Validation of the Malay Version of Autoimmune Bullous Disease Quality of Life (ABQOL) Questionnaire

E. W. Y. Yap[1], S. E. Choon[1], D. F. Murrell[2], K. E. Tey[1], Subramaniam P.[3]
[1]*Department of Dermatology, Hospital Sultanah Aminah Johor Bahru, Johor, Malaysia*
[2]*Murrell, Dedee F, Department of Dermatology, St George Hospital, Sydney, Australia*
[3]*Subramaniam, Premaa, Clinical Research Centre, