Hindi translation and validation of quality of life score in Indian patients with epidermolysis bullosa; and its correlation with the clinical severity assessment scores: A cross-sectional study

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Abstract

Background: Quality of life (QoL) has not been evaluated in Indian patients having epidermolysis bullosa (EB).

Aims: The aims of the study were to measure health-related QoL in Indian patients having EB using the quality of life in epidermolysis bullosa (QoLEB) questionnaire, and to find its correlation with clinically measured disease severity.

Methods: In this observational cross-sectional study, the QoLEB questionnaire was translated from English to Hindi (QoLEB-Hin) and culturally adapted without a change in concept following standard guidelines. QoLEB-Hin and three clinical scores that have been independently validated in EB, that is, Birmingham Epidermolysis Bullosa severity score (BEBs), Instrument for Scoring Clinical Outcomes of Research for Epidermolysis Bullosa (iscorEB) and Epidermolysis Bullosa Disease Activity and Scarring Index (EBDASI), were administered to EB patients/their parents in the presence of an expert. This was followed by validity and correlation studies.

Results: Fifty-four patients were recruited (19-females, 35-males; median age 5 years, range 0.025–36 years and 12 patients with an age >13 years). The parents answered the questions for 42 patients (age <13 years). Dystrophic epidermolysis bullosa was diagnosed in 32 (59.2%) patients (dominant dystrophic epidermolysis bullosa [DDEB]-19 [35.2%] and recessive dystrophic epidermolysis bullosa [RDEB]-13 [24.1%]). Junctional epidermolysis bullosa (JEB) and epidermolysis bullosa simplex (EBS) were each diagnosed in 11 (20.4%) patients. The mean ± standard deviation (SD) of QoLEB-Hin score of all epidermolysis bullosa patients was 11.3 ± 7.6 (range 0–28; median and interquartile range [IQR], 10, 10) and reflected an overall moderate degree of affliction on QoL of patients. Mean ± SD of QoLEB-Hin scores for EBS, JEB, DDEB and RDEB were 5.4 ± 3.7 (range, 1–13; median and IQR, 6, 6), 11 ± 6.2 (range, 1–22; median and IQR, 10, 6), 9 ± 5.7 (range, 0–19; median and IQR, 10, 10) and 20.1 ± 6.4 (range, 12–28; median and IQR, 19, 12.5), respectively ($P < 0.001$, Kruskal–Wallis analysis of variance). Cronbach's alpha coefficient of 0.946 was obtained for all items indicating excellent internal consistency and reliability. Mean sample adequacy was 0.91; absolute fit based off diagonal values was 0.99; indices root mean square error of approximation and root mean square residual were 0.04 and 0.05, respectively, and Tucker Lewis index was >1 indicating overfit. The mean time taken to complete the questionnaire was 6.1 min (range, 6–8 min). QoLEB-Hin correlated significantly ($P < 0.001$) with BEBs ($\rho = 0.79$), iscorEB ($\rho = 0.63$) and EBDASI ($\rho = 0.77$). Three multiple linear regression models were used to ascertain the strength of relationship between QoL-Hin, and BEBs, iSCOREB and EBDASI, respectively, after adjusting for age, gender and disease subtype. The EBDASI clinical score accounted for approximately 74% ($R^2 = 0.736$, $P < 0.001$) of the variability in QOL-Hin, as compared to 73% and 55% by BEBs ($R^2 = 0.731$, $P < 0.001$) and iscorEB ($R^2 = 0.545$, $P < 0.001$), respectively.

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Limitations: Parents filled out the questionnaires for many patients and probably led to an overall moderate degree of affliction of QoL. Comparison with Dermatology Life Quality Index and other QoL scores were not done in this study. Furthermore, the scoring was done at one point in time, and test-retest measurements could not be performed.

Conclusion: This study validated QoLEB-Hin in an Indian population finding an overall moderate reduction in QoL due to EB. Maximally affected QoL was seen in patients with RDEB. Furthermore, QoLEB-Hin had a variable positive correlation and association with all clinical severity assessment scores.

