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## RESEARCH ARTICLE

# KNOWLEDGE AND PERCEIVED DIFFICULTIES REGARDING GLUTEN FREE DIET AMONG CELIAC DISEASE PATIENTS

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### ARTICLE INFO

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Celiac disease patients.

### ABSTRACT

**Background of the study:** Celiac disease is an autoimmune disorder that can occur in genetically predisposed people where the ingestion of gluten leads to damage in the small intestine. It has emerged as an increasingly recognized public health problem and is one of the main cause of morbidity and mortality.

**Objectives:** To assess the knowledge and level of perceived difficulties regarding gluten free diet among celiac disease patients.

**Methodology:** A non-experimental descriptive research design was used and 100 celiac disease patients were selected by using convenience sampling technique. A structured questionnaire was used to assess the knowledge and Likert scale was developed to assess the level of perceived difficulties among celiac disease patients.

**Results:** It was found that maximum numbers of celiac disease patients (46%) were having good knowledge and about (67%) of patients had high level of perceived difficulties regarding gluten free diet. The study also focused that the most frequently occurring perceived difficulty in individual difficulties was in finding gluten free food at restaurants (91.3%), in emotional and psychological difficulties, was to control themselves while watching others eating normal diet (71.6%), under the social difficulties was in attending meal invitations (77.6%), in financial difficulties they found gluten free food more costly (90%). A significant relationship ( $p \leq 0.05$ ) of knowledge with marital status and family income and perceived difficulties with disease duration and adherence to gluten free diet ( $p \leq 0.05$ ) was found among celiac disease patients.

**Conclusion:** The finding of the study concluded that maximum number of celiac disease patients had good knowledge and majority of patients had high level of perceived difficulties regarding gluten free diet. The study also focused that, the most frequently occurring perceived difficulties were in finding gluten free food at restaurants, in controlling themselves while watching others eating normal diet, in attending meal invitations because of dietary restrictions, and in finding gluten free food more costly. Also the study revealed that there was significant relationship of knowledge with marital status and family income, level of perceived difficulties with disease duration and adherence to gluten free diet among celiac disease patients.

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## INTRODUCTION

Celiac disease is an enteropathy characterized by damage to small intestinal mucosa due to ingestion of dietary gluten in genetically-susceptible individual (Fasano, 2001). The precise cause of celiac disease is not known. When the body's immune system over-reacts to gluten in food, the immune reaction damages the villi that line the small intestine and triggers the immune system to produce certain antibodies (<http://www.mayoclinic.org/diseases-conditions/celiac-disease/basics/definition/con-20030410>. Accessed on 3<sup>rd</sup> Dec, 2014).

Celiac disease symptoms vary among sufferers and include abdominal bloating, pain, gas, diarrhoea, pale stool and weight loss, dermatitis herpetiformis, anemia, muscle cramps, joint and bone pain, growth problems and failure to thrive in children (<http://my.clevelandclinic.org/health/disease-conditions/hic-celiac-disease>. Accessed on 3<sup>rd</sup> Dec, 2014). Blood test that find and measure these antibodies include Ig anti-TTG.<sup>4</sup> The treatment for celiac disease is lifelong adherence to strict gluten free diet.

### Objectives

- To assess the knowledge regarding gluten free diet among celiac disease patients.

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- To assess the level of perceived difficulties regarding gluten free diet among celiac disease patients.
- To determine the association of selected socio-demographic characteristics and clinical profile with knowledge and level of perceived difficulties regarding gluten free diet among celiac disease patients.
- To develop and disseminate IEC guidelines regarding gluten free diet among celiac disease patients.

## MATERIALS AND METHODS

**Research setting-** Gastro OPD and Medicine OPD of DMC&H, Ludhiana.

**Target Population-** Celiac disease patients.

**Inclusion criteria:** Celiac disease patients who:

- Visited Gastro OPD and Medicine OPD of DMC&H, Ludhiana during the time of data collection.
- Were >15 years of age.
- Were willing to participate in the study.

