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# Quality of Life in Adult Celiac Disease in a Mountain Area of Northeast Italy

## ABSTRACT

The aim of this study was to evaluate the health-related quality of life in patients diagnosed as having celiac disease and to study the factors involved in its impairment of quality of life. We conducted a cross-sectional study in a randomized sample of patients with celiac disease by administering the Celiac Disease Questionnaire distributed by mail. The association between the quality of life and sociodemographic and clinical variables was verified by means of a stepwise multiple regression model. One hundred ninety-one questionnaires were returned (participation rate = 63.66%), and 187 were analyzed. Women comprised 78.61% of the participants, and the median age was 36 years, 10 months. The mean summary total score in the Celiac Disease Questionnaire was 154.53 (possible range 1-196; higher scores equate with higher quality of life), and the score was lower in the subscale of emotion. Women scored significantly lower than men. Participants with the symptomatic disease scored significantly lower than the nearly asymptomatic patients in the total score and in all the subscales. Symptomatic patients need interventions for improving their quality of life, in particular psychological support.

Celiac disease (CD), a gluten-sensitive enteropathy, is common in Europe, with prevalence between 1:200 and 1:500 in the general European population (Rewers, 2005). Chronic conditions modify perceived health in affected individuals. For this reason, Casellas, López Vivancos, and

Malagelada (2005) wrote that CD as a chronic condition may impair the patient's health-related quality of life (HRQOL).

## Literature Review

The quality of life (QoL) in celiac patients seems to be influenced by the presence of physical problems such as abdominal pain, diarrhea, fatigue, or weight loss (Cranney et al., 2007). Moreover, patients suffer from a high burden of general and extraintestinal symptoms that reduces the HRQOL (Häuser, Gold, Stein, Caspary, & Stallmach, 2006). Not surprisingly, therefore, atypical/silent CD patients have a significantly better baseline QoL than those with classic symptoms (Nachman et al., 2009). Furthermore, a gluten-free diet (GFD) impacts various lifestyle aspects of the QoL for individuals with CD.

In a study in the United States led by Lee and Newman (2003), participants described difficulties in dining out (86%) and traveling (82%) and reported an impact on their family (67%), with less of a negative impact on career or work (41%). In addition, disorders in sexual behavior (Ciacci et al., 1998), anxiety, and depression (Addolorato et al., 2001) can affect the

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QoL in patients with CD. In an Italian study, the presence of affective disorders seems to be related to difficulties in adjusting to the chronic nature of the disease rather than directly to the disease itself (Fera, Cascio, Angelini, Martini, & Guidetti, 2003).

The studies comparing CD patients with a QoL comparable to that of the general population show different findings; namely, the QoL of individuals with CD was comparable with the mean QoL of the healthy population in Canada (Cranney, Zarkadas, Graham, & Switzer, 2003). Conversely, in Sardinia (Italy), CD patients presented with a significantly lower HRQOL ( $p \leq .05$ ) than healthy controls (Usai, Manca, Cuomo, Lai, & Boi, 2007).

Furthermore, the association between sociodemographic factors and QoL in celiac patients has been debated in the literature. Roos, Kärner, and Hallert (2006) demonstrated in Sweden that women with CD showed a significantly lower score on a psychological general well-being index than men with CD (score of 97 and 95% CI [91, 103] vs. 111 and 95% CI [106, 117];  $p < .003$ ); however, another study in the same country did not confirm these data. Roos, Kärner, and Hallert (2009) found that women with CD living on a GFD showed a lower HRQOL and reported a higher rate of gastrointestinal (GI) symptoms than men with CD. In a study by Hallert et al. (2002), women with CD adhering to the treatment regimen for several years perceived the disease burden to be worse than men did.

