

A mixed method study to explore the problems and interventions adopted among patients with Celiac disease with the view to develop and utilise the assessment tool in selected Hospitals of Maharashtra. – A Pilot Study.

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Background: Celiac disease, a chronic autoimmune disorder triggered by gluten consumption, poses significant challenges to patients' physical, emotional, and social well-being. Effective management requires a thorough understanding of the problems faced and interventions adopted by patients. This study aims to explore these dimensions and develop a comprehensive assessment tool for use in selected hospitals of Maharashtra.

RESEARCH OBJECTIVES –

PHASE 1 -

1. To explore the problems among patients with celiac disease.
2. To assess the adopted intervention among patients with celiac disease.

Methods: This mixed-method study was conducted in selected hospitals of Maharashtra. Phase 1 focused on qualitative data collection through semi-structured face-to-face interviews with 30 celiac disease patients aged 25 and above, using purposive sampling until data saturation was reached. Verbatim transcripts and field notes were analysed thematically. Demographic data were also gathered and analysed descriptively.

Analysis –

Section – I Demographic data.

Section – II –In-depth interviews (Semi-structured) until data saturation to assess the problems and interventions adopted among celiac patients.

- The interviews for this study were transcribed and both the transcripts and audio recordings, along with the interviewer 's field notes, were analysed for themes.
- It was observed that after 24 samples, there was repetition of themes and subthemes. New themes did not emerge from further interviews. So, sample size is fixed to 30 samples for pilot study.

SECTION I : Overall analysis of the demographic characteristics of samples at Hospitals.

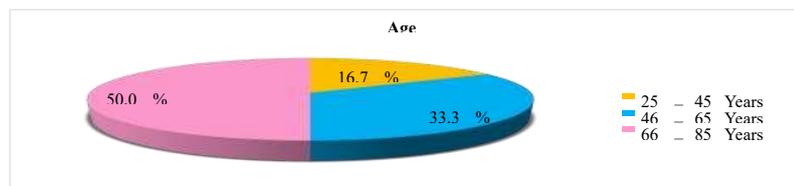


Figure 1: Age of Celiac Disease Patients (n=30).

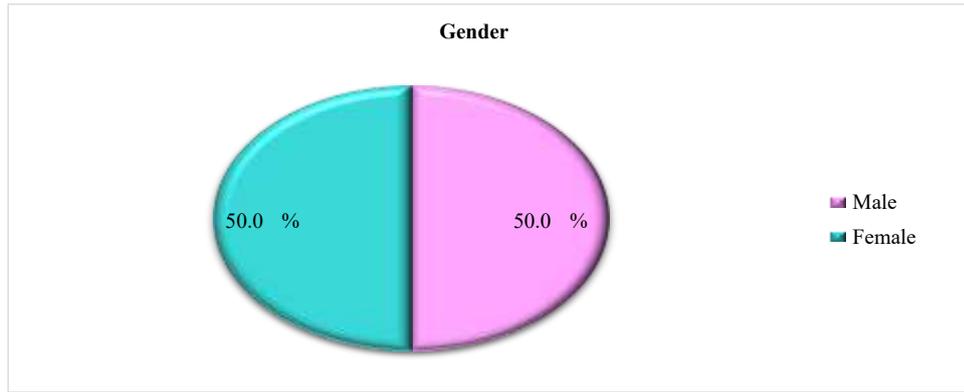


Figure 2: Gender distribution of Celiac Disease Patients (n=30).

