



Quality of Life and Psychological Problems in Children with and without Celiac Disease

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Abstract

Background: Celiac disease (CD) triggers an autoimmune response in the body involving the immune system.

Objectives: This study was designed to evaluate and compare the quality of life (QOL) in children with CD and those without CD. Additionally, the study aimed to contrast the self-reported QOL of children with CD with the assessments made by their parents.

Methods: In this cross-sectional, case-control study, the QOL of children with CD, aged 6-12 years, was compared with that of age- and gender-matched children without CD. Additionally, the study involved a comparison of the QOL assessments reported by both parents and children. The Quality-of-Life Questionnaire (Kid-KINDL) was used to appraise QOL from the perspectives of both children and their parents. Specifically, the parents completed the Pediatric Symptom Checklist (PSC).

Results: The present results indicated significant differences between children with and without CD in terms of QOL, psychological problems, attention, internalizing symptoms, and externalizing symptoms (as reported by the parents), as well as school performance, self-esteem, and emotional well-being (as reported by children) ($P < 0.05$). Furthermore, significant differences were observed in the QOL and self-esteem reports between children with CD and their parents ($P < 0.05$).

Conclusions: This study offered valuable insights into the QOL, psychological disorders, and related factors in children with and without CD. Additionally, it underscored the tendency of parents with children suffering from CD to underestimate their children's QOL.

Keywords: Celiac Disease, Quality of Life, Child, Parents

1. Background

Celiac disease (CD) is a chronic autoimmune disorder that impacts the entire body. The condition is triggered by the ingestion of gluten, a protein present in a variety of foods, such as wheat, rye, and barley. According to blood tests, the global prevalence of CD is estimated to be 1.4% (1). In Iran, the prevalence of biopsy-proven silent CD is approximately 0.6% in children (2). The clinical symptoms of CD vary significantly. In typical or classic cases, patients often experience gastrointestinal manifestations

as the primary symptoms, including chronic diarrhea, abdominal distension, and failure to thrive (3).

Additionally, CD is a major predisposing factor for developing an array of common neuropsychiatric diseases, such as depression, anxiety, and panic disorder (4). Individuals with chronic conditions, including CD, may experience a reduced quality of life (QOL) due to the constraints of adhering to a gluten-free diet (5). Generally, adopting and adhering to this diet can be a challenge due to the significant alterations required in a person's dietary habits and lifestyle (6). The assessment of QOL is typically

carried out using a questionnaire. This evaluation can be either generic, examining various facets of an individual's health, or specific, concentrating on distinct instances of a disease (6).

In previous studies, several questionnaires have been developed and presented to assess the QOL of children and adolescents with CD (7-9). Children with CD who adhere to a gluten-free diet may be susceptible to certain psychiatric disorders, including anxiety, depression, feelings of isolation, headaches, and attention-deficit/hyperactivity disorder (ADHD) (5, 10, 11). A study conducted by Simsek et al. (12) on 25 children with CD and 25 healthy children indicated that CD negatively affected their QOL.

In a study by Sevinc et al. (13) involving 52 children with CD and 40 healthy children, CD was associated with psychiatric diagnoses and reduced QOL. In another study by Mazzone et al. (14) on 100 healthy children and 100 children with CD, the results indicated increased anxiety and depression among individuals with CD. The increasing incidence of emotional and behavioral problems in children and adolescents with CD underscores the importance of early detection and diagnosis of mental health problems in this demographic. On the other hand, in a study conducted on 1,602 children with CD in Spain, children and their parents did not report the negative effects of the disease on their lives (15).

Considering the unique socio-cultural environment of Iran, including the Iranian diet, which is distinct from European and American diets, besides the limitations of previous studies on children with CD in Iran, we aimed to provide a comprehensive description and comparison of the psychological problems and QOL of children with and without CD by examining the experiences of both children and their parents.

2. Objectives

This study was designed to evaluate and compare the quality of life in children with CD and those without CD. Additionally, the study aimed to contrast the self-reported QOL of children with CD with the assessments made by their parents.

3. Methods

3.1. Participants

This descriptive, cross-sectional, case-control study was carried out at the gastroenterology clinic of Hazrat Ali Asghar Hospital in Zahedan, Iran, during 2021 - 2022. The study was approved by the Research Ethics Committee of Zahedan University of Medical

Sciences (IR.ZAUMS.REC.1397.327). According to the ethical requirements, all parents signed the informed consent forms for participation in the study before their recruitment. Individuals eligible for the study met the following criteria: A diagnosis of CD made at least in the last three months, the child's age range of 6 - 12 years, and the willingness of both children and their families to actively participate in the research. On the other hand, individuals with intellectual disability or any other medical condition that could impede their ability to complete the questionnaire were excluded from the study.

