



## Original Research

# The quality of life in epidermolysis bullosa (EB-QoL) questionnaire: Translation, cultural adaptation, and validation into the Farsi language



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## ABSTRACT

**Background:** Defining the quality of life in the patients with epidermolysis bullosa (EB) is important in patient care and management. Evaluation of quality of life requires a valid and reliable scale. The Quality of Life in Epidermolysis Bullosa (EB-QoL) questionnaire, which is an English 17-item questionnaire, has emerged as a useful tool for assessing the quality of life in the patients with EB.

**Objective:** This study aimed to evaluate the psychometric properties of the Farsi version of the EB-QoL questionnaire among a group of Iranian patients with EB.

**Methods:** The Farsi version of the EB-QoL questionnaire was finalized after translation and back-translation. From the 100 patients with EB invited to participate in the study, 83 completed the questionnaire (response rate: 83%). Subsequently, the content validity and construct validity of the questionnaire were assessed. The reliability of the questionnaire was assessed with Cronbach's alpha. Moreover, the correlation between EB-QoL scores and EB severity scores (based on the Birmingham Epidermolysis bullosa severity score scale) was evaluated.

**Results:** A total of 83 patients (40 male and 43 female) with a median age of 15 years (interquartile range, 9–24 years) and an age range between 3 and 43 years were enrolled in this study. Mean  $\pm$  standard deviation scores from the EB-QoL questionnaire were  $43.7 \pm 9.9$ . The translated EB-QoL questionnaire showed a high internal consistency (Cronbach alpha = 0.90) and adequate item-total correlation. Also, there was a significant correlation between EB-QoL and EB severity scores ( $r = 0.39$ ;  $p < .001$ ).

**Conclusion:** The Farsi version of EB-QoL questionnaire has acceptable validity and reliability. Thus, the questionnaire can be used for future studies to assess the quality of life among Iranian patients with EB.

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## Introduction

Epidermolysis bullosa (EB) refers to a rare genetic group of dermatologic conditions that are clinically characterized by blistering of the skin and sometimes the mucous membranes after a mild friction or trauma (Fine et al., 2014). The prevalence of EB reportedly ranges from 1 per 130,000 in the United States (Pfundner et al., 2001) to 1 per 100,000 in Italy (Tadini et al., 2005) and 1 per 20,000 in Scotland (Horn et al., 1997). Although there is no accurate estimate of the prevalence of EB in Iran, available data

suggest that the proportion of affected cases, particularly recessive forms of EB, appear to be higher in Iran due to the higher number of consanguineous marriages (Parvizi et al., 2017).

EB can be classified into four major types based on the ultrastructural site in the skin where the blister can form: EB simplex, junctional EB, dystrophic EB, and Kindler syndrome. Also, each type is further divided into 34 subtypes based on clinical and laboratory findings (Fine et al., 2014).

EB has a significant impact on many aspects of daily life for both patients and their families. Chronic skin and mucosal blistering, pain, itching, odor, and time-consuming dressing are some of the problems that affect the personal, physical, emotional, and professional aspects of a patient's life (Tabolli et al., 2009).

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Frew et al. (2009) developed and validated a questionnaire (Quality of Life in Epidermolysis Bullosa [EB-QoL]) covering the physical and emotional impact of EB on patients' personal and social lives, as well as their productivity at work and school. Accordingly, the EB-QoL questionnaire has emerged as a useful tool for assessing quality of life in the patients with EB and can be used to identify the dimension of quality of life as a target of new therapeutic intervention and research. The EB-QoL questionnaire was originally written in English and has already been translated and validated into other languages, such as Spanish (Frew et al., 2013), Dutch (Yuen et al., 2014), Brazilian Portuguese (Cestari et al., 2016), and Romanian (Dănescu et al., 2019).

This study aimed to develop a valid and reliable translation of the EB-QoL questionnaire in Farsi to allow its use as a quality-of-life assessment instrument for patients with EB in Iran.

