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KNOWLEDGE AND PRACTICES AMONG PARENTS OF CHILDREN SUFFERING FROM CELIAC DISEASE

***Sadia Chishty, Monika and Nimali Singh**

Department of Foods and Human Nutrition, University of Rajasthan, Jaipur, Rajasthan

**Author for Correspondence*

ABSTRACT

A lifelong commitment to a Gluten free diet is essential for patients with celiac disease. Knowledge and practices of parents of celiac children play a very significant role. Objective of the study was to study knowledge and practices of parents of celiac children regarding celiac disease and gluten free diet. Fifty parents of confirmed celiac children were personally interviewed. The knowledge and practices of purposively selected parents of celiac children regarding celiac disease and gluten free diet was assessed through questionnaire. Information was gathered through fifteen questions comprising of maximum (20) and minimum score (0). Total knowledge scores of parents were found to be associated with compliance for gluten free diet of their celiac children. Since GFD is the only treatment, awareness about disease, its treatment and importance of follow up should be increased. Labeling laws and guidelines for acceptable amount of gluten content for Indians should be generated and strongly implemented.

Keywords: *Knowledge and Practices, Celiac Disease, Knowledge Scores of Celiac Parents*

Abbreviation: GFD-gluten free diet, CD- Celiac disease.

INTRODUCTION

Celiac disease is still treated with a life-long gluten-free diet, a diet without wheat, barley or rye products. Complete removal of gluten from the diet of celiac disease patients will result in symptomatic, serologic, and histological remission in most patients (Kurppa *et al.*, 2011). The diet may pose as a hardship; a Gluten free diet can offer the patient a much better quality of life (Smith and Goodfellow, 2011). A gluten-free diet is critical for people with celiac disease, because eating gluten causes the body's immune system to attack and damage the small intestine. Dietary counseling of the patient and the family is the cornerstone of the treatment of celiac disease (Gupta *et al.*, 2009).

Knowledge is an important tool for adherence to Gluten free diet. Education about the disease for both parents and children may increase GFD 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).

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 *et al.*, (2000) found that parents who felt that they had too little information about celiac disease and the gluten-free diet were hindered in their ability to cope with their child's pain and diagnosis (Sallfors and Hallberg, 2003). Parents and other family members along with the adolescent can attend celiac disease support groups to gain information regarding the condition and maintaining the gluten-free diet (Allen, 2004).

Objective: To study knowledge and practices of parents of celiac children regarding celiac disease and gluten free diet.

MATERIALS AND METHODS

Parents of Celiac disease patient (n=50, 7-12 years old, following gluten free diet) of Jaipur, Rajasthan were selected. List of patients was taken from wheat free stores and clinics. Parents were contacted personally and they were visited at home. Only confirmed cases of celiac disease were enrolled. The knowledge and practices of parents of celiac children regarding celiac disease and gluten free diet was assessed. Information was gathered through fifteen questions comprising of maximum (20) and minimum

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score (0). Parents were classified on the basis of scores attained by them into three categories i.e., Poor who scored equivalent to 25% or less than 25% scores (≤ 5), the average scores were less than 75% and more than 25% (6-14) and good category consisted of parents who scored more than 75% (15-20). Statistical analysis was done using SPSS version 19.0.

RESULTS AND DISCUSSION

Results

The mean scores of knowledge among parents of 7-9 years old were 9.57 ± 3.04 (out of score 20). The knowledge of parents among 10-12 years old was almost similar to the parents of younger group (9.58 ± 2.88).

