# Chapter 12

## Quality of Life and Psychological Distress in the Patient with CD

Claudia Herrera de Guise, Francesc Casellas

Digestive System Research Unit, Hospital Universitari Vall d'Hebron, Centro de Investigación Biomédica en Red de Enfermedades Hepáticas y Digestivas (Ciberehd), Barcelona, Spain.

cherreradeguise@gmail.com, fcasellas@vhebron.net

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## Abstract

Celiac disease (CD) is a chronic disorder that can impact patients in many ways including their health-related quality of life (HRQOL). There are several factors that can affect HRQOL in CD patients; from manifestations of the disease to the compliance with a gluten-free-diet. Furthermore, there has been a beneficial response to treatment with a gluten-free diet. Measuring HRQOL in celiac disease offers important advantages, not only for healthcare providers and caregivers but also for patients. The purpose of focusing on HRQOL is to go beyond the presence and severity of symptoms of disease or side-effects of treatment, examining how patients perceive and experience these manifestations in their daily lives. We describe the instruments to measure HRQOL in CD patients and recent studies that evaluate the impact that CD has on patient's HRQOL.

## Keywords

Celiac disease, health-related quality of life, questionnaires for HRQOL in CD.

## 1. Introduction

Celiac disease (CD) is an immune-based reaction to dietary gluten that primarily affects the small intestine in those with a genetic predisposition and resolves with exclusion of gluten from the diet. Over the last 50 years there has been a substantial increase in the prevalence of CD and an increase in the rate of diagnosis in the last 10 years[1]. CD is a chronic disorder that can impact patients in many ways including their health-related quality of life (HRQOL). In recent years the health-related quality of life has become an important issue in this context, and most studies carried out so far have shown impaired quality of life in untreated patients compared with healthy controls. Furthermore, there has generally been a beneficial response to treatment with a gluten-free diet[2].

The purpose of focusing on HRQOL is to go beyond the presence and severity of symptoms of disease or side-effects of treatment, examining how patients perceive and experience these manifestations in their daily lives[3].

## 2. Definition of Quality of Life

There is no universal agreement on the definition of 'quality of life'. 'Quality of life' is a term, which has been applied to various disciplines, such as politics, economics and religion. However, this term has been used mainly in medical studies. Quality of life as applied to medicine is more specifically known as HRQOL or 'subjective health status'. Despite the lack of universal consensus on a definition most researchers agree that quality of life is a subjective, multidimensional and dynamic concept[4,5]. HRQOL represents a subjective appraisal of an individual's perceptions, beliefs, feelings and expectations. Therefore, the person's own appraisal of his or her health and well-being is a key factor in quality of life studies[6]. Quality of life construct is made up of a number of domains or dimensions; physical, social and psychological[7]. Lastly, quality of life is dynamic, since it varies over time and it depends on changes within the patient and the patient's surroundings[5].

HRQL can be formally defined as: "The extent to which one's usual or expected physical, emotional and social well-being are affected by a medical condition or its treatment"[8].

## 3. Benefits of Utilization of HRQOL Measurement

Measuring HRQOL in celiac disease offers important advantages, not only for healthcare providers and caregivers but also for patients. Information regarding the impact of a medical condition on quality of life can used to capture changes in clinical status before, during and after treatment[4]. It can also aid in planning tools for clinical care and for treatment decision-making, and can be used as a predictor of the outcome of treatment[9]. Measuring HRQOL is also useful for patients because it allows them to explain the impact of disease in other dimensions of their life.

## 4. HRQOL Measurement in Celiac Disease

The instruments mainly used to measure HRQOL are questionnaires. These instruments are classified as generic or disease specific, according to the target population addressed. Generic instruments can be administered to the normal population or to any patient, with any disease. These instruments are used to describe the general impact of chronic diseases on patients' health and to compare the HRQOL of patient groups across different diseases. The generic questionnaires that are most used in celiac disease are shown in Table 1. The Short Form Health Survey (SF-36) is mainly used as a generic instrument in gastroenterology. The SF-36 is a brief (36-item), comprehensive measure of general health status originally developed for use in the Medical Outcomes Study[10]. It was designed for use in clinical practice and research, evaluation of health policy, and general population surveys. The SF-36 is currently the most widely used health status measure, particularly in the gastroenterology literature. There are abbreviated versions of this instrument, the SF-20 and SF-12, although their reliability and validity are slightly lower than for the

