

# Rosacea-Specific Quality of Life Scale (RosaQoL): The Study of Adaptation and Validation for Turkish Rosacea Patients

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## ABSTRACT

**Objective:** Rosacea-Specific Quality of Life Scale (RosaQoL) developed specifically for rosacea. The aim of the study was to adapt the RosaQoL Scale that is specific to Rosacea used in evaluating the quality of life of patients with Rosacea into Turkish, and evaluate its validity and reliability.

**Methods:** The RosaQoL Scale is a 21-item index that is specific to Rosacea, and was developed originally in English. The Turkish Scale, which was created after the clinical examinations of the patients, was applied to the patients. A total of 285 people, 240 females (84.2%) and 45 males (15.8%), who were diagnosed with Rosacea, admitting to the dermatology clinic between May 2019 and August 2019 were included in the study.

**Results:** The mean age of the patients was found to be  $44.8 \pm 12.5$  years in the study. The internal consistency of the scale (Cronbach's Alpha Coefficient) was found to be 0.952. The correlation coefficient was calculated as  $r=0.988$  in the test-retest reliability. The total RosaQoL score was  $62.4 \pm 11.5$  (Mean  $\pm$  SD), and the total DLQI score was  $7.85 \pm 5.04$  (Mean  $\pm$  SD). For validity analysis, the correlation coefficient between RosaQoL and DLQI was calculated as  $r=0.411$  ( $p<0.05$ ).

**Conclusion:** The Turkish version of the RosaQoL was valid and reliable for evaluating the quality of life of Turkish Rosacea patients.

**Keywords:** Quality of Life, Turkish version, Validation, Reliability, Rosacea

## 1. INTRODUCTION

Rosacea is a common and chronic inflammatory skin disease that involves the middle part of the face. Although its prevalence varies among countries, it ranges between 1% and 20%, is more common in women between the ages of 30-50 and in people who have skin phenotype as 1-3. It can be seen in the central region of the face, which is always visible, in various clinical forms with erythema, telangiectasia, rhinophyma, papules, and pustules (1, 2). There are 4 subtypes of Rosacea identified as Erythematotelangiectatic, Papulopustular, Phymatous, and Ocular (3).

Since Rosacea is a chronic disease progressing with attacks through various triggering environmental factors, and is in the visible area of the face, it brings serious limitations to the daily lives of patients. It affects the quality of life of patients and causes psychosocial problems (4).

Studies conducted on Rosacea showed that patients complain about embarrassment, disappointment, and low

self-confidence scores. Patients face rude comments, jokes, and misunderstandings from their circles (5).

If merely the physical symptoms and findings are considered when the severity of Rosacea is evaluated, the perception of the patient regarding his/her disease is not evaluated. For this reason, quality of life scales were developed to measure the quality of life to enable patients to express their own perceptions. In this way, it is ensured that the psychosocial condition and quality of life are evaluated along with the dermatological findings in determining the severity of the disease (6, 7).

The Rosacea-specific Quality of Life (RosaQoL) Scale is a disease-specific scale that is employed for evaluating the quality of life of patients with Rosacea, and was developed by Nicholson et al. in 2007. The scale consists of 21 questions and 3 sub-dimensions (8). The validity and reliability of the scale were shown for many languages, and was used in studies conducted in many countries worldwide (9, 10).

The DLQI Scale was developed in 1994 by Finlay and Khan. Its reliability and validity study for Turkish was conducted by Öztürkcan et al. It is a practical questionnaire form that consists of 10 short and easily understandable questions on emotions, symptoms, daily activities, leisure time activities, school and work life, personal relations, and treatment parameters, and is prepared to understand the effects of the existing dermatological disorders on the life of the patient. The answers consist of “not relevant / none, little, more, and too many” options with a Likert-type scale. In the evaluation of the scores, 0, 1, 2 and 3 points are given for these answers, respectively; and the resulting scores are added up. In this way, the minimum score is obtained as 0, and the maximum score is 30 (11, 12).

There is no specific scale that is used for Rosacea in our country. For this reason, the purpose of our study was to adapt the RosaQoL Scale, which is used commonly in other countries, into Turkish to evaluate the quality of life of patients with Rosacea.

