

Compliance among North Indian Celiac Children to Gluten Free Diet

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ABSTRACT Gluten free diet is the only treatment for healing and recovery of mucosa and normalization of symptoms in celiac disease. To study the compliance rate for gluten free diet and consumption of gluten containing items among confirmed Celiac disease patients. Celiac disease patient (7-12 years) previously diagnosed were selected. An interview schedule was developed and pre-tested on 10 percent of sample, then used for data collection by a skilled dietician. Compliance information was derived on the basis of: 1.) 45 gluten containing items 2.) Two day 24 hour dietary recall 3.) Children receiving pocket money. The compliance rate was poor in both the age groups. The mean compliance score was comparatively more in children (7-9 years) than pre-adolescents. Relationship between pocket money receivers and non-compliance was found highly significant (Chi-square value=100.64 at $p < 0.01$). Compliance rate between both the age groups (that is, 7-9 and 10-12 years) was very poor. Preadolescents are more prone to noncompliance. There is positive impact of knowledge and regular follow up on strict adherence to GFD.

INTRODUCTION

Coeliac disease (CD) represents a unique disorder in which consumption of a food ingredient, namely gluten, in conjunction with genetic susceptibility, is essential for the development of an insidiously evolving auto-immune reaction affecting the gut and other organs (Nijhawan and Goyal 2015). Treatment of CD consists of a strict life-long gluten-free diet, which usually offers a protective effect against complications of malabsorption and extraintestinal involvement (Schuppan and Zimmer 2013).

Non-compliance in relation to gluten free diet (GFD) is a major problem and the greatest challenge physicians face in treating the children with celiac disease. Non-compliance may occur due to factors like temptation and not liking the taste of gluten-free food and alternative food grains (Chauhan et al. 2010). In adolescents, peer pressure, unclear labeling on ready-to-eat food, and non-availability of gluten-free food at party, marriages, and so forth have contributed to non-compliance. An increasingly hectic lif-

estyle of teenagers has contributed to a greater reliance on packaged foods which often contain gluten, and thus making it inconvenient for them to adhere to restrictive diet (Errichiello et al. 2010). Therefore, the present study was undertaken to study the compliance of GFD in previously diagnosed celiac disease (CD) patients aged 7-12 years.

METHODOLOGY

On the basis of prevalence of disease (1 in 96 as per Makharia et al. 2011), statistically the total sample size calculated was 15 (using the formula for sample size calculation). A lple size was taken for making it statistically viable, the number of subjects enrolled in the study were 50.

Formula used for calculation of sample size

$$n = \frac{(Z^*Z)^* P(1-P)}{d^2}$$

where,

d = Precision

P = Prevalence (1 in 96) (Makharia et al. 2011)

Z = Crit at P=0.05

Sample Selection

Celiac disease patient in the age group of 7-12 years following gluten free diet, registered in

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records of various hospitals, clinics and wheat free stores of Jaipur were selected. The list of children was procured from hospital and gluten free store; only children residing in Jaipur were approached. The care takers of children were approached personally.

Inclusion Criteria

Individuals were eligible for the study if they fulfilled the following criteria-Children 7-12 years old with celiac disease; willing to participate in the study; absence of any other complication like TB, cancer or diabetes.

Approval by the Ethics Committee

For carrying out the present study, approval by Ethical Committee was obtained.

Written Consent

An informed written consent was obtained from the subject's caretakers. In order to do so, a consent form was developed and consent was taken prior to enrolling the patient in study.

Development of Tool

An interview schedule was developed and pretested on 10 percent of sample approximately ten children and was used by a skilled dietician. Information was elicited on various aspects which are enlisted: 1.) Children receiving Pocket money, 2.) Compliance for gluten free diet was evaluated through checklist and 3.) Two day 24 hour recall method. A check list of 45 gluten containing items was developed.

This included products which were not mentioned gluten free by the manufacturer. Information gathered on consumption of gluten containing 45 food items that could be eaten either intentionally or unintentionally from both the age groups. Consumption was assessed in last two weeks period by a skilled dietician. Consuming =zero; not consuming=one mark, on this scoring the subjects were decided to be compliant or non-compliant. (Maximum score =45, minimum score=zero Cut-offs used to categorize children in compliant and non compliant was ≥ 34 (out of 45 items list) and ≤ 34 respectively. The checklist reported on basis of more the scores attained more the compliance rate criteri-

on. 24 hour dietary recall part was also scrutinized for gluten containing items. ($\leq 25\%$ score = poorly compliant, below 75% =average compliance and above 75%=good compliance).

Data Analysis

The data analysis was done using SPSS version 19.00. The statistical tests carried out were percentage and arithmetic mean. Chi-square test was done to test the relationship between the variables, p values < 0.05 were accepted as significant and < 0.01 as highly significant. Estimated sample size calculation was done prior to implementation of study.

