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ORIGINAL ARTICLE

Gluten Free Diet, Perceptions and Concerns of People Living with Celiac Disease in India: Internet-based Survey of Members of 'Zero Gluten' on Facebook

Sanjay Verma

ABSTRACT

Introduction: Gluten free diet (GFD) for the treatment of celiac disease (CD) remains a lifelong challenge for patients and their parents in India. There is little knowledge available about how these patients experience and cope with their dietary needs in India.

Aims: (i) To assess the status of gluten free diet and problems faced while managing GFD. (ii) To get an incite about their perceptions and concerns.

Study design: Cross-sectional descriptive internet-based survey.

Materials and methods: A predesigned semistructured questionnaire was prepared and mailed to members of 'zero gluten' on Facebook; an internet-based social support group for Indian CD patients, who were on GFD for a variable period of time. Those who decided to participate returned the filled questionnaire along with consent, which were analyzed.

Results: Out of 120 members, 32 filled the questionnaire and returned back. These computer literate CD patients were from different Northern states of India. Age ranged from 3 to 36 years with mean age 20.75 years. Mean duration of GFD was 3 years and average age at diagnosis was 13.7 years. Knowledge about possible options in GFD was limited. Branded GF products were in demand; 71.9% were buying them. Follow-up was poor and involvement of dieticians while managing GFD was rare. Their major concerns were professional needs, transmission to kids, marriage and peer pressure.

Conclusion: Managing GFD in India is difficult; help of trained dieticians, regular follow-up and psychological support is needed to sustain these dietary changes for life.

Keywords: Celiac disease, Gluten free diet, India.

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INTRODUCTION

Many years ago, we used to eat fruits, nuts, perhaps tubers and the occasional feast of meat. But eventually, we learned to cultivate plants and the agricultural revolution began. Our gut has developed over 2 million years and nobody knows when actually it started reacting to dietary antigens like gluten which lead to celiac disease (CD). The history of CD has spanned over 2,000 years. But only in 1900's have doctors discovered that the treatment included eliminating gluten.[1] CD is a permanent intolerance to gluten, a term that is broadly used to describe the storage proteins in wheat, rye and barley. It manifests as a result of an interplay that involves the host's genetic makeup, immunologic factors and gluten in diet.

CD was first reported from India in 1966, but it has come to attention of physicians in the past 2 decades.[1] Prevalence of CD in Northern India is probably not different from that in Western Caucasian population and diagnosed cases of CD are increasing.[2] The triad of symptoms of chronic diarrhea/malabsorption, failure to thrive and anemia was common until 2000 in India. However, the presentation of disease seems to have changed over the past few years. An upsurge has been observed by clinicians from North-West India.[3,4] More cases of CD are being diagnosed with atypical presentation mainly because of increasing awareness among health professionals.[5,6]

The only treatment available for CD is strict adherence to gluten-free diet for life. The major source of gluten in India remains wheat, especially in North Indian population. Survival after excluding wheat from diet remains a challenge for these patients and their relatives; because of poor awareness and limited availability of gluten free food options. Even among health professionals knowledge about gluten free options in India is limited. Most of gluten free recipes and literature available does not suit to the needs of Indian taste. Most of studies done on CD children and adolescents were targeted on different aspects of presentation and diagnosis of CD. However, little has been done on how these patients experience after diagnosis and how they cope with dietary treatment in India. So, this study was basically done to assess the status of gluten free diet (GFD), problems faced while managing GFD and also to get an incite about their perceptions and concerns.

MATERIALS AND METHODS

Study Design and Subjects

This cross-sectional, descriptive study was conducted from January to July 2011. A predesigned questionnaire was prepared, which included questions related to GFD, diagnosis, follow-up, support and psychological issues.

Questionnaire was mailed to all the members of 'zero gluten' on Facebook, one of the largest internet-based social support group for Indian CD patients. All those who were diagnosed to be having CD and were on GFD for a variable period of time, irrespective of their age; were allowed to participate in this survey. Parents were allowed to fill the questionnaire for those whose age was less than 18 years. All the members were free to participate or not in this survey. Those who decided to participate returned the filled questionnaire along with consent and later filled questionnaires were analyzed.

Data about Celiac Disease

Data was collected using a predesigned semistructured questionnaire, which was prepared by author. Demographic profile of these celiac patients who were on GFD for variable period of time was collected. Information about presenting symptoms, criteria for diagnosis and duration of GFD was collected. Questions related to type of GFD and problems encountered in managing GFD in India were included. Concepts about follow-up with doctor and dietician were also included. Their psychological state of mind and future concerns were also recorded.

