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## COMPLIANCE TO GLUTEN FREE DIET-ISSUES AND CHALLENGES

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Adhering to the gluten free diet can be extremely challenging for individuals with celiac disease. Noncompliance is a major issue in treating celiac disease, especially in children and adolescents; they may purposely or unintentionally ingest gluten due to number of reasons. Various factors influence its management like ignorance about the diet, non availability of gluten free foods, isolated social life, social pressure, limited choices, not liking the taste of foods made out of alternative food grains. Awareness among people and knowledge about celiac disease in families of celiac patients is low. Importance of follow up and connection with social groups is also very low. Scarce labeling and no guidelines for gluten free foods in India is also a cause of concern. All these factors make it more difficult to follow gluten-free diet. Conclusion: Improving knowledge about complications of untreated celiac disease, knowledge about disease, gluten-containing food products, availability of gluten-free products, regular follow-up and involvement in social support groups may improve compliance.

**Keywords:** Compliance, Adherence, Gluten free diet, Problems, Management, Economic burden, Quality of life, Challenges

## INTRODUCTION

Adhering to the gluten free diet can be extremely challenging for individuals with celiac disease regardless of age. Although there is a lack of good evidence concerning the benefits of follow-up, there is good evidence that adherence to a strict gluten free diet reduces the risks of complications (Haines *et al.*, 2008), associated diseases (Cosnes *et al.*, 2008) and improves quality of life (Johnston *et al.*, 2004). Noncompliance is a major problem in management of celiac disease, especially in children and adolescents which may occur due to several factors like ignorance about the diet, non availability of gluten free foods, social pressure especially, in teenagers, temptation and not liking the taste of foods made of alternative food grains (Chauhan *et al.*, 2010).

A systematic review that used qualitative methods estimated that adherence to a strict gluten-free diet ranged

from 42% to 91%, although complete non-adherence was rare (Hall, Rubin and Charnock, 2009). Strict dietary compliance was shown to vary from 45% to 81% in children (Hill *et al.*, 2005), 95% in a Canadian study on children <16 years of age (Rashid *et al.*, 2005), and 75% in a study by Chauhan *et al.* (2010) among children 2-17 years of age. Garg and Gupta (2014) found decreased dietary compliance above 9 years of age. The percentage of compliant children dropped from 75.92% in children >2-5 years to 41.37% in children above 9 years of age.

In a study conducted by Barratt *et al.* (2011) it was demonstrated that gluten-free living was an end-product rather than, more accurately, a complex process of continual dietary vigilance and transactions in which the availability, choice and intake of non-toxic 'safe' food products which are vitally important to health. A high level of gluten free diet adherence was reported by Barratt *et al.* (2011) adherence

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showed by subjects was as follows-Full Adherence 65%, Partial Adherence 31%, and Non-Adherence 4%. Eighty percent of celiac disease patients perceived adhering to the gluten free diet as difficult: impossible 5%, mostly difficult 14%, sometimes difficult 61%, not difficult 20%.

## METHODOLOGY

An extensive bibliographical search was conducted using the following keywords: compliance; adherence; gluten free diet; problems; management; economic burden; quality of life; challenges. The articles that covered celiac disease; compliance influencing factors, problems and management of celiac disease on children and adolescents were analyzed and the key findings are summarized under different headings.

### Barriers to Dietary Compliance

Correctly following the gluten free diet is not easy. Children with celiac disease may inadvertently or purposely ingest gluten for a number of reasons. In a survey conducted by the Canadian Celiac Association with biopsy-confirmed adults and children with celiac disease, 45% of the adults surveyed indicated that they found the gluten free diet to be very difficult to moderately difficult to follow (Crannery *et al.*, 2003; and Rashid *et al.*, 2005). Verma (2013) reported that few expectations of Indian celiac consumers from manufacturers were reduced cost, more availability and advertisement, improving taste, better labeling. They were more interested in buying GF bread and cakes, which were not available. One thing is sure: Following a gluten-free diet is extremely challenging (<http://celiacdisease.about.com/od/theglutenfreediet/a/Compliance.htm>). Some of the reasons of not following gluten free diet are “Gluten-free food is expensive.” or “Gluten-free food can be hard to find.” or “Gluten-free food doesn’t taste as good as ‘regular’ food.” or “Gluten doesn’t make me feel sick, so why should I follow the diet?” or “It’s hard to know when gluten is hidden in food or medications.” Or “We didn’t get enough dietary counseling.” Or “We got good information at first, but then we didn’t continue to get support.” Or “I used to have celiac disease when I was a kid.” <http://celiacdisease.about.com/od/theglutenfreediet/a/Compliance.htm>

### FACTORS INFLUENCING ADHERENCE TO GLUTEN FREE DIET

The National Institutes of Health statement (James, 2005) has published six key elements of follow-up, which reiterates

some of the factors affecting compliance with a gluten free diet and also includes some of the potential benefits to the patient that should improve long-term health:

C : consultation with a skilled dietitian;

E : education about the disease;

L : lifelong adherence to a gluten free diet;

I : identification and treatment of nutritional deficiencies;

A : access to an advocacy group;

C : continuous long-term follow-up by a multi disciplinary team.