## 2. METHODS

### 2.1. Ethics

For the study Sivas Cumhuriyet University ethics committee permission was received (2019-04/53). The purpose and contents of the study were explained to patients, and informed consent forms were received from volunteering ones. The study was conducted in line with the World Medical Association Declaration of Helsinki, Regulation of Patient Rights, and Ethical Rules.

### 2.2. Subjects

A total of 285 patients (240 females, 45 males) diagnosed with Rosacea admitting to dermatology clinic between May and August 2019 were included in this study.

Patients who were illiterate, who had a history of psychological diseases, or conditions which could affect the ability to understand the conditions of the study, and patients who were under the age of 18 were excluded from the study.

### 2.3. Rosacea-specific Quality of Life Scale (RosaQoL)

It was developed by Nicholson et al. in 2007. The scale consists of 21 questions and 3 sub-dimensions as the Emotions Dimension (7 items), Functions Dimension (3 items), and Symptoms Dimension (11 items). The answer options are structured in 5-Point Likert style as “never, rarely, sometimes, often, and always”. The source language of the scale is English. The scale determines the specific problems and expectations of patients with Rosacea about their disease, enabling the doctor to record the viewpoints of patients (8).

### 2.4. Translation Process

– Communication was established with Dr. Chen (the responsible author), who is one of the authors of the scale, and the necessary permission was obtained for the scale to be adapted into the Turkish Language and to conduct its validity and reliability study.

– Firstly, the scale was translated into Turkish by 3 experts, two of whom were in the field of dermatology and one in the field of linguistics. The 3 texts obtained in this way were converted into a common text by 2 different dermatologists. This text was then translated into English by a bilingual person.

– The English form was then sent to Dr. Chen (the responsible author), and his opinions were received.

– Then, the English of the text was reviewed by the linguists, clinicians, and academicians board, and the language validity of the scale was approved. A pilot scheme was administered to 20 people with this scale, whose language validity was approved, and the scale was evaluated in terms of understandability to give its final form.

### 2.5. Field Testing

The final Turkish version of the RosaQoL scale was applied to 285 patients diagnosed with Rosacea treated in the dermatology clinic. Dermatology Quality of Life Index (DLQI) generic tool was also applied consequently to the same patients for the purpose of demonstrating convergent validity. The data of this pilot application were used in the reliability and validity analyses. The Turkish Language version of the RosaQoL is presented in Table I.

### 2.6. Statistical Analysis

The data were analyzed by the SPSS version 22.0 Statistical Package. In the evaluation of the data, in addition to the descriptive statistics (mean, standard deviation), One-Way ANOVA was used in the comparison of quantitative data means of more than two groups.

Internal consistency, item-total score correlations test-retest reliability were used for reliability analyses. Internal consistency was tested using the Cronbach  $\alpha$  value, whereas item–score and total-score relationships were explored by using the Pearson Correlation Analysis. For Test-Retest Reliability, the Scale was applied twice, initially and 2 weeks later, to 30 patients. The Test-Retest Reliability was evaluated with Pearson Correlation Test in statistical terms.

Validity Analysis was carried out using convergent and construct validity. The DLQI, a well-documented and widely used generic health-related QoL scale, was used in parallel to the RosaQoL in order to test convergent validity. Construct Validity was tested by using the principal components factor analysis, and convergent validity by Pearson correlations. The significance level of the  $p$  value was taken as  $p < 0.05$ .