Even though a number of studies on this topic have just been published, the HRQOL in celiac patients has not been tested, and many published studies used the generic 36-Item Short Form Health Survey (SF-36) questionnaire (e.g., in Italy; Usai et al., 2007). These generic questionnaires may not be adequately valid in the evaluation of QoL in patients with CD. As a new specific tool, the Celiac Disease Questionnaire (CDQ) was introduced (Häuser, Gold, et al., 2007).

The aim of this observational cross-sectional study was to (1) determine a measure of the QoL in celiac patients with a specific HRQOL instrument and (2) evaluate the sociodemographic factors associated with the QoL in these patients.

## Methods

### Sample and Ethical Issues

The province of Trento is a small mountain area in the northeast of Italy. A randomized sample of adult (18–65 years of age) patients diagnosed with CD who are members of the Italian Celiac Association, Trento's section, was used in this study. From a total of 468 eligible participants, we randomly selected 300 patients, using the software Statistical Package for the Social Sciences (SPSS), version 15.0.

### Procedure

Questionnaires were distributed by mail to the selected members by the Celiac Association. The envelope included the questionnaire and another self-addressed stamped envelope to return the completed instrument. Responses were collected between June and July 2009.

### Instruments

All participants included in the study also completed a sociodemographic questionnaire, which included standard demographic questions on gender, marital status, age, education, occupational status, and the duration of the disease after the diagnosis was made. A disease-specific questionnaire was used for the measurement of HRQOL: the CDQ developed and validated by Häuser, Gold, et al. (2007) for adult patients. The CDQ includes 28 items related to four subscales (emotion, social, worries, and GI) and evaluated on a 7-point Likert scale.

The total score and each subscale score were calculated with the sum of the score attributed to each item. A higher score indicates a higher QoL. The highest score possible was 196 points, with 49 points for each subscale. The English version of the CDQ was translated and adapted to the Italian language by a forward-backward translation by two professional bilingual translators (two nurses) and three Italian CD patients. The translated questionnaire was initially tested on a focus group of 10 patients with CD and subsequently modified to ensure the clarity of the questions.

We categorized the sample participants into two groups: (1) the “nearly asymptomatic” participants who responded with options “5” (“a little of the time”), “6” (“hardly any of the time”), “7” (“none of the time”) to items “1” (“How many times during the past two weeks was your life affected by a sudden urge to visit a bathroom for a bowel movement?”), “5” (“How often during the last two weeks have your bowel movements been loose?”), “8” (“How many times during the last two weeks have you been troubled by cramps in your abdomen?”), and “11” (“How many times during the last two weeks did you suffer from bloating or flatulence?”) of the CDQ; and (2) the “symptomatic” participants who responded with option 1 through 4 to at least one of items “1,” “5,” “8,” or “11.”

### Ethical Issues

The study was approved by the president and the executive committee of Trento province's session of the Italian Celiac Association. All subjects gave informed consent. Data protection requirements were observed throughout the study.

### Data Analysis

Data were entered into a computer database; double entry was used to ensure accuracy of the data. Data

were analyzed using STATA 8.2 (Stata Corp. LP, College Station, TX). The mean, standard deviation, and minimum and maximum values were used for a descriptive analysis of the data. For comparison of the means, the Wilcoxon-Mann-Whitney and Kruskal-Wallis nonparametric tests were used. Furthermore, stepwise multiple regression analyses were also used to investigate the relationship between sociodemographic factors and the QoL. In these analyses, gender, age, marital status, duration of disease, education, and occupational status were used as independent variables, and QoL scores were dependent variables. The significance level was set at  $p < .05$ .

## Results

There was a 63.66% response rate ( $n = 191$ ). Of the respondents, four individuals were excluded from analysis because they did not complete at least 75% of the questionnaire. A total of 187 CD participants took part in the study; 147 (78.60%) were women (female-to-male ratio, 3.7:1). The mean age of the participants was 35.4 years ( $SD = \pm 12.8$ ). The mean duration of the disease after the diagnosis was 10 years ( $SD = \pm 10.6$ ). Most participants were not single (67.60%), 75% had some postsecondary education, and 73% were employed. Table 1 shows the distribution of sociodemographic characteristics and clinical features by gender.