### Age

Individuals diagnosed with celiac disease at a young age are reported to have the highest rates of compliance, while adolescents have the most difficulty with adhering to the gluten free diet (Pietzak, 2005). Dietary compliance was better (>80%) in children aged < 9 yr of age as compared to adolescent age group, *i.e.*, 10-17 yr (44%) (Chauhan *et al.*, 2010). Another study suggested that children diagnosed at the age of 4 years or younger had greater compliance than those diagnosed after age 4 years or in adulthood (Hogberg, Grodzinsky and Stenhammar, 2003). Chauhan *et al.* (2010) in his study found decreased dietary compliance during 10-17 yr of age (44%, compared to >80% in <9yr age group). These results are in accordance with Ljungman and Myrdal (1993), who also reported compliance rates of 93% at 12 years of age decreasing to 76% in 15-17 yr age group.

### Gender

Females tend to be more compliant with the gluten free diet than males (Ciacci *et al.*, 2003). Contrary to this Chauhan *et al.* (2010) observed that non-compliance was more common in female patients, *i.e.*, 61.8%. Higher dietary non-compliance in women patients may be due to various socio-cultural factors common in north India: family pressure as they grow and approach marriage age; and gender bias. This study also found maternal education as a significant factor affecting the compliance. In another study compliance was not significantly associated with the sex of the child (Garg and Gupta, 2014).

### Unavailability of Gluten Free Products

It is extremely difficult for children to adhere to the gluten free diet. An increasingly hectic lifestyle has contributed to a greater reliance on packaged convenience foods and more meals eaten away from home. These convenience meals

often contain gluten, and thus, make navigating meal time more complex for individuals with celiac disease. Logistical problems (e.g., child does not have access to GF food at school, gluten is added to otherwise “safe” foods in processing) and psychological barriers (e.g., child feels deprived by not being able to ingest gluten containing products, such as birthday cake or snack treats, child wants to eat what other kids are eating) make adherence to a gluten free diet difficult (Jessica *et al.*, 2006).

Identified problems with compliance of a gluten-free diet include the lack of available gluten-free alternatives in social settings (Olsson, 2008). Eighty-five percent of adults and 90% of children surveyed by the Canadian Celiac Association reported that just finding GF foods was a major barrier in adhering with the diet (Crannery *et al.*, 2003).

In the United States, food manufacturers have begun to produce different processed and pre-packaged foods specifically for those who follow a gluten free diet. On comparing gluten containing processed foods with gluten free foods, higher amounts of fat, calories, sodium and sugar and lower amounts of dietary fiber, vitamins and minerals are found in gluten free processed foods (Wild *et al.*, 2010). In India commercially available gluten free food products were needed from many years but were not available earlier. Fortunately now, few Indian manufacturers have started marketing these GF products at small scale, although their gluten free claim for many still remains unchecked (Verma, 2013).

### Knowledge and Education

Adherence to a GFD requires education, attention and time (Ludvigsson *et al.*, 2015). Education about the disease for both parents and children may increase gluten free diet adherence, particularly in lower socioeconomic families. The school psychologist can be helpful in assessing the child and family’s knowledge base, providing educational materials, and suggesting expert nutritional counseling as appropriate (Jessica *et al.*, 2006).

In non-compliant group, lower maternal education has been reported by Chauhan *et al.* (2010). Results of study by Anson, Weizman and Zeevi in 1990 also show that maternal education is important factor affecting compliance because mother is responsible for preparation of food items and providing gluten free diet (Chauhan *et al.*, 2010).

The lack of knowledge of restaurant staff was a common source of frustration for adolescents (Rosen *et al.*, 2011).

Garg and Gupta (2014) study also highlighted that higher degree of compliance is noted when parents have better knowledge about celiac disease and the gluten containing items, understand importance of gluten-free diet for betterment of health and development of child, and are able to distinguish gluten containing from gluten-free food so that they handle the menu better. Mother’s education is found as a significant factor related with the compliance. It may be because mother is responsible for buying and preparation of food items. With her knowledge, she is able to identify better which food stuff is gluten free. Anson *et al.* (1990) study also showed similar correlation of parental knowledge and dietary compliance. Barratt *et al.* (2011) associated greater gluten free diet adherence with university education. Intelligence may be associated with better problem-solving skills and planning abilities, which allow the patient to overcome obstacles encountered following a gluten free diet. Their study results reflected that a university education confers social mobility, access to the professions and therefore a potentially greater capacity for wealth.