## RESULTS

**Objective 1: To assess the knowledge regarding gluten free diet among celiac disease patients**

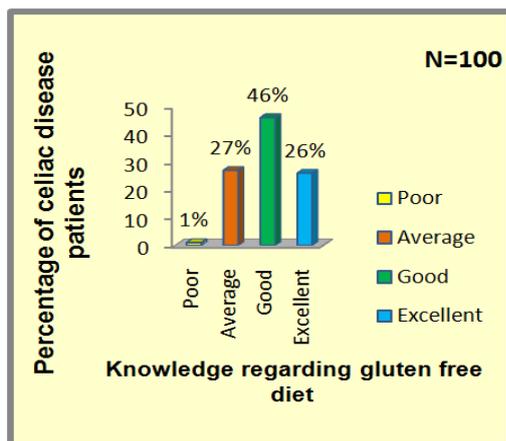


Figure 1: Percentage distribution of celiac disease patients as per their level of knowledge regarding gluten free diet

**Objective 2: To assess the level of perceived difficulties regarding gluten free diet among celiac disease patients**

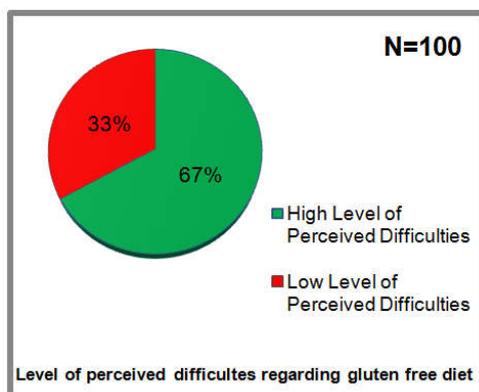


Figure 2. Distribution of celiac disease patients as per their level of perceived difficulties regarding gluten free diet

**Exclusion criteria:** Celiac disease patients who:

- Were not available at the time of data collection.
- Were not able to read and write.

## Sample and Sampling technique

The sample was celiac disease patients who visited Gastro OPD and Medicine OPD of DMC&H, Ludhiana during the time of data collection. Convenience sampling technique was used to draw sample from the target population.

**Sample size-** 100 celiac disease patients.

## Description of research tool

**Part A:** Socio-demographic characteristics and clinical profile of celiac disease patients.

**Part B:** A structured questionnaire to assess the knowledge regarding gluten free diet.

**Part C:** Likert scale to assess the level of perceived difficulties regarding gluten free diet.

## DISCUSSION

The present study showed that maximum number of celiac disease patients (46%) were having good knowledge regarding gluten free diet. These findings were supported by study of Sdepanian VL1 (2011) who evaluated compliance to a gluten free diet and knowledge of the disease in celiac disease patients registered at the Brazilian Celiac Association(BCA). (67.1%) answered that gluten is a protein and according to 92.1% questionnaires this protein is present in wheat, rye, barley and oat. It was concluded that the more the patients know and understand about the disease, the better they were able to comply with the diet (Sdepanian, 2011). The study presented that about 2/3<sup>rd</sup> i.e. (67%) of celiac disease patients had high level of perceived difficulties related to gluten free diet. These findings were supported by J. K. H. Whitaker (2009) who conducted a study to assess patient perceptions of the burden of celiac disease and its treatment in the UK.

Two- thirds (68%) reported that their dietary restrictions reduced their enjoyment of food; (46%) believed that their food cost them more and estimated this to be an extra £10 per week. Half (54%) reported that doing things they enjoyed less often, because of their diet, with the most common activity sacrificed being dining out (Whitaker, 2009). There was significant relationship of knowledge with marital status ( $p=0.04$ ) and family income ( $p=0.00$ ). It was found that there was significant relationship of level of perceived difficulties with disease duration ( $p=0.04$ ) and adherence ( $p=0.006$ ). O' Donnell Brigit Dieticians (2008) conducted a study in which dieticians reported that patients had difficulty in eating a gluten free diet because of a lack of knowledge of the appropriate foods to eat ( $p= 0.032$ ). (48%) of participants reported that patients did not follow a strict gluten free diet because of lack of access to gluten free foods ( $p= 0.036$ ) (O' Donnell Brigit Dieticians, 2008).

**Table 3 (a). Association of knowledge and level of perceived difficulties with the selected socio demographic profile of celiac disease patients**