The CDQ was used to estimate the specific QoL. The average summary score was 154.5 points (range, 83–195;  $SD = \pm 26.5$ ); the mean score was 39.1 for “GI symptoms” (range, 15–49;  $SD = \pm 8.5$ ), 33.0 (range, 10–48;  $SD = \pm 9.5$ ) for “emotional problems,” 42.2 (range, 15–49;  $SD = \pm 7.0$ ) for “social problems,” and 40.2 (range, 12–49;  $SD = \pm 7.6$ ) for “worries.” Table 2 shows the bivariate analysis of the relationship between the QoL and some sociodemographic and clinical characteristics. The average CDQ was significantly greater in males than in females for the total score (CDQ = 168.7 [ $\pm 20.8$ ] vs. 150.9 [ $\pm 26.8$ ];  $p < .001$ ); furthermore, the average CDQ was significantly greater in “nearly asymptomatic” than “symptomatic” participants for the total score (CDQ = 173.8 [ $\pm 16.2$ ] vs. 139.8 [ $\pm 23.8$ ];  $p < .001$ ). The association between marital status and QoL approached but did not reach the level of significance, showing a lower QoL in married women. When the subscales were separately analyzed, the scores were always lower ( $p < .001$ ) in symptomatic participants (Table 3).

The results of the multivariate stepwise linear regression are shown in Table 4. The variables related to the QoL were symptomatic disease, gender, and age. Analyzing the single subscales, the emotion score was related to symptomatic disease and gender, the social score was related to symptomatic disease and occupational status, and the worries score was related to symptomatic disease.

## Discussion

This study was performed in a small province. A total of 187 CD patients took part in the research. The average total score for the CDQ was 154.5, which is comparable with the study by Hauser, Gold, Stallmach, Caspary, and Stein (2007), where the mean score was 151.1. Celiac patients in Trento province seem to have a good QoL, considering that the highest score possible on the CDQ is 196 points. We confirmed that the emotional subscore was affected as in the study by Usai et al. (2007); however, in that study, “social functioning” and “mental health” were also significantly affected, phenomena that we did not observe. A high HRQoL could also be influenced by the services that local health institutions guarantee to celiac patients. Because Trento province has a special statute, it is possible to have a monthly contribution for buying gluten-free products, which is greater than that in other part of Italy (in Trentino, adult patients receive 180 euros monthly instead the 140 euros, which is the maximum in other regions). This financial incentive means that the residents here have more possibilities to select more tasteful and preferred foods.

In this study, the average CDQ was significantly greater in males than in females, both for the total score and also for the subscales, in particular for the “emotion” subscale. Hallert et al. (1998) also showed that the low scoring of the CD patients in the SF-36, notably within the “general health” and “vitality” domains, was confined to the female patients who also reported significantly more GI symptoms in the GSRS than the male celiac patients.

Sverker, Ostlund, Hallert, and Hensing (2009) suggested that this result could be correlated to the fact that women and men reported having a different social position in relation to preparing food, making decisions about purchases, buying food products, and preparing meals. Ciacci (2006) suggested that women with CD have a worse perception of the burden of the disease than males with CD. The reasons for the difference may lay in the severe interference of a GFD with social life. We also speculate that women are still conditioned by the archaic need to provide food for themselves and their family; they may, therefore, feel the restriction in shopping for food, in cooking, and in feeding their children. An interpretation of this result was given in Sweden, using a phenomenographic approach, with an interview given to 10 CD patients. Women experienced more bowel symptoms than men, despite observing a strict diet. The women also described more distress caused by the restrictions in their daily life, which was closely related to their controlling of food content. The men with CD took advantage of using a problem-oriented coping approach, whereas the women, seeking an emotionally