## Methods

This study was performed at the Skin Research Center of the Shohada-e-Tajrish Hospital as a national referral center for patients with EB in Iran. The study sample size was determined in terms of the Quality Criteria for Health Status Questionnaires (Terwee et al., 2007), suggesting that, to appropriately analyze the construct validity, reproducibility, responsiveness, and ceiling/floor effect, enrolling at least 50 patients is necessary. The criteria also suggest at least 100 patients for the internal consistency analysis. In light of the rarity of EB and the difficulty of recruiting patients, the statistical analysis was conducted after 80 patients were enrolled in the study.

In this study, we used convenience sampling of consecutive cases. The inclusion criteria were as follows: patients aged >3 years who (themselves or their parents) were able to read and understand Farsi. The exclusion criteria were as follows: the presence of chronic nondermatological or concomitant dermatological disease. From the 130 patients with EB who visited our center during 2017, 100 patients met the inclusion criteria and were eligible and volunteered to complete the EB-QoL questionnaire. Children were assisted by their parents. Supplementary data on age, sex, education, EB major types, and the severity of EB were collected during the patients' interview and examination. The diagnosis of major types of EB was clinical in some cases and performed based on immunofluorescence antigen mapping (Barzegar et al., 2015) and mutational analysis (Vahidnezhad et al., 2017) in other cases.

To assess the severity of the disease, the Birmingham Epidermolysis Bullosa Severity score (Moss et al., 2009) was used. This score covers all the important manifestations of EB and contains 10 items: involvement of the nails, mouth, eyes, larynx, and esophagus; scarring of the hands; skin cancer; presence of chronic wounds; scarring alopecia; and nutritional compromise. The score also includes the percentage of damaged body surface area affected by blisters, erosions, scabs, erythema, and atrophic scars. Body surface area was scored up to 50 points and the 10 other items up to a maximum of 5 each, providing a maximum score of 100 (Moss et al., 2009).

The study was approved by the university research ethics committee. A signed consent form was obtained from all participants.

## Quality of life in epidermolysis bullosa questionnaire

The EB-QoL questionnaire is a validated and reliable measurement tool to accurately assess the impact of EB on patients' quality of life. The questionnaire contains 17 questions divided into two domains: functional (questions 1–7, 9, 10, 12, 13, and 15) and emo-

tional (questions 8, 11, 14, 16, and 17) aspects. For each question, four optional answers exist and are scored from 0 to 3 points, yielding a total score from 0 to 51. Higher scores represent worse health-related quality of life (Frew et al., 2009).

## Translation of EB-QoL questionnaire into Farsi

According to World Health Organization recommendations for the translation and cross-cultural adaptation of quality-of-life instruments (World Health Organization, 2017), the study was conducted in two stages. In the first stage, the forward translation of the EB-QoL questionnaire into Farsi was performed by two independent, qualified translators. This version was later reviewed by two translators and a dermatologist to reach a consensus on the final version. In the second stage, the Farsi version of the questionnaire was back-translated into English by a different independent, qualified translator who was not aware of the original version of the EB-QoL questionnaire. To verify the content validity of the Farsi version, the English-translated version was compared with the original EB-QoL questionnaire. The discrepancies were found and reviewed by the translators, and some words in Farsi version were modified or replaced with new words to convey the correct meaning of the words in the original EB-QoL questionnaire. The revised Farsi version then was translated into English and sent to the author of the original questionnaire (Frew) for approval. The Farsi EB-QoL questionnaire is provided in the [appendix](#) and directly available from the corresponding author.

## Statistics

The statistical analysis was performed with SPSS software, version 21 for windows (SPSS Inc., Chicago, IL). Categorical variables were expressed as absolute and relative frequencies (percentage), and continuous variables reported as mean  $\pm$  standard deviation or median and interquartile range (IQR; 25th–75th percentile). The normality of the continuous variables was examined using the Shapiro-Wilks *W* test and normal probability plot (P-P plot and histogram). For continuous variables with skewed distributions, nonparametric statistical methods were applied.