Those who consented to participate filled the questionnaire and returned. Feedback and guidance about their concerns and problems were given online.

Statistical Analysis

Data was analyzed using SPSS 17.0 computer program.

RESULTS

Sociodemographic Characteristics

Out of 120 members, 32 consented to participate in survey. They filled up the questionnaire and returned back for analysis. Majority of these computer literate celiac patients were from urban background. Age ranged from 3 to 36 years with the mean age of 20.75 years (Table 1). They belonged to different North Indian states like Punjab, Delhi, Uttar Pradesh, Rajasthan, Chandigarh, Haryana, Himachal Pradesh and Madhya Pradesh, where wheat is the staple diet. Job profile of those, who were adults varied from business class to professionals.

Diagnostic Issues

Age at diagnosis also varied from 1 to 32 years of life with mean age of 13.7 years. Most common symptoms at diagnosis were anemia (71.9%), not gaining weight (65.6%) and frequent loose stools (62.5%). Aphthous ulcers (31.3%) and skin manifestations (25%) were another common associations noted; skin manifestations varied from eczema, rashes to dermatitis herpetiformis (Table 1). Tissue transglutaminase (tTG IgA) was the commonest serological test done for diagnosis and biopsy was done only in 59.4% of cases.

Gluten Free Diet

All of them were following a GFD for a variable period of time having mean duration around 3 years. Knowledge about possible options in GF diet was limited. GF options in breakfast, lunch/dinner, at restaurants while outing, flours used were variable (Table 2). Only few were aware about grain combinations which can be used as flour for

Table 1: Demographic and diagnostic features of study population (N = 32)

Variable	*Frequency (%)*
• Sex	
– Male	14 (43.8)
– Female	18 (56.3)
• Age group (years)	
– Below 5	4 (12.5)
– 5-12	2 (6.3)
– 12-18	3 (9.3)
– Above 18	23 (71.9)
• Marital status	
– Unmarried	24 (75.0)
– Married	8 (25.0)
• Residence	
– Urban	30 (93.8)
– Rural	2 (6.3)
• Informer	
– Self	23 (71.9)
– Parents	9 (28.1)
• Age group at diagnosis	
– Childhood	10 (31.3%)
– Adolescence	5 (15.6%)
– Adulthood	17 (53.1%)
• Symptoms at diagnosis	
– Anemia	23 (71.9)
– Not gaining weight	21 (65.6)
– Loose motion	20 (62.5)
– Abdominal distention	15 (46.9)
– Abdominal pain	10 (31.3)
– Vomiting	8 (25.0)
– Short stature	5 (15.6)
– Delayed period	4 (12.5)
• Associated illnesses at diagnosis	
– Aphthous ulcers	10 (31.3)
– Skin manifestations	8 (25.0)
– Thyroiditis	3 (9.4)
– Diabetes (type I)	1 (3.1)
– Arthritis	1 (3.1)
• Criteria for diagnosis	
– Blood test and biopsy	19 (59.4)
– Blood test only	13 (40.6)
• Blood test	
– tTG IgA	23 (71.9)
– Antiendomysial antibody	7 (21.9)
– Both	2 (6.2)
• Doctor who diagnosed	
– Government doctor	7 (21.9)
– Private	25 (78.1)

replacement of wheat. Around 13 (40.6%) were using branded GF flour from shops and rest 19 (59.4%) were using homemade flour. Those using homemade flour, 14 out of them were having their own grinder (chakki). Doctor who diagnosed them was the main source for their dietary advice. Around 20 (62.5%) had the feeling that their dietician are not adequately trained to address their needs and 18 (56.3%) had never received any advice from regular dietician.

Almost all agreed that at least once in a week they come across a situation when nothing gluten free is available to eat. While handling such situation, 28 (87.5%) eat fruits/salad, 3 (9.4%) eat gluten, 1 (3.1%) skip meal. Even on GFD, 14 (43.8%) felt that their intestine finds difficult to digest large amount of butter/ghee. Twenty-two (68.8%) agreed that they have started enjoying their GF food and the meal appearance does not bother them.

Branded Gluten Free Products

Many of them were aware about availability of branded GF products in the market. Around 23 (71.9%) were buying these products, varying from once a week to once a month. Regarding the reliability of their gluten free claim, 20 (62.5%) trust them to be gluten free; rest 12 (37.5%) are still not sure.

Alternative Medicine

Since the diagnosis, 8 (25%) decided to restart gluten in diet in between. Commonest reason was a trial of alternative medicines for cure, which failed in all of them and they end up restarting GF diet again. All of them tried homeopathy, five were still continuing it along with GF diet. Majority were not sure whether this alternative medicine helps them or not in tolerating gluten, but they were continuing it because of their parent's willingness.