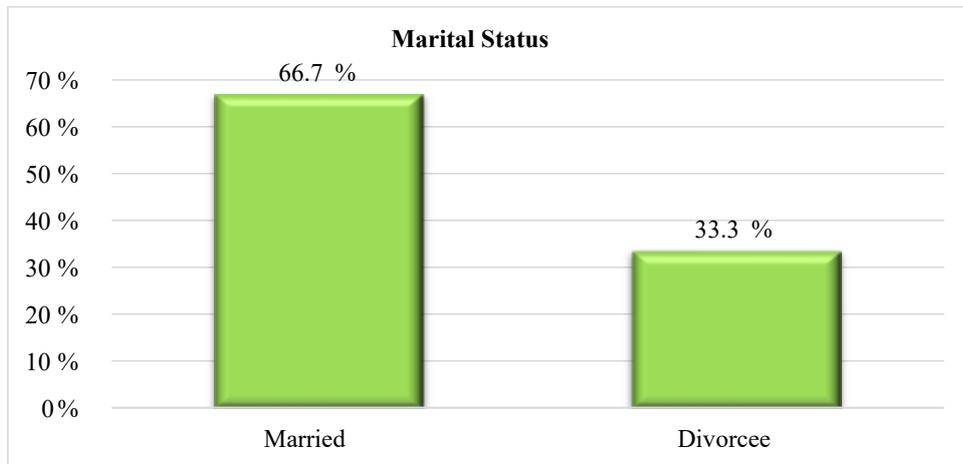


Figure 3: Marital Status of Celiac Disease Patients (n=30).

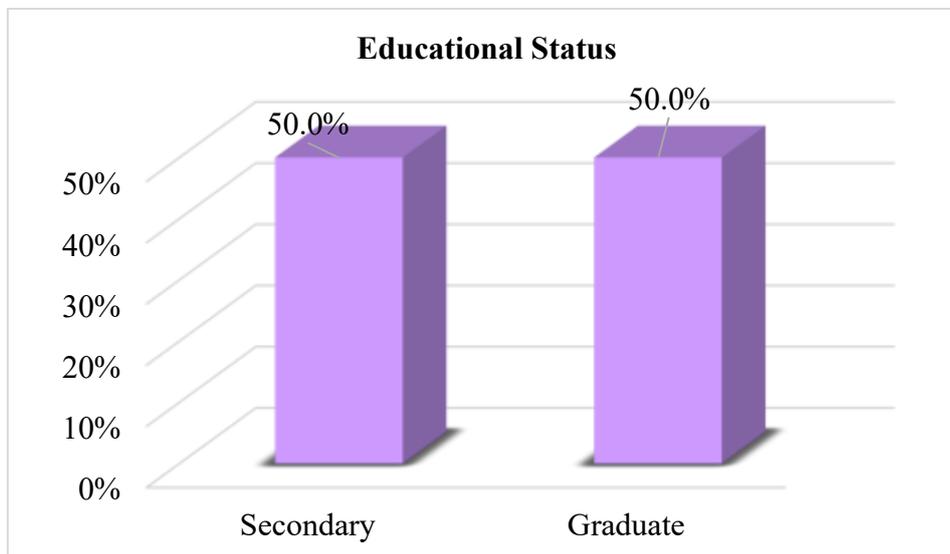


Figure 4: Educational Status of Celiac Disease Patients (n=30).