## Psychometric measures of the questionnaire

### Reliability

The reliability of the instrument was determined by analyzing the internal consistency of every domain, using Cronbach's alpha coefficient. The alpha coefficient was considered good at  $\geq 0.7$  (Cöster et al., 2012; Yuen et al., 2014).

### Validity

The validity of the questionnaire was measured by content validity with the ceiling and floor effects. Floor and ceiling effects for individual items were considered when  $\geq 85\%$  of participants scored the highest or lowest possible scores.

### Other clinical data

The EB-QoL scores were compared among the four main EB types using the nonparametric Kruskal-Wallis test; correlation between EB-QoL and EB severity scores was examined using Spearman's correlation coefficient. To evaluate the correlation of the EB-QoL domain scores with themselves, Spearman's correlation coeffi-

cient was used. Values of  $p < .05$  were considered statistically significant.

## Results

From the 100 patients with EB invited to participate, 83 were included in the study (response rate: 83%). The remaining 17 patients were excluded due to unreturned or incomplete questionnaires. The burden of time was low, the average time being 9.1 minutes (median: 6.5; IQR, 4–10 min) to complete the questionnaire. Table 1 shows the clinical and demographic data of the study population. Of the 83 included patients, 40 (48.2%) were male and 43 (51.8%) were female. The median age was 15 years (IQR, 9–24 years), and age ranged from 3 to 43 years.

### Validity

The content validity of the questionnaire was addressed through the forward–backward translation, which showed conceptual equivalence to the original questionnaire. No floor or ceiling effects were present in the 17 items of the questionnaire.

### Reliability

The internal consistency of the 17 EB-QoL items (Cronbach's alpha coefficient: 0.90; 95% confidence interval [CI], 0.87–0.93) and its two domains, functional (Cronbach's alpha coefficient: 0.87; 95% CI, 0.83–0.91) and emotional (Cronbach's alpha coefficient: 0.83; 95% CI, 0.76–0.88), were considered satisfactory. No significant increase was observed in total and interdimensional Cronbach's alpha when removing any item from the questionnaire (Table 2).

### Analysis of clinical data

No statistically significant differences were seen in EB types for the EB-QoL scores ( $p = .33$ ), but a significant correlation was observed between EB-QoL and EB severity scores ( $p < .001$ ). Both EB-QoL domains have been shown to have a statistically significant correlation with total EB-QoL score (Table 3).

### Result of EB-QoL questionnaire

The results of the 17 individual EB-QoL items are listed in Table 2. Mean  $\pm$  standard deviation EB-QoL scores were  $43.7 \pm 9.9$ . Using the Student  $t$  test, no significant differences were detected between the scores of female ( $43.6 \pm 8.7$ ) and male patients ( $43.8 \pm 11.2$ ;  $p = .96$ ). The items contributed to the total scores the most and the least were questions 9 (move around outside the house) and 17 (teasing/staring), respectively.

## Discussion

The EB-QoL questionnaire is a recently reported and validated questionnaire that was written originally in English (Frew et al., 2009) and has been translated into and validated in different languages. The translation, cross-cultural adaptation, and validation of the EB-QoL questionnaire enable this tool to be used to measure the quality-of-life aspects that affect patients with EB in different countries. It also can be used either as a measuring tool for determining clinical improvement in clinical trials or for interpreting and evaluating therapeutic interventions as well as prognosis (Frew and Murrell, 2010).

In the present study, we studied the cross-culture adaptation and reliability of the Farsi EB-QoL questionnaire, and showed that the questionnaire can be considered an appropriate tool to assess quality of life among Iranian patients with EB.

We used floor and ceiling effects to evaluate content validity. Floor and ceiling effects show the proportion of individuals who achieved the highest or lowest possible numerical values for a score and are considered to be present when  $>85\%$  of individuals achieve these values (Cöster et al., 2012). A high floor and ceiling effect reduces the ability of the questionnaire to distinguish patients from each other and to measure changes in patients after intervention (Cöster et al., 2012). In our study, alongside the original questionnaire, our questionnaire was free from the ceiling or floor effects.

