Validity and Reliability of the Thai version of the Family Dermatology Life Quality Index

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ABSTRACT

Objective: This study aimed to investigate the validity and reliability of the Thai version of FDLQI.

Materials and Methods: Patients and their accompanying family members attending the Dermatology Outpatient Clinic at Siriraj Hospital were asked to complete the Dermatology Life Quality Index (DLQI), FDLQI, and the global question of their QoL (GQoL). The severity of the disease was assessed by physicians, the patients and the family members of the patients. **Results:** One hundred family members accompanying 92 patients with dermatological diseases (63% with inflammatory skin diseases and 37% with non-inflammatory skin diseases) were included. The mean age of the family members was 43.5 ± 12.1 years and 70% were women. They had been mostly employed (74%) and graduated from universities (65%). Validity was demonstrated by a positive correlation between FDLQI and GQoL scores (r_s =0.695, P<0.001), and between FDLQI and severity of the patient's disease (r_s =0.578, P<0.001) as evaluated by family members. The FDLQI showed high internal consistency (Cronbach's alpha=0.84) and test-retest reliability (ICC= 0.85).

Conclusion: The construct validity, internal consistency, and test-retest reliability of the Thai FDLQI demonstrated acceptable validity and reliability. The Thai version of FDLQI can be used to assess the QoL of family members of patients with any dermatological diseases.

Keyword: Validity; reliability; Family Dermatology Life Quality Index; FDLQI (Siriraj Med J 2023; 75: 369-376)

INTRODUCTION

Dermatological diseases such as urticaria, atopic dermatitis, psoriasis, epidermolysis bullosa, acne, and hair disorders can have a tremendous impact on mental health of patients, sometimes even more than other physical diseases. ¹⁻⁴ This impact may not only affect patients, but also cause a negative impact on their close individuals, especially their close family members and partners. ^{2,5} Many instruments were developed aimed at capturing and measuring quality of life (QoL) of family members of patients with dermatological diseases in order to improve holistic care to a patient as much as possible. Moreover, this dimension has grown much of interest during the

last two decades. The Family Dermatology Life Quality Index (FDLQI) is one of the questionnaires designed to measure the QoL of family members of patients affected by dermatologic diseases.⁶ It was originally developed in English⁷ and was translated and validated for use in many countries, for example, Japan⁸, Iran⁹, Ukraine¹⁰, etc. This study aimed to investigate the validity and reliability of the Thai version of FDLQI.

MATERIALS AND METHODS

The protocol of this study was approved by the Siriraj Institutional Review Board (COA no. Si 905/2021). Patients and their accompanying family members or

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All material is licensed under terms of the Creative Commons Attribution 4.0 International (CC-BY-NC-ND 4.0) license unless otherwise stated. partners attending the Dermatology Outpatient Clinic at Siriraj Hospital were asked if they were willing to participate in the study. Informed consent was obtained if the patient agreed to participate. The inclusion criteria for the family members or partners of the patients were: (i) 18 years or older, (ii) the first-degree relative who lived in the same household, and (iii) the ability to read and understand Thai language. Family members or partners of patients who had other severe concomitant diseases other than dermatological disease were excluded.

Questionnaires

FDLQI: is a questionnaire that was developed by Basra et al. to measure the QoL of family members or partners of patients with dermatological diseases in 10 aspects over the past month. Ten aspects comprise (i) emotional, (ii) physical well-being, (iii) relationships, (iv) reactions of people, (v) social life, (vi) leisure activities, (vii) burden of care, (viii) extra housework, (ix) job / study and (x) additional expenditure. Each aspect will be evaluated by each question, which will be rated by the score 0 = 'not at all / not relevant', 1 = 'a little', 2 = 'quite a lot' and 3 = 'very much'. Therefore, the score ranges from 0 to 30, indicating 'no' and 'maximum' impacts on quality of life, respectively.