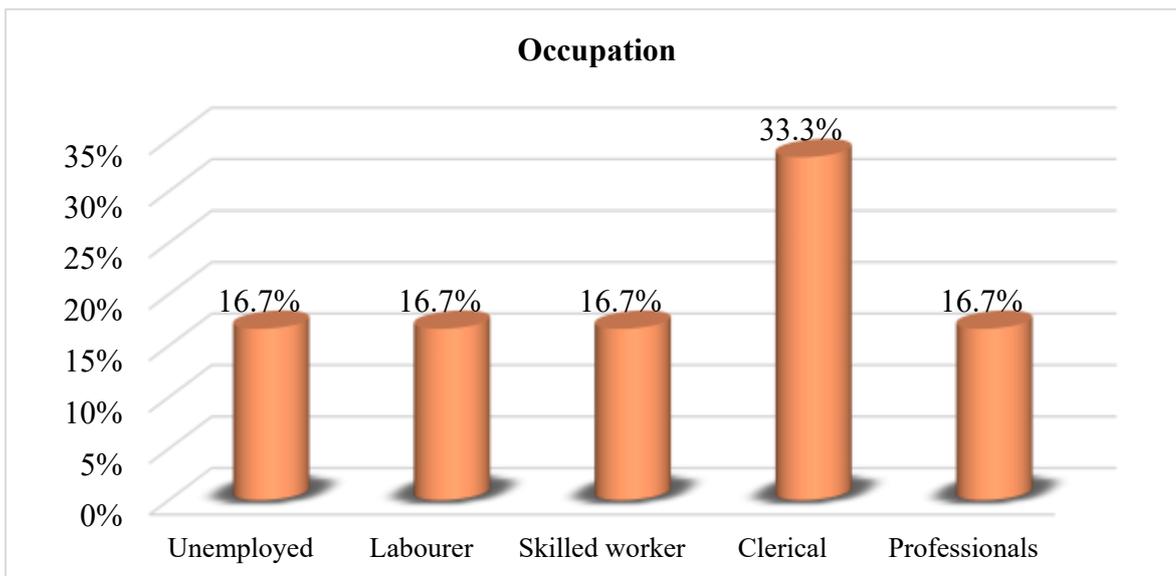


Figure 5: Occupation of Celiac Disease Patients (n=30).

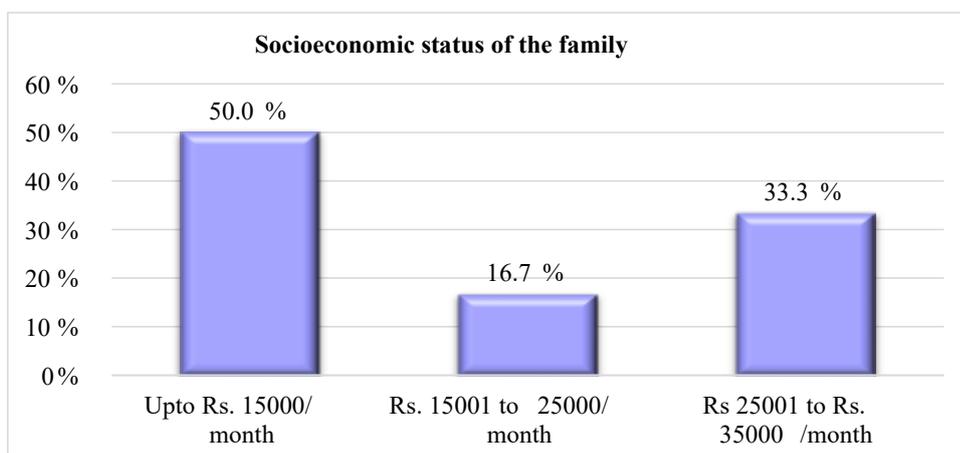


Figure 6: Socioeconomic Status of Celiac Disease Patients (n=30).

