Original Article

Health-Related Quality of Life among Patients with Celiac Disease in Saudi Arabia

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Abstract

Background: Celiac disease can have a huge negative impact on the quality of patients' life. Various clinical pictures can be presented ranging from asymptomatic patients to multiple organs symptoms mainly GI symptoms. Malabsorption, weight loss, chronic diarrhea, and steatorrhea are considered as the typical manifestations of CD. Hence, it's a major cause of mortality, morbidity, and a notable health burden. CD affects about 1% of total world population. **Aims:** to assess health-related quality of life in patients with celiac disease. **Methods:** Cross-sectional study using self-administrated Short-Form survey (SF-36) questionnaire that has been completed by CD patients in Saudi Arabia. χ^2 tests were used for categorical variables and the Mann-Whitney U test for continuous variables; P<0.05 considered statistically significant. **Results:** A total of 264 subjects, 72.7% of them were females while 27.3% were males. 23.9% were between 5 - 14 years, 26.1% were between 15 - 24 years, 48.9% were between 25–64 and 1.1% ≥ 64 years. SF-36 has 8 subscales: physical functioning, Role functioning/physical, Role functioning/emotional, energy/fatigue, emotional well-being, social functioning, pain, and general health. Emotional well-being had the lowest mean (mean=57.8, 20.3 SD) compared to baseline (mean=70.38, 21.9 SD) then social functioning mean=67.95 (baseline=78.77), 23.16 SD (baseline=25.4SD) followed by Role functioning/emotional mean=55.8 (baseline=65.78), 43 SD (baseline=40.7SD). However, females scored significantly lower than males in Role functioning/physical (females: 51.56, males: 70.14) and Role functioning/emotional (Females: 50.52, males: 69.91). Patients ≥ 64 years scored lowest in Role functioning/emotional (33.33, 57.74 SD) especially in role functioning/physical. (59.13-44.64) and role functioning/emotional (58.3-45.24). **Conclusion:** HRQOL in celiac patients scored low in all subscales. However, Emotional well-being, social functioning and Role functioning/emotional were the most significant. Females scored lower than males in all subscales except in general health. Furthermore, Adherence to GFD has a major role in improving HRQOL.

Keywords: Celiac disease; Health-related quality of life; Saudi celiac patients; Gluten free diet

Introduction

Living with celiac disease (CD) can have a huge negative impact on the quality of patients' life. Celiac disease is a hereditary autoimmune disorder characterized by hypersensitivity to gluten which is a major protein found in different kinds of food including wheat and grains. Various clinical pictures can be presented ranging from asymptomatic patients to multiple organs symptoms mainly gastrointestinal symptoms. Malabsorption, weight loss, chronic diarrhea, and steatorrhea are considered as the typical manifestations of celiac disease. However, there are atypical manifestations mainly dermatitis herpetiformis, hair loss, osteoporosis, growth retardation and epilepsy. [1,2] Hence, it's a major cause of mortality, morbidity, and a notable health burden. CD diagnosed by antibody testing and biopsies are needed for confirmation. Several studies have concluded that the risk of malignancy significantly increased in celiac patients. [3-7] Celiac disease affects about 1% of total world population. Females are usually two to three times affected compared to males. [8] On the other hand, A cohort study was done in Saudi Arabia estimated that 2.2% of young healthy students are diagnosed with celiac disease. [9] In fact, prevalence in Saudi Arabia of CD among children was (1.5%) which is higher than the average rate in Europe and North America 42. The only therapy for this disease until now is gluten free diet. Furthermore, compliance to a gluten-free diet can remarkably diminish the risk of malignancy. However, there is poor compliance to this diet which reaches up to 30% of patients. [10] The cost and the availability of gluten-free diet are important aspects of patients' compliance. One Saudi study concluded that out of 113 samples, 100 (88.5%) of them reported that gluten-free products are not easily available in their area and 93% describe gluten-free products as very expensive. [11] Celiac disease can have an impact on patients' Health-Related Quality of Life (HRQOL) which is the patient's perceived physical and mental health over time. Patients usually suffer from abdominal complains and signs of malnutrition if they are on gluten-containing diet. [12] One study revealed that symptomatic celiac