All children in the control group were tested for transglutaminase-immunoglobulin A (TTG-IgA) and total IgA. Children with CD typically undergo serological testing to detect specific antibodies associated with the condition. The diagnosis is further confirmed through a biopsy of the small intestine. A specialist (corresponding author) ruled out psychiatric and medical disorders in both groups, using the Structured Clinical Interview for DSM-5-Research Version (SCID-5-RV) and medical interviews. The children in the CD group were matched with children without CD based on age and gender to ensure a fair comparison of differences.

Children aged ≥ 7 years and their parents independently completed the Quality-of-Life Questionnaire (Kid-KINDL) under the supervision of one of the authors. The children aged six years completed the Kid-KINDL questionnaire after the researcher had read and explained the questions to them. Additionally, the parents of children with and without CD completed the Kid-KINDL questionnaire, as well as the Pediatric Symptom Checklist (PSC). The QOL of children with CD was assessed by the corresponding author after collecting the questionnaires and conducting the face-to-face interviews.

A total of 105 children diagnosed with CD were purposefully selected from the gastroenterology clinic of Hazrat Ali Asghar Hospital in Zahedan, Iran. The participants in the study chose to take part of their own accord. A sample size of 200 was established using a free statistical calculator based on an anticipated effect size of 0.2, a desired statistical power of 0.8, and a confidence level of 0.95 (16, 17).

3.2. Measurements

3.2.1. Structured Clinical Interview for DSM-5-Research Version

This scale serves as a guide for conducting semi-structured interviews pertaining to the major diagnoses outlined in the DSM-5. The process is undertaken by a proficient clinician or healthcare professional with a thorough understanding of the disorder classification and diagnostic criteria stipulated

in the DSM-5 (18). The SCID-5-RV is typically conducted in a single session lasting between 45 and 90 minutes (19). The research version contains more disorders than the clinician version (20). Several studies have shown that SCID-5-RV has acceptable reliability and validity (18). The Persian version of SCID-5-RV has shown acceptable kappa reliability (0.57-0.72), internal consistency (0.95-0.99), and test-retest reliability (0.60-0.79) (21).

3.2.2. Pediatric Symptom Checklist

This scale was developed by Gardner in 1999 as a comprehensive tool to evaluate the psychosocial functioning of children aged 6-12 years. This checklist, which is administered to parents, comprises 35 items. Responses are rated on a scale ranging from 0 ('never') to 2 ('often') (22). Previous research has reported a cutoff score of 28 in general pediatric populations (23). The PSC encompasses three distinct subscales: Externalizing, internalizing, and attention (24). The results of reliability analysis revealed strong test-retest reliability, with a Pearson's correlation coefficient of 0.86 and high internal consistency, as indicated by Cronbach's alpha coefficient of 0.86 (25).

3.2.3. Quality of Life Questionnaire (Kid-KINDL)

This questionnaire was revised in 1998 by Ravens-Sieberer and Bullinger to determine the general QOL of children with chronic diseases, including CD (26). It comprises six domains: Physical well-being, emotional well-being, self-esteem, family, friends, and school. Each domain consists of four items, culminating in a total of 24 items. Responses to each item are rated on a five-point Likert scale, with options including 'never', 'rarely', 'sometimes', 'often', and 'always'. Finally, the scores are converted into a range of 0 - 100. In a study by Valizadeh et al., the Cronbach's alpha coefficient was estimated to be 0.8 for the total scale and approximately 0.7 for the dimensions (27).

3.3. Data Analysis

Data analyses were conducted using SPSS Version 23. First, the demographic characteristics of the participants were analyzed based on frequency, mean, and standard deviation (SD). Second, differences in physical well-being, emotional well-being, family, friends, school, self-esteem, QOL, psychological problems (PP), attention, internalizing symptoms, and externalizing symptoms were examined between the two groups, using independent samples *t*-test.

4. Results

This study was performed on 105 children with CD and their parents, as well as 105 children without CD and their parents. The mean age of children with and without CD was 9.97 (SD = 1.03) and 9.66 (SD = 1.20) years, respectively. The descriptive statistics related to the research variables (age, sex, child's education level, and family type) are presented in Table 1.