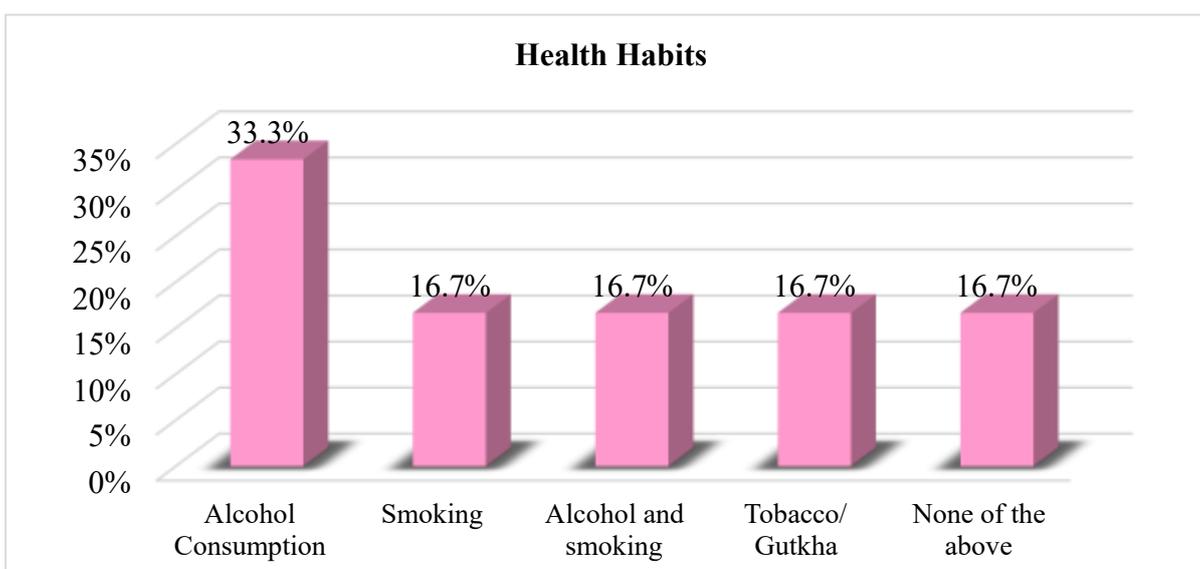


Figure 7: Health Habits of Celiac Disease Patients (n=30).

- 16.7% of the patients with Celiac disease had age 25-45 years, 33.3% of them had age 46-65 years and 50% of them had age 66-85 years.
- 50% of them were males and 50% of them were females.
- 66.7% of them were married and 33.3% of them were divorcees.
- 50% of them had secondary education and 50% of them had graduated.
- 16.7% of them were unemployed, 16.7% of them were laborers, 16.7% of them were skilled workers, 33.3% of them were clerk and 16.7% of them were professionals.
- 50% of them had monthly family income upto Rs. 15000, 16.7% of them had monthly income Rs.15001-25000 and 33.3% of them had monthly income Rs. 25001-35000.
- 33.3% of them had habit of consuming alcohol, 16.7% of them had habit of smoking, 16.7% of them had habit of alcohol and smoking, 16.7% of them had habit of tobacco/gutkha and 16.7% of them did not have any of these habits.

Qualitative analysis: 1. To explore the problems among patients with celiac disease.

2. To assess the adopted intervention among patients with celiac disease.

Description of themes generated

Table No. 1		n=30
The Problems among patients with celiac disease.	Disease experience Illness Manifestation Diet Concerns Lifestyle changes.	
The adopted intervention among patients with celiac disease.	Treatment seeking behaviour Commitment to treatment Support system Stress management Coping strategy	

Table No. 2			n=30
Sr. no.	Theme	Subtheme	Codes
1	Disease experience	Everlasting Treatment	Temporary relief Not diagnosed Not keeping well Not so good since long. Repeated hospitalisation Continuous follow up
		Food Disorder	Stomach problem Celiac illness Digestion problem Disease of eating certain grains Food sensitivity
2	Illness Manifestation	Pain	Pain in stomach after lunch or dinner Pain in abdomen Pain on eating Acidity
			Feeling of vomiting Constipation

		Feeling tired	Tiredness Couldn't go out from home Look pale Loose motions Diarrhoea
3	Diet concerns	Restrictive eating	Follow Diet chart Diet has to be followed strictly Avoid grains Avoid bakery products Be careful about what you eat Avoiding food in social gathering Stick to diet
		Food Dissatisfaction	Don't get satisfaction of eating food Miss favourite food Lost choices about food Need to eat similar kind of food
4	Lifestyle changes	changed physical activities	Can not travel much Feel tired Social life is completely changed Do not go out most of the times Tired easily so can do limited daily activities Need rest Avoid traveling
		Emotional impact	Misunderstood by others as I avoid functions and gatherings Feel bad Feel burden on wife Worried about health all the time Awkward social situation Become little isolated Avoid social gatherings
		Financial issues	Facing problem with the money Hospital expenses Food expenses Need to save money for health Cost of gluten free food

2. To assess the adopted intervention among patients with celiac disease.

Description of themes generated

Table No. 3

n=30

The adopted intervention among patients with celiac disease.	Treatment seeking behaviour Commitment to treatment Support system Stress
	Coping strategy

Table
n=30

No.

