

## Management of Celiac Disease: The Role of Significant Others

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### ABSTRACT

Celiac disease is a relatively new disease in India. Like other chronic disease it also requires a holistic and team approach for its management but there are various barriers in the adherence to GFD and management of CD by the patient and the role of significant others become very important when it comes to adhering to the treatment plan and management of CD. There is a stigma related to the removal of wheat from the diet of the patient thus, It becomes important to create awareness about celiac disease with the help of psycho-education, informational campaigns and workshops and challenging the irrational beliefs of significant others and provide psychological consultation to the family members.

*Keywords: Celiac Disease, Wheat, Gluten, Significant Others*

### What is Celiac Disease?

Celiac disease (CD) is also known as celiac sprue, non-tropical sprue or gluten sensitive enteropathy, is primarily considered as a genetic autoimmune disease caused by ingestion of a protein called gluten, which is found in wheat, barley and rye. It is a serious and incurable condition with permanent intolerance to gluten (Beyond Celiac, 2019). CD damages the villi of the small intestine that leads to poor absorption of nutrients from food.

### Symptoms of CD

The most common symptom of CD is diarrhoea and other abdominal symptoms include abdominal pain, bloating and flatulence, indigestion, constipation and vomiting (National Health Service, 2019). The symptoms of CD may differ and vary from person to person but the main symptoms of the disease in children are anaemia, anxiety, diarrhoea, irritability, infertility, skin rash, failure to thrive (Celiac Disease Foundation, n.d.). Diarrhoea, bloating, vomiting, malabsorption can come under gastrointestinal symptoms. Irritability, depression, anxiety, inability to concentrate etc. constitute behavioural symptoms. Type 1 diabetes, hyperthyroidism, hypothyroidism and other autoimmune diseases can also co-occur with CD. Nutritional symptoms constitute weight loss, stunted growth, and failure to thrive. Neurological symptoms include seizures, migraines, peripheral neuropathies and other related conditions. Skeletal symptoms of the disease are joint pain, muscle pain,

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osteoporosis etc. Eczema, psoriasis, acne and other related conditions of the skin constitute symptoms related to dermatologic and mucus membranes (Celiac Disease Foundation, n.d.).

### **Gluten Free Diet**

Gluten free diet (GFD) refers to a diet which is free from gluten. Gluten is a protein found in wheat, barley and rye. GFD is the only treatment currently available for CD management; the patient has to strictly adhere to a diet which is free from gluten for the entire lifetime. Patients with CD are advised to limit their gluten content to not more than 10-50 mg and the GF products are defined as containing 20 parts per million gluten (Cohen, Day & Shaoul, 2019).

### **Prevalence of CD**

CD is considered as a major public health concern (Singh et al., 2018). Singh et al. (2018) conducted a review of the studies which were published between January 1991 to March 2016 and found that the total global prevalence of the disease to be 1.4% in individuals tested positive on diagnostic tests for anti-tissue transglutaminase and anti-endomysial antibodies and 0.7% in individuals confirmed by biopsy.

According to Gujral et al. (2012) the prevalence rate of CD was approximately 0.5-1 % in different parts of the world. North Indian states show a higher prominence of CD as wheat is grown and consumed as a staple in these regions. It includes states of Punjab, Delhi, Uttar Pradesh, Haryana, Bihar, Maharashtra, Rajasthan, Madhya Pradesh, Uttaranchal and Gujarat. Earlier, this disease was assumed to be absent in the Southern part of India, though now some rare diagnoses have been made (Celiac India, n.d.).

### **Role of Significant Others in the Management of CD**

Management of chronic illness becomes easy when support of significant others is available. CD like other chronic diseases requires a more holistic approach for its management. Behavioural interventions involving the effect of close relationships on health can be effective in decreasing the burden as a result of illness management on society. (Martire & Helgeson, 2017). Families can help in creating an environment that was beneficial to support and family engagement (Whitehead et al., 2018).

India being a collectivistic society, the role of significant others become very important in the management of CD but at the same time the awareness about CD is very low in India. Most people hear the term “celiac disease” for the first time when the diagnosis is made. According to Celiac India (2014) celiac disease and gluten free diet both the terms are comparatively new in India. The low awareness about CD coupled with unacceptance on the part of the extended family members and friends makes the situation tough for the patient and primary caretakers.

The unacceptance of CD largely stems from the fact that wheat is considered a highly nutritious and irreplaceable grain in the diet of especially North Indians. The concern related to removing wheat is not just limited to its nutritious value but it is believed that removing wheat can potentially affect the marital life of a girl. According to Vohra (2016) concerns related to marriage were found especially for a girl child because the girl can't eat wheat.

The joint family system in India can also act as a promoter of well-being in CD patients as well as its deterrent. The chance of cross-contamination of GF food is high if food is cooked in a shared kitchen. The recommended practice in a shared kitchen is to cook GF food first

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followed by gluten containing food. At the same time if other family members eat in front of the patient especially if the patient is a child or bring outside food that the patient can't eat, it can give rise to feelings of deprivation in the patient and lead to resentment and frustration in the patient.

