



Adherence to Gluten-Free Diet, Knowledge and Health-Related Quality of Life among Children with Celiac Disease

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ABSTRACT

Background: Living gluten-free is a well-known concept for children with celiac disease who need to be knowledgeable and closely adherent to a gluten-free diet (GFD) to ensure good health-related quality of life. **The study was conducted to** assess adherence to GFD, knowledge, and health-related quality of life of children with celiac disease. **Subjects and Methods:** a descriptive cross-sectional study was conducted on 103 children with celiac disease at the outpatient clinic of Gastroenterology and the Bakery for Special Therapeutic Nutrition at Zagazig University Hospitals. **Data collection tools included;** Leffler's questionnaire for adherence, GFD knowledge quiz, and celiac disease-specific pediatric health-related quality of life (CDPQOL). **Results:** Less than one-fifth of the studied celiac children reported excellent adherence to GFD and less than one-sixth of them had good knowledge about GFD. Low total health-related quality of life scores were found in about three-fifths of children aged 8-12 years and nearly half of adolescents aged 13-18 years. Furthermore, adherence to GFD showed a significant positive correlation with health-related quality of life. **Conclusions:** Children with celiac disease had poor knowledge about GFD and poorly adhered to it. They also reported low health-related quality of life that was affected by poor adherence to GFD. **Recommendations:** Continuous evaluation of children's adherence to GFD and discussion of children's beliefs and concerns about dietary regimens should be done routinely. Also, tailored multifaceted interventions designed to meet the needs of children with celiac disease would help manage adherence.

Keywords: Adherence, Children with celiac disease, Gluten-free diet, Health-related quality of life, knowledge

Introduction

Celiac Disease (CD) is a chronic autoimmune disorder with multisystem affection that is triggered by gluten (the protein found in wheat, barley, and rye) consumption in the diet and damages the small intestine (Lebwohl et al.,

2018). It is marked by an inflammatory enteropathy with varying severity, a range of extra-intestinal symptoms, and the presence of celiac-specific autoantibodies (Hill et al., 2016; Al-Toma et al., 2019). The global prevalence of CD

is around 1%, but there are significant variations between countries (**Lionetti & Catassi, 2011**).

The prevalence of CD in Egypt has been documented to be 0.5%. It appears to be a common condition among Egyptian children, with a prevalence of 0.53% in the general population and 6.4% in at-risk groups (**Abu-Zekry et al., 2008**). Across countries such as Iran, Turkey, Saudi Arabia, Jordan, and Egypt, the pooled seroprevalence of CD is estimated to be 1.6% (**Singh et al., 2018**).

The clinical features of celiac disease (CD) vary significantly with the age at which symptoms appear. In young children diagnosed within the first few years of life, intestinal symptoms and failure to thrive are common. In contrast, when the disease manifests later in childhood, extraintestinal signs are more prevalent, including short stature, delayed puberty, anemia, enamel hypoplasia, osteopenia, or bilateral occipital calcifications, all of which are related to gluten in the diet (**Lasa et al., 2014; Leffler et al., 2015**).

The only treatment for celiac disease (CD) is strict, lifelong adherence to a gluten-free diet (GFD), which involves excluding wheat, rye, barley, and other gluten-containing foods from the diet. This leads to the disappearance of symptoms and improvements in nutritional status (**Barrio & Cillerulo, 2022**). Maintaining a GFD requires careful monitoring of food labels, avoiding unsafe grains, and ensuring there is no cross-contact with gluten-containing foods. These restrictions can be particularly challenging for adolescents, who are

often concerned with fitting in with their peers, want to feel normal, and may find gluten-free foods unappealing (**Ludvigsson et al., 2016**).

Adhering to a gluten-free diet (GFD) presents several challenges, including a lack of knowledge about the diet, gluten contamination, labeling inconsistencies, and the restrictive nature of the diet (**Rashid et al., 2005**). Like other chronic conditions, celiac disease (CD) can have adverse physical and psychosocial effects on children and adolescents. The need for lifelong adherence to a GFD, which is crucial for managing CD, requires significant commitment from young patients and can be difficult due to the major changes in eating habits and lifestyle (**Crocco et al., 2021**). The need to follow a GFD, combined with the chronic nature of the illness, may also lead to social stigma, negatively impacting peer relationships and potentially lowering the quality of life (QoL), especially in adolescents (**Olsson et al., 2009**).

Several factors contribute to the negative impact of celiac disease (CD) on the health-related quality of life (HRQoL) of affected patients. The chronic nature of CD, its impact on health, psychological distress, social and family implications, and the necessity for lifelong treatment all adversely affect HRQoL (**Biagetti et al., 2015; Burger et al., 2017**). Evidence has shown that treatment adherence is influenced by various factors, including sociodemographic characteristics, knowledge, attitudes, experiences, symptoms, and quality of life (QoL) (**Abu-Janb & Jaana, 2020; Dimidi et al., 2021**).

Significance of the study

Celiac disease (CD) is a chronic autoimmune disorder triggered by gluten consumption, leading to damage in the small intestine and a range of symptoms from intestinal symptoms to anemia and delayed puberty (Caio et al., 2019). The only treatment is strict, lifelong adherence to a gluten-free diet (GFD) (Martin, 2008), which poses challenges, especially for adolescents. These challenges, along with the chronic nature of CD, can negatively impact the health-related quality of life (Ben Houmich & Admou, 2021).