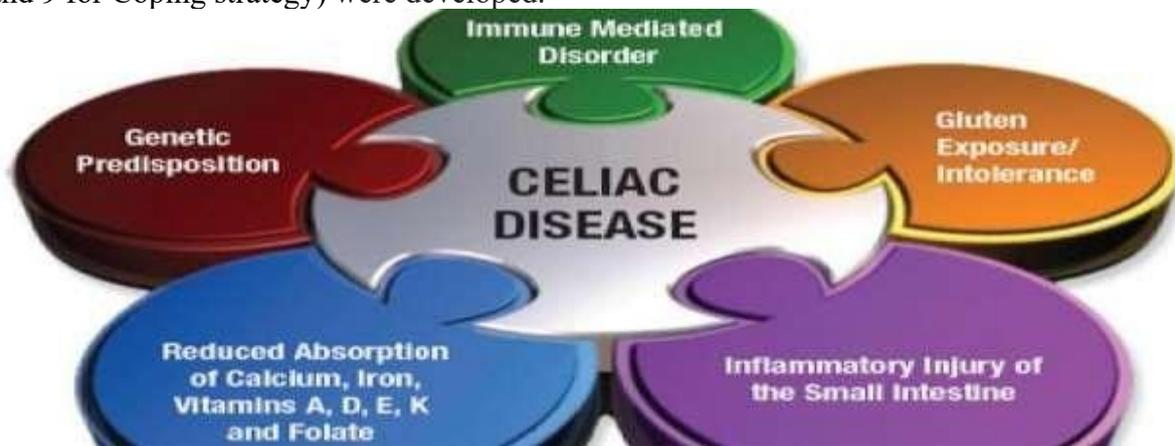
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Sr. no.	Themes	Subthemes	Codes
5	Treatment seeking behaviour	Changing Doctors	Changed doctor when not got relief Not diagnosed soon Have to undergo many tests at different hospitals Changed Hospitals
		Seeking information more	Started reading books and articles on this illness Started reading food labels Dietary consultations
6	Commitment to treatment	Health Priority	Reduced smoking, alcohol & gutkha Stick to diet Diet has to be followed strictly Get modification in diet Avoid eating outside food Avoid traveling Avoid social gathering Avoid going to see places Understand your health and symptoms carefully
		Treatment Schedule	Taking medicines Regular check up Weight monitoring In touch with doctor and dietician
7	Support system	Family Members	Family and friend's support Cooking restrictions on family Get support from relatives and family members
		Spouse	Cooks food free of gluten Reads the food labels for gluten Gives home made gluten free food while traveling
		Healthcare team	Diet chart Diet modification Medications Treatment Follow up Reliving symptoms
8	Stress management	Financial	Facing problems with the money Hospital expense Food expense
		Emotional	Trying to be happy Life has become boring Not able to eat similar kind of food most of the time. Life is very restricted Monotonous life Eat in separate plate to avoid food contamination

9	Coping Strategies	Reinforcement	Keep myself safe by gluten free diet Avoid traveling Avoid functions or gatherings Taking medicines regularly Avoid certain grains Understand social isolation Save money for health Take good care of yourself Listen to your doctor
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The analysis revealed 9 themes: 1. Disease experience, 2. Illness Manifestation, 3. Diet Concerns 4. Lifestyle changes, 5. Treatment seeking behaviour, 6. Commitment to treatment, 7. Support system, 8. Stress management and 9. Coping strategy

From the 9 themes, 102 candidate items i.e. (11 for Disease experience, 11 for Illness Manifestation, 11 for Diet Concerns, 19 for Lifestyle changes, 7 for Treatment seeking behaviour, 13 for Commitment to treatment, 12 for Support system, 9 for Stress management and 9 for Coping strategy) were developed.



Conclusion: The study provides a nuanced understanding of the multifaceted challenges faced by celiac disease patients and the strategies they adopt. The findings serve as a basis for developing a standardized assessment tool aimed at improving patient care and support systems.

References:

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- **Chou, R., & Turner, J. A.** (2019). *Celiac disease management: Systematic review of evidence-based guidelines.* Journal of the American Medical Association, 321(2), 234-245. <https://doi.org/10.1001/jama.2018.19093>