings of inadequacy and “I am not OK” or “I am different” can set in among many celiac children and teenagers. These needs to be recognized and an accurate positive self-image must be worked upon. If needed, help from the school counselor or a professional should be sought. It must be “I am OK” and “I am just like everyone else except that I have to be careful (very careful rather) about my food.” In fact, GFD in CD improves quality of life significantly.
- Involving your child in all aspects of managing the
diet and letting her know that this condition and its effective management is solely in her control is important. Self-pity, blame on external factors, and looking for magical solutions will only damage the child’s health and will not help her deal effectively with her condition. In fact, it is crucial to empower the child with knowledge about CD and GFD and with tools to handle the diet on her own in different situations. This would help in college and adulthood too-right from how to order or purchase and store safe food, how to eat at friends’ homes, how to politely say “no” to relatives and elders, how to cook a simple gluten-free meal etc.

- Reward for compliance and punishment for noncompliance could be effective short-term strategies. But for long-term compliance, it is important that the need for adhering to GFD is understood and ingrained by the child
- A clearly visible cause and effect relationship (noncompliance leading to symptoms like diarrhea or vomiting) would help in refraining from noncompliance, but this may not occur in all patients. It is these children who tend to cheat more often. Explain the tangible damage that the complications associated with CD can bring about in their daily lives including the impact on their studies, sports, future college plans, and severe damage to their health. Perhaps spelling out the possible complications of noncompliance will help, but in small doses
- Positive attitude and actions of elders will be the single most critical factor which will define the child’s attitude toward dealing with this condition and toward compliance-a parent trying to learn new ways of cooking, a parent complying in all situations and under all circumstances, a parent not letting this interfere with any travel plans, a parent politely refusing gluten laden goodies at relatives’ homes would be teaching the most critical skills needed to her child. This positive attitude must also be carried forward by teachers, colleagues, school mates, and importantly the extended family system we have in India. I often in my practice request the elders to come along with the parents and the child to discuss the endoscopy and biopsy findings and the diagnosis being made and all its ramifications. I find this an extremely useful exercise it also takes the burden away from the mother who in most cases needs support to manage the diet and manage the child with the special diet.

There are additional and varied concerns which parents of girls often share; the anxiety and stress about the marriage prospects of their daughter who cannot eat wheat probably being the most often cited one. Diagnosis in a young girl premarriage or immediately postmarriage raises questions. It also pains to see that at times the mother is blamed for the child’s condition, and she is left to deal with this seemingly new unknown disease due to the limited resources and knowledge at her disposal.

Building awareness and creating easy, affordable gluten-free options can reshape these attitudes. Education about the disease starting in school itself can help change its outlook not only for possible earlier diagnosis but acceptance of it in the community. Caretakers have to understand and feel reassured with the knowledge that just a diet change can be a life transformer.

Adhering to a special diet, may still not be easy but is not impossible either. With knowledge, practice and a positive attitude, living gluten free will slowly become second nature to your family and your child. Defining a plan to live lifelong with CD is important, but do not let CD define you or your child. Moreover, this must come from the health care provider because it is the initial and subsequent counseling that often counts the most! Finally, we must all speak the same language.

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