Follow-up Issues

Once diagnosis was made, majority 19 (59.4%) used to visit doctor only if there was any problem. There was no concept of regular visit to doctor or dietician among them. Only six had repeat tTG IgA levels done in last 1 year for monitoring and 3 out of them showed raised levels.

Support Groups and Psychological Aspects

Majority were in opinion that celiac support groups are almost nonexistent in India. The need for societies was felt basically to improve the interaction among those who have this, information about GF outlets and new upcoming research (Table 3).

Table 3: Support and psychological issues (n = 32)

Variables	*Frequency (%)*
• Greatest support in sustaining GFD	
– Self	15 (46.9)
– Parents	15 (46.9)
– Doctors	1 (3.1)
– Spouse	1 (3.1)
• Family support in sustaining GFD	
– Yes	30 (93.8)
– No	2 (6.2)
• Major concerns	
– Professional needs like hostel stay	28 (87.5)
– Transmission to kids	19 (59.4)
– Marriage (n = 24)	14 (58.3)
– Peer pressure	11 (34.4)
• Needs from society	
– More GF outlets	24 (75.0)
– Better food labeling laws	24 (75.0)
– More awareness	24 (75.0)
– More research	22 (68.8)
• Main source of information	
– Internet	29 (90.6)
– Doctors	14 (43.8)
– Media	6 (18.8)
– Societies/support groups	3 (9.4)
• General perception of non-celiac people toward celiacs	
– Sympathetic	15 (46.9)
– Doesn't matter for them	9 (28.1)
– Worried	8 (25.0)
• Prefer your spouse to be on GF diet	
– Yes	6 (18.8)
– No	11 (34.4)
– Does not matter	15 (46.9)
• Present state of mind	
– Adjusted and happy	17 (53.1)
– Depressed	4 (12.5)
– Angry	2 (6.3)
– Does not know	9 (28.1)
• Do you feel your activities and lifestyle is limited because of GFD	
– Yes	14 (43.8)
– No	18 (56.2)
• Do you enjoy being special on GF diet	
– Yes	15 (46.9)
– No	17 (53.1)

Table 2: Commonly used GFD options

Variables	*Options*
Breakfast	Poha, pulav, besan puda, besan chilla, yogurt, cornflakes, dosa, idli, fruits, dal chilla, boiled potato, egg omelet, chana, daliya, GF paratha with milk/tea/coffee.
Lunch/dinner	Dal chawal, GF roti sabji, chicken/meat/fish, beans, chole chawal, roti made of makki/jowar/buckwheat/Amaranth/rice/pulses in different combinations
Restaurants	Masala-dosa, idli-sambhar, uttapam, chicken/meat, dal makhni/paneer sabji with rice, fried rice, chilli potato, french fries, curd rice, paneer tikka, egg curry, popcorn, seafood, shakes, ice creams
GF flour	Maize, gram, sorghum (jowar), bajra, buckwheat, rice, amaranth flours in different combinations

Present state of mind in 17 (53.1) was happy as they have adjusted with this new diet (Table 3). Professional needs, transmission to kids, marriage and peer pressure were their major concerns. Marriage and managing GFD after marriage were important concerns for unmarried females.

DISCUSSION

Study participants were diagnosed cases of CD on GFD from different Northern states, where wheat is the staple diet. All of them were computer literate urban background. Age at diagnosis of CD in India is usually delayed compared to west as shown in our study; Puri et al also reported mean age to be 10.8 years.[7] In our study, anemia was the most common symptom observed at the time of diagnosis followed by not gaining weight and frequent loose stools. Atypical symptoms like anemia, short stature, skin manifestations are more common when diagnosis is made at later age.[8] Refractory anemia has been reported earlier also as a common presentation of CD.[7,9,10] Although reason is not clear, but recurrent aphthous stomatitis (RAS) has been a well known association reported (33%) in diagnosed CD patients.[11,12] In the present study also, it was associated in 31.3% of cases. Irrespective of duodenal biopsy being gold standard in diagnosing CD, still at many places GFD is started only on basis of positive serology; mainly because of unavailability of intestinal biopsy facilities for small children, as shown in our study population. tTG IgA was found to be the single preferred serological test for diagnosing CD probably because of being quick, available and inexpensive.[13,14]

In our study, most patients received dietary advice regarding gluten free options from diagnosing physician only. Physicians must familiarize themselves with some of the difficulties encountered by patients in trying to obtain a perfect GFD. Patients often feel that they are left out with not many options, after this diagnosis. Majority of patients in this study were only advised to take rice or Makki roti. Only few were aware about different flour combinations which can be used as replacement for wheat. Involvement of trained dieticians in managing these patients is not a routine at many places at peripheral level. There are only a few dieticians very experienced in the GFD usually limited to bigger medical centers. Exposure to trained dietician was lacking in studied patients.