Table 1. The Demographic Characteristics of Participants ^a

Variable	Non-celiac	Celiac
Age, y	9.66 ± 1.20	9.97 ± 1.03
Gender		
Girl	69 (65.7)	71 (67.6)
Boy	36 (34.3)	34 (32.4)
Child education		
Literate	1 (1)	0
Elementary school	68 (64.8)	79 (75.2)
Middle school	20 (19)	17 (16.2)
High school	16 (15.3)	9 (8.7)
Family type		
Nuclear family	92 (87.6)	79 (75.2)
Extended family	13 (12.4)	26 (24.8)

^a Values are presented as No. (%) or mean ± SD.

According to Table 2, the skewness for all research variables (physical well-being, emotional well-being, family, friends, school, QOL, and self-esteem) was between -3 and +3, and kurtosis was between -10 and +10. Therefore, the normal distribution of the data was confirmed.

Table 3 demonstrates the results of the independent samples *t*-test, which indicated no significant difference in terms of physical and emotional well-being, family, friends, and school dimensions between the parents' QOL reports and the children's QOL reports in the group of children with CD. The parents' QOL report (M = 78.08, SD = 8.15) scored significantly higher than that of the children's QOL report (M = 78.00, SD = 9.64, $t(208) = 0.06$, $P < 0.05$, two-tailed) in the group of children with CD. The children's QOL reports (M = 14.04, SD = 3.39) scored significantly higher on the self-esteem dimension compared to the parents' QOL reports (M = 13.58, SD = 2.85, $t(208) = -1.07$, $P < 0.05$, two-tailed) in the group of children with CD.

According to the parents' reports, there was no significant difference in terms of QOL, physical well-being, emotional well-being, self-esteem, family, and friends between the two groups of children with and without CD. Children without CD (M = 15.65, SD = 2.20) scored much

Table 2. Skewness and Kurtosis of All Research Variables

	Skewness				Kurtosis			
	Celiac		Non-celiac		Celiac		Non-celiac	
	Child Report	Parent Report	Child Report	Parent Report	Child Report	Parent Report	Child Report	Parent Report
Emotional well-being	0.15	-0.11	-0.94	-0.49	-0.62	-0.32	1.36	0.11
Self-esteem	-0.26	-0.22	-0.84	-0.66	-0.63	0.74	0.89	0.52
Family	-0.20	0.18	-0.25	-0.22	-0.11	-0.09	0.67	0.27
Friends	-0.43	-0.66	-0.89	-0.72	-0.14	0.87	2.51	1.25
School	-0.26	-0.31	-0.11	0.01	0.13	0.19	0.18	-1.17
Physical well-being	0.29	-0.20	-1.01	-1.42	-0.44	-0.28	0.80	3.04
Quality of life	0.17	-0.07	-0.94	-0.72	0.00	0.05	2.13	1.89

Table 3. Comparison of Mean Scores of All Outcome Measures

	Mean Difference	Standard Difference	df	t	ρ	F
Quality of life total score	0.07	1.23	208	0.06	0.05 ^a	3.77
Emotional well-being	0.59	0.40	208	1.44	0.35	0.86
Self-esteem	-0.46	0.43	208	-1.07	0.02 ^a	4.96
Family	0.14	0.29	208	0.48	0.81	0.05
Friends	-0.49	0.31	208	-1.55	0.89	0.01
School	-1.05	0.43	208	-2.45	0.93	0.00
Physical well-being	1.36	0.42	418	3.20	0.33	0.94

^a Significant ($P < 0.05$).

higher on the school dimension compared to children with CD ($M = 12.59$, $SD = 3.20$, $t(208) = -8.07$, $P < 0.05$, two-tailed). Moreover, children with CD ($M = 68.85$, $SD = 11.86$) obtained much higher total scores of PP compared to children without CD ($M = 48.59$, $SD = 9.53$, $t(208) = 13.64$, $P < 0.05$, two-tailed). Also, children with CD ($M = 10.40$, $SD = 2.47$) obtained much higher scores on the attention dimension compared to children without CD ($M = 7.36$, $SD = 2.17$, $t(208) = 9.49$, $P < 0.05$, two-tailed). The results showed that children with CD ($M = 10.26$, $SD = 2.31$) scored much higher on the dimension of internalizing symptoms compared to children without CD ($M = 6.95$, $SD = 1.91$, $t(208) = 11.31$, $P < 0.05$, two-tailed). Also, children with CD ($M = 8.21$, $SD = 1.87$) scored much higher on the dimension of externalizing symptoms compared to children without CD ($M = 5.61$, $SD = 1.40$, $t(208) = 11.39$, $P < 0.05$, two-tailed). The findings are presented in [Table 4](#).