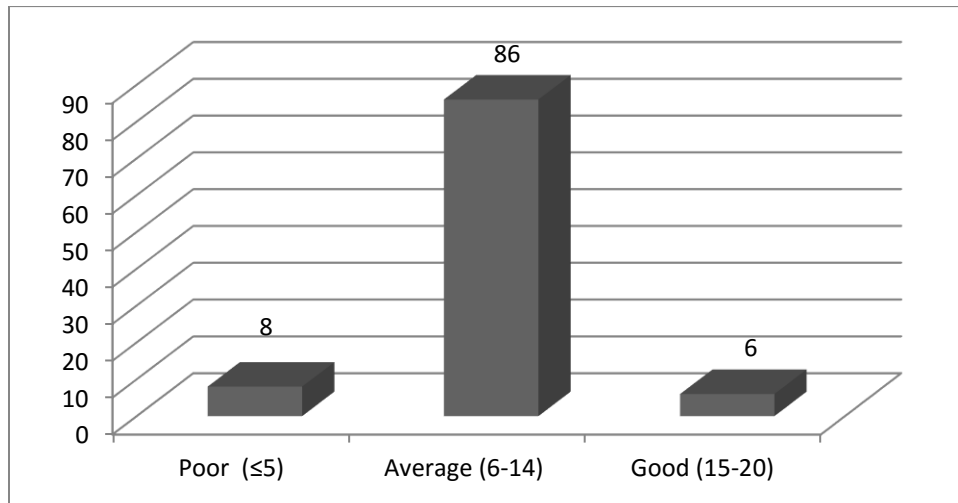


Figure 1: Percent Distribution of Parent's Knowledge and Understanding Score on Celiac Disease

Eight percent parents were categorized under poor category, average scores were found in 86% parents whereas only 6% parents attained good knowledge scores.

Table 1: Percent Distribution of Parent's Knowledge and Understanding about Celiac Disease

	Parents Knowledge
1) Which part of body do you think is mostly affected by celiac disease	(n=50)
a) Small intestine	46 (23)
b) Stomach	12 (6)
c) Liver	10 (5)
d) Skin	0 (0)
e) Other	4 (2)
f) Don't know	28 (14)
2) Gluten is present in	
a) All cereals	0 (0)
b) Wheat and wheat products	76 (38)
c) Rye barley	0 (0)
d) Oats	0 (0)
e) Don't know	16 (8)
f) Wheat, rye, barley and oats	8 (4)
3) Do you think that there is cure for this disease?	
a) Yes	20 (10)
b) No	80 (40)

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4) Which part of the cereal causes the disease?	
a) Gluten	24 (12)
b) Zein	2 (1)
c) don't know	74 (37)
5) Do you think restrictions in diet is necessary for normal development of child	
a) Yes	88 (44)
b) No	8 (4)
c) Don't know	4 (2)
6) Do you read label before purchasing food items for your child	
a) Yes	48 (24)
b) No	50 (25)
c) Doesn't give ready to eat food	2 (1)
7) Do you check your child's weight every 3 months	
a) Yes	46 (23)
b) No	54 (27)
8) Do you pay special attention while purchasing Flour for your child (do you get it grind in front of you)	
a) Yes	74 (37)
b) No	26 (13)
9) Had difficulty finding good quality gluten free foods	
a) All the time	20 (10)
b) Most of the times	20 (10)
c) Some of the times	48 (24)
d) Never	12 (6)
10) Whether you go for follow up	
a) Yes	42 (21)
b) No	58 (29)
11) More and immediate improvements required in area	
i. Gluten free outlets	
a) Yes	30 (15)
b) No	42 (21)
ii. Food labeling laws for gluten free products	
a) Yes	76 (38)
b) No	24 (12)
iii. Awareness programs	
a) Yes	54 (27)
b) No	46 (23)
iv. Research	
a) Yes	40 (20)
b) No	60 (30)
v. Government funding policy	
a) Yes	92 (46)
b) No	8 (4)

Parenthesis depicts frequencies

1) Knowledge on Body Part Most Affected

46% parents had reported that small intestine is adversely affected by celiac disease, 12% thought it to be stomach, 10% responded it to be liver, 4% of parents expressed other than these options while 28% had no knowledge related to basic body part affected by this disease.

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2) Cereals Containing Gluten

Seventy six percent reported it to be affected by only wheat and wheat products while 16% had no knowledge regarding the cereal responsible for celiac disease. Eight percent responded correctly that to reduce its aggravated outcomes one should restrict the intake of wheat and products, rye, barley and oats. No one responded it to be affected by rye, barley or oats individually.

3) Cure for Celiac Disease

Twenty percent parents responded positively and 80% had revealed that they had no hope for treating this disease and were determined to believe that no treatment can cure Celiac disease.