**TABLE 1.** Sociodemographic and Clinical Characteristics of Study Sample

Variable	Male		Female		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Age (years)						
18–33	18	47.4	50	34.7	68	37.4
34–48	15	39.5	73	50.7	88	48.4
49–65	5	13.2	21	14.6	26	14.3
Marital status						
Single	17	43.6	31	21.2	48	26.0
Married/common-law husband/wife	20	51.3	105	71.9	125	67.6
Divorced/widowed	2	5.1	8	5.5	10	5.4
Other	0	0.0	2	1.4	2	1.1
Highest educational level						
Primary school	0	0.0	1	0.7	1	0.6
Secondary school	10	25.6	30	21.0	40	22.0
High school	23	59.0	74	51.6	97	53.3
University	6	15.4	34	23.8	40	22.0
Other	0	0.0	4	2.8	4	2.2
Occupational status						
Student	6	15.8	12	8.8	18	10.3
Without job/housewife	0	0.0	22	16.1	22	11.4
Self-employed person	9	23.7	18	13.1	27	15.4
Employee	21	55.3	80	58.4	101	57.7
Pensioner	2	5.3	5	3.7	7	4.0
Duration of disease (years)						
0–15	36	92.3	109	76.2	145	79.7
16–30	1	2.6	21	14.7	22	12.1
> 30	2	5.1	13	9.1	15	8.2
Symptoms						
Nearly asymptomatic	27	69.2	54	36.7	81	43.6
Symptomatic	12	30.8	93	63.3	105	56.5

oriented strategy, showed less satisfaction with the outcome. The authors concluded that the intriguing difference in the HRQOL between men and women with CD may have some of its origin in the way living with the disorder is conceptualized and coped with (Hallert, Sandlund, & Broqvist, 2003).

The same study (Hallert et al., 2003) also suggested that the relationship between QoL and other social characteristics does not influence QoL; gender was, in fact, the only variable that influenced the HRQOL scores. This result could be explained by considering that economic and social help offered by the National

**TABLE 2.** Quality of Life of Celiac Patients by Sociodemographic and Clinical Factors

Variable	Quality of Life, <i>M</i> ± <i>SD</i>	<i>p</i>
Gender		
Males	168.70 ± 20.8	< .001
Females	150.90 ± 26.8	
Age (years)		
18–33	158.90 ± 22.8	.360
34–48	152.39 ± 28.3	
49–65	148.39 ± 29.1	
Marital status		
Single	162.19 ± 21.1	.049
Married/common-law husband/wife	151.59 ± 28.1	
Divorced/widowed	160.50 ± 26.3	
Highest educational level		
Primary school/secondary school	151.40 ± 28.3	.668
High school	155.80 ± 26.5	
University	154.00 ± 21.1	
Occupational status		
Student	161.90 ± 22.7	.648
Without job/housewife	149.70 ± 27.7	
Self-employed person	151.50 ± 31.8	
Employee	153.80 ± 26.1	
Pensioner	154.70 ± 27.8	
Duration of disease (years)		
0–15	154.50 ± 25.5	.149
16–30	150.00 ± 28.2	
> 30	154.00 ± 28.4	
Symptoms		
Nearly asymptomatic	173.80 ± 16.2	< .001
Symptomatic	139.80 ± 23.8	

and Regional Health Service in Italy is distributed, to a similar degree, among patients and is not related to their economic or social situation. The duration of disease does not seem to influence QoL, but the symptomatic status is related to a worse QoL in all dimensions, as suggested by Cranney et al. (2007) and in Italy by Usai et al. (2002).

A multivariate linear regression showed that gender and age are variables related to QoL; in this sample, women have lower QoL and QoL decreased in older patients. Häuser, Stallmach, Caspary, and Stein (2007), using a multivariate approach with the SF-36, showed that a younger age at diagnosis was predictive of a mental summary score. In the same study, it was also described that a reduced physical summary score of the SF-36 was associated with physical comorbidities and mental disorders, aspects that this study did not evaluate.

