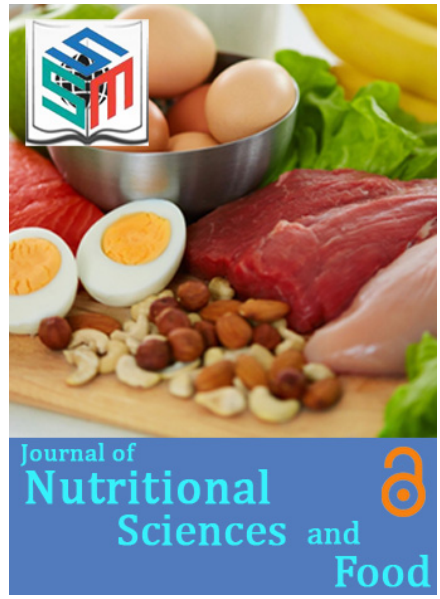
Mini Review

Psychological Experiences Associated With the Removal of Wheat from the Diet of Celiac Disease Patients in India



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Abstract

Wheat is a staple food especially in the north of this country. A complete deletion of gluten found in wheat, rye and barley from the diet is the only treatment for Celiac Disease (CD). However, removing wheat from the diet is challenging and disturbs the quality of life of the CD patients as well as for their family members. High cost of gluten-free items, social pressure, and lack of gluten-free options outside the home causes certain psychological experiences associated with the adherence to wheat (gluten)-free diet to CD patients. These psychological issues can be minimized by creating an awareness about CD in the general population, counselling, educating the family and friends regarding CD, improving labelling of the gluten-free products and creating easily accessible gluten-free options outside the home.

Keyword: Celiac Disease; Gluten-Free; India; Psychological Experiences; Wheat

Introduction

Celiac Disease (CD) is described as an autoimmune disorder that occurs in genetically predisposed individuals with HLA DQ2/DQ8 on ingestion of gluten [1]. Gluten is a protein found in wheat, and related grains such as barley, and rye. The only treatment available for CD is a lifelong Gluten-Free Diet (GFD) i.e. a complete elimination of wheat (i.e. gluten) from the diet.

CD is hereditary disease that can occur at any age. Individuals with a first-degree relative with CD have a 1 in 10 chance of getting a diagnosis of CD with a high concordance rate (up to 86%) in monozygotic twins [2,3].

CD can be symptomatic as well as asymptomatic. The common symptoms of CD are abdominal pain, bloating, chronic diarrhea, vomiting, weight loss, delayed growth, and puberty, which are more common in children than adults [4]. The common symptoms in adults are fatigue, bone or joint pain, arthritis, osteoporosis, depression or anxiety, infertility, miscarriages, etc [5].

Prevalence of CD in India

The global prevalence of CD varies from 0.7% to 1.4% [6]. The prevalence of CD in northern India is 1.04% [7]. CD was thought to be uncommon in the southern and north-eastern parts of India, primarily due to different dietary patterns in these regions. However, a study by Ramakrishna et al. [8] found that the prevalence of higher rates of CD in the northern part of India is related to the wheat intake in those areas and unrelated to the differences in genetic background. The authors found higher prevalence of CD in northern India in comparison tothe southern part of India (where wheat consumption is 455 grams per day compared to 25 grams per day respectively) but the HLA-DQ distribution was almost similar in both regions [8]. CD in India is associated with genotype HLA-DQ 2 and HLA-DQ8 [9].

Importance of Wheat in the Indian diet

The diet of CD patients includes the removal of food items that contain gluten, items that are consumed every day like roti (wheat

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flatbread), bread, and paratha which are considered staple food items in India [10].

Wheat is considered India's prime harvest after rice. North India is a major wheat-dependent region. Three varieties of wheat are majorly grown in India i.e. T. aestivum or bread wheat, T. durum or pasta wheat, and T. dicoccum or emmer wheat [11].