**Table 1.** Turkish-language Rosacea-Specific Quality of Life Scale (RosaQoL)

RosaQoL Items	Domains
1. Rosacea hastalığının ciddi olabileceğinden endişelenirim (kaygı duyuyorum).	Emotion
2. Rosacea hastalığım batma veya yanma hissettirir.	Symptom
3. Rosacea hastalığımdan kaynaklanan izlerden dolayı endişelenirim (kaygı duyuyorum).	Emotion
4. Rosacea hastalığının daha kötü olabileceğinden endişelenirim (kaygı duyuyorum).	Emotion
5. Rosacea tedavisinden kaynaklanan yan etkilerden endişelenirim (kaygı duyuyorum).	Emotion
6. Rozaze lezyonlarım beni tedirgin (rahatsız) eder.	Symptom
7. Rosacea hastalığımdan dolayı utanırım.	Emotion
8. Rosacea hastalığımdan dolayı hayal kırıklığına uğrarım.	Emotion
9. Rosacea hastalığım cildimi hassas yapar.	Symptom
10. Rosacea hastalığımdan dolayı sinirlenirim.	Emotion
11. Cildimin görünüşünden (kızarıklık, leke) dolayı sıkılırım.	Emotion
12. Rosacea hastalığım beni utangaç yapar.	Emotion
13. Rosacea lezyonlarımı makyaj ile örtmeye (gizlemeye) çalışırım.	Function
14. Rosacea hastalığının sürekli olmasından veya tekrarlamasından dolayı sıkıldım.	Emotion
15. Rosacea hastalığıma neden olan bazı yiyecek veya içeceklerden uzak dururum.	Function
16. Cildimi pürüzlü hissederim (düzensiz, eşitsiz, pürüzlü).	Symptom
17. Cildim kızarıır.	Symptom
18. Cildim kolayca tahriş olur (kozmetikler, temizleyiciler, tıraş losyonu).	Symptom
19. Gözlerim beni rahatsız eder (kuru veya pütürlü).	Symptom
20. Rosacea hastalığım ile ilgili düşünürüm.	Emotion
21. Rosacea hastalığıma neden olan belirli çevresel etkenlerden (nem, sıcak, soğuk) kaçınırım.	Function

### 3. RESULTS

Demographic characteristics of the Rosacea patients are presented in Table II.

The Study Group consisted of a total of 285 people, 240 women (84.2%) and 45 men (15.8%). The ages of the patients who were included in the study ranged between 21 and 72, and the mean age was  $44.86 \pm 12.50$ . The mean disease duration was found to be  $28 \pm 31.2$  (months), and the mean age of onset of disease was found as  $42 \pm 12.2$  (years).

When the educational status of the patients was evaluated, it was found that 227 (79.6%) were primary school graduates, 55 (19.3%) were high school, and 3 (1.1%) were university graduates. When the subtypes of Rosacea were evaluated, it was found that 75% (214) of the patients had Erythematotelangiectatic, 17.8% (51) had Papulopustular, 4.2% (12) had Phymatous, and 3% (8) had Ocular type. The severity of Rosacea disease was found to be moderate in 58.2% (166), mild in 26.7% (76), and severe in 15.1% of patients (43). In evaluating the reliability of RosaQoL,

an internal consistency analysis was conducted, and the Cronbach's Alpha Coefficient score was found to be 0.952. When the corrected item-total correlation values were evaluated, no items were excluded from the scale because all of the items of the scale were higher than 0.30.

Test-Retest was administered to 30 patients for reliability analysis. A total of 30 patients, who were selected with the Simple Random Sampling Method, and to whom the questionnaire was administered, were called again 2 weeks later, and the questionnaire was administered again. The level (degree) of the Pearson Correlation Coefficient between the first and the second test administrations was found as 0.988 (98.8%). A very strong (very high) positive correlation was detected between the first and the second administration.

Data from the 285 Rosacea patients were analyzed with Factor Analysis with a rotational method of Varimax, and three factors were extracted: Symptoms and Feelings (questions 1, 2, 4, 6-12, 14, 16, 17-20); Anxiety (questions 3, 5, 13); and Functions (questions 15 and 21).

The total RosaQoL score was found as Mean  $\pm$  SD of  $62.4 \pm 11.5$  points (range 38-82). The values for individual domains were (Mean  $\pm$  SD)  $3.16 \pm 0.57$  for the symptoms and feelings domain,  $2.42 \pm 0.68$  for the anxiety domain,  $2.56 \pm 0.81$  for the domain of the function. No significant differences were detected between gender, age, and total RosaQoL score ( $p > 0.05$ ). Statistically significant differences were detected between disease duration, disease severity, and total RosaQoL score ( $p < 0.05$ ).