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disease patients showed poor HRQOL compared to silent celiac disease patients. [13]

However, other studies concluded that with early diagnosis and strictly gluten free diet, HRQOL can be improved. [14] Although several studies clearly concluded that gluten-free diet improves HRQOL, [15-17] another study found that patients' HRQOL remained poor regardless of gluten-free diet. [18] One explanation is that patients may have social limitations because of the treatment. [18,19]

The diagnosis of celiac disease is usually delayed in both primary health care provider and the secondary care. [20] Early diagnosis and intervention will improve the quality of life and decrease the incidence of many complications which include osteoporosis, anemia and malignancy. [11,21]

There is a lack of literature on HRQOL and symptoms experienced by celiac patients in Saudi Arabia.

Aim

This research aims to assess health-related quality of life in patients with celiac disease, to determine the impaction of the disease in everyday life, to identify and evaluate the factors associated with poorer HRQOL.

Evaluation of HRQOL can help us find solutions to the identified contributing factors therefore improve the overall HRQOL.

Objectives of the study

General objective: To assess health-related quality of life in patients with celiac disease and to determine the impaction of the disease in everyday life.

Specific objectives

• To describe health-related quality of life (HRQOL) of Saudi patients with celiac disease.

• To identify and evaluate physical, psychological and social factors associated with HRQOL

• To identify and describe the symptoms of Saudi patients with celiac disease, identify and evaluate its associated factors.

Methodology

Study area/setting

Researchers conducted the study using self-administrated Short-Form survey (SF-36) questionnaire that has been completed by patients or their parents.

Study subjects

All patients who are diagnosed with celiac disease satisfying the criteria.

Study design

Cross-sectional study

Data collection

The SF - 36 questionnaires have been sent to one of the well-known celiac group advocacy social group. This social group is helping CD patients to share their knowledge and experience through various social platforms (WhatsApp, twitter, and so on). Our questionnaire has been sent to the whole group. There are more than 600 patients around the kingdom is connected to this patients' advocacy group. The questionnaire has been sent anonymously and each patient voluntarily answered the questionnaire. Young children's responses were asked to be done by their parents.

Inclusion and exclusion criteria

The inclusion criteria: both genders, Saudi nationality who are diagnosed with Celiac disease and agreed to be part of the research, excluding patients who have neurological, communication abnormalities, malignancies, bowel diseases, chronic renal failure, heart failure, or chronic obstructive pulmonary diseases(COPD) as they may have an influence on the accuracy and validity of the results.

Instruments used/Measurements

An online version of the Short-Form survey (SF-36) was distributed to an online local Celiac disease community.

Short-Form survey (SF-36) is a 36-question survey. It has both physical and mental domains which measure the presence and the severity of symptoms and their limitation on daily activities.

Furthermore, it is subdivided into physical functioning, role limitation due to physical health problems, bodily pain, general health, vitality, social functioning, role limitation due to emotional health problems, and mental health. Scores had a range of between 0 and 100, with a higher score indicating a better health related quality of life.

SF-36 was tested and showed reliability and validity as a measurement of quality of life. [22]

An Arabic translated form of SF-36 showed validity, reliability, and equivalence to the original version. [23]

Data Management and Analysis Plan

Statistical analysis

All values analyzed using software statistical Package of Social Science (SPSS 18 for windows evaluation version). In addition, $\chi 2$ tests used for categorical variables and the Mann-Whitney U test for continuous variables; $P<0.05$ considered statistically significant.

Data management and confidentiality

Data was identified initially and then coded in the database excel sheet using a unique identification number. The data have been stored on a password-protected laptop with PI and CI, and all data maintained confidential. Only the research teams have

access to the database for analyses purpose. The publication will only present summary statistics and no identifying information will be used. The name that used for determining the current health status was kept in a separate database; so it cannot be linked with any medical data.