The most popular dish made from wheat in northern India is wheat flatbread (locally known as roti). It is made in every household of the region. Wheat flatbread is fondly eaten by people of all age groups. Wheat is consumed in the form of rotis, naans (-a form of wheat flatbread baked in a clay pot and smeared with butter), puris (÷round small wheat flatbreads deep-fried in oil), sheermal (÷a sweetened variety of wheat flatbread with lots of clarified butter and sugar), and paratha (÷another wheat flatbread fried with oil). Therefore, in northern India, wheat is eaten in a variety of ways including bread, rusks, and biscuits. All these popular variants of wheat flatbread are available in the market and elaborately served during parties, weddings, and other functions. Most of the street food in north India is made primarily of wheat, for example, chole bhature (chickpeas curry with fried wheat flatbread) or samosa (potatoes filled in a wheat pastry) [12].

Psychological Experiences Associated with Removal of Wheat from the Diet

CD is now a common disease in India however the awareness about CD in general population including medical practitioners and dieticians is low [8,13]. Imposing a GFD, compromised the quality of life of CD patients [14]. Various generic and specific instruments to measure HRQOL of the patients with CD are there, 18 CD specific instruments to measure patients' HRQOL have been developed [15]. Patient reported outcome instruments include CDSD, CeD-PRO measure, Celiac Symptom Index (CSI), Celiac Disease Assessment Questionnaire (CDAQ), Celiac Disease Questionnaire (CDQ), and Celiac Disease Gastrointestinal Symptom Rating Scale (CeD-GSRS) [16].

There is an impact of CD and lifelong GFD on QOL of children with CD. Chishty et al. [17] conducted a study on children with CD in India. The authors found a better QOL in non-celiac children as compared to celiac children. But the higher level of QOL was found in celiac pre-adolescents than non-celiac adolescents. The study found that in emotional, mental and family outlook domains, children without CD had done significantly better than celiac children. Deepak et al. studied the HRQOL of 60 CD patients in India using SF-12 questionnaire and the specific CD-QOL score. The authors found that CD effects physical and mental health of the patients.

According to Verma [18] management of GFD is difficult in India; help of trained dieticians is required along with regular follow-up and psychological support that can help the patient to adjust to these dietary changes.

However, in India thereare multiple alternatives grains to wheat are available. The availability of a variety of millets provides a great gluten-free option for patients with CD. Patients diagnosed with CD can consume different kinds of millets to make flatbreads. Most of the patients with CD draw a comparison between the quality of flatbreads made with wheat and those made with millets. For newly diagnosed celiac patients, initially, it is not easy to make gluten-free flatbread as compared to wheat flatbread. The absence of stickiness in GF flour makes it difficult to make flatbreads. After the diagnosis of CD, it is not easy to comprehend and accept that how someone can lead their life without eating wheat?

According to Vohra [10], in Indian CD patient and their families sometimes after the diagnosis of an illness and initiation of GFD, emotional reactions like anger, blame, sadness,an outright rejection of GFD, and depression can be seen. Furthermore, this happens becauseof the lack of GF options available in the Indian market, and leads to a sense of loss in the patients as well as their families. An alternative like gluten-free samosa or a bhatoora is hard to find and this subsequently leads to a feeling of loss and deprivation among them [10].

On a day-to-day basis, Indian families prefer cooking their meals from fresh ingredients. India is a collectivistic society where a family bond is of great value. Indians prefer to have food together with their family members [19]. It is difficult for CD patients, especially if a patient is a child or a teen, to control the temptation of not eating wheat especially in the presence of other family members who eat food items made-up of wheat. The patient in sucha situation can feel angry, sad, or deprived.

The constant fear of cross-contamination can also make the patient stressful. There is a chance of cross-contamination during handling and preparation of GF meals in the kitchen. If GF food is cooked in the same utensil in which gluten containing food was cooked then the GF food can get contaminated by gluten. So, avoiding cross-contamination becomes very important. The threshold should be at 20mg/kg [20].