SF-36[11]. The EuroQol five-dimensional (EQ-5D) questionnaire is used worldwide as a patient-reported outcome instrument for the measurement and valuation of health. Developed by the EuroQol Group[12], this instrument measures health in five dimensions; mobility, self-care, usual activities, pain/discomfort, and anxiety/depression with three levels of severity in each dimension; no problems, some/moderate problems, and extreme problems/unable to perform the activity. Eypasch et al. developed the gastrointestinal quality of life index (GIQLI) to measure HRQOL in multiple gastrointestinal diseases[13]. It contains 36 items, scored on a five point Likert scale (range 0-144). It evaluates the past two weeks.

Generic questionnaires may not focus adequately on the area of interest for a specific patient or disease, and may lack the sensitivity to detect important changes in status over time. Disease-specific instruments have the potential for increased responsiveness and as they address specific diseases they are considerably more sensitive to the effects of interventions and time trends in a specific disease condition[14]. There are few disease-specific HRQOL instruments designed for CD. The Celiac Disease Questionnaire (CDQ) was developed and validated by Haüser et al.[15]. This instrument evaluates 4 domains with 7 items each: emotional and social problems, disease-related worries, and gastrointestinal symptoms, in the last two weeks. The CDQ discriminates in all subscales patients with CD-associated diseases from patients without CD-associated diseases. The CDQ has also been validated in Italy[16].

The celiac disease quality of life survey (CD-QOL) is a reliable and valid celiac disease specific instrument developed by Dorn et al.[17]. It includes 20 questions across four clinically relevant subscales (Limitations, Dysphoria, Health Concerns, and Inadequate Treatment). The instrument assesses the respondent’s feelings to particular celiac disease-associated symptoms over the previous 30 days. The questions consist of a five-point Likert scale labeled 1 through 5, where 1 is not at all and 5 is a great deal. For analysis, the responses are reverse coded and totaled. A higher score, with a maximum value of 100, may mean a higher quality of life and a decreased degree of celiac disease symptoms.

*Table 1. Generic instruments for evaluation of the HRQOL in CD patients*

| **Instrument** | **Items** | **No of items** | **Categories or domains** |
|---|---|---|---|
| SF-36 | Questions | 36 | Physical functioning<br>Bodily pain<br>Role limitations-physical<br>Social functioning<br>General mental health<br>Role limitations–emotional<br>Vitality (energy/fatigue) General health perception |
| EQ-5D | Statements<br>VAS* | 5 + VAS | Mobility<br>Self-care<br>Usual activities<br>Pain/discomfort<br>Anxiety/depression |
| GIQLI | Questions | 36 | GI symptoms<br>Physical function<br>Social function<br>Emotional function<br>Subjective treatment assessment |
| TACQOL (children) | Questions<br>Scales | 56 | Pain and symptoms (body)<br>Basic motor functioning (motor)<br>Autonomy (auto)<br>Cognitive functioning (cognition)<br>Social functioning (social)<br>Global positive emotional functioning (emo-pos)<br>Global negative emotional functioning (emo-neg) |

VAS: visual analogue scale

*Table 2. CD-specific instruments for evaluation of the HRQOL in CD patients.*

| Instrument | Items | No of items | Categories or domains |
|---|---|---|---|
| CDQOL | Statements | 20 | Limitations<br>Dysphoria<br>Health Concerns<br>Inadequate Treatment |
| CDQ | Questions | 28 | GI symptoms<br>Emotional problems<br>Social problems<br>Disease-related worries |
| CDDUX (children) | Questions | 12 | Communication<br>Diet<br>Having CD |

The CDQOL differs from the CDQ in that the latter focuses on both physical and psychological symptoms, as well as impairments in daily function, while the former employs a needs-based model that is more proximate to the attitudes and perceptions of individuals with CD that relate to meeting the basic needs of the condition[18]. The needs-based model postulates that life gains its quality from the ability of the individual to satisfy his or her needs. Quality of life is high when these needs are fulfilled and low when few needs are satisfied[19]. Needs-based measures are more sensitive to changes over time[20]. The CDQOL has also been translated and validated in Spain[21].