Dermatology Life Quality Index (DLQI): is a questionnaire that was developed by Finlay A.Y. and Khan G.K.¹¹ It measures the QoL of patients with dermatological diseases over one week. Six aspects of the 10 questions include (i) symptoms and feelings, (ii) daily activities, (iii) social or leisure activities, (iv) work or study, (v) personal relationships, and (vi) effect of treatment. The total DLQI score ranges from 0 to 30 (0 to 3 points for each question), and the higher the score reflects a greater impact on the patient's QoL. This questionnaire has also received the formal permission of the developers to translate into Thai and has already been validated and widely used in Thailand.¹²

Global question: is a simple question used to assess the severity and quality of life of the disease over the past month on a numerical rating scale, with 0 and 10 indicating 'no' and 'worst', respectively.

Translation process of the FDLQI

After receiving permission for the translation into Thai language from the FDLQI developers, our translation process was performed according to their instructions. The translation of the original English language into Thai was carried out by two independent translators who were bilingual. Then, these two Thai versions were read and discussed by four Thai dermatologists (KK, LC, PT,

CR) resulting in minor changes to make a conceptual equivalence to the original questionnaire. Afterwards, this version was independently translated back into English by two bilingual English-language experts, who were unaware of the original version. Finally, the same four Thai dermatologists read and discussed both translations in order to find a consensus version. After the backtranslation for FDLQI was approved by one of the developers, a cognitive debriefing was performed in family members of five patients comprised: 1) a 30-year-old woman accompanying her husband with pityrosporum folliculitis for two months, 2) a 54-yearold woman accompanying her daughter with chronic eczema of the left foot for one month, 3) a 28-year-old male accompanying her father with androgenic alopecia for five years, 4) a 58-year-old woman accompanying her mother with xerotic eczema for 18 months and 5) a 60-year-old male accompanying his daughter with post inflammatory hyperpigmentation from acne for 4 months. All agreed that the form of the questions was clear and easily understandable, leading to no change for the final Thai version of the FDLQI.

Participants

A total of 100 family members accompanying 92 patients with dermatological diseases were included. On the visit date, patients were asked to rate their QoL using DLQI and a global QoL question for patients (GQoLP). Their family members were also asked to complete their QoL by the FDLQI and a global QoL question for family members (GQoLF). The physicians, patients themselves, and their family members completed a global question regarding the severity of the patient's disease. After finishing all processes within 10-15 minutes, patients' family members were asked their convenient time for a telephone interview to complete another FDLQI sheet the next day for reliability of the test.

Psychometric Evaluations

Validity: was investigated by comparing the test to other tests that measure the relevant construct. The correlation between patient evaluation scores (DLQI, GQoLP and a global question for patient's disease severity) and the assessment scores of family members (the Thai version of FDLQI, GQoLF, a global question for patient's disease severity) were investigated using Spearman's rank correlation. A correlation coefficient of approximately 0.3, 0.5, and 0.7 was interpreted as a weak, moderate, and strong correlation, respectively.¹³ We expected the highest correlation between the Thai version of the FDLQI and GQoLF.

Reliability: Reliability was investigated by Cronbach's alpha and the intraclass correlation coefficient (ICC). The Cronbach value of < 0.5, 0.5- 0.6, 0.6-0.7, 0.7-0.8, 0.8-0.9, >0.9 was interpreted as unacceptable, poor, questionable, acceptable, good and excellent, respectively. An ICC of 0.5 to 0.7, and >0.7 was considered to indicate moderate to good and excellent reproducibility, respectively. All statistical analyses were performed with PASW Statistics version 18.0 (SPSS, Inc., Chicago, IL, USA). A p-value (P) < 0.05 was considered statistical significance.

RESULTS

Of 100 family members with a mean age of 43.5 \pm 12.1 years, 70% were women (Table 1). Thirty-one participants were parents of patients. They had been mostly employed (74%) and graduated from universities (65%). On the other hand, 54 (58.7%) of the 92 patients were men and the mean age was 42.8 \pm 21.0 years. The median duration of their dermatological diseases was 12 months. Fifty-eight patients (63.0%) were diagnosed with inflammatory diseases, while the remaining (34/92; 37.0%) had non-inflammatory diseases. Eczema (13/92; 14.1%) and androgenic alopecia (11/92; 12.0%) were primary diseases of each group, respectively.