Acceptance of CD by the child depends on how much the child's illness has been accepted by the parents [21]. The parents of children with CD evaluate their children's QOL lower as compared to children's evaluation of their QOL [22]. The factors related to GF products, better adherence to GFD and integration into the society are some of the factors responsible for better QOL in children with CD [23]. According to Rodrigues et al. [24], the social, cultural, economic, and practical pressures related to GFD make compliance especially difficult in teenagers and most of thetransgressions happened during parties or at home. Age at presentation, education of mothers, nuclear families and parents' knowledge of CD were some factors associated with better compliance in Indian children [25]. Peer pressure, unclear labelling on GF products and non-availability of GF food at marriages or parties can contribute to non-compliance to GFD in adolescents [26].

The lack of GF options outside the home, the high cost of GF food items, and the lack of knowledge regarding CD make the situation even worse. For most of the patients with CD, going out to attend social functions like weddings, and parties is difficult because of the fear of cross-contamination and lack of GF options. CD patients in most cases either avoid going out or compromise on their diet, thinking eating a little bit of wheat will not cause any problem. Rajpoot and

Makharia [19] elaborated the factors that pose a challenge of adhering to GFD in India. The factors include lack of information about the disease, contamination of food, inadequate labelling of food products. Dietary compliance was also found to be higher in Indian children as compared to Indian adolescents with CD and dietary compliance was better in children with lesser number of siblings coming from nuclear families and families with higher per capita income.

According to Rajpoot and Makharia [19], the inadequate information related to CD and subsequent dietary restrictions can cause a problem for the patient and the patient's family.

There are limited choices when it comes to varieties and choosing GFD. Lack of GFD items outside home can influence the travel, professional life, and occupation of a celiac [19]. The lack of GF food options at school and college canteens also make the situation problematic for an Indian celiac teenager. The need to identify with the peer group often leads to non-compliance with GFD. The growing autonomy of a teenager along with reduced parental control can create a tussle in the parent-child relationship when it comes to managing CD. Socializing around food helps in strengthening social bonds, so there is a burden on the adolescent to identify with peer groups and gain their approval. As there are limited food choices outside the home for a celiac in India, it may occur sometimes that for the peer group acceptance, the person indulges in wheat or gluten-containing food.

In India's budding gluten-free market, packaged gluten-free items are either difficult to find or expensive, or non-standardized. This lack of availability causes a sense of loss and deprivation in children with celiac disease and in their parents [27,28].

The lack of GF options with unacceptance on the part of relatives and friends regarding the harmful effects of wheat aggravate the problem. The significant burden on the celiac patient from relatives and friends to eat wheat on different occasions is a source of distress. The ever-present queries and the pressure to eat wheat can cause significant stress in the life of the patient. After explaining about CD, even if there is non-acceptance by others, then the only solution available for the patient is to avoid meeting them or to succumb to the pressure. This lack of acceptance on the part of relatives and friends gives rise to a feeling of isolation, and depression in the CD patients. The unavailability of adequate information about gluten on packaged products also makes the situation difficult for celiac patients. Lack of awareness about CD in the general population also gives rise to an increased chance of cross- contamination in food that makes socializing with others even more difficult. These social restrictions may influence the mental health of celiac patients and impact their overall well- being. According to Chauhan et al. [29] children with CD face difficulty in adjusting when it comes to maintaining a diet at school, going on trips, or eating out at restaurants. The nature of the disease was not understood by the teachers in 45% of the total sample. The pediatric symptom checklist items like complaints of pains, irritability, anger, blaming others for mistakes, not listening to the rules, and teasing others were found to be more common in children with CD [29].

An activity as simple as play dough can be restrictive for the child as it contains wheat. Activities at school can be a source of loneliness and deprivation when CD is not properly understood by the school staff. Activities like snack time at preschool, school activities like field trips, parties, or sports events that help in the social development of the child can notonly become a source of unhappiness but may also create a sense of being different from others.

Due to lack of knowledge regarding CD and high dependence on wheat, girls face issues in adjustment after marriage, this can cause a serious problem when the spouse and his familyare not aware of GFD or they do not ready to accept the diagnosis of CD [19]. Apart from the celiac patients, their partners can also experience the burden of the medical condition. Roy et al. [30] found that partner burden is more common in CD. Approximately, more than one-third of the partners undergo mild to the moderate burden which is directly related to the severity of the symptoms. Siniscalchi et al. [31] found that celiacs on a GFD report high levels of depression as compared to the celiac on a normal diet.