Evaluating adherence to the gluten-free diet (GFD) and the knowledge of both patients and their families about GFD is essential for managing celiac disease. Strict adherence to the GFD and CD-related issues has a significant impact on the patient's Health-Related Quality of Life. Therefore, the present study was conducted to assess adherence to the gluten-free diet, knowledge, and HRQoL of children with celiac disease.

Aim of the study:

The present study aimed to assess adherence to GFD, knowledge, and health-related quality of life of children with celiac disease.

Research Design

In this study, a descriptive cross-sectional design was used.

Research questions:

- 1- What is the level of celiac children's adherence to a gluten-free diet?

- 2- What is the level of celiac children's knowledge about gluten-free diet?
- 3- How does celiac disease affect the health-related quality of life of the studied children?
- 4- What is the relationship between adherence to GFD, knowledge, and health-related quality of life among children with celiac disease?

Subjects and Methods

Settings

The present study was carried out at the outpatient clinic of Gastroenterology and the Bakery for Special Therapeutic Nutrition at Zagazig University Hospitals which is affiliated with the Ministry of Higher Education and Scientific Research.

Sample size:

The calculated sample size was 103 children with celiac disease using the Open Epi software program with a confidence level of 95% and 80% power of the study, considering the results of Pedoto et al., (2020) who declared that 59.4% of the studied pediatric patients were excellent adherent to GFD.

Subjects

The study included 103 children diagnosed with celiac disease who are on a gluten-free diet for at least one year and aged 8 to 18 years. Children under 8 years, children following GFD less than 1 year, and children suffering from non-celiac wheat sensitivity were excluded from the study.

Tools for data collection

Tool (I): A Structured Interview Questionnaire was designed by the researchers and had the following two parts:

Part A: Demographic characteristics of the studied children and their parents.

Part B: Clinical characteristics of the studied children (age at diagnosis, duration of disease, and associated diseases)

Tool II: Leffler's Questionnaire for Adherence of Pediatric Patients with Celiac Disease

A questionnaire designed especially for pediatric patients and adapted from **Leffler et al. (2009)** was used to assess adherence to GFD. It had eight questions about self-efficacy, individual perceptions of the disease, outdoor food intake, perceived adherence to the GFD, and GFD-specific knowledge. A score (0–3) was assigned to each response. Children with celiac disease were categorized into three adherence levels based on their score: ≤ 2 indicated excellent adherence, 3–6 indicated fair adherence, and ≥ 7 indicated low adherence. Celiac children who are older than 12 years were asked to fill out the questionnaire on their own; parents might assist if necessary. Parents were asked to complete the questionnaire for celiac children under the age of twelve, although the children's cooperation was always needed.

Tool III: Gluten-Free Diet Knowledge Quiz

Gluten-Free Diet knowledge was assessed through a quiz prepared by the researchers, guided

by **Silvester et al., (2016)**. It contained details about the GFD substitutes, permitted and not permitted foods, food additives, food labels, hidden gluten, food preparation, food storage, and medicine verification. It consisted of 35 true and false questions. The scoring of this tool was developed by the researchers. The answers of participants are graded as 1 for a correct answer and 0 for an incorrect answer to a maximum total of thirty-five points. The participant's knowledge level was classified as follows; poor (<60%), fair (60–75%), and good (>75%).

Tool IV: Celiac Disease-Specific Pediatric Health-Related Quality of Life (CDPQOL)

Health-related quality of life was assessed through a specific scale (CDPQOL) (**Jordan et al., 2013**). The 13-item CDPQOL for children aged 8 to 12 is made up of negative emotions (7 items), school (4 items), and enjoyment (2 items). The 17-item CDPQOL for children aged 13 to 18 is made up of social items ($n = 7$), uncertainty items ($n = 3$), isolation items ($n = 4$), and limitation items ($n = 3$). Children with celiac disease answered questions on Likert scales, with 0 = Never to 4 = Almost Always. Values from the Likert scale were converted into an inverse numerical scale and then added together to create subscales and a total score. Better QOL was indicated by higher CDPQOL scores, with an overall score range of 0 to 100.

Methods

Validity and Reliability

All the study tools were examined by five professors: two in pediatric nursing, one in pediatric medicine, one in pediatric gastroenterology, and one in medical statistics. All jury members (100%) agreed that the existing research tools and their validity were relevant to the study's purpose. The Cronbach's alpha test was used to judge the tools' reliability. The reliability coefficient was (0.876) for the GFD Knowledge Quiz, (0.830) for Leffler's Questionnaire for Adherence, and (0.917) for (CDPQOL).

Ethical consideration

The Zagazig University Faculty of Nursing's Research Ethics Committee gave its approval to the study. According to ethical guidelines, all participants received written notification of the main objectives of the study, and the gathered information would only be utilized for scientific reasons. Additionally, the confidentiality of the participants' identities and all data received will be ensured. In addition, they were advised that they might withdraw from the study at any point and that they could choose not to participate.

Pilot study

A pilot study with ten celiac children was conducted to evaluate the clarity and applicability of the instruments and estimate the time needed to collect all the data. This pilot investigation indicates the necessary changes to be implemented. Those children who took part in the pilot study were not included in the study.

Fieldwork

The directors of the study settings formally granted permission to carry out this study. Children with celiac disease who satisfied the study's inclusion requirements were progressively enrolled, and participation was entirely voluntary. The researchers outlined the fundamental objectives of the study. Before taking part in the study, the parents and children with celiac disease submitted their written agreement for inclusion. Celiac children and their parents attended the Gastroenterology outpatient clinic every Monday for a regular follow-up visit and the Bakery of Special Therapeutic Nutrition every Tuesday and Wednesday to buy GFD products. The researchers attended the study settings on the same previous days every week from May 2023 until January 2024. During the visit, Celiac children and their parents completed questionnaires by themselves, separately, and under the supervision of the researchers.

Statistical Analysis

The collected data was coded and entered into IBM SPSS Statistics for Windows, version 24 (IBM Corp., Armonk, NY, USA). The data was then reviewed to detect any entry errors. It was then analyzed by the same program to create frequency tables with percentages. Qualitative data was presented as numbers and percentages, and quantitative data was described as mean or standard deviation. The inferential statistic tests included; a t-test, analysis of Variance (ANOVA), Chi-square test, and the correlation coefficient.

The results were considered statistically significant at $P \leq 0.05$ and highly significant if $p < 0.01^{**}$.

Results

Table I Shows that 65% of the studied children were aged ≤ 12 years, with a mean age of 11.09 ± 3.9 . Males represented 54.4% of the studied sample, and 44.7% were primary school students. It was also found that 56.3% of the studied children resided in rural areas. Of the studied fathers, 61.2% had a university education, compared to 59.3% of mothers.

The medical history of the studied children is represented in **Table II**. The mean age at diagnosis was 7.8 ± 3.8 years, and the mean duration of disease was 4.32 ± 2.1 years. Also, it was shown that 54.4% still experience symptoms of CD, with the most common being stomach pain (75%), difficulty gaining weight (46.4%), diarrhea (41.1%), bloating (39.3%), gases (33.9%), and dermatitis (21.4%). Approximately 69.9% of the studied children had other associated diseases, primarily type I diabetes (43.1%), dermatitis (29.2%), allergy (19.4%), and thyroiditis (8.3%). A family history of celiac disease was positive in 20.4% of cases, with mothers (42.9%) and brothers (28.6%) being the most frequently affected relatives.

As observed from **Table III**, a low total health-related quality of life score was reported by 59.7% of the studied children aged 8–12 years and by 47.2% of the studied adolescents aged 13–18 years.

Figure I illustrates that 54.4% of the studied children were low adherent and 27.2% were fairly adherent, while only 18.4% were excellent adherent to GFD.

As noticed from **Table IV**, 51.5% of the studied children could identify the symbol of a food label, which indicates that the product is gluten-free. Children with CD who could correctly identify that “pasta is not gluten-free”, “wheat-free” is not the same as gluten-free, and “fresh meat, fish, eggs, and dairy products are gluten-free” represented 31%, 38.8%, and 60.2% of the studied sample, respectively. Meanwhile, 76.7% and 92.2%, respectively, of the studied children answered incorrectly that “malt vinegar is not gluten-free”, and “hydrogenated margarine, soy sauces, and ketchup are not gluten-free”.

Figure II Shows that 65.1% of the studied children had poor knowledge about gluten-free diet, while 19.4% had fair knowledge about GFD. Only 15.5% of the studied children had good knowledge.

Table V Shows that total GFD knowledge was significantly positively correlated with adherence to GFD ($r = 0.498$, $p = 0.007$) and HRQoL ($r = 0.399$, $p = 0.008$). Additionally, adherence to GFD showed a significant positive correlation with HRQoL ($r = 0.560$, $p < 0.001$).

Table VI Reveals a highly significant relation between experiencing any symptoms of celiac disease and having any other associated diseases with the studied children's health-related quality of life at a p -value $< 0.01^{**}$.

Table VII Portrays a highly significant relation between gluten-free diet adherence of the studied children and the following factors: the child's age, experiencing any symptoms of celiac disease, having any other associated diseases, and the educational level of their fathers and mothers, at a p-value <0.01**.

Table VIII Presents a highly significant relation between a child's age, the educational level of the father, and the educational level of the mother and their children's total knowledge about GFD at a p-value <0.01**.

Table (I): Percentage Distribution of Studied Children with Celiac Disease and Their Parents Regarding Their Demographic Characteristics (n=103)

Items	No	%
Age:		
• 8 -<12	67	65.0
• 12 - 18	36	35.0
Mean± SD	11.09 ± 3.9	
Gender:		
• Male	56	54.4
• Female	47	45.6
Educational level:		
• Primary stage	46	44.7
• Middle school	38	36.9
• Secondary school/ Diploma	19	18.4
Residence:		
• Rural	58	56.3
• Urban	45	43.7
Educational level of father:		
•Primary	4	3.9
•Preparatory	6	5.8
•Secondary	30	29.1
•University	63	61.2
Educational level of mother:		
•Primary	2	1.9
•Preparatory	3	2.9
•Secondary	37	35.9
•University	61	59.3
Fathers' occupation:		
• Working	99	96.1
• Not-working	4	3.9
Mother's occupation:		
• Housewife	69	67.0
• Working	34	33.0

Table (II): Percentage Distribution of Studied Children with Celiac Disease Regarding their Medical History (n=103)