In the present study, we found a high positive correlation between the EB-QoL and Birmingham severity scores, indicating that patients with EB who have more severe disease have a lower quality of life. These results are in concordance with a recent publication by Dănescu et al. who compared the quality of life and disease severity of Romanian populations with EB using the Romanian

**Table 1**  
Clinical and demographic characteristics of the study population.

	Patients with EB (n = 83)	Female (n = 43)	Male (n = 40)
Age (year), median (interquartile range)	15 (9–24)	14 (9–24)	16 (11–24.7)
Main EB types, n (%)			
Simplex	2 (2.4%)	1 (2.3%)	1 (2.5%)
Junctional	1 (1.2%)	0	1 (2.5%)
Dystrophic	61 (73.5%)	34 (79.1%)	27 (67.5%)
Kindler syndrome	3 (3.6%)	0	3 (7.5%)
Indeterminate	16 (19.3%)	8 (18.6%)	8 (20%)
Education, n (%)			
No schooling	18 (21.6%)	9 (20.9%)	9 (22.5%)
Primary schooling	31 (37.3%)	18 (41.8%)	13 (32.5%)
Secondary schooling	25 (30.1%)	13 (30.2%)	12 (30.0%)
Academic education	9 (10.8%)	3 (6.9%)	6 (15.0%)
EB-QoL scores (mean $\pm$ SD)			
Total (0–51)	43.7 $\pm$ 9.9	43.6 $\pm$ 8.7	43.8 $\pm$ 11.2
Functional (0–36)	30.9 $\pm$ 7.1	30.6 $\pm$ 6.3	31.3 $\pm$ 7.9
Emotional (0–15)	12.5 $\pm$ 3.7	13.0 $\pm$ 3.1	12.0 $\pm$ 4.2
EB severity scores (mean $\pm$ SD; 0–100)	50.7 $\pm$ 15.4	50.0 $\pm$ 16.9	51.5 $\pm$ 13.8

EB, epidermolysis bullosa; EB-QoL, Epidermolysis Bullosa Quality of Life questionnaire; SD, standard deviation.

**Table 2**  
Results of 17-item Epidermolysis Bullosa Quality of Life questionnaire.

Options	0 n (%)	1 n (%)	2 n (%)	3 n (%)	Weight of contribution of each item to the total score	Alpha if one item deleted
<i>Questions</i>						
1 Move around inside the house	13 (15.7)	31 (37.3)	21 (25.3)	18 (21.7)	0.70	0.84
2 Ability to bathe/shower	15 (18.1)	18 (21.7)	13 (15.7)	37 (44.6)	0.54	0.84
3 Physical pain	2 (2.4)	33 (39.8)	28 (33.7)	20 (24.1)	0.45	0.85
4 Ability to write	24 (28.9)	30 (36.1)	19 (22.9)	10 (12)	0.30	0.85
5 Ability to eat	3 (3.6)	38 (45.8)	42 (50.6)	0 (0)	0.39	0.85
6 Ability to shop	9 (10.8)	24 (28.9)	33 (39.8)	17 (20.5)	0.66	0.84
7 Sport activities	0 (0)	9 (10.8)	24 (28.9)	50 (60.2)	0.53	0.85
8 Frustration	19 (22.9)	23 (27.7)	27 (32.5)	14 (16.9)	0.47	0.85
9 Move around outside the house	12 (14.5)	29 (34.9)	18 (21.7)	24 (28.9)	0.80	0.83
10 Family relationship	25 (30.1)	34 (41.0)	17 (20.5)	7 (8.4)	0.63	0.84
11 Embarrassment	25 (30.1)	28 (33.7)	12 (14.5)	18 (21.7)	0.56	0.84
12 Home modification	43 (51.8)	29 (34.9)	8 (9.6)	3 (3.6)	0.46	0.85
13 Friendship relations	23 (27.7)	34 (41.0)	11 (13.3)	15 (18.1)	0.73	0.83
14 Anxiety	5 (6.0)	28 (33.7)	30 (36.1)	20 (24.1)	0.66	0.84
15 Financial burden	1 (1.2)	14 (16.9)	29 (34.9)	39 (47.0)	0.29	0.86
16 Depression	19 (22.9)	29 (34.9)	27 (32.5)	8 (9.6)	0.65	0.84
17 Teasing/staring	2 (2.4)	32 (38.5)	34 (41.0)	15 (18.1)	0.09	0.89

**Table 3**  
Correlation among EB Quality of Life questionnaire domain scores and EB severity according to Birmingham EB severity scores.