Two instruments are used to assess the quality of life in children with celiac disease. The generic Health related quality of life measure for children (TACQOL) is an instrument applicable to children in the age group of 6-15 years[22]. It evaluates seven domains of HRQOL: pain and symptoms (body), basic motor functioning (motor), autonomy (auto), cognitive functioning (cognition), social functioning (social), global positive emotional functioning (emo-pos) and global negative emotional functioning (emo-neg). Items are scored 0 for no health status problem, 1 for a health status problem without negative emotional responses and 2 for a health status problem with negative emotional responses.

The Disease-specific HRQOL Questionnaire for Children with CD (CDDUX) is an instrument designed for CD patients ages 8 to 18 years[23]. The CDDUX includes 12 items across 3 subscales: ‘‘Communication’’, ‘‘Diet’’, and ‘‘Having CD’’. The CDDUX has also been translated and validated in Argentina[24].

The difference between the TACQOL and the CDDUX is that the latter is disease-specific, therefore it elicits information about aspects of life that are influenced by CD. These specific aspects may be evaluated by the children as negative, but this does not mean that their perception of their generic QOL is negative as well.

## 5. Impact of Celiac Disease in Patient’s HRQOL

Health-related quality of life (HRQOL) as an aspect of living with CD has been studied frequently[25-30]. The HRQOL of CD patients’ is reduced compared to that of the general population. Factors that affect HRQOL in CD patients can be related to the manifestations of the disease itself, the compliance with a gluten-free-diet (GFD) or even the timing of diagnosis.

Symptomatic, untreated CD patients have a markedly reduced QOL compared to the general population[26-29]. One study using EQ-5D collected retrospective data concluded that the HRQOL before CD diagnosis is quantitatively similar to that of stroke patients[25]. A multicenter, cross-sectional prospective study found that the HRQOL of untreated, recently diagnosed CD patients is significantly impaired, on almost all of the dimensions and on the overall score of both the EQ-5D and the GIQLI[26]. Female patients have a tendency to do less well during the course of a GFD in some studies[31,32], but not in others[33].

Impact of the timing of diagnosis of CD and the HRQOL has also been evaluated. Often in adult patients, the diagnostic process for CD is often very late and can generate health complications that would be avoided by earlier diagnosis. A recent large cross-sectional study found that long duration and severity of symptoms predisposed CD patients to persistency of symptoms and a reduced quality of life[34]. Screen-detected patients have shown a better HRQOL than symptom-detected patients. Paavola et al. studied a cohort of 466 screen-detected and symptom-detected CD patients[35]. The authors found that QOL of screen-detected CD patients was comparable to non-celiac controls. This was not affected by a GFD. Fatigue is a symptom that many CD patients complain about and it can impair HRQOL. In a study evaluating fatigue in CD, fatigue-related problems and intensity of fatigue were higher in untreated CD patients, and fatigue was inversely correlated with patients' perception of health[36].

## 5.1. Gluten-Free-Diet and Quality of Life

Currently, a lifelong GFD is the only treatment for CD. A GFD requires a radical and lifelong change in daily habits. GFD can be troublesome, expensive and socially restrictive, which makes for difficulties in adherence and it can impact patients' QOL. Changing life-long dietary patterns can be laborious and compliance with a GFD varies from 42% to 91% depending on the method of assessment[37], however up to 50% of patients do not strictly adhere with the diet (either voluntary or involuntary) and will develop an active symptomatology[38]. Nevertheless, in symptomatic CD patients the GFD results in rapid recovery from symptoms and improvement in HRQOL[30,31,35,39-41], and adherence to GFD also allows progressive restoration of HRQOL perception[33]. It seems that this improvement is maintained long-term, and strictly compliant patients can have comparable long-term HRQOL to healthy people[26,42-44]. A longitudinal study that reported long-term data for patients followed for 4 years from diagnosis found long-term deterioration of HRQOL in patients who were poor-compliers with a GFD[45]. An interesting study by Barratt et al. evaluated the perceived degree of difficulty following a GFD among 225 CD patients[46]. The authors found a reduction in HRQOL among patients who had a higher perceived difficulty to follow the GFD.

Studies of the effect of GFD on HRQOL of asymptomatic, screen-detected CD have shown that it either remains the same as healthy controls[43,44] or it improves[29].

## 6. Conclusion

Celiac disease involves permanent changes in different aspects in the life of patients leading to an impairment of their quality of life.

The global attention to the person with celiac disease should be directed towards improvement of physical symptoms and minimize the psychosocial impact of the disease.

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