The total scores of the FDLQI ranged from 0 to 24. Fig 1 shows the percentage of each response to each item. The responses to most items (except burden of care and extra expenditure) were not at all/not relevant, and 'a little'. The burden of care was the most frequently reported problem of family members. The minimum, maximum, and median scores of each questionnaire are shown in Table 2. The median total score of DLQI and FDLQI was equal. Comparison of total scores between inflammatory and non-inflammatory diseases, the median total score of DLQI score of patients with inflammatory diseases (score = 6) was significantly higher than that of patients with non-inflammatory diseases (score = 3) (P < 0.03). However, the median total score of FDLQI (score = 4) with inflammatory disease was lower than that of patients with noninflammatory diseases (score = 5.5) but there was no statistical significance (P = 0.840) (data not shown).

Table 3 shows the correlations between FDLQI and other instruments. As expected, there was a high correlation between FDLQI and GQoLF ($r_s = 0.695$, P < 0.001). The correlation between FDLQI and the severity of the disease of the patients as assessed by family members was moderate ($r_s = 0.578$, P < 0.001). No and weak correlations were found between FDLQI, DLQI, GQoLP, and the severity of the diseases of the patients as assessed by the patients themselves and the physicians.

The reliability of internal consistency according to the Cronbach alpha scale was 0.84 and this was not significantly improved by deleting individual items (0.81-0.84) (Table 4). Regarding the reliability of the test-retest, there were 79 family members who responded to the FDLQI retest. The intraclass correlation value for the total FDLQI score was 0.85 which indicated good reproducibility. The difference scores of the test and retest ranged from 0 to 7 with a mean score of 1.16 (SD = 2.4).

DISCUSSION

The burden of skin disease is defined into three dimensions: "now", "long-term" and "family members". 16 The first two affect patients, while the third dimension causes a burden to partners and family members. As the patient is the center, the first two dimensions have been extensively explored, whereas there are relatively limited data for the third dimension. A systematic review of dermatology-specific instruments to evaluate the impact of dermatological conditions on family and caregivers found that there were nine instruments. Eight of them are specific instruments for dermatologic diseases (4 for atopic dermatitis, 2 for psoriasis, 1 for epidermolysis bullosa acquisita, 1 for ichthyosis). Only one of them is the generic questions for dermatologic diseases, the FDLQI.¹⁷ The FDLQI has been used in family members of patients with epidermolysis bullosa³, atopic dermatitis^{10,18}, psoriasis^{19,20}, vitiligo^{21,22}, leg ulcers²³, and pemphigus.²⁴ One advantage of FDLQI is that it can be used to compare the QoL of family members under different skin conditions.

In this study, the total FDLQI score ranged from 0 to 24, with a score of 0 reported in 2% of the family members. This demonstrated that there may be no floor or ceiling effect in the Thai version of FDLQI. However, to our knowledge, there are no standard criteria for floor and ceiling effects. McHorney et al. 25 proposed that both effects should be less than 15% and this was supported by other studies^{26,27}, while other studies proposed that number should be 25%. 28,29 The median total score of DLQI and FDLQI in our study was 4.5 out of the maximum score of 30, which was quite low. These corresponded to those of the United Kingdom⁶ and Japan.⁸ The reason may be that all the studies were carried out in the outpatient clinic where most patients tend to have mild to moderate disease severity. Additionally, the median duration of the disease of the patients in this study was 12 months. Sajedianfard et al. reported that longer disease duration and more recurrences could decrease the FDLQI score.²⁴

The construct validity of the FDLQI was shown by a strong and moderate positive correlation with GQoLF and the severity of the disease of the patients rated by