Sometimes the extended family members', friends and colleagues can pressurize the patient to eat a little bit of gluten containing food, saying that a little bit will not harm the patient. It can lead to non-adherence of GFD. Studies have found that social support especially family support was related to good adherence to treatment (Stanton, 1987; Lorenc & Branthwaite, 1993; Kyngäs, 1999).

Eating GFD because of one's CD can also lead to disrespectful behaviour or teasing sometimes by the significant others. Disrespectful behaviour can affect patient's confidence and can make the patient to provide information or ask questions (Grissing, 2017).

Being on a GFD can lead to a change in family dynamics. Change in roles and the adaptation required for the disease can cause stress (Whitehead et al., 2018). CD of one family member often affects the social outings of the family and other family members have to adjust according to the demands posed by CD. The restrictive social outings and necessity of maintaining adherence of GFD at home can lead to stress in the family members. Often the non-celiac child has to adjust according to the situation and the parents feel helpless when they are unable to cater to the demands of all their children. A child's CD diagnosis and its management have been found to affect the entire family (Russo et al., 2020). GFD creates a pressure on everyone who lives with the patient and CD has an influence on psychological functions, familial and social relationships of the patients (Rocha et al., 2016). Partner burden was also found to be common in CD (Roy et al., 2016).

### ***Measures to Remove CD Stigma and Increased Support from Significant Others***

Psychoeducating the patient and the family members about the illness is considered as an important part of the treatment plan and medical practice (Motlova et al., 2017). According to Motlova et al. (2017) psychoeducation was considered to involve giving systematic information that is relevant for the patient and the family. The information should be up-to-date and include giving information about an illness, its diagnosis and treatment. The information given consists of disease-specific information and general information.

Psycho-education was found to improve outcomes for patients and their families (Sharif, Shaygan & Mani, 2012). Involving extended family members in the psycho-education process can help to resolve their doubts regarding CD. Psycho-education helps the patient and the family by improving the coping skills, problem solving abilities and communication (Srivastava & Panday, 2017).

Sharing information about CD with the patient and the family members can help in dissipating the stigma attached with the removal of gluten especially wheat from the diet of a CD patient and can lead to better management of CD. According to Vohra (2016) educating about CD could help in changing the perception that can lead to its acceptance in the community. Ludvigsson (2015) highlighted that patient support and information should be an essential part when it comes to management of CD.

Caregivers of children with chronic illness report significant stress in managing their child's disease and high parenting stress was found to be related with poor psychological

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adjustment in children and their caregivers (Cousino & Hazen, 2013). According to Morawska et al. (2015) interventions are required to help the adolescent with a chronic illness and parents to cope with the stressors caused by chronic illness of the adolescent.

Challenging the thought of significant others can help in reducing the stress related to the diagnosis of CD. Drawing a comparison between CD and other chronic diseases like type 1 diabetes and cancer can help family members to understand that unlike other diseases, CD does not require any medical treatment but only a diet alteration. It can help in changing the perspective of the family members towards CD and thus can reduce the psychological stress associated with managing CD in family members which in turn can help the patient to better manage CD.

People who are managing their CD efficiently and leading successful professional and marital lives can work as role models for other CD patients and their families. These role models along with informative campaigns and workshops on CD awareness can help in reducing the stigma attached with CD and increasing CD awareness in the general population.

GF products are more expensive and less available as compared to non GF products (Lee et al, 2019). According to Rajpoot and Makharia (2013) the production of GFD is small scale industry based and varieties of GFD available in the India are limited and there is a fear of cross-contamination.

Cost effective GF food items and restaurants/ eating out places can help to alleviate the stress and problems related to the management of CD in non-celiac family members and thus can help to restore the healthy family dynamics.

Psychological help for the patient to manage CD is important (Verma, 2013; Rajpoot & Makharia, 2013). Psychological help is also very important for the family members to help them cope with the demands of CD so that they can accept the diagnosis and help the patient to adhere to the treatment plan. According to Drotar (2006) children with chronic illnesses and their families want psychological support to assist them to follow orders from health professionals and better manage the illness and issues such as limited physical activity, frequent absence from school, and problems related to social life.

Martire and Schultz (2007) highlighted the importance of interaction with close family members and its influence on the well-being (physical and emotional) of the patient with chronic physical illnesses. In their view the involvement of a close family member in a psychosocial intervention is a rational approach which can positively influence the outcome of the intervention but the effectiveness of these treatments can be improved when focusing on a certain interaction that can be identified as improving or preventing healthy behaviours and attitudes.

Combination of patient and family management interventions have the potential to give rise to better outcomes for patient as well as their family (Gilliss, Pan & Davis, 2019).

## CONCLUSION

There are various barriers in the adherence to GFD and management of CD by the patient. The role of significant others is very important and helpful when it comes to adhering to the treatment plan and management of CD. As CD is relatively a new disease in India, it is

important to create awareness about the disease with the help of psycho-education, informational campaigns and workshops and at the same time it is also important to challenge the irrational beliefs of significant others and provide psychological consultation to the family members. Variety of cost-effective GF products should be made available along with the cost effective GF restaurants.

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