Key words: EBQoL, epidermolysis bullosa, quality of life

Plain Language Summary

The present study was carried out among patients having epidermolysis bullosa. Epidermolysis bullosa is a very rare genetic disorder which results in either dysfunction or absence of important structural proteins of human skin causing it to become fragile. Depending on the type and the depth of the structural proteins affected by this disease, there can be various subtypes including simplex, junctional and dystrophic. Dystrophic epidermolysis bullosa can further be divided into recessive and dominant subtypes depending on the pattern in which the successive generations are affected. From what has been seen previously, junctional and recessive dystrophic epidermolysis bullosa are severe subtypes. The aim of the present study was to assess the quality of life in patients affected by this rare genetic disease.

This study was carried out in the pediatric dermatology clinic of a tertiary care hospital and research institute in Northern India, and 54 patients having epidermolysis bullosa were recruited. To assess the quality of life in Indian epidermolysis bullosa patients, the questionnaire previously available in English was translated into Hindi. The authors administered this questionnaire to patients or their parents. A few available clinical scores were also performed by the physicians to assess the severity of the disease. The authors found an overall moderate degree of reduction in the quality of life of their patients due to epidermolysis bullosa. Patients having recessive dystrophic epidermolysis bullosa had maximal negative impact on their quality of life. The authors also found that reduction in the quality of life had a positive correlation with the disease severity as assessed by the clinical severity assessment scores.

Introduction

Epidermolysis bullosa (EB) is a rare inherited mechanobullous disorder with multiple types and subtypes. These subtypes vary broadly in their clinical manifestations and severity. In patients having junctional and dystrophic epidermolysis bullosa, and some variants of EB simplex, the disease often runs a chronic course. This leads to significant morbidity and socio-economic burden for the patient and the family alike.[1,2] Therefore, it is of importance to ascertain health-related quality of life (HRQoL) among the patients with EB and their families.

There were initial attempts to evaluate QoL among EB patients using the Dermatology Life Quality Index (DLQI) and other HRQoL scores.[3,4] However, gross variations in the clinical phenotypes of EB coupled with ceiling effects and content validity issues in these scoring tools made HRQoL measurements difficult among EB patients. Subsequently, Frew *et al*. developed and validated an EB -specific HRQoL measurement tool that could be used across all EB subtypes (quality of life in epidermolysis bullosa [QoLEB]).[5] The present study aimed to produce a "regional translation (Hindi)" of QoLEB to measure the QoL in Indian EB patients and correlate QoL (a patient's perspective) with clinical severity assessment scores (a physician's perspective).

Methods

Study site and population

This observational cross-sectional study was planned and performed in the pediatric dermatology clinic of postgraduate institute of medical education and research, Chandigarh, India. After the conception of this study, an EB registry was formulated in our department, and all subsequent patients presenting with EB were enrolled in the said registry. Ethical approval was obtained from the Institute's Ethical Committee before recruiting patients for this study.

Recruitment and design

This was an observational cross-sectional study that was carried out from June 2016 to July 2018.

Inclusion criteria were:

1. Patients having EB (all age groups)
2. Native speakers of Hindi language (patients and/or parents).

The patients were classified into four main EB subtypes: epidermolysis bullosa simplex (EBS), junctional epidermolysis bullosa (JEB), dominant dystrophic epidermolysis bullosa (DDEB) and recessive dystrophic epidermolysis bullosa (RDEB), using clinical diagnostic matrix,[6] immunofluorescence antigen mapping and/or

electron microscopy. Written consent was obtained from all participants. Parents consented for patients aged <18 years; though an assent was also obtained from children aged 13–18 years as per Indian Council of Medical Research guidelines.[7]

Study measurement tools

The English version of QoLEB is a validated EB specific HRQoL tool consisting of a 17-item questionnaire, and measures two factors: functioning (questions 1–7, 9–10, 12–13 and 15) and emotions (question 8, 11, 14, 16–17).[5] For each question, four optional answers exist that are scored from 0 to 3 points (0: Not at all, (1) A little, (2) A lot and (3) very much; of least to the most impact). The total score ranges from 0 to 51 points ("functioning" scale ranges from 0 to 36, "emotions" scale ranges from 0 to 15). A higher score represents a worse HRQoL in EB. Recently proposed grading for the stratification of the overall measurement of QoLEB is as follows: very mild (0–4 points), mild (5–9 points), moderate (10–19 points), severe (20–34 points) and very severe (35–51 points).