Items	No	%
Age at diagnosis:		
• < 2 years	6	5.8
• 2 – 6	39	37.9
• 7 – 11	40	38.8
• 12 – 16	13	12.6
• 16 – 18	5	4.9
Mean \pm SD	7.8 \pm 3.8	
Duration of disease:		
• 1 – 4	68	66
• 5 – 8	23	22.3
• 9 – 12	12	11.7
Mean \pm SD	4.32 \pm 2.1	
Still experience any symptoms of celiac disease:		
• Yes	56	54.4
• No	47	45.6
If yes: *		
• Diarrhea	23	41.1
• Constipation	5	8.9
• Tiredness	6	10.7
• Gases	19	33.9
• Stomach pain	42	75.0
• Bloating	22	39.3
• Mouth ulcers	4	7.1
• Vomiting	2	3.6
• Difficulty gaining weight	26	46.4
• Poor growth	11	19.6
• Dermatitis	12	21.4
Have any other diseases associated with the disease:		
• Yes	72	69.9
• No	31	30.1
If yes; *		
• Thyroiditis	6	8.3
• Allergy	14	19.4
• Asthma	0	0
• Dermatitis	21	29.2
• Type I diabetes	31	43.1
Family history of the disease:		
• Yes	21	20.4
• No	82	79.6
If yes, degree of consanguinity		
• Father	4	19.0
• Mother	9	42.9
• Brothers	6	28.6
• Others	2	9.5

*More Than One Answer

Table (III): Percentage Distribution of Studied Children with Celiac Disease related to their Health-Related Quality of life (n=103)

	High		Moderate		Low		Mean ± SD
	No	%	No	%	No	%	
Celiac disease-specific pediatric health-related quality of life (CDPQOL) for 8-12-year-old children. (n= 67)							
Negative emotions	8	11.9	22	32.8	37	55.3	12.5 ± 3.7
School	7	10.4	20	29.9	40	59.7	6.9 ± 2.7
Enjoyment	10	14.9	18	26.9	39	58.2	3.1 ± 1.4
Total	8	11.9	19	28.4	40	59.7	22.5 ± 5.9
Celiac disease-specific pediatric health-related quality of life (CDPQOL) for 13-18-year-old children. (n= 36)							
Social	5	13.9	11	30.6	20	55.5	10.3 ± 2.9
Uncertainty	8	22.2	10	27.8	18	50.0	5.4 ± 1.8
Isolation	9	25.0	11	30.6	16	44.4	7.6 ± 2.3
Limitations	7	19.4	12	33.4	17	47.2	5.9 ± 2.01
Total	8	22.2	11	30.6	17	47.2	29.2 ± 7.3

Figure (I): The Level of Gluten-Free-Diet Adherence of The Studied Children with Celiac Disease (N=103)

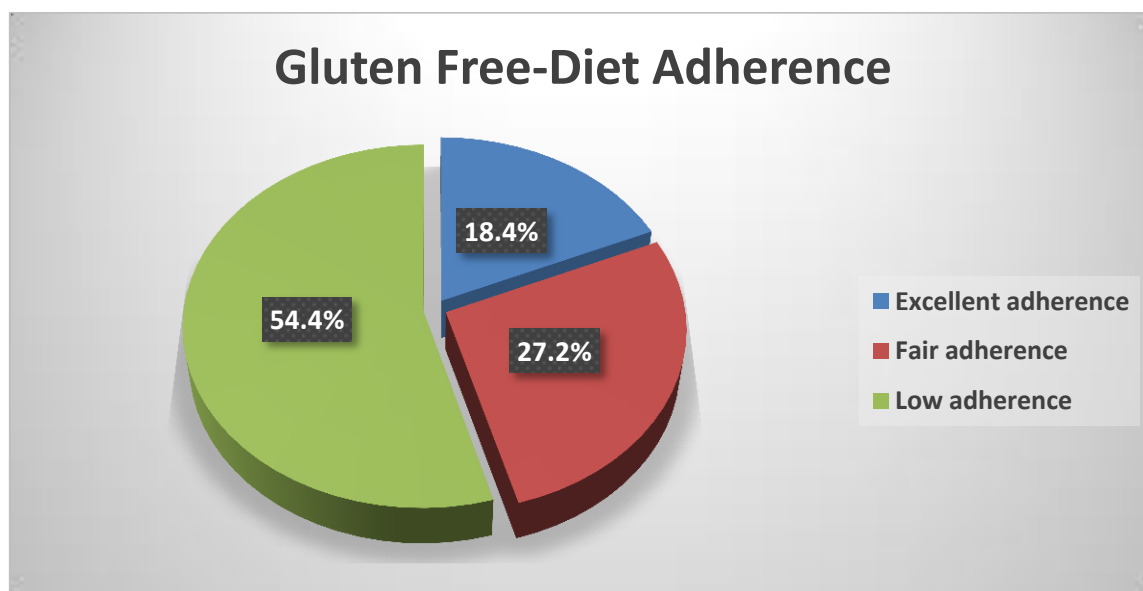
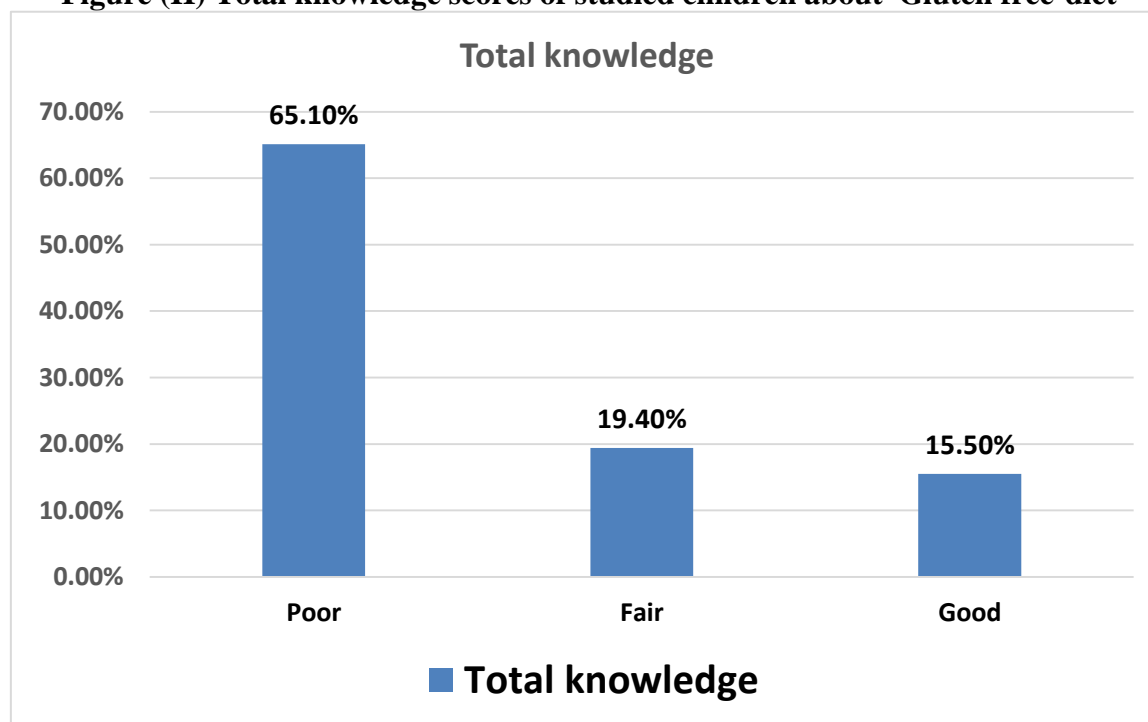