Socio-demographic characteristics	Minimum perceived difficulty score- 20						
	Knowledge regarding gluten free diet				Perceived difficulties regarding gluten free diet		
	N	Mean±SD	F/t value	p value	Mean±SD	F/t value	p value
Age(yrs.)							
16-30	47	13.6±3.27	1.05	0.37 <sup>NS</sup>	43.59±7.48	0.51	0.67 <sup>NS</sup>
31-45	24	12.75±3.62			43.54±8.56		
46-60	26	12.73±3.36			43.00±7.86		
61-75	03	10.67±1.15			49.00±9.53		
Gender							
Male	39	12.28±3.43	-1.90	0.98 <sup>NS</sup>	42.89±7.24	0.69	0.28 <sup>NS</sup>
Female	61	13.59±3.23			44.03±8.23		
Marital status							
Married	58	12.36±3.25	3.3	0.04*	43.77±8.24	0.03	0.96 <sup>NS</sup>
Unmarried	41	14.07±3.32			43.37±7.47		
Widow	01	14.00±			43.00±		
Religion							
Hindu	57	13.25±3.40	0.19	0.82 <sup>NS</sup>	44.45±8.04	1.52	0.22 <sup>NS</sup>
Sikh	42	12.88±3.36			42.26±7.47		
Others	01	12.00±0.00			52.00±0.00		
Habitat							
Urban	88	13.24±3.32	1.28	0.77 <sup>NS</sup>	43.19±8.06	1.37	0.08 <sup>NS</sup>
Rural	12	11.92±3.50			46.50±5.45		
Type of family							
Joint	42	13.28±3.39	0.94	0.39 <sup>NS</sup>	43.83±8.12	0.04	0.95 <sup>NS</sup>
Nuclear	57	12.77±3.30			43.45±7.77		
Extended	01	18.00±0.00			42.00±0.00		
Educational status							
Illiterate	01	10.00±0.00	1.14	0.33 <sup>NS</sup>	52.00±0.00	1.02	0.38 <sup>NS</sup>
Elementary	15	13.87±2.77			42.00±8.93		
Higher secondary	46	12.54±3.25			44.67±7.82		
Graduate or above	38	13.50±3.65			42.70±7.39		
Income/month (Rs.)							
<5,000/-	07	11.00±2.08	6.52	0.00*	47.29±8.03	1.05	0.37 <sup>NS</sup>
5001-10,000	13	11.31±2.81			42.92±7.62		
10,001-15,000	33	12.21±3.62			44.66±7.90		
>15,000	47	14.49±2.89			42.48±7.82		
Eating habits							
Vegetarian	66	12.88±3.13	0.35	0.70 <sup>NS</sup>	43.55±8.17	0.003	0.99 <sup>NS</sup>
Eggetarian	11	13.36±3.58			43.73±7.72		
Non-vegetarian	23	13.52±3.95			43.64±7.24		

Maximum knowledge score -20

Minimum knowledge score – 0

Maximum perceived difficulty score-60

Minimum perceived difficulty score- 20

\* Significant (p≥0.05)

NS –Non Significant

**Table 3 (b). Association of knowledge and level of perceived difficulties with the clinical profile of celiac disease patients**

Clinical Profile of celiac disease patients	N=100						
	Knowledge regarding gluten free diet				Perceived difficulties regarding gluten free diet		
	n	Mean±SD	F/t value	p value	Mean±SD	F/t value	p value
Disease duration (yrs)							
<1	11	12.82±3.94	2.22	0.09 <sup>NS</sup>	46.45±4.67	2.80	0.04*
1-5	43	12.33±3.24			44.00±8.01		
6-10	25	13.24±3.62			45.08±8.65		
>10	21	14.57±2.58			39.57±6.72		
Family history							
Yes	14	13.79±2.83	0.84	0.18 <sup>NS</sup>	45.31±7.76	0.84	0.77 <sup>NS</sup>
No	88	12.97±3.43			43.33±7.87		
Adherence to gluten free diet							
Always	70	13.49±3.24			42.04±7.89		
Sometimes	20	11.65±3.85	1.83	0.14 <sup>NS</sup>	48.40±6.11	4.35	0.006*
Mostly	06	13.83±2.56			43.17±5.94		
Never	04	12.00±2.86			44.00±7.70		

Maximum knowledge score -20

Minimum knowledge score – 0

Maximum perceived difficulty score-60

Minimum perceived difficulty score- 20

\* significant (p≥0.05)

NS-Non Significant

## Conclusion

The finding of the study concluded that maximum number of celiac disease patients had good knowledge regarding gluten free diet and high level of perceived difficulties regarding gluten free diet.

The study also focused that, the most frequently occurring perceived difficulties were in finding gluten free food at restaurants, in controlling themselves while watching others eating normal diet, in attending meal invitations because of dietary restrictions, and in finding gluten free food more costly. Also the study revealed that there was significant relationship of knowledge with marital status and family income and level of perceived difficulties with disease duration and adherence to gluten free diet among celiac disease patients.

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