Three clinical severity scores – Birmingham Epidermolysis Bullosa severity score (BEBs),[8] Instrument for Scoring Clinical Outcomes of Research for Epidermolysis Bullosa (iscorEB),[9,10] and Epidermolysis Bullosa Disease Activity and Scarring Index (EBDASI)[11,12] have been independently developed and validated to ascertain the disease severity. Required permissions were obtained before the use of these assessment tools for the present study.

Study procedures

The study was performed in three phases.

1. The first step involved translation of the English version of QoLEB into Hindi, that is, QoLEB-Hin. India has an extremely rich and diverse culture with no national language, though 22 languages have been granted official status. Hindi is the most frequently spoken language in India and was therefore chosen for the present study. Forward translation of the QoLEB to Hindi was performed by an independent qualified translator. Back-translation to English was performed by a different independent qualified translator and reviewed by the original author of the instrument to ensure that the translated QoLEB-Hin conveyed a similar meaning to that of the QoLEB. Subsequently, these forward and back translations were discussed by experts in EB (RM and SH), who were bilingual (native speakers in Hindi and fluent in English), to ascertain the content validity. Hindi version of QoLEB was the exact translation and had no conceptual change (no questions were added or removed from the original questionnaire)[13,14]
2. In the second phase, consenting patients and/ or parents were requested to complete and return QoLEB-Hin questionnaires. An experienced physician (SM) administered BEBs, iscorEB and EBDASI on the same day to assess the disease severity of the patients. Further, reliability and factorial validity for QoLEB-Hin were determined at this stage
3. In the third phase, the correlation between QoLEB-Hin and clinical severity scores, namely, BEBs, iscorEB and EBDASI was ascertained.

Statistical analysis

Construct validity was assessed by Exploratory Factor Analysis using generalized least squares techniques. Kaiser-Meyer-Olkin (KMO) criterion was used to assess the measure of sampling adequacy. Factor selection was carried out using Very Simple Structure (VSS), scree plot and eigenvalue criterion to observe any discrepancy due to a different selection criterion. Absolute fit indices verify how well a model fits or reproduces the data. Absolute fit indices include root mean square error of approximation (RMSEA) and root mean square residual (RMSR). The RMSEA and RMSR values range from 0 to 1 with smaller values closer to 0.05 indicating better model fit. Tucker Lewis index (TLI) is a relative fit index with values over 0.90 considered acceptable. The reliability and internal consistency of the QOLEB-Hin were measured using Cronbach alpha (α). Data quality was assessed using the corrected item-to-total correlation which should exceed >0.3 for each item. The floor and ceiling effect for the individual items was considered when ≥80% of the participants scored the lowest or highest possible scores. The respondent burden was assessed by the self-reported completion time for the QOLEB-Hin and was considered brief if <15 min.

Means and standard deviations (SD) were calculated and reported for all study measurement tools. Box-whisker plots were used to demonstrate the scores measured across different EB subgroups. The discriminative validity and multiple comparisons were calculated between four main epidermolysis bullosa subtypes (EBS, JEB, DDEB and RDEB) using a Kruskal–Wallis analysis of variance (ANOVA). Subsequently, *post hoc* tests were carried out using Bonferroni corrections to find the significant difference between groups. Assessment of correlation and convergent validity between QoLEB-Hin and clinical severity assessment scores, that is, BEBs, iscorEB and EBDASI was performed using matrix plots and was demonstrated using Spearman correlation coefficient rho (ρ). Multiple linear regression (MLR) using ordinary least squares was employed to determine the strength of relationship between QoLEB-Hin and the change in clinical severity scores. These scores were adjusted for important confounders with $P < 0.10$ to be included in the MLR model.