According to the children's QOL reports, there was no significant difference regarding QOL, physical well-being, family, and friends between the two groups of children with and without CD. Children without CD ($M = 15.04$, $SD = 2.45$) scored much higher on the school dimension

compared to children with CD ($M = 13.64$, $SD = 3.02$, $t(208) = -3.68$, $P < 0.05$, two-tailed). Also, children without CD ($M = 16.89$, $SD = 2.65$) scored much higher on the self-esteem dimension in comparison to children with CD ($M = 14.04$, $SD = 3.39$, $t(208) = -6.77$, $P < 0.05$, two-tailed). Furthermore, children without CD ($M = 15.28$, $SD = 2.27$) scored much higher on the emotional well-being dimension as compared to children with CD ($M = 11.70$, $SD = 3.05$, $t(208) = -9.63$, $P < 0.05$, two-tailed). These findings are presented in [Table 5](#).

5. Discussion

An evaluation of QOL is essential for a comprehensive understanding of health and illness processes. The findings of this study indicated significant differences regarding the dimensions of QOL, PP, attention, internalizing symptoms, and externalizing symptoms (as reported by the parents), as well as school performance, self-esteem, and emotional well-being (as reported by children) between children with and without CD. Moreover, a discrepancy was observed in the reports

Table 4. Comparison of Mean Scores of All Outcome Measures

	Mean Difference	Standard Difference	df	t	ρ	F
Total score of quality of life	-16.35	1.27	208	-12.84	0.20	1.63
Emotional well-being	-3.00	0.36	208	-8.14	0.06	3.53
Self-esteem	-2.93	0.37	208	-7.83	0.21	1.53
Family	-2.53	0.30	208	-8.27	0.32	0.95
Friends	-2.37	0.31	208	-7.64	0.20	1.16
School	-3.06	0.37	208	-8.07	0.00 ^a	11.31
Physical well-being	-2.44	0.39	208	-6.15	0.09	2.87
Total score of PSC	20.26	1.48	208	13.64	0.00 ^a	1.99
Attention	3.04	0.32	208	9.49	0.00 ^a	1.22
Internalizing	3.31	0.29	208	11.31	0.00 ^a	2.58
Externalizing	2.60	0.22	208	11.39	0.00 ^a	10.05

^a Significant ($P < 0.05$).

Table 5. Comparison of Mean Scores of All Outcome Measures

	Mean Difference	Standard Difference	df	t	ρ	F
Quality of life	-16.87	1.32	208	-12.76	0.17	1.87
Emotional well-being	-3.58	0.37	208	-9.63	0.00 ^a	12.72
Self-esteem	-2.84	0.42	208	-6.77	0.00 ^a	9.17
Family	-3.02	0.30	208	-9.93	0.96	0.00
Friends	-2.50	0.31	208	-7.96	0.40	0.71
School	-1.40	0.38	208	-3.68	0.00 ^a	7.19
Physical well-being	-3.51	0.42	208	-8.21	0.22	1.51

^a Significant ($P < 0.05$).

of QOL and self-esteem between children with CD and their parents. Specifically, the parents reported higher QOL scores for their children with CD. This implies that some factors influencing the children's QOL may have been underestimated by the parents. These findings are consistent with those of previous studies (28, 29). Overall, the observed differences in evaluations by children and their parents underscore the significance of considering the children's viewpoints on their QOL.

The comparable levels of QOL observed in children with and without CD align with the results of previous research (30). In this regard, Wagner employed a generic instrument and found no significant difference in terms of QOL between healthy children and those with CD (31). In contrast, Hopman et al. utilized a questionnaire assessing social and clinical data and found that the QOL of children with CD was lower than that of the healthy group (32). This observation contradicts the reported similar levels of QOL, physical well-being, and family and friends subscales between children with CD and healthy children.

The findings of the present study diverge from those of a study conducted by Bystrom et al., which compared the assessments of QOL in children with CD as reported by both parents and children themselves. In the study by Bystrom et al. (28), the parents reported lower QOL scores than the children themselves. Moreover, according to a study by Eiser and Morse, the parents of chronically ill children are often better equipped to evaluate their child's health-related QOL than those of healthy children (33). These children often experience recurrent abdominal pain, which can adversely influence their attentional performance, particularly in complex situations (34, 35). This pain can potentially interfere with their concentration at school, resulting in academic difficulties. Furthermore, abdominal pain often leads to extended absences from school (36).