Roma *et al.* (2010) found that parents of compliant adolescents were better educated about the disease and were more able to choose gluten-free items from a menu. Barlow, Shaw and Wright (2000), found that parents who felt that they had less information about celiac disease and the gluten-free diet lacked in their ability to cope with their child’s pain and diagnosis (Sallfors and Hallberg, 2003). Parents and other family members along with the celiac child can attend celiac disease support groups to gain information regarding the condition and maintaining the gluten-free diet (Allen, 2004).

### Socio Economic Status

Ciacchi *et al.* (1998) found a positive relationship between knowledge about the disease and socioeconomic status. Similarly Barratt *et al.* (2011) Demographic assessment suggested that an affluent background and a university education promote greater adherence for gluten free diet. Wealthy Achievers were three times more likely to be fully gluten free diet adherent than their less affluent counterparts.

### Type of Family

Chauhan *et al.* (2010) in their study on compliance reported that compliance was better in nuclear families; with less number of siblings (68.3% of compliant had <2 siblings compared to 23% in non-compliant); in families with more per capita income. Compliance was better in patients belonging to nuclear family (51% compared to 38.4%), in

families with higher per capita income, with less number of siblings (70% of the dietary compliant patients had 1 or no sibling). Significant differences were found in all the above parameters (Chauhan *et al.*, 2010). Joint family may lead to noncompliance as with many people around the child having all varieties of food, tempts the child to consume gluten containing food (Garg and Gupta, 2014).

### Lack of Proper Counseling

Assuming that an accurate diagnosis has been made, the doctor spends at most 20 minutes counseling the patient and may recommend a dietician (limited dieticians have knowledge of gluten free foods). But for the most part, patients are left on their own, at the mercy of the internet and pamphlets listing common foods that contain gluten. Many live in smaller cities and may not have continuous access to the internet or to a doctor familiar with this condition. Key advice, such as “No gluten ever for life,” “Look for hidden sources of gluten,” and “Inform the school,” may not have been given (Vohra, 2014).

Bebb *et al.* (2006) reported evidences that when asked to choose among several referral options, patients themselves express a preference for dietetic follow-up (Mahadev *et al.*, 2013). Nevertheless, according to Nelson, Mendoza and McGough, (2007) availability of expert dietetic counselors is limited and may impact upon patient outcomes (Mahadev *et al.*, 2013).

In Lee *et al.* (2009) study, a review of the Celiac’s diet was done by a dietitian who is a specialist in Celiac disease and reported that substituting the alternative grains increased the nutrient profile significantly.

Butterworth *et al.* (2004) have reported lower compliance in south Asian migrants to UK, who were less satisfied with the explanation by the physician.

The clinical implications of non adherence was studied by Barratt *et al.* (2011), in the study the focus was on which member of the multi-disciplinary team is best placed to safeguard the celiac individual’s QoL in the long term and with the greatest potential for benefit. They contend that this falls within the domain of the dietician and not the gastroenterologist in whom we believe is more appropriate to diagnose and address the medical complications of celiac disease; not know successful and satisfactory management of gluten-free living.

According to Verma (2013) Doctors who diagnosed celiac patient was the main source for their dietary advice,

62.5% had the feeling that their dietician were not adequately trained to address their needs and 56.3% had never received any advice from dietician (Verma, 2013). There are strong recommendations that an expert dietitian should be involved. Not all dietitians are familiar with the complexity of a gluten-free diet, and local or national support groups may provide most of the information required (Bai *et al.*, 2012).

### Support

Family involvement is almost inevitable in celiac disease. It is common in chronic disease generally and celiac disease specifically for family members to take on some responsibility for dietary adherence (even in adults) (Gregory, 2005). The involvement of the family in celiac disease of course is not just their support in aiding dietary adherence, but also in reducing the effect of diagnosis on them. An accompanying family member will have all the same social restrictions of a gluten free diet placed on them (for example, choice of restaurants when they are with the patient), or will be likely to face dilemmas around their relationship with the patient, or to impair dietary adherence (Sverker *et al.*, 2007). This results in reducing quality of life (de Lorenzo *et al.*, 2012) and clearly the recognition of this by health care professionals is desirable (Ludvigsson *et al.*, 2015).