Statistical analyses were conducted using SPSS version IBM SPSS Statistics, Chicago, USA and the https://personality-project.org/r/psych/ in https://www.r-project.org/. A two-tailed $P \leq 0.05$ except for *post hoc* tests (≤0.008) was considered to declare statistically significant results.

Results

Study population

Fifty-four patients were recruited in the study (19 females and 35 males). The mean age of the study group was 7.6 ± 8.8 years (median 5, IQR 11.22, range 0.025–36 years). Twelve patients were aged >13 years; three were aged 18 years and four were aged >18 years. The parents answered the questionnaire for 42 (77.7%) patients, the rest responded for themselves (age >13 years, 22.3%). A diagnosis of dystrophic epidermolysis bullosa was offered in 32 (59.2%) patients. Of these 32, 19 (35.2%) were diagnosed as DDEB, while 13 (24.1%) were diagnosed as RDEB. JEB and EBS were each diagnosed in 11 (20.4%) patients each.

Validation of QoLEB-Hin

Cronbach's alpha coefficient of 0.946 was obtained for all items indicating excellent internal consistency and reliability. KMO demonstrated mean sample adequacy of 0.91. VSS complexity achieved a maximum of 0.94 with 1 factor and 0.95 with 2 factors. Absolute fit based off diagonal values was 0.99; indices RMSEA and RMSR were 0.04 and 0.05, respectively, and TLI was >1 indicating overfit. Table 1 shows a comparison between the psychometric properties of the present score and the QoLEB-E score.

QoLEB-Hin scoring in our patients

The mean ± SD QoLEB-Hin score of our cohort was 11.3 ± 7.6 (range 0–28; median and IQR, 10, 10) and reflected an overall moderate degree of affliction on QoL of patients. Mean ± SD QoLEB-Hin scores in EBS, JEB, DDEB and RDEB subgroups were 5.4 ± 3.7 (range, 1–13; median and IQR, 6, 6), 11 ± 6.2 (range, 1–22; median and IQR, 10, 6), 9 ± 5.7 (range, 0–19; median and IQR, 10, 10) and 20.1 ± 6.4 (range, 12–28; median and IQR, 19, 12.5), respectively [Figure 1 and Table 2], $P < 0.001$, Kruskal–Wallis ANOVA.

Overall, a very mild, mild, moderate and severe affliction of QoL was seen in 10 (18.5%), 14 (25.9%), 22 (40.7%) and 8 (14.9%) patients, respectively. The mean ± SD QoLEB-Hinscore for females 12.7 ± 8.9 (range, 0–28; median and IQR, 11, 13) was higher than males 10.6 ± 6.9 (range, 0–27; median and IQR, 10, 9), but not significantly different ($P = 0.342$). Furthermore, there was an inverse correlation between age and QoLEB-Hin scoring (Spearman rho -0.19), though not significant ($P = 0.163$). The mean time taken to complete the QoLEB-Hin questionnaire was 6.1 min (range, 6–8 min).

The clinical severity assessment scores

Mean ± SD values of BEBs, iscorEB and EBDASI scores for our cohort were 15 ± 13.4 (range 0.5–64; median and IQR, 13, 17), 39.7 ± 23.5 (range 0.5–88; median and IQR, 39.7, 40.5) and 45.8 ± 39.8 (3–141; median and IQR, 36, 64.5), respectively. The values of clinical severity measurement tools in individual disease subtypes are summarized in box plots in Figure 1 and Table 2.

Multiple comparisons

Bonferroni *post hoc* test for multiple comparisons demonstrated significant disease severity and QoL affliction in RDEB [Figure 1].