RESULTS

Forty-four percent Celiac children were living in joint families while and 56 percent had nuclear families. Educational status of parents was poor. The literacy rate was low with (16 %) fathers (16%) and mothers (28%) being illiterate. Mothers of Celiac children who reached primary and upper primary level were 45 percent and 10 percent respectively. Mothers of Celiac children who acquired secondary and senior secondary were 16 percent, graduate were 10 percent and post-graduation level were 8 percent. Fathers of Celiac (20%) children were involved in small businesses. Other occupations included skilled labor, small businesses or private jobs. The majority of mothers of Celiac children were home makers. 62 percent had per-capita income ranging between Rs.1000-3000. The least per capita income was 1000 and highest was above 7000 rupees.

Celiac disease was confirmed using both serology and biopsy in 80 percent children while 20 percent were confirmed on serological tests only. Predominantly 58 percent of parents were not going for follow up visits and 42 percent were visiting doctors for follow up.

Both the genders and age category (that is, 7-9 and 10-12 years of age) included in the study were in similar proportion. (that is, $n=24$ and $n=26$). Seventy-two percent celiac children were getting pocket money no matter what the economic group they belonged to. The mean duration of the disease was 3 years. Siblings either keep a check or invite the Celiac subject to munch on gluten rich products. Mainly 90 percent Celiac children had 1 to 3 siblings and 8

percent children in both the groups had 4-6 siblings. It was observed that compliance rate was poor in both the age groups. The mean (SD) compliance score was comparatively more in children aged 7-9 years 24.19 (13.22/45) than pre-adolescents 22.96 (12.49/45). Children were classified into three categories, that is, poor, average and good. Poorly compliant children were 18 percent who scored ≤ 11 while 48 percent had average compliance and scored between 12-33. Good compliance was noticed in 34 percent only (≥ 34).

Consumption of Gluten Containing Foods by Celiac Children

The compliance of children was investigated by their intake of gluten rich foods in last two weeks period. The average consumption of gluten containing food product was comparatively more among pocket money receivers whether it be wheat containing foods, milk products, gluten containing sweets or miscellaneous products (Table 1). Similarly the celiac pre-adolescents were found to be consuming more gluten

Table 1: Average number of Celiac children consuming gluten containing product on the basis of pocket money

Food items	Pocket money receivers (n=36)	No pocket money (n=14)
	Consuming GF products	Consuming GF products
Wheat and its product	13.75 (165)	1.10 (13)
Milk and its product	22.33 (134)	2.67 (16)
Gluten containing sweets	18.17 (140)	1.87 (15)
Gluten containing miscellaneous products	22.70 (419)	3.68 (70)

Notes: Parenthesis depicts numbers; GF- gluten free wheat and its products included *sevaiyyan*, cornflakes, wheat *roti*, *samosa/kachori*, toast *suji*/ wheat biscuit, *aata* noodles/ *maggi*, bread *pav*, oats, cake/pastry, *upma/dalia*, *golgappe*, pasta; Milk and milk products included cheese, flavored milk, market *paneer*, market *khoya*, milkshake, milk cake; Gluten containing sweets included *besan laddoo*, market *jalebi*, *gulabjuman*, *besan burfi*, fruit custard, *mavakulfi*, *faluda*-ice-cream, fruit cream; Gluten containing miscellaneous products included *aaloo tikki*, Chinese food, squash, chocolate, *éclair*, pickles (market), packed soup, ketchup, soya sauce, asfoetida, *jaggery*, *dalbadi/mungodi*, *chaavanpraash*, readymade *curry masala*, readymade puree, canned fruits, baking powder, brewer's yeast, horlicks/boost.

containing foods and were less compliant. The gluten containing foods that were frequently eaten among both the age groups: *samosa*, *kachori*, cake, pastry, wheat biscuits, *paneer* (market), milk cake, *besan laddoo*, *aaloo tikki*, chocolate, milk shake, *jalebi*, market *kulfi*, *éclair* toffee, baking powder, asfoetida, market soup, Chinese foods, ketchup, *jaggery*, pickles etc. (Table 2).

Table 2: Average consumption of gluten containing food products by celiac children of both age groups

Food items	Celiac children (n=50)	7-9 years 10- 12 years (n=24)
	Yes	Yes
Wheat and its product	30.13 (94)	33.33 (96)
Milk and its product	48.08 (75)	52.08 (75)
Gluten containing sweets	32.32 (122)	40.62 (78)
Gluten containing miscellaneous products	48.57 (240)	55.47 (253)

Notes: Parenthesis depicts numbers; Wheat and its products included *sevaiyyan*, cornflakes, wheat biscuit, *aata* noodles/ *maggi*, bread *pav*, oats, cake/pastry, *upma/dalia*, *golgappe*, pasta; Milk and milk products included cheese, flavored milk, market *paneer*, market *khoya*, milkshake, milk cake; Gluten containing sweets included *besan laddoo*, market *jalebi*, *gulabjuman*, *besan burfi*, fruit custard, *mavakulfi*, *faluda*-ice-cream, fruit cream; Gluten containing miscellaneous products included *aaloo tikki*, Chinese food, squash, chocolate, *éclair*, pickles (market), packed soup, ketchup, soya sauce, asfoetida, *jaggery*, *dalbadi/mungodi*, *chaavanpraash*, readymade *curry masala*, readymade puree, canned fruits, baking powder, brewer's yeast, horlicks/boost.