Rosen *et al.* (2011) found that parents play an important role in compliance with a gluten-free diet. Parents influence knowledge, ability, and strategies for handling life situations (Sallfors and Hallberg, 2003). Parental coping has a major influence on the coping of other members of the family, including the patient (Sallfors and Hallberg, 2003). Parents must manage their own feelings of uncertainty and loss of control, as they face added responsibilities while caring for an adolescent with special dietary needs (Gerhardt *et al.*, 2003).

### Gluten Free Products Not Same as Wheat Products

Many patients find available gluten-free foods unpalatable and report social difficulties related to eating out (Mooney, Hadjivassiliou and Sanders, 2014).

### Gluten Free Products are Expensive

Gluten-free products are usually more expensive and harder to find than common gluten-containing foods (Lee, 2007). Stevens and Rashid (2008) and Thompson *et al.* (2005) explains that gluten free diet is significantly more expensive, and may be deficient in certain nutrients, when compared to a regular diet (Mahadev *et al.*, 2013).



## Travelling and Social Outings

Traveling and eating in restaurants and at social functions often prove to be especially difficult for children attempting to maintain the gluten free diet. The major problem is faced by the patients and families on biscuits, social functions, and traveling (Gupta *et al.*, 2009). Various reasons which may be responsible for increasing noncompliance with increasing age include increased social interaction, increasing peer group pressure, increased outdoor activities, and need for experimentation (Garg and Gupta, 2014).

A survey by Zarkadas *et al.* (2006) included individuals reporting avoiding eating out and traveling because of being a Celiac. They reported that there were problems finding stores that sold gluten-free products and there is a need for better food labeling to identify gluten-free foods.

There is clear evidence that patients with celiac disease are less likely to dine out in restaurants or at friend's houses as a result of concerns regarding cross-contamination or inadvertent exposure to gluten (Karajeh *et al.*, 2005). Patients may worry about the consequences of social situations leading to difficulties in dietary adherence (Ludvigsson *et al.*, 2015).

## Labeling

Another serious challenge to maintaining the gluten free diet is unclear labeling. Eighty-five percent of adults surveyed said that it is a struggle to determine if foods are GF (Crannery *et al.*, 2003). Although gluten is a common ingredient in many foods, ingredient lists often make it difficult for individuals to determine if a food product is truly gluten free (Jessica *et al.*, 2006). Zarkadas *et al.* (2006) reported that poor labeling can make it difficult to determine which foods are gluten free, and options may be very few when eating out and traveling (Mahadev *et al.*, 2013). Garg and Gupta (2014) also highlighted the necessity of widespread availability of gluten free food and more clear and apparent labeling of gluten-free items of as much importance as proper counseling and reinforcement during subsequent visits (Garg and Gupta, 2014). Verma (2013), views lack of labeling about gluten status in marketed products like chocolate, biscuits, ice-cream etc was a problem and there is no legislation for gluten labeling in India.

The labeling of food is still a matter of debate in many countries and at the moment there are various rules for labeling gluten containing food. Most European countries have accepted the definition of "gluten-free" as <20 parts

per million (ppm; 6mg equivalent), while those food products that contain 20-100 ppm gluten (up to 30 mg equivalent) are classified as "very low gluten" (European Commission, 2009). In a study to investigate the accuracy of labeling gluten-free, Cawthorn Steinman and Witthuhn (2010) reported that ten of seventeen labeled gluten free products contained gluten. This clearly indicates the misleading problems faced by individuals attempting to maintain a gluten-free diet.

Compliance with a GFD is improved by education and knowledge of the diet and the disease, by membership of a self-help society, by availability of gluten-free products and by accessibility to a physician and dietitian (Leffler *et al.*, 2008). Since most of this support can be provided by regular follow-up with healthcare professionals with specialized expertise, the enhancement of compliance with a GFD is the main reason for regular follow-up (Stuckey *et al.*, 2009).

It is therefore reasonable to suggest that interventions planned to improve knowledge about celiac disease and about the GFD, and specifically how to identify gluten-containing products, may improve compliance with a GFD. Improving knowledge regarding gluten-containing food products and additives would also likely improve self-confidence in choosing gluten-free foods (Lamontagne, West and Galibois, 2001). Improved knowledge of complications of untreated celiac disease may also improve compliance (Rostom, Murray and Kagnoff, 2006).

Membership in a local celiac society appears to be an effective means of promoting compliance with a GFD (Lamontagne, West and Galibois 2001).

## CONCLUSION

Improving knowledge regarding disease, gluten-containing food products, availability of gluten-free products and promoting regular follow-up with healthcare professionals is key to success in adherence and health benefits to the celiac patient. Social activities should be planned through social support groups. Improving knowledge about outcomes of untreated celiac disease and social life may also improve compliance.

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