The correlation among QoLEB-Hin and clinical severity assessment scores [Figure 2, matrix plots].

QoLEB-Hin correlated significantly ($P < 0.001$) with clinical severity scores measured by BEBs (ρ 0.79), iscorEB (ρ 0.63) and EBDASI (ρ 0.77).

Regression analysis

Three MLR models were used to ascertain the strength of relationship between QoL-Hin, and BEBs, iSCOREB and EBDASI, respectively, after adjusting for age, gender and disease subtype. The EBDASI clinical score accounted for

Table 1: A comparison of the psychometric properties between QoLEB-Hin and QoLEB-E

Psychometric properties	QoLEB-Hin (Present study)	QoLEB-E[5], original score
Content validity	Acceptable, addressed through appropriate forward and back translation, and review by bilingual experts	Produced through item generation
Data quality	Corrected item-to-total correlation≥0.5	-
Construct validity	Cronbach's alpha 0.946	0.92
Convergent validity	Correlation done with clinical severity measurement tools (rho, the coefficient of correlation) being 0.79 with BEBs, $P<0.001$	Correlation done with dermatology life quality index (rho 0.77)
	rho 0.63 with iscorEB, $P<0.001$	Stanford health assessment questionnaire for mobility (rho 0.78)
	rho 0.77 with EBDASI, $P<0.001$	Hospital anxiety and depression scale, rho 0.57 and 0.58 with anxiety and depression, respectively
Discriminative validity	$P<0.001$ (Kruskal–Wallis ANOVA)	$P<0.01$
Internal consistency and reliability	Cronbach's alpha 0.946	0.922

BEBs: Birmingham epidermolysis bullosa severity score, iscorEB: Instrument for scoring clinical outcomes of research for epidermolysis bullosa, EBDASI: Epidermolysis bullosa disease activity and scarring index, QoLEB-Hin: Quality of life in EB-Hindi score, QoLEB: Quality of life in EB-English score