CD was associated with an increased risk of subsequent depression [32]. High treatment burden is associated with CD as compared to other chronic illnesses [33]. The factors related to high treatment burden were found to be high food cost, poor adherence to GFD, higher income, eating out, lack of college education, and time constraints in preparing food [33]. Sharma et al. [34] were of the view that CD causes different neuro psychiatric disorders. Patients with CD have a high risk of developing headaches, depression, anxiety, panic disorder, epilepsy and dysthymia.

To the best of our knowledge so far the Indian government does not have programs for the CD patients which can help the patients to access the GF elements. We hope that future CD studies will influence the law makers to initiate such provisions for Indian CD patients.

The GF products in India do not undergo a strict quality control for knowing the gluten content and the production of GF products is done at a small level [19]. According to Raju et al. [28] about 9.8% products labelled gluten-free in India and 36.7% products from naturally occurring GF grains contain above 20mg/kg gluten. Products made from natural GF grains 35.9% flour samples and 85% of oats sample were contaminated with gluten and 70% of unbranded samples of flour from local markets and 30% from local mills contained gluten above Codex safety limits (20-400mg/kg). Even in 51 products labelled GF, 5 products contained gluten above 20 mg/kg though the gluten levels were within 100 mg/kg [28]. Mehtab et al. [27] found that in India about 10.1 % of GF food products labelled GF as well as non-labelled contains gluten greater than the prescribed limits of less than 20 mg/kg.

Way Forward

Following a strict GFD is a challenging task for celiac patients. Following this diet becomes more challenging and demanding when there is a lack of awareness and knowledge regarding CD in India. Lack of awareness regarding CD and GFD gives rise to a high probability of cross-contamination in the food. There is a high prevalence of contamination in GF foods worldwide including India. The contamination can occur during harvesting, transporting, storage, handling and consumption. This contamination of GF food products impacts the GFD adherence of the CD patient thus influencing their

quality of life. 10.1 % of GF food products available in India labelled or unlabeled have gluten content more than the prescribed limit [27]. As India has a developing GF market, the unavailability of common GF items that can serve as an alternative to wheat items is a major problem. Highcost of GF items, nutritional quality of GF items, and unacceptance of CD by the family and friends, and lack of GF options outside the home can cause a sense of deprivation, depression, and isolation in a patient with CD. The schools and college canteens should have an option of reliable GF food items for celiac children. Counsellors in schools along with the teachers should create an environment where peer support should be available for children with different food allergies and other health conditions, and they can freely express their needs and requirements to their friends and teachers. On the other hand all the patients after the diagnosis of CD should be referred to a nutritionist/dietician to better adapt to the social and emotional challenges of the GF lifestyle [19]. Lack of GF restaurants and food services offering GF meals can affect the social well-being of the CD patient. The high cost of food available at the dedicated GF restaurants along with expensive packaged GF food products available in the market affect the psychosocial adjustment of the CD patient.

Along with wheat, other food grains like millets should be increasingly used in north Indian households so that the dependency on wheat as the main grain could be avoided. Adolescents with CD should be empowered by educating them about GF cooking and alternatives to wheat. Children with CD should be encouraged to attend social events and find alternatives to eating wheat at the events like having cut fruits, cold drinks (popular brands), or eating food at home before going out.

The psychological challenges associated with the removal of wheat following a CD diagnosis from an Indian diet can be minimized by creating awareness regarding CD in the general population like by involving celiac support groups and mass media including print media and digital media to help in dissipating CD related information among the general population as well as among the celiac patients, improving labelling of GF products, educating family and friends regarding CD and creating more viable and easily available GF options outside the home.

Conclusion

Wheat is a staple in north India and removing gluten found in wheat, rye and barley from the diet is not only a big challengefor the celiac patient but also their family. The patient and the kin both bear the burden. Proper counselling, education, and awareness regarding CD and GFD in the general population can help in mitigating the psychological challenges associated with wheat removal from the diet of the patient.

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