4) Causative Agent in Cereals

Seventy four percent of the parents had no or least knowledge about the protein part which is responsible for the disease and 24% had responded correctly i.e. gluten and 2% assumed it to be zein protein found mainly in maize.

5) Dietary Restrictions Important for Normal Development

Majority of the parents (88 percent) thought and agreed that restrictions in diet is necessary for normal development of child while 8% completely disagreed and 4% of them were ignorant and had no knowledge about it.

6) Reading Labels before Purchasing Food Items

Almost half (50 %) of the parents did not read label before purchasing food items for their children and 48% were found to be giving emphasis on reading labels, 2% did not give ready to eat foods.

7) Checking Child's Weight

More than half (54%) of the parents did not keep check on the child's weight. Around 46% parents were cautious and punctual in keeping a track of their child's growth status.

8) Special Attention while Purchasing Flour for your Child

Many of the parents claimed that only once they had given instruction to the owner of flour mill and they keep in mind, 74% specified that they give extra attention while purchasing gluten free flour and 24% hardly gave importance for buying gluten free flour.

9) Difficulty Finding Good Quality Gluten Free Foods

Around 88% of the parents had difficulty in finding good quality gluten free foods either of the times i.e. 48% had difficulty some of the times, 20% said to have problem all the time and 20% had it most of the time while rest of the parents about 12 % had no difficulty in finding gluten free flour.

10) Regular follow up

Predominantly 58% of parents were not going for follow up visits and 42% were visiting doctors for follow up.

11) More and Immediate Improvements Required in Area:

i. Gluten Free Outlets

Primarily 30% wanted immediate improvement in more and easily accessible Gluten free outlets.

ii. Food Labeling Laws for Gluten Free Products

Mainly 76% wanted immediate food labeling laws for gluten free products and food labeling guidelines in India.

iii. Awareness Programs

Fifty four per cent needed immediate changes in awareness programs which happen only once a year in particularly on celiac disease day in their respective hospitals and if they are availing health facility from clinic or not going for follow up then they are left only on mercy of internet or unreliable sources. They were desirous that each and every one should be aware about the disease and its treatment. Many of the parents revealed that they had to explain this disease multiple times to relatives.

iv. Research

Forty per cent emphasized on urgent actions for more researches in this field.

v. Government Funding Policy

Mainly 92% required immediate steps in availing funds from Government funding policies. Since this disease is lifelong and needs to be economically sound for its treatment.

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b. Child's Understanding towards Disease

Child's understanding towards Celiac disease was assessed by simply asking questions based on their disease.

Table 2: Percent Distribution on Aspects of Child Understanding Towards Disease at Different Stages

Child's Understanding	(n=50)
Is the child aware of his/her disease?	
Yes	76 (38)
No	24 (12)
Does the child get irritated because of his/her diet?	
Yes	66 (33)
No	34 (17)
Does the child ask for food restricted in his/her diet?	
Yes	72 (36)
No	28 (14)
Since the gluten free diet is started the child is eating	
Less food than normal/before	12 (6)
More food than normal/before	14 (7)
Same amount of food	74 (37)

Parenthesis depicts frequencies

Understanding of Celiac Children towards the Disease

The results of the study indicated that 76% of the Celiac children were aware about their disease condition. Sixty six percent of the Celiac children became irritated because of the restricted diet while about 34% took it as a new change as they started feeling better from past worse health status. Majority (72%) of the children ask for restricted food items and revealed cravings for gluten rich foods. Seventy four percent of children with CD were having same amount of food after they had been diagnosed with celiac disease, 14% children had started consuming more food than normal whereas 12% had reduced intake as they were introduced to gluten free diet.

Table 3: Relationship between Compliance and Total Knowledge Scores

Variables	Chi Square
Total Knowledge and Compliance	0.584**

*Significant at 5% level, **Highly significant at 1% level, NS -Non-significant

In the present study, total knowledge scores of parents were found to be associated with compliance of their Celiac children. It was reported in past studies also that parent's knowledge was major influencing factor in compliance and treatment of celiac disease.