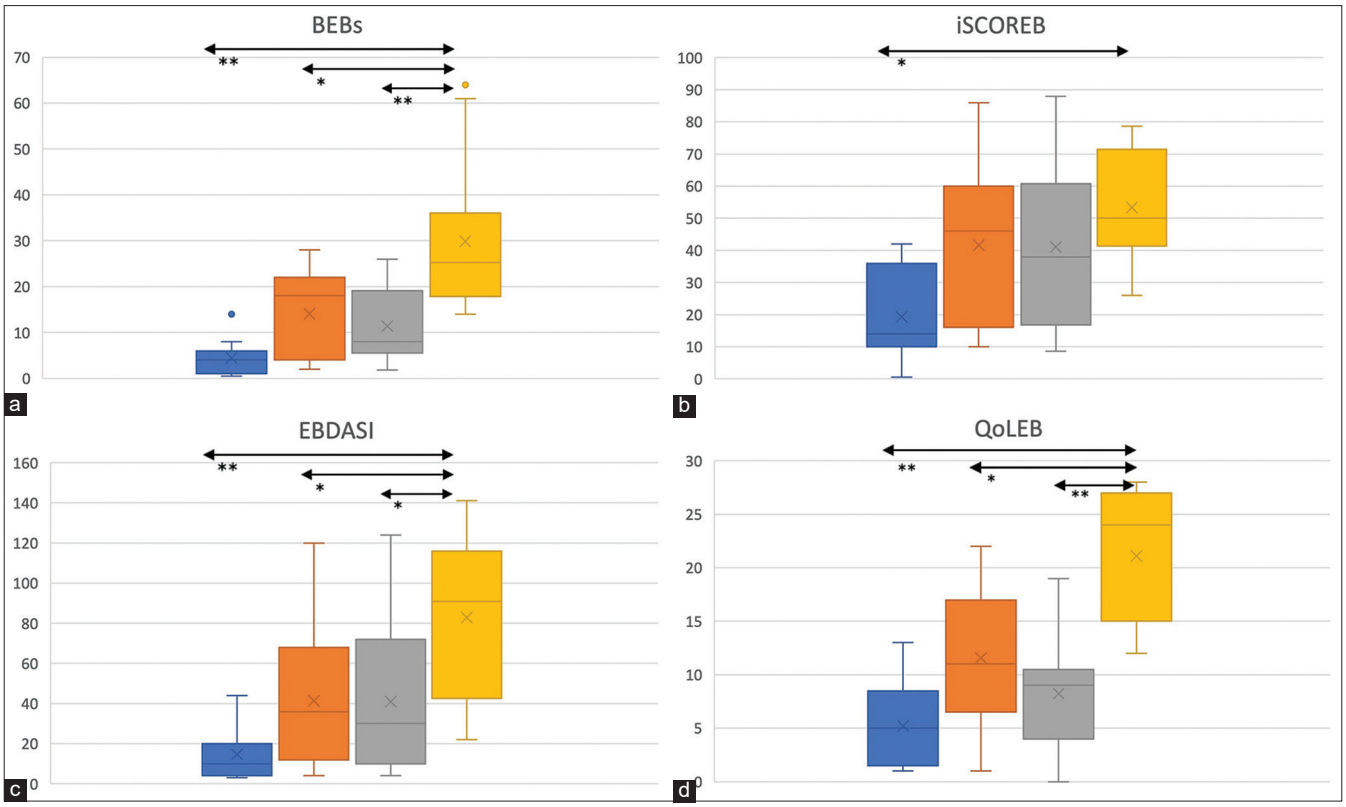

Figure 1. Box-whisker plots demonstrating the BEBs (1a), iscorEB (1b), EBDASI (1c) and QoLEB-Hin (1d) scores, and significant differences across the 4 subtypes of epidermolysis bullosa (BEBs- Birmingham epidermolysis bullosa severity score, iscorEB- instrument for scoring clinical outcomes of research for epidermolysis bullosa, EBDASI- epidermolysis bullosa disease activity and scarring index, QoLEB-Hin – quality of life in EB-Hindi score, EB- Epidermolysis bullosa, EB simplex - blue colour, Junctional EB - orange colour, Dominant dystrophic EB- grey colour, and Recessive dystrophic EB- amber colour; SD- Standard deviation, IQR- Interquartile range; *p<0.008, **p<0.001, horizontal lines inside the boxes represent the medians, and x signs represent the means).

approximately 74% ($R^2 = 0.736$, $P < 0.001$) of the variability in QOL-Hin, as compared to 73% and 55% by BEBs ($R^2 = 0.731$, $P < 0.001$) and iscorEB ($R^2 = 0.545$, $P < 0.001$), respectively.

Discussion

Assessment of QoL helps to measure the morbidity and impact of a disease perceived by the patient and his family members. EB is a complex hereditary disease with an overwhelming psychosocial component. Therefore, a comparison of the baseline and subsequent values can reflect on the overall benefits of the multi-modality treatments provided to the patients. Furthermore, a more objective and meaningful comparison of the QoL scores and clinical severity assessment tools shall be possible, if these would correlate and agree well with each other. QoLEB was initially developed in English and has since been translated and validated in several languages.[5,14-17] Translation and validation in other languages have the potential to provide reliable comparisons of HRQoL in EB across different ethnicities, especially while performing multicenter and cross-cultural research.

No language has been granted the status of the national language in India, but many have been provided the status of official language. Hindi has been granted the status of first, second, third, fourth and fifth language in 11, 8, 7, 1 and 4 states and union territories, respectively. Further, 57.1% of total Indian population could speak Hindi with 43.6% of total population speaking it as their first language.[18-20] For the purpose of the present study, it seemed reasonable to translate QoLEB-English questionnaire to Hindi to have a regional translation of QoLEB (QoLEB-Hin) that could be understood by majority of the regional population. We further quantified the disease severity of these patients using previously validated clinical severity assessment scores and studied their correlation with QoLEB-Hin scores. The QoLEB-Hin score had an excellent construct and discriminative validity; and internal consistency and reliability. The average time taken to complete this questionnaire was 6.14 min.