**Table 2.** Demographic characteristics of rosacea patients (n = 285).

Items	Results
Age (years), mean $\pm$ SD	44.86 $\pm$ 12.5
Sex, n (%)	
Female	240 (84.2)
Male	45 (15.8)
Education, n (%)	
Primary education	227 (79.6)
High school	55 (19.3)
University	3 (1.1)
Age at onset (years), mean $\pm$ SD	42 $\pm$ 12.2
Disease duration (months), mean $\pm$ SD	28 $\pm$ 14.3
Rosacea disease severity, n (%)	
Mild	76 (26.7)
Moderate	166 (58.2)
Severe	43 (15.1)
Subtype of rosacea, n (%)	
Erythematotelangiectatic	214 (75)
Papulopustular	51 (17.8)
Phymatous	12 (4.2)
Ocular	8 (3)

The total DLQI score was found as Mean  $\pm$  SD of  $7.85 \pm 5.04$  points. The values for individual domains were (Mean  $\pm$  SD)  $3.28 \pm 1.2$  for the symptoms and feelings (items 1 and 2) domain,  $1.58 \pm 1.21$  for the daily activities (items 3 and 4) domain,  $1.31 \pm 1.40$  for the leisure (items 5 and 6) domain,

0.50± 0.81 for the work / school (item 7) domain, 0.75± 1.0 for the personal relationships (items 8 and 9) domain, and 0.38± 0.68 for the treatment (item 10) domain.

The relation between total RosaQoL and total DLQI scores was calculated with the Pearson Correlation Coefficient, and a high-level correlation was detected between the scales ( $r = 0.411$ ) (Table III).

The correlation coefficients between the total RosaQoL scale and its subscales varied between 0.374 and 0.979. A high level correlation was detected between the total RosaQoL scale and its subscales ( $p < 0.05$ ) (Table IV).

**Table 3.** Pearson correlation analysis between RosaQoL and DLQ.

DLQI							
RosaQoL	Symptoms and feelings	Daily activities	Leisure	Work/school	Personal relationships	Treatment	Total DLQI
	r	r	r	r	r	r	r
Symptoms and feelings	0.247***	0.288***	0.278***	0.253***	0.395***	0.324***	0.367***
Anxiety	0.310***	0.337***	0.371***	0.262***	0.317***	0.317***	0.403***
Function	0.172***	0.220***	0.258***	0.129***	0.247***	0.099	0.257***
Total RosaQoL	0.291***	0.316***	0.316***	0.294***	0.413***	0.356***	0.411***

\*\*\* $p < 0.05$

**Table 4.** Pearson correlation analysis between RosaQoL domains

RosaQoL	Symptoms and feelings	Anxiety	Function
	r	r	r
Symptoms and feelings			
Anxiety	0.614***		
Function	0.516***	0.374***	
Total RosaQoL	0.979***	0.678***	0.607***

\*\*\* $p < 0.05$

#### 4. DISCUSSION

Rosacea is a very common inflammatory disease that is characterized by papule, pustule, erythema and skin tenderness in the middle area of the face (13). It is a chronic disease with several clinical manifestations in the visible face area, and might be accompanied by eye involvement and rhinophyma. It usually appears after the age of thirties, and might cause important limitations in the daily lives of patients with the effects of various triggering environmental factors (14).

Because rosacea clinical severity scores are based on physical symptoms, they are insufficient to reflect the true burden of disease experienced by patients and thus the negative impact on their quality of life. Not all rosacea patients are affected to the same degree. It is important to determine how much the patient is affected and to give individualized treatment. Emotional distress occurs both as a triggering factor for rosacea and as a result of the disease. In monitoring the effectiveness of therapeutic approaches, quality of life should be evaluated on standard scales. To achieve ideal medical outcomes, the doctor-patient relationship must be developed and the patient must be provided with the correct response. The use of scales that evaluate the quality of life is

an inexpensive and practical method that contributes to the documentation and storage of this situation (4).

The evaluation of the patient's quality of life with subjective criteria often reveals different results from the physician's prediction and clinical evaluation. Studies of the severity of the disease indicated by the patient show that it is higher than determined by the physician. Measuring quality of life is of primary importance (11).

In Rosacea, the patient, who constantly faces his/her skin findings in the mirror, becomes unhappy and remains under the follow-up of people around him/her. Also, the chronic progression of Rosacea causes psychosocial problems to increase gradually. The clinical severity scores used by doctors for Rosacea are insufficient in determining the negative effects on the quality of life and the actual disease burden. For this reason, quality of life scales was developed to evaluate the opinions of patients. It is necessary that clinical severity scores and quality of life scales are evaluated together before and after the treatment by the doctor (6).