### Limitations

The main limitation of this study is related to the small sample size because the study was performed in only one province. It should be noted, however, that the study population was made up of adult celiac patients recruited among the members of the Celiac Society. The consequent selection bias is obvious, even if in the province of Trento these participants represent more than 80% of patients with a confirmed diagnosis. It should be considered that it is not demonstrated that the views of those living in northeast Italy reflect all those around the world with CD. Another possible bias is related to the fact that there were more female than male responders, even if there are more females affected by CD.

Another limitation could be the use of the CDQ because only one other study that used this questionnaire (in Germany) is available; for this reason, the results are difficult to compare because, in many studies, such as in Johnston, Rodgers, and Watson (2004) in the United Kingdom or Usai et al. (2007) in Italy, QoL was measured using the simpler, generic SF36 questionnaire.

This study correlates the QoL of patients with a number of symptoms, which are relevant from a clinical standpoint; however, we did not use biological indicators because these were impossible to obtain for the purpose of the study. Another difficulty is comparing our data with the other published Italian studies because again, only generic questionnaires were used to measure the HRQOL (Usai et al., 2007), or other psychological problems, such as depression, were investigated (Ciacci et al., 2003; Fera et al., 2003).

### Conclusions

This study confirmed the results reported in a cross-sectional study among some members of the Italian Celiac Association who answered a mail questionnaire

**TABLE 3.** Domain of Quality of Life of Celiac Patients by Symptomatic Disease

Quality of Life	Nearly Asymptomatic, <i>M ± SD</i>	Symptomatic, <i>M ± SD</i>	<i>p</i>
Gastrointestinal (GI)	46.40 ± 3.2	33.90 ± 7.2	< .001
Emotion (E)	39.50 ± 7.1	27.90 ± 8.0	< .001
Social (S)	44.30 ± 6.1	40.40 ± 7.2	< .001
Worries (W)	43.70 ± 5.2	37.60 ± 68.0	< .001
Total score	173.80 ± 16.2	139.80 ± 23.8	< .001

that demonstrated that CD does not appear to be associated with a low level of a self-perceived QoL (Ciacci et al., 2003). The reduction in QoL, in particular in the “emotional” subscales, suggests that these patients need psychological support. This is an intervention that could be offered by nurses during diagnostic procedures and treatments in health institutions, but also at community level, in particular in collaboration with the Celiac Patient Society. The clinical implications of these findings are that healthcare professionals need to develop family-oriented information in relation to CD.

The difference in the QoL in men and women implies that in the management of CD patients, gender-related aspects need to be taken into account to improve treatment outcomes, using different approaches and interventions. Also, the status of the disease (“symptomatic” vs. “nearly asymptomatic”) should be taken into consideration because patients with physical manifestations of disease should receive greater support.

In conclusion, the CDQ is an easy-to-administer instrument for CD patients. It could be useful to extend the present study to the national level for comparison of

**TABLE 4.** Stepwise Regression Analysis Between Quality of Life and Sociodemographic and Clinical Characteristics of Study Sample

Quality of Life				
Variable	Regression Coefficient	95% Confidence Interval		<i>P</i>
		LL	UL	
Symptomatic	−33.0	−41.3	−24.6	< .001
Gender	−13.2	−24.1	−2.2	.018
Age	−0.5	−1.0	−0.0	.041
Emotion (E)				
Symptomatic	−11.0	−14.0	−8.0	< .001
Gender	−4.2	−0.8	−0.3	.036
Social (S)				
Symptomatic	−4.1	−6.8	−1.4	.003
Occupational status (housewife)	4.0	0.8	7.2	.013
Worries (W)				
Symptomatic	−6.6	−9.4	−3.7	< .001

*Note.* Independent variables = gender, age, marital status, duration of disease, education, occupational status, gastrointestinal symptoms. LL = lower level; UL = upper level.

these results in other Italian regions and to include biological indicators of the disease and psychological problems in the overall assessment. ✪

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