Domain	Functional	Emotional	Total
Functional scores	1.00		
Emotional scores	0.62*	1.00	
Total scores	0.93*	0.79*	1.00
EB severity scores	0.35 <sup>†</sup>	0.34 <sup>‡</sup>	0.39*

EB, epidermolysis bullosa.

\* Spearman coefficient  $p < .001$ .

<sup>†</sup>  $p = .001$ .

<sup>‡</sup>  $p = .002$ .

version of the EB-QoL questionnaire and the EB Disease Activity and Scarring Index. In this study, the authors concluded that patients with EB and higher perceived disease severity had a lower quality of life (Dănescu et al., 2019).

In accordance with previous studies (Cestari et al., 2016; Tabolli et al., 2009), we found no significant differences in EB-QoL scores among patients with different EB subtypes, indicating heterogeneity within a given subtype. In each subtype, disease severity varies from mild to severe; for instance, disease severity in a patient with dystrophic EB is not necessarily greater than that in a patient with simplex type EB (Pagliarello and Tabolli, 2010). An evaluation of clinical severity based on the validated objective scoring system seems more accurate than what is expected from the clinical subtypes. Despite the reported lower level of health status and quality of life in women with EB (Tabolli et al., 2009), in our study, there was no difference between male and female patients in all scores.

In this study, we evaluated reliability as internal consistency, using Cronbach's alpha. Internal consistency estimates the degree of interrelatedness among items, indicating that all items on the scale measure the same general construct. Accordingly, the Farsi version of the EB-QoL questionnaire demonstrated excellent internal consistency (0.90), similar to the coefficient of the original questionnaire (0.93; Frew et al., 2009). Cronbach's alpha for each subdomain was also acceptable, indicating that items are correlated within each subdomain. The results also show that removal of each item did not lead to a significant difference in the measurement power of the instrument.

The question concerning "move around outside the house" mostly contributed to total EB-QoL scores. A similar finding was reported in the Brazilian population of patients with EB, where

moving around inside and outside the house contributed the most to the total QoL scores (Cestari et al., 2016). Therefore, these aspects of the disease should be better addressed.

Interestingly, the questions on emotional aspects of quality of life (in our questionnaire, teasing and staring; in the Brazilian version [Cestari et al., 2016], embracement) had the least impact on total scores, which can be attributed to the resilience phenomenon. EB usually occurs at birth and lasts throughout the patient's lifetime, and patients are capable of accepting their disease and coping with its consequences (Tabolli et al., 2009). In this regard, coping strategies might explain why the emotional aspects appear to have the least impact on quality of life; however, further research is needed to ascertain the validity of this assumption.

One of the limitations of this study was the response rate of 83%, which makes the generalizability of the study limited. We did not compare the characteristics and properties of respondents with those of the nonrespondent population, but previous studies conducted on nonresponse in health surveys have found that, compared with respondents, nonrespondents are characterized by worse health status, lower health care utilization, higher age, and lower level of education (Rupp et al., 2002).

## Conclusion

The Farsi version of the EB-QoL questionnaire showed an acceptable level of reproducibility and validity for measuring quality of life among Iranian patients with EB. The questionnaire exhibits excellent coordination between EB-QoL and EB severity scores, indicating good construct validity. Our results suggest that the Farsi version of the EB-QoL questionnaire has great potential to be used in multinational clinical trials for assessing the efficacy of new treatment modalities.

## Conflict of Interest

None.

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## Study Approval

The author(s) confirm that any aspect of the work covered in this manuscript that has involved human patients has been conducted with the ethical approval of all relevant bodies.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijwd.2020.05.012>.

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