Table (IV) Distribution of studied children related to their knowledge about Gluten-free diet by GFD knowledge Quiz (n=103).

Items	Correct		Incorrect	
	No	%	No	%
The symbol on a food label indicates that a product is gluten-free*	53	51.5	50	48.5
Pasta is gluten-free	32	31.0	71	69
“Wheat-free” is the same as gluten-free	40	38.8	63	61.2
Malt vinegar is gluten-free	24	23.3	79	76.7
Couscous is gluten-free	20	19.4	83	80.6
Potatoes are gluten-free*	62	60.2	41	39.8
Rice is gluten-free*	58	56.3	45	43.7
Pearl Barley is gluten-free	16	15.5	87	84.5
Corn is gluten-free*	54	52.4	49	47.6
Soya beans are gluten-free*	20	19.4	83	80.6
Oatmeal is gluten-free*	46	44.7	57	55.3
Crouton (toast) is gluten-free	21	20.4	72	79.6
Egg noodles are gluten-free	25	24.3	78	75.8
Sausages (processed meat) is gluten-free	29	28.2	74	71.8
Mustard is gluten-free	16	15.5	87	84.5
Hydrogenated margarine is gluten-free	8	7.8	95	92.2
Soy sauces, soymilk, soy flour, soy protein are gluten-free	8	7.8	95	92.2
Ketchup (tomato sauce) is gluten-free	8	7.8	95	92.2
Spices are gluten-free	29	28.2	74	71.8
Mayonnaise is gluten-free	4	3.9	99	96.1
Chocolate is gluten-free	20	19.4	83	80.6
Cinnamon is gluten-free	0	0	103	100
Spicy and flavored nuts are gluten-free	4	3.9	99	96.1
Fresh meat, fish, and eggs are gluten-free*	62	60.2	41	39.8
Dairy or milk products are gluten-free*	62	60.2	41	39.8
Fresh fruits and vegetables are gluten-free*	58	56.3	45	43.7
Legumes are gluten-free*	36	35.0	67	65
Food coloring is gluten-free	32	31.1	71	68.9
Fruit juices are gluten-free	40	38.3	65	61.1
A takeaway white coffee and tea are gluten-free	16	15.5	87	84.5
Storing gluten-free and gluten-containing foods separately*	16	15.5	87	84.5
Cleaning surfaces after preparing foods containing gluten*	8	7.8	95	92.2
Clean oil should be used when deep frying. *	0	0	103	100
Use separate water in a clean pot for cooking gluten-free foods*	4	3.9	99	96.1
Checking medications for containing gluten is necessary. *	20	19.4	83	80.6

*Correct answers

Figure (II) Total knowledge scores of studied children about Gluten free-diet**Table (V) Correlation between GFD Knowledge, Adherence, and Health-Related Quality of Life of The Studied Children with Celiac Disease (n=10*)**