Compliance has a major role in the treatment of Celiac disease and factors associated were studied. Pocket money and compliance was found to be significantly associated (Chi-square value=100.64 at $p < 0.01$). It was observed that compliance was more in children who were not receiving pocket money. Buying capacity was increased due to pocket money in Celiac children and thus the child spent it in buying gluten rich food items like cake, pastry, biscuits, chocolates, sweets, flavored milk etc.

DISCUSSION

This study was planned on previously diagnosed cases of Celiac disease. One-fourth children

were fully compliant and rest three-fourth were partially compliant. Since the compliance was assessed on an account of gluten containing 45 food items list and two-day 24 hour recall, very less number of children were found to be fully compliant.

Present study reported very less compliance rate which is in contrast with previously reported studies. Strict adherence to GFD was reported 60.2 percent (Sarkhy et al. 2015), good compliance 53.8 percent (Taghdir et al. 2016), strict compliance to a strict GFD 44.4 percent (Charalampopoulos et al. 2013). Higher degree of compliance is reported when parents have better knowledge about Celiac disease and the gluten containing items, understand importance of GFD for their child's overall growth and development, and are able to distinguish gluten containing from gluten-free food so that they handle the menu better (Garg and Gupta 2014). Parental perceived knowledge was significantly associated with dietary compliance (Charalampopoulos et al. 2013). Similarly, in a previous study, total knowledge scores of parents were found to be associated with compliance for GFD of their celiac children (Chishty et al. 2016). Mother's education was found as a significant factor related with the compliance (Garg and Gupta 2014).

In this study the compliance rate was comparatively better in children aged 7-9 years than pre-adolescents (10-12 years) which is similar to a previous study by Garg and Gupta (2014). They reported higher compliance rate in children up to 9 years of age as compared to children aged above 9 years. Adolescence is the time, when non-compliance is more likely because of ignorance, peer pressure and temptation (Puri et al. 2009). 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 (Roma et al. 2010).

Compliance reduces if the patient is not regular for follow-up visits. In a similar study of compliance carried out by van Koppen et al. (2009) in Netherlands on 12-14 years old based on interview reported that after 10 years follow up the compliance rate was low.

The term "lifelong dietary modification" seems normal and easy to implement but it is difficult for a child to exclude the basic food items from his diet which other family mem-

bers or his /her friends are consuming and he has grown eating those food item daily twice or thrice. After the of three years the GFD was not followed well. It was observed that parents of some of celiac children lost hope in gluten free treatment and were inclined to homeopathic treatment which allows wheat in diet. The sample included in study comprised of low or middle income group.

North Indian diets comprise of delicacies like wheat flour Batis, puris, bhature, aaloo tikki, gol gappe etc which children cannot resist to control hence affect the likelihood of compliance.

The primary reasons for noncompliance could be attributed to less knowledge (Charalampopoulos et al. 2013; Garg and Gupta 2014) about hidden sources of gluten containing foods like jaggery, asafoetida, icecreams, baking powder, yeast, soups, sauces etc, less availability of GF foods, less acceptability of gluten free foods, inadequate support from family and peers, peer pressure, unclear labelling (Errichiello et al. 2010), lack of knowledge of the health-related harms of gluten ingestion (Olsson et al. 2008), irregularity in follow up (van Koppen et al. 2009), poverty, illiteracy, ignorance (Garg and Gupta 2014), limited resources, lack of awareness, limited time, monotonous menu, fewer inexpensive gluten free options, temptation (Chauhan et al. 2010) and poor counseling session for CD patients. An additional barrier to adherence is the economic feasibility of living with the GFD (Stevens and Rashid 2008). Lack of labeling about gluten status in marketed products like chocolate, biscuit, ice-creams, etc. was another problem as there is no legislation for gluten labeling in India (Verma 2013). Pocket money is a contributing factor for non-compliance too. Sometimes families being religious finds it hard to stop child from eating prashad which mostly include wheat based sweets. To improve compliance other than annual follow ups by physician and skilled dietician; improved knowledge and participation in a local support groups are almost nonexistent in India (Verma 2013).

CONCLUSION

Pre-adolescents are more prone to non-compliance. There is a positive relation between knowledge and regular follow up on strict adherence to GFD. More emphasis should laid on

dietary adherence and diet quality, so to combat the nutritional deficiencies. This should be both through group and individual approach.

RECOMMENDATIONS

There is a strong need to monitor and revise the gluten free diet. Therefore emphasis should be laid on regular monitoring, awareness, follow up on gluten free diet and compliance among celiac patients and their families. Labeling laws and gluten free guidelines for Indians should be formulated to simplify the complications of disease.

What is Already Known?

- After many years of follow up the compliance rate was low in celiac patients.

What this Study Adds?

- Consumption pattern of gluten containing items among celiac children, rate of compliance among children and pre-adolescents. Pocket money, is significantly associated with non compliance in celiac children.

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