A recent study has compared QoLEB (Romania) with EBDASI and found a significant correlation between the two.[21] We performed the clinical severity assessment of our patients using all three validated tools, BEBs, iscorEB and EBDASI. Initial univariate analysis using Kruskal–Wallis ANOVA and multiple comparisons revealed maximum affliction of QoL in patients having RDEB, followed by those having JEB. The same was demonstrated on a robust MLR, and QoL seemed to be significantly dependent on

Table 2: Clinical severity measurement and QoLEB-Hin scores in individual EB subtypes

Score	Total (n = 54)			EBS (n = 11)			JEB (n = 11)			DDEB (n = 19)			RDEB (n = 13)		
	Mean (SD)	Range	Median (IQR)	Mean (SD)	Range	Median (IQR)	Mean (SD)	Range	Median (IQR)	Mean (SD)	Range	Median (IQR)	Mean (SD)	Range	Median (IQR)
QoLEB-Hin	11.33 (7.63)	0–28	10 (10)	5.36 (3.75)	1–13	6 (6)	11 (6.18)	1–22	10 (6)	9.0 (5.72)	0–19	10 (10)	20.08 (6.36)	12–28	19 (12.5)
BEBs	14.98 (13.37)	0.5–64	13 (17)	4.45 (4.04)	0.5–14	4 (5)	14.09 (9.68)	2–28	18 (18)	11.40 (7.15)	1.9–26	8 (13.6)	29.87 (16.06)	14–64	25.25 (18.12)
iscorEB	39.7 (23.5)	0.5–88	39.7 (40.5)	19.31 (14.14)	0.5–42	14 (26)	41.64 (27.33)	10–86	46 (44)	41.06 (22.8)	8.6–88	38 (44)	53.33 (16.80)	26–78.6	50 (30.15)
EBDASI	45.76 (39.78)	3–141	36 (64.5)	14.64 (13.86)	3–44	10 (16)	41.36 (37.1)	4–120	36 (56)	40.95 (33.09)	4–124	30 (62)	82.85 (40.09)	22–141	91 (73.5)

BEBs: Birmingham epidermolysis bullosa severity score, iscorEB: Instrument for scoring clinical outcomes of research for epidermolysis bullosa, EBDASI: Epidermolysis bullosa disease activity and scarring index, QoLEB-Hin: Quality of life in EB-Hindi score, QoLEB: Quality of life in EB-English score, EB: Epidermolysis bullosa, EBS: EB simplex, JEB: Junctional EB, DDEB: Dominant dystrophic EB, RDEB: Recessive dystrophic EB, SD: Standard deviation, IQR: Interquartile range