	Total GFD Knowledge	Adherence to GFD	Health-Related Quality of Life
Total GFD Knowledge			
Adherence to GFD	r. 0.498 p. 0.007**		
Health-Related Quality of life	r. 0.399 p. 0.008**	r. 0.560 p. 0.000**	

** Highly statistically significant differences

Table (VI) Relation between Characteristics of The Studied Children with Celiac Disease and their Health-Related Quality of Life

Items	Health-Related Quality of Life	
	Mean± SD	Test p. value
Age: <ul style="list-style-type: none"> • 8 -<12 • 12 – 18 	22.5± 5.9 29.2± 7.3	t test 4.013 0.012*
Gender: <ul style="list-style-type: none"> • Male • Female 	26.5± 3.1 27.1± 4.6	ANOVA test 0.976 0.081
Education level of father: <ul style="list-style-type: none"> •Primary •Preparatory •Secondary •University 	25.5± 3.6 24.8± 3.8 26.3± 3.7 27.2± 4.1	ANOVA test 1.200 0.064
Education level of mother: <ul style="list-style-type: none"> •Primary •Preparatory •Secondary •University 	24.8± 4.0 25.1± 5.7 27.2± 4.6 26.3± 3.8	ANOVA test 1.142 0.071
Age at diagnosis: <ul style="list-style-type: none"> • < 2 years • 2 – 6 • 7 – 11 • 12 – 16 • 16 – 18 	21.4± 3.2 26.8± 5.0 28.7± 4.7 29.4± 3.9 30.7± 5.6	t test 4.001 0.014*
Duration of disease: <ul style="list-style-type: none"> • 1 – 4 • 5 – 8 • 9 – 12 	24.7 ± 2.9 26.5± 4.4 29.03± 3.9	t test 3.980 0.023*
Still experience any symptoms <ul style="list-style-type: none"> • Yes • No 	21.6± 4.7 30.7± 5.1	ANOVA test 8.241 0.004**
Associated diseases <ul style="list-style-type: none"> • Yes • No 	23.6 ± 4.0 31.2± 6.1	ANOVA test 7.650 0.005**

**** Highly statistically significant differences**

Table (VII): Relation between Characteristics of The Studied Children with Celiac Disease and their Adherence to GFD.

Items	Gluten free-diet adherence						Chi-square p. value
	Excellent N=19		Fair N=28		Low N=56		
	No	%	No	%	No	%	
Age:							
• 8 -<12	4	21.1	15	53.6	48	85.7	9.002
• 12 – 18	15	78.9	13	46.4	8	14.3	0.000**
Gender:							
• Male	10	52.6	16	57.1	30	53.6	1.005
• Female	9	47.4	12	42.9	26	46.4	0.078
Father’s educational level							
•Primary	0	0	0	0	4	7.1	6.774
•Preparatory	0	0	0	0	6	10.7	0.006**
•Secondary	7	36.8	8	28.6	15	26.8	
•University	12	63.2	20	71.4	31	55.4	
Mother’s educational level							
•Primary	0	0	0	0	2	3.5	7.666
•Preparatory	0	0	0	0	3	5.4	0.004**
•Secondary	6	31.6	7	25.0	24	42.9	
•University	13	68.4	21	75.0	27	48.2	
Age at diagnosis:							
• < 2 years	1	5.3	2	7.1	3	5.4	1.576
• 2 – 6	6	31.6	9	32.1	24	42.9	0.054
• 7 – 11	8	42.1	12	42.9	20	35.7	
• 12 – 16	3	15.8	4	14.3	6	10.7	
• 16 – 18	1	5.3	1	3.6	3	5.4	
Duration of disease:							
• 1 – 4	2	10.5	13	46.4	53	94.6	4.006
• 5 – 8	8	42.1	12	42.9	3	5.4	0.011*
• 9 – 12	9	47.4	3	10.7	0	0	
Still experience any symptoms							
• Yes	5	26.3	8	28.6	43	76.8	8.001
• No	14	73.7	20	71.4	13	23.2	0.002**
Associated diseases							
• Yes	3	15.8	15	53.6	54	96.4	9.775
• No	16	84.2	13	46.4	2	3.6	0.000**

** *Highly statistically significant differences*

Table (VIII): Relation between Characteristics of The Studied Children with Celiac Disease and their Total Knowledge.

Items	Total knowledge						Chi-square p. value
	Good 16		Fair 20		Poor 67		
	No	%	No	%	No	%	
Age: <ul style="list-style-type: none">8 -<1212 – 18	4 12	25.0 75.0	6 14	30.0 70.0	57 10	85.1 14.9	7.902 0.004**
Gender: <ul style="list-style-type: none">MaleFemale	8 8	50.0 50.0	11 9	55.0 45.0	37 30	55.2 44.8	0.995 0.140
Father’s educational level <ul style="list-style-type: none">PrimaryPreparatorySecondaryUniversity	0 1 5 10	0 6.25 31.25 62.5	1 0 4 15	5.0 0 20.0 75.0	3 5 21 38	4.5 7.5 31.3 56.7	6.908 0.007**
Mother’s educational level: <ul style="list-style-type: none">PrimaryPreparatorySecondaryUniversity	0 0 4 12	0 0 25.0 75.0	0 0 3 17	0 0 15.0 85.0	2 3 30 32	3.0 4.5 44.8 47.7	6.113 0.008**
Age at diagnosis: <ul style="list-style-type: none">< 2 years2 – 67 – 1112 – 1616 – 18	0 7 6 2 1	0 43.8 37.5 12.5 6.2	1 7 7 3 2	5.0 35.0 35.0 15.0 10.0	5 25 27 8 2	7.5 37.3 40.3 11.9 3.0	1.080 0.067
Duration of disease: <ul style="list-style-type: none">1 – 45 – 89 – 12	3 5 8	18.8 31.2 50.0	6 10 4	30.0 50.0 20.0	59 8 0	88.1 11.9 0	3.665 0.021*
Still, experience any symptoms <ul style="list-style-type: none">YesNo	7 9	43.8 56.2	12 8	60.0 40.0	37 30	55.2 44.8	0.882 0.337
Associated disease: <ul style="list-style-type: none">YesNo	11 5	68.8 31.2	13 7	65.0 35.0	48 19	71.6 28.4	2.001 0.058