TABLE 1. Demographic data of patients and their family members

Demographic data	N (%)
Family Members (N=100)	
Sex	
Female	70 (70.0)
Male	30 (30.0)
Mean age ± SD (years)	43.5 ± 12.1
Relation with the patient	
Parent	31 (31.0)
Spouse/partner	27 (27.0)
Sibling	14 (14.0)
Son/daughter	28 (28.0)
Marital status	
Single	31 (31.0)
Married	65 (65.0)
Divorced/widowed/separated	4 (4.0)
Occupation	, ,
Employed	74 (74.0)
Retired	5 (5.0)
Housewife	11 (11.0)
Student	6 (6.0)
Unemployed	4 (4.0)
Educational status	(113)
Primary school	8 (8.0)
Secondary school	28 (28.0)
Vocational	9 (9.0)
University	65 (65.0)
Patients (N=92)*	33 (33.3)
Sex	
Female	20 (44 2)
Male	38 (41.3)
	54 (58.7) 42.8 ± 21.0
Mean age ± SD (years)	
Median duration of disease (P25, P75) (months)	12 (2.3, 36.0)
Diseases	F0 (C0 0)
Inflammatory	58 (63.0)
Eczema	13 (14.1)
Urticaria	8 (8.7)
Acne	6 (6.5)
Psoriasis	5 (5.4)
Abscess	3 (3.3)
Seborrheic dermatitis	3 (3.3)
Granuloma	3 (2.2)
Pityrosporum folliculitis	2 (2.2)
Insect bite reaction	2 (2.2)
Othersa	13 (14.1)
Non-inflammatory	34 (37.0)
Androgenic alopecia	11 (12.0)
Alopecia areata	8 (8.7)
Vitiligo	3 (3.3)
Post inflammatory hyperpigmentation	2 (2.2)
Others ^b	10 (10.9)

^{*}One patient could be accompanied by more than one of their family members

^aatopic dermatitis, candidiasis, chelitis, chronic paronychia, discoid lupus erythematosus, insect bite reaction, kaposi hemagioendothelioma, lichen simplex chronicus, lupus profundus, pyoderma gangrenosum, rosacea, sporotrichosis, *systemic lupus erythematosus*, urticarial vasculitis

 $^{^{\}mathrm{b}}$ aqugenic pruritus, basal cell carcinoma, chronic arsenism, dermatofibroma, filler complication, hyperhydrosis, keloid, melasma, onychomychosis, pearly penile papules

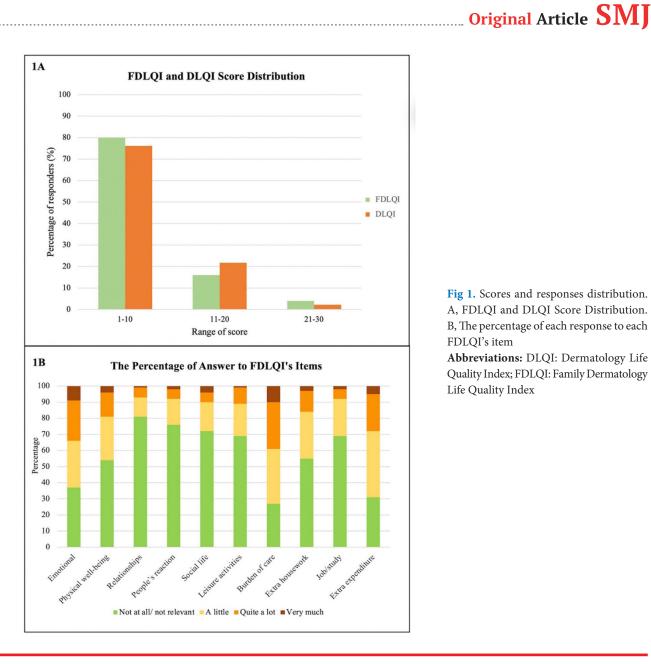


Fig 1. Scores and responses distribution. A, FDLQI and DLQI Score Distribution. B, The percentage of each response to each FDLQI's item

Abbreviations: DLQI: Dermatology Life Quality Index; FDLQI: Family Dermatology Life Quality Index