In Rosacea, 3 types of quality of life scales can be used, which are the general quality of life scales, dermatology-specific quality of life scales, and Rosacea-specific quality of life scales. The general quality of life scales and dermatology-specific

quality of life scales might overlook some disease-related challenges, remain time-consuming and complex; and when they are used to measure changes after an intervention related to the disease, they might not be as sensitive to change as the disease-specific scales (15).

The general quality of life scales and dermatology-specific quality of life scales provide clinicians with the opportunity to compare different diseases. However, Rosacea-specific scales focus on the dimensions related to the disease more. For this reason, the general quality of life scales is less sensitive to the changes in terms of the severity of Rosacea than Rosacea-specific scales. Hence, using Rosacea-specific scales can be more specific guidance in the follow-up and treatment of the disease and in studies conducted on Rosacea. The only quality of life scale that is specific to Rosacea, RosaQoL, was developed by Nicholson et al. in 2007. It evaluates 21 characteristics of 3 subclasses in terms of emotions, symptoms, and functions, and it is a quality of life scale that was created by considering the symptoms that are specific to Rosacea and the negative factors expected by patients (8).

In order to make the most accurate evaluation and impression of the results, it is imperative that these scales are adapted to religion, language, and socio-cultural according to the societies in which they are used, and that their validity and reliability are shown. These scales should be standardized at the national and international levels in order to compare the results of different treatment programs and different patient groups in the same disease group in the society and to make comparisons between societies.

In the present study, the purpose was to adapt the RosaQoL Scale, which is a quality of life scale acknowledged globally for Rosacea, into Turkish; and to test its validity and reliability in the follow-up and treatment of Rosacea patients in our country, and also to present it for use in studies related to Rosacea. The RosaQoL Scale is used in studies in many countries all around the world, and its validity and reliability were proven for different languages (9, 10).

Internal Structure Consistency and Test-Retest Methods were applied to measure the reliability of the scale. The Cronbach Alpha Coefficient was found to be 0.952 for the entire scale, and the Correlation Coefficient of the Test-Retest Method was found to be  $r = 0.988$  in internal structure consistency ( $p < 0.001$ ). The results obtained in this way show that the Turkish reliability of our scale is proven. None of the items were removed from the scale.

Explanatory Factor Analysis and External Tests Method were used for the validity study of the scale; the structural validity of the scale was evaluated with the DLQI Scale, which measures similar conceptual structures and which is frequently used in dermatological diseases with correlation analysis.

According to the Factor Matrix, 1, 2, 4, 6, 7, 8, 9, 10, 11, 12, 14, 16, 17, 18, 19, and 20 were grouped under the first factor structure; questions 3, 5, and 13 under the second factor; questions 15 and 21 were grouped under the third

factor structure. Considering the meanings of the items in the factors, and by using the alternating factor loads, since the questions in the first factor were related with mood and symptoms, it was called the "Symptoms and Emotions" dimension; since the questions in the second factor were about anxiety, it was called the "Anxiety" dimension; and since the questions in the third factor were related with the functions of the organs, it was called "Functions" dimension.

In the present study, a high-level correlation was detected between the total and subscale scores of RosaQoL and DLQI. Also, a high correlation was detected between the RosaQoL total score and the RosaQoL subscale scores, and it was demonstrated that the whole scale was in an important relation with subscales. This result supports the validity of the scale.

There was a statistically significant difference between the RosaQoL total score and all subgroups of the scale and the severity of the disease. According to the results obtained in our study, as the severity of the disease increases, the RosaQoL score also increases.

No statistically significant differences were detected between gender, age, and total RosaQoL Score ( $p > 0.05$ ); however, statistically significant differences were detected between the duration and severity of the disease and total RosaQoL score ( $p < 0.05$ ), which supports that patients are negatively affected in social and psychological terms due to the presence of the disease in a visible area and due to the prolonged and severe course of the disease.

## 5. CONCLUSION

In conclusion, the results of this validation study have clearly demonstrated that the Turkish version of the RosaQoL is an appropriate, clinically firm, and valid instrument with strong psychometric properties to be used with Turkish-speaking patients who have Rosacea disease.

We recommend that the scale is applied before and after the Rosacea treatment in future studies to examine the extent to which the scale is beneficial in evaluating the treatment response and patient follow-ups.

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## Conflicts of interest

The authors declare that they have no conflict of interest.

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