** *Highly statistically significant differences*

Discussion

Celiac disease is an autoimmune condition that necessitates a lifelong adherence to a gluten-

free diet (GFD). Evaluating adherence to this diet is crucial for effectively managing the disease. So, assessing the adherence to GFD of children with

celiac disease was the aim of conducting the present study. It was found that more than half of the studied children had low adherence and more than one quarter had fair adherence, while only less than one-fifth were excellent adherent to GFD, suggesting that the majority of the studied children showed problems with adherence to GFD.

On the contrary, other studies reported higher percentages of excellent or high adherence and lower percentages of poor or low adherence to GFD among children with celiac disease (Halmos et al., 2018; Pedoto et al., 2020; Monzani et al., 2023). Poor adherence to GFD that was found among the majority of the children in the current study may be attributed to a lack of parents' knowledge and awareness as well as consumption of hidden gluten sources. The limited availability of gluten-free products and their high cost were other reported causes of poor adherence to GFD in Egypt (Shehab et al., 2017).

The observed contradiction between the findings of the present study and other studies may be due to familial, social, and cultural differences and the use of different assessment tools. Evidence suggests the use of a multidisciplinary approach in assessing adherence to a GFD in children because relying solely on questionnaires to assess adherence may be influenced by bias (Monzani et al., 2023).

Statistically significant relationships were found between adherence to GFD and the child's age, educational level of the father, educational

level of the mother, duration of the disease, presence of celiac disease symptoms, and the presence of other associated diseases. Mager et al. (2018) supported these findings and reported that GFD adherence was related to the age of the child and the presence of gastrointestinal symptoms. Also, these results are in harmony with Chauhan et al. (2010) and Taghdir et al. (2016) who found that parents' educational level significantly impacts adherence. Moreover, Pedoto et al. (2020) noted an inverse relationship between the degree of adherence and the average duration of follow-up.

On the other hand, no significant relationships were found between adherence to GFD and gender or age at diagnosis. The same results were reported by both Al Nofaie et al. (2020) and Pedoto et al. (2020), as age at disease diagnosis and gender did not significantly affect adherence to GFD.

The reasons for diet failure among children with celiac disease are diverse and vary across different growth stages, so evaluating diet adherence is very challenging (Sbravati et al., 2020). Evidence classifies these factors into eight groups as follows; GFD-specific factors, GF product factors, psychological and sociodemographic factors, celiac-related factors, symptoms-related factors, quality of life, and other factors (Xhakollari et al., 2019; Guennouni et al., 2021).

Although some factors, like age or family type, are unchangeable, other factors could be

modified, such as parental and patients' knowledge about CD, which can significantly impact adherence to GFD (**Macedo-Campos et al., 2021**). The results of the current study revealed that about two-thirds of the studied children had poor knowledge, and slightly less than one-sixth of them had good knowledge about GFD. The total score of GFD knowledge was positively correlated with the studied children's adherence to GFD.

In the same line with these findings, **Pohoreski et al. (2023)** found that nearly two-thirds of the studied children had insufficient knowledge about GFD. However, a better knowledge level was reported by **Roma et al. (2010)** where slightly more than two-fifths of the studied sample had sufficient knowledge about disease and GFD.

In analyzing the studied children's responses to the GFD Knowledge Quiz, it was found that slightly more than half of them could identify the symbol of a food label, which indicates that the product is gluten-free. Slightly less than one-third could correctly answer that pasta is not gluten-free. Nearly two-fifths correctly answered that wheat-free" is not the same as gluten-free, and more than two-fifths could correctly identify that Oatmeal is gluten-free. About two-thirds of the studied children could correctly identify that fresh meat, fish, eggs, and dairy products are gluten-free.

In the same context, more than three-quarters of the studied children incorrectly

answered that malt vinegar is not gluten-free, and the vast majority incorrectly stated that hydrogenated margarine, soy sauces, and Ketchup are not gluten-free. **Pohoreski et al. (2023)** reported similar results regarding both correct and incorrect answers to the gluten-free diet quiz (GFD-Q). Also, **Silvester et al. (2016)** found that nearly one-quarter of respondents were able to correctly identify gluten-containing foods.

This contrasts with the results of a study of members of the Canadian Celiac Association in which the majority of respondents could correctly determine at least six of seven food items not allowed in a GFD (**Zarkadas et al., 2013**). Also, these findings don't resonate with **Silvester et al. (2016)** who found that nearly all respondents could determine that wheat is a forbidden grain, many foods contain hidden gluten, and most of them could correctly identify that wheat-free does not mean gluten-free.