Due to the special dietary requirements of children with CD, they may suffer from maldigestion and malabsorption, leading to nutritional deficiencies (37). Previous studies have emphasized the significant role of

nutritional deficiencies in a child's learning abilities (38). Additionally, the special diet that these patients adhere to can lead to social limitations (39). As demonstrated by Lee and Robbins, there is a link between social connectedness and self-esteem, emphasizing the interrelation of these two factors (40). Therefore, it can be inferred that children with CD may have lower self-esteem due to diminished social connectedness. Moreover, adhering to a gluten-free diet can heighten concerns about body image, which can subsequently impact self-esteem (34, 41).

Children with CD often encounter mental health challenges, including higher rates of anxiety and depression compared to the general population (42). Consistently, our results indicated lower emotional well-being in children with CD. The restrictive diet in this population can evoke feelings of deprivation, depression, anger, and anxiety (43). Frustration and isolation are particularly significant negative emotions in this population (44). All children, both with and without CD, surpass a cutoff score of 28 on the PSC. Psychological impairment in children without CD is a matter of concern. Therefore, future studies should investigate children's mental health in Zahedan, Iran.

Previous studies have reported a significant relationship between CD and ADHD (45), which is consistent with our findings regarding the high score of attention impairment in children with CD. Furthermore, there is a connection between eating disorders and CD (46). A previous study showed that eating disorders are associated with internalizing symptoms (47). These results are consistent with our findings, as we observed a high level of internalizing impairment in children with CD (48).

5.1. Conclusions

This study offered valuable insights into QOL and its associated factors among children with and without CD. The results highlighted a discrepancy between the reports of parents and children, underlining the necessity of incorporating multiple viewpoints when evaluating the QOL of these children. According to the parents' reports, children with CD were perceived to have a better QOL compared to the children's reports. However, in the evaluation of self-esteem, children themselves reported higher levels of self-esteem. Moreover, the reports of both parents and children suggested that children without CD exhibited higher levels of school functioning compared to children with CD. According to the children's reports, children without CD had better emotional well-being and self-esteem compared to children with CD. Therefore, there is a pressing need to develop effective treatment plans that specifically address the emotional challenges in this particular population. By establishing effective

interventions and support systems, we can potentially enhance the emotional well-being of children with specific needs. Finally, it is strongly recommended to provide comprehensive education to the parents of these children. Also, equipping parents with the necessary knowledge and resources to understand and support their children is important for their overall well-being. Educational programs targeted at parents can also play a pivotal role in cultivating a supportive and inclusive environment for these children.

5.2. Limitations

There are some limitations in our study. In addition to exploring the differences between the scores of parents and children, it is crucial to consider potential factors that may influence the responses of both groups in self-report questionnaires. Factors such as the child's developmental stage and the presence of social desirability bias can significantly influence how children respond to questionnaires. To address this concern, future research should consider employing alternative assessment methods, such as interview instruments, or utilizing diverse measurement tools to enhance the reliability and validity of the findings. Furthermore, it is important to acknowledge that our study sample was confined to individuals residing in Zahedan, which carries certain limitations. This geographical restriction may hinder the generalizability of the results to a broader population. To overcome this shortcoming and increase the external validity of subsequent investigations, researchers should consider expanding the sample size and adopting cluster sampling techniques to recruit participants from diverse cities and towns across Iran.

Footnotes

Authors' Contribution: TSh drafted the manuscript; NB and JSY developed the study protocol and revised the manuscript; NB, JSY, SF, AM, MM, MSh, H.Sh, and TSh provided assistance in data collection and revised the manuscript. All authors read and approved the final manuscript.

Conflict of Interests: The authors declare no conflicts of interest, whether actual or potential, including any financial, personal, or other relationships with individuals or organizations that could inappropriately influence the submitted work outcomes.

Data Reproducibility: The dataset utilized in the study can be obtained upon request from the corresponding author during submission or following publication. The

data is not publicly accessible due to privacy and ethical considerations.

Ethical Approval: This study is approved under the ethical approval code of (IR.ZAUMS.REC.1397.327).

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Informed Consent: Written informed consent was obtained from all participants.

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