TABLE 2. Score of each questionnaire

Scores	Median total score (P25, P75)	Minimum score	Maximum score
Patient assessment			
DLQI (range 0-30)	4.5 (2.0, 10.0)	0	26
GQoLP (range 0-10)	3.0 (1.0, 5.0)	0	10
Global question of patient's disease severity (range 0-10)	4.0 (2.0, 5.0)	0	10
Family Members' assessment			
FDLQI (range 0-30)	4.5 (3.0, 10.0)	0	24
GQoLF (range 0-10)	2.0 (0.8, 5.0)	0	10
Global question of patient's disease severity (range 0-10)	4.0 (2.0, 5.0)	0	10
Physicians' assessment			
Global question of patient's disease severity (range 0-10)	3.0 (2.0, 5.0)	0	9

Abbreviations: DLQI; Dermatology Life Quality Index, FDLQI; Family Dermatology Life Quality Index, GqoLF; global QoL question for family members, GqoLP; global QoL question for patients, P; percentile

TABLE 3. Validity of Family Dermatology Life Quality Index (FDLQI) to other questionnaires

Scores	FDLQI	LQI	
	$r_{\rm s}$	<i>P</i> -value	
Patient's assessment			
DLQI	0.143	0.174	
GQoLP	0.284	0.006*	
Global question of patient's disease severity	0.231	0.027*	
Family member's assessment			
GQoLF	0.695	<0.001*	
Global question of patient's disease severity	0.578	<0.001*	
Physician's assessment			
Global question of patient's disease severity	0.318	0.002*	

^{*}A *p*-value of less than 0.05 indicates statistical significance

Abbreviations: DLQI; Dermatology Life Quality Index, FDLQI; Family Dermatology Life Quality Index, GqoLF; global QoL question for family members, GqoLP; global QoL question for patients

TABLE 4. Reliability analysis of the items of the Family Dermatology Life Quality Index (FDLQI)

Item number (FDLQI aspects)	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Emotional impact	0.604	0.823
Physical well-being)	0.697	0.813
Relationships	0.564	0.829
People's reaction	0.528	0.830
Social life	0.637	0.820
Leisure activities	0.553	0.828
Burden of care	0.441	0.841
Housework	0.372	0.844
Job/study	0.560	0.828
Financial burden	0.521	0.831

Abbreviation: FDLQI; Family Dermatology Life Quality Index

family members, respectively. This is in line with that of the Japanese version.⁸ As expected, the DLQI score of patients with inflammatory diseases was significantly higher than those with non-inflammatory diseases.^{9,30} However, this pattern was not consistent with the FDLQI results. The Thai version of the FDLQI showed high reliability, which corresponds to the original version and those of other countries, including Japan, Iran and

Ukraine.³¹ The Cronbach alpha was not significantly improved by removing any item of the FDLQI. Basra et al.⁶ and Higaki et al.⁸ also demonstrated that the FDLQI could be used to monitor the QoL of family members of patients with chronic skin diseases, such as eczema, psoriasis, and squamous cell carcinoma, etc. In a follow-up period of three to six months, the FDLQI could detect changes overtime.

Different culture, socioeconomic status, and educational levels could reflect different effects on the QoL of individuals.^{3,9,32,33} This could be one of the reasons that the correlation between the DLQI and the FDLQI score in Thailand and other countries was not very close. The DLQI was completed by a patient while the FDLQI was completed by a patient's family member. During the process of our study, some participants explained why they had rated those scores. For example, some patients had horrible acnes while their family members felt little or no effect on their lives. In contrast, some family members, especially parents and partners, felt very worried and used a lot of time to care for the skin diseases (ex. alopecia areata, basal cell carcinoma, and pearly penile papules) while the patients did not feel that it was the problem of their lives.

Some limitations of this study should be noted. First, it had a small sample size. Second, it was carried out only in only urban area of Thailand, where daily life, culture, socioeconomic status, and educational levels are much different from the rural area.^{34,35}

CONCLUSION

All three dimensions of skin burden must be taken into account to provide the best holistic care to a patient. FDLQI is one of the most widely used instruments for measuring the QoL of the dermatological patients. This study shows the acceptable validity and reliability of the Thai version of the FDLQI. It is a generic questionnaire that can be used to assess the QoL of family members of patients in any dermatological disease.

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Data Availability

The data used to support the findings of this study are included within the article.

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