As regards the studied children's knowledge about cross-contamination, the study results revealed that the majority couldn't correctly answer questions about storing gluten-free and gluten-containing foods separately, cleaning surfaces after preparing foods containing gluten, using separate water in a clean pot for cooking gluten-free pasta, and using clean oil after deep frying.

Monzani et al. (2023) noted that cross-contamination can be problematic for patients with celiac disease (CD), as even tiny amounts of gluten can provoke an immune response and

cause symptoms. People with CD need to be aware of potential contamination sources, such as shared cooking utensils, contact with gluten-containing foods, and non-food items that may contain gluten. So the studied children need continuous education about GFD, GF products, and cross-contamination.

The results of the present study revealed that three-fifths of the studied children aged 8-12 had a low total HRQoL score, which was reported across negative emotions, school functioning, and enjoyment. In addition, nearly half of the studied children aged 13-18 had a low total HRQoL score reported regarding social functioning, uncertainty, isolation, and limitations. The observed diminished HRQoL in all items of CDPQoL reveals the negative impact of celiac disease and its restrictive nature (GFD) on the HRQoL of celiac children (**Biagetti et al., 2015; Burger et al., 2017**).

These findings go in line with the results of previous studies where low scores of QoL were reported among celiac children and adolescents who follow GFD and those who do not adhere to GFD (**Hopman et al., 2009; Taghdir et al., 2016; Cadenhead et al., 2019; Guennouni et al., 2022**). On the contrary, a meta-analysis of 6 studies from different countries reported a neutral HRQoL experience of children with CD and their parents. Despite this, low scores were found in the "having CD" and "diet" domains. This indicates that children with celiac disease, regardless of their nationality, tend to worry about similar aspects of their condition. Their primary concern

is maintaining a gluten-free diet, which makes them feel different from their peers (**Nikniaz et al., 2020**).

Different findings were reported by other studies where good to very good perceptions of HRQoL were reported by the studied children and adolescents with celiac disease (**Jordan et al., 2013; Crocco et al., 2024; Jarweh et al., 2024**). Different healthcare systems, availability of gluten-free products, variable levels of disease awareness, and diverse social, and familial factors as well as different ethnic origins of the studies' population, may play a role in the discrepancy in these reported results.

Statistically significant relationships were found between the health-related quality of life of the studied children and experiencing symptoms of celiac disease, having associated diseases, child age, age at diagnosis, and duration of disease. **Jarweh et al. (2024)** agreed with the results of the present study and stated that the HRQoL of the studied patients was significantly affected by the presence of celiac disease symptoms. Also, **Högberg et al. (2003)** and **Stojanović-Jovanović et al. (2019)** supported the present findings and reported significant differences in HRQoL scores with disease duration.

In agreement with the findings of the current study, the age of the child and the age at disease diagnosis were reported as significant factors affecting HRQoL scores in celiac pediatric patients (**Byström et al., 2012; Jarweh et al., 2024**). However, contradictory results were found

by **Crocco et al. (2024)** who stated that the health-related quality of life in celiac children and adolescents was not significantly affected by disease duration. Also, **Jarweh et al. (2024)** denied the effect of the presence of other diseases and disease duration on celiac children's HRQoL.

The results of the present study revealed a significant positive correlation between adherence to GFD and health-related quality of life in celiac children. A plethora of literature supports these findings, as better adherence to GFD is associated with better or improved but not normal HRQoL (**Pico et al., 2012; Biagetti et al., 2015; Casellas et al., 2015; Barrio et al., 2016; Taghdir et al., 2016; Burger et al., 2017; Al Nofaie et al., 2020; Dimidi et al., 2021**). In addition, poor adherence to GFD negatively affects the health-related quality of life of celiac children (**Mager et al., 2018**). On the contrary, other studies conducted on adolescents who strictly adhered to GFD revealed significantly lower overall QOL scores (**Wolf et al., 2017; Wolf et al., 2018**).

The current study addresses a significant positive correlation between total GFD knowledge and adherence to GFD. Many studies report the same findings; having good knowledge about celiac disease and GFD is significantly associated with better adherence (**Roma et al., 2010; Wolf et al., 2017; Halmos et al., 2018; Paganizza et al., 2019; Abu-Janb & Jaana, 2020; Nikniaz et al., 2020**). **Jamieson & Gougeon (2019)** discovered that individuals who intentionally consumed gluten more frequently

tended to have fewer correct answers on a food label quiz.

This indicates the need to provide celiac children and their families with suitable education about CD and GFD. As, nutritional counseling, knowledge of gluten-free foods, and the ability to understand food labels are important factors that influence adherence to a gluten-free diet (**Muhammad et al., 2019**).

Conclusion

Children with celiac disease (CD) had poor knowledge about the gluten-free diet (GFD) and poorly adhered to it. This poor adherence significantly impacted their health-related quality of life, resulting in lower overall well-being. These findings suggest that children with CD not only need more education about the importance and implementation of a GFD but also require better support to follow it consistently to improve their quality of life.

Recommendations

- Continuous evaluation of children's adherence to GFD and discussion of children's beliefs and concerns about dietary regimens should be done at each visit to the clinic.
- Tailored multifaceted interventions designed to meet the needs of children with celiac disease would help manage adherence.

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