Relationship of Knowledge and Practice Scores with Various Factors

Knowledge and practice of parents was assessed by few set of questions about celiac disease, through which their knowledge scores were tabulated then its association was established with various factors. Their compliance was estimated through checklist of gluten containing items and on consumption basis they were classified as complaint and non compliant children.

Among parents of compliant children, Knowledge was positively significant correlation was established with carbohydrate intake, energy, phosphorous, pulses, insoluble dietary fiber while, highly significant correlation was found with protein intake, riboflavin intake, niacin, folic acid, magnesium, zinc and

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vitamin B₁₂. Knowledge was negatively correlated with roots and tubers intake which was highly significant among compliant children’s parents.

Among Non compliant children parents the knowledge was positively correlated with protein intake, folic acid, magnesium, total dietary fiber, insoluble and soluble. Significantly positive correlation was found with calcium intake, phosphorus intake, iron intake, riboflavin intake.

Table 4: Association of Knowledge and Understanding with Other Variables among Compliant and Non Compliant Children

Compliant Variables	R	Non –Compliant Variables	R
Knowledge total score and protein	0.476**	Knowledge total score and protein	0.403**
Knowledge total score and carbohydrate	0.271*	Knowledge total score and calcium	0.314*
Knowledge total score and energy	0.332*	Knowledge total score and phosphorus	0.377*
Knowledge total score and phosphorus	0.330*	Knowledge total score and iron	0.323*
Knowledge total score and riboflavin	0.468**	Knowledge total score and riboflavin	0.333*
Knowledge total score and niacin	0.338**	Knowledge total score and folic acid	0.454**
Knowledge total score and folic acid	0.415**	Knowledge total score and magnesium	0.421**
Knowledge total score and magnesium	0.374**	Knowledge total score and total dietary fiber	0.512**
Knowledge total score and zinc	0.381**	Knowledge total score and insoluble fiber	0.521**
Knowledge total score and vitamin B ₁₂	0.334**	Knowledge total score and soluble fiber	0.514**
Knowledge total score and insoluble dietary fiber	0.296*	Knowledge total score and Other vegetable	0.381*
Knowledge total score and Pulses	0.312*		
Knowledge total score and Root	-0.342**		
understanding total score and total dietary fiber	0.380**	Understanding total score and carbohydrate	-0.375*
Understanding total score and insoluble dietary fiber	0.339**		
Understanding total score and soluble dietary fiber	0.341**		

*Significant at 5% level, ** Highly significant at 1% level, NS -Non-significant

Discussion

Total knowledge scores of parents were found to be associated with compliance to gluten free diet of their Celiac children. Primarily their nutrient and dietary intake was found to be associated with knowledge and understanding scores. Positive correlation was found between knowledge scores and intake of Protein, fiber, phosphorous, riboflavin, magnesium and folic acid among both complaint as well as non compliant children. Garg and Gupta (2014), highlighted in their study 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 their child’s overall growth and development, and are able to

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distinguish gluten containing from gluten-free food. 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.

The gluten free stores in Jaipur are very few at nearby places and are far away from their residences therefore parents still had difficulty in reaching wheat free stores from distant localities. Economic factor can also be ascribed to actually not consuming gluten free products because GF products are expensive. 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). Present study emphasizes on requirement of gluten labeling guidelines for Indians. According to Zarkadas *et al.*, (2006), poor labeling can make it difficult to determine which foods are gluten free, and options may be limited when eating out and traveling. There is no legislation for gluten labeling in India, therefore, a patient with celiac disease will not be able to know if any of the food items is safe (Gupta *et al.*, 2009). Verma, (2013) considered lack of labeling regarding gluten status in marketed products like chocolate, biscuits, ice-cream, etc, was a problem in managing GFD. 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). Most of the 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).

One can only imagine how difficult it is 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 CD. 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 GFD difficult (Jessica *et al.*, 2006).

Conclusion

This could be concluded that knowledge scores were positively correlated and increasing awareness about celiac disease, gluten free diet, importance of follow up, framing and implementing guidelines on Gluten content and gluten free labeling laws will definitely improve the disease condition and current scenario of Indian celiac.

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Conflict of Interest

There are no conflicts of interest.

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