There is a need to spend more time in explaining options available to them, so that they can gradually diversify their diet as their knowledge about GFD increases. In India, it is common practice for families to purchase whole grain and have the flour processed at a small neighborhood flour mill, where other cereals like corn and rice are ground separately at a different time slot after cleaning the grinding machine. Despite cleaning the flour making machine, there may be mixing during grinding of cereals. They often through away the initial part of grinded flour and use the rest one, but this seems inadequate as some quantity of wheat get mixed while grinding, so it is not advisable to use such flour. It might make sense for patients to use solely home grinding for GF flour.[15] In our study, around 13 (40.6%) were using branded GF flour from shops and rest 19 (59.4%) were using homemade flour. Those using homemade flour, 14 out of them were having their own grinder (chakki). Lack of labeling about gluten status in marketed products like chocolate, biscuits, ice creams, etc. was another problem, as there is no legislation for gluten labeling in India. Most difficult part was managing GFD when they go out for traveling, birthdays, marriages or other social functions, where no gluten free food is available. Gradually they have started adjusting with such situations. Many of them had a concept of carrying gluten free bag, which contain all gluten free foods including fruits and nuts, whenever, they go out to some family function.

Commercially available gluten free food products were needed from many years, but they 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. In our study, 71.9% were buying these products, varying from once a week to once a month. GF cookies and GF flour was most commonly bought items. Regarding the reliability of their gluten free claim, 62.5% trust them to be gluten free; rest 37.5% are still not sure. Things they wish from these manufacturers were: Reduced cost, more availability and advertisement, improving taste, better labeling. They were more interested in buying GF bread and GF cakes, which were not available.

Changes in dietary habits are difficult to maintain and studies have shown that compliance decrease as they grow up, so there is a need for continuous reinforcement about sustaining GFD.[16] Adolescence is the time, when noncompliance is more likely because of ignorance and temptation.[17] However, several authoritative bodies have published guidelines on the management of CD that recommend regular follow-up. The consensus of the recommendations for follow-up suggests an annual review by a physician and dietician. But in our study, majority did not realize the need for regular follow-up with dietician or physician; neither was it emphasized at the time of diagnosis. Follow-up in these patients is often difficult unless stressed at time of diagnosis, many patients get lost to follow-up after a single visit. Once diagnosis was made, majority (59.4%) used to visit doctor only if there was any problem.

Only six had repeat tTG IgA levels done in last 1 year for monitoring and three out of them showed raised levels, which showed that noncompliance was prevalent.

Overall compliance rates to GFD in many studies have varied from 45 to 80%. To improve compliance other than annual follow-ups by physician and skilled dietician; improved knowledge and participation in a local support group is important. But such celiac support groups are almost nonexistent in India. Proposed factors for improvement of quality of life were: Better food labeling laws (75%), more awareness (75%) and outlets with cheaper gluten free products (75%).

Compliance with GFD is essential factor to obtain optimal quality of life. Early diagnosis and adherence to GFD has been shown to be associated with better physical health and less social problems.[18,19] Present state of mind in 17 (53.1) was happy as they have adjusted with this new diet. Professional needs (87.5%), transmission to kids (59.4%), marriage (58.3%) and peer pressure (34.4%) were their major concerns. Marriage and managing GFD after marriage were important concerns for unmarried females. Small family size was the most imp factor they would like to consider before marriage; as managing GFD in big combined families might be difficult. It is important to take psychological and social aspects into account in the treatment of patients with CD.[20] Coordinated efforts are needed for evolution of celiac support groups; and for widespread dissemination of knowledge through all available media for better management of this chronic illness. Limitations of our study were firstly, majority of the patients were educated urban patients (not poor and uneducated patients; those might face more difficulties); secondly, criteria used for diagnosing CD in majority was blood test only (biopsy was done only in few, which still remains a gold standard for confirming the diagnosis).

CONCLUSION

Managing GFD for life as a treatment for CD is a challenging task in India. There is a need to stress more upon exploring available GFD options by involving trained dieticians. It is important to incorporate the concept of regular annual follow-up at time of diagnosis for better GF compliance. Psychological and social aspects must be taken into account while managing them, as it helps in sustaining these datary changes for life.

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ABOUT THE AUTHOR

Sanjay Verma

Assistant Professor, Department of Pediatrics, Postgraduate Institute of Medical Education and Research, Chandigarh, India, e-mail: sanjay06verma@yahoo.com