Results

A total of 264 subjects, 72.7% of them were females while 27.3% were males. 23.9% were between 5 - 14 years, 26.1% were between 15-24 years, 48.9% were between 25–64 and 1.1% ≥ 64 years. SF-36 has 8 subscales: physical functioning, Role limitations due to physical health, Role limitations due to emotional problems, energy/fatigue, emotional well-being, social functioning, pain, and general health [Table 1]. Emotional well-being had the lowest mean (mean=57.8, 20.3 SD) compared to baseline (mean=70.38, 21.9 SD) then social functioning mean=67.95 (baseline=78.77), 23.16 SD (baseline=25.4SD) followed by Role functioning/emotional mean=55.8 (baseline=65.78), 43 SD (baseline=40.7SD). However, females scored significantly lower than males in Role functioning/physical (females: 51.56, males: 70.14) and Role functioning/emotional (females: 50.52, males: 69.91) [Table 2]. Patient's ≥ 64 years scored lowest in Role functioning/emotional (33.33, 57.74SD). Patients who are adherent to GFD scored higher than non-adherent patients. Especially in role functioning/physical (59.13-44.64) and role functioning/emotional (58.3-45.24).

Table 1: Role limitations

	Results		Control	
Item	Mean	Standard deviation	Mean	Standard deviation
Physical functioning	69.36	35.23	70.61	27.42
Role functioning/physical	56.63	49.50	52.97	40.78
Role functioning/emotional	55.81	49.69	65.78	40.71
Energy/fatigue	49.77	26.48	52.15	22.39
Emotional well-being	57.80	20.30	70.38	21.97
Social functioning	67.95	23.10	78.77	25.43
Pain	66.83	26.03	70.77	25.46
General health	56.65	26.65	56.99	21.11

Table 2: Role functioning.

Item	Male (mean)	Female (mean)
Physical functioning	72.50	68.18
Role functioning/physical	70.14	51.56
Role functioning/emotional	69.91	50.52
Energy/fatigue	55.83	47.50
Emotional well-being	62.78	55.94
Social functioning	69.44	67.38
Pain	71.56	65.05
General health	55.56	57.06

Discussion

HRQOL in Celiac disease patients was reduced among multiple studies. [24,25] However, in our study CD patients had low scores in all subscales. Emotional well-being, social functioning and Role functioning/emotional were the most significant. a study concluded that HRQ6L improved by some factors such as early diagnosis, availability of GFD and education about the disease. [26] Majority of CD cases remain undiagnosed clinically, in particular, diagnosed cases account only for a minority of CD patients. [27] However, females scored lower than males in all subscales except in general health. Other study reported that females had also lower scores than male and significantly more gastrointestinal symptoms. Poor HRQOL status in female celiac patients was unrelated to their biopsy findings. CD patients with atypical silent symptoms show a significantly higher HRQOL than patients with classical symptoms. Accordingly, treating symptomatic patients can significantly improve their HRQOL. Furthermore, Adherence to GFD has a major role in improving HRQOL. Providing patients with information about the disease by physicians could encourage adherence to GFD and improve their HRQOL. Poor quality of life after the first year of adherence to GFD was directly related to lack of compliance of the diet. In addition, CD patients enhanced to be adherent to GFD could increase their HRQOL level to be similar to general population. On the other hand, a study was made over 10 years revealed that after 10 years of adherence to GFD; CD patients fail to achieve the same health degree of general population suggesting that other factors may have importance in improving HRQOL. Finally, HRQOL in CD patients requires more studies to be done in the future.

Conclusion

HRQOL in Celiac patient had low scores in all subscales. However, Emotional well-being, social functioning and Role functioning/emotional were the most significant. In fact, females scored lower than males in all subscales except in general health. There was no relation between age groups, educational degree and HRQOL. Furthermore, Patients who are adherent to GFD scored higher than non-adherent patients. Concluding that adherence to GFD has a major role in improving HRQOL.

Limitations of the study

Samples were taken once at some point, multiple factors may influence the results, as patients may complain of other systemic illnesses affecting their quality of life rather than celiac disease. Questionnaire was sent to multiple social groups including both genders and different age groups, unfortunately, female responses (72.7%) were much more than male responses (27.3).

Conflict of Interest

All authors disclose that there was no conflict of interest.

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