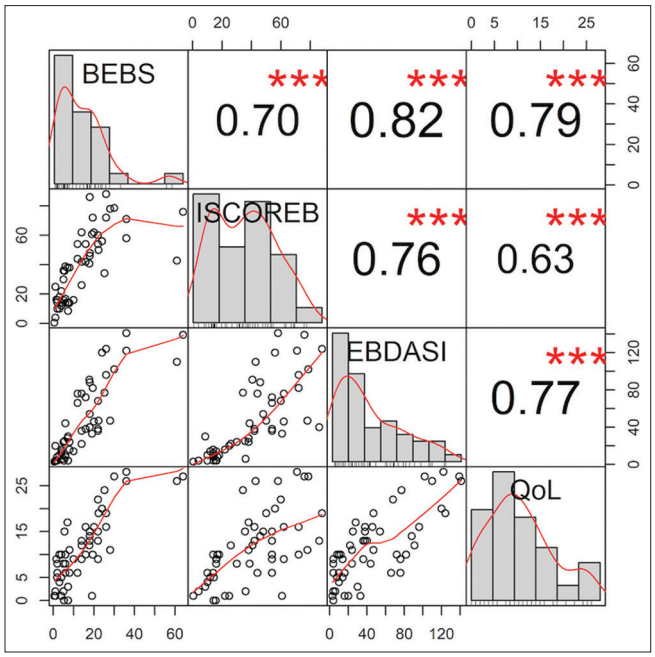

Figure 2: Matrix plots showing correlation amongst QoLEB-Hin and clinical severity assessment tools (BEBs – Birmingham epidermolysis bullosa severity score, iscorEB – instrument for scoring clinical outcomes of research for epidermolysis bullosa, EBDASI – epidermolysis bullosa disease activity and scarring index, QoL – quality of life in EB-Hindi score)

the disease subtype, as well as the values of all clinical severity assessment tools (BEBs, EBDASI and iSCOREB). Importantly, few patients in DDEB subgroup scored 0 signifying no impact on QoL (e.g., children with isolated anonychia affecting toes). QoLEB scores for JEB and DDEB were comparable and could be explained by less severe phenotype of disease in our JEB cohort.

An important secondary aim of the present study was to see if any one clinical severity assessment score correlated better with the QoL than the others. However, in the absence of a gold standard, it was difficult to directly compare the three clinical severity assessment scores (we tried using Bland Altman score; data not shown). Therefore, we have presented data in the form of individual correlations between QoL and each clinical assessment score. All clinical scores (BEBs, iscorEB and EBDASI) showed a statistically significant correlation with QoLEB-Hin.

In our patients, the top three questions that contributed maximally to the final QoLEB-Hin score were question number 3 (pain), 7 (involvement in sports) and 1 (inability to move around at home). No significant correlation was seen between QoLEB-Hin, and age or gender of the subjects.

Limitations

1. Genetic diagnosis was not done in this patient cohort
2. Thirty-five patients were <13 years (including newborns), necessitating the need for the parents to fill the questionnaires which might not provide a true reflection of the patient's QoL, and thus explaining an overall moderate QoL score
3. Comparison with DLQI and other QoL scores was not done
4. The scoring was performed at one point in time, and test-retest measurements could not be performed
5. We were not able to fill QoLEB and QoLEB-Hin simultaneously in bilingual patients
6. Future studies can focus on formulating a pictorial score specific for smaller children, and attempts have already been initiated in this direction.[22]

Strengths

Regional translation and validation of QoLEB in a Hindi speaking population makes for better understanding of the disease burden in Indian patients and establishing its correlation with all three available disease severity assessment tools in Indian patients. Another strength of the present study was that the majority of the participants (77.7%) were children <14 years of age. Many of the previous works on this aspect had either more adult patients or an equal proportion of both adults and children. EB is predominantly a disease of childhood; and the majority of the phenotypes, especially the more severe ones present in childhood itself.[23] An adequate representation from all disease subtypes (especially 11 patients with JEB) adds to the generalizability of the present work.

Conclusion

This study validated regional Hindi translation of QoLEB in an Indian population finding an overall moderate reduction in QoL due to EB. Furthermore, QoLEB-Hin had a variable positive association with disease subtypes and all clinical

severity assessment scores (providing objective evidence that the impact on the QoL varied with the severity of disease affliction in different EB subtypes).

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Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

Glossary of terms

BEBs - Birmingham epidermolysis bullosa severity score, DDEB - dominant dystrophic Epidermolysis bullosa, EB - Epidermolysis bullosa, EBS - EB simplex, EBDASI - epidermolysis bullosa disease activity and scarring index, GLS - Generalized least squares, iscorEB - instrument for scoring clinical outcomes of research for epidermolysis bullosa, IQR - Interquartile range, JEB - junctional EB, MinRes - Minimal residual solution using unweighted least squares, QoLEB-Hin - quality of life in EB-Hindi score, QoLEB - quality of life in EB - English score, RDEB - recessive dystrophic EB, RMSEA - root mean square error of approximation, RMSR - root mean square residual, SD - Standard deviation, TLI - Tucker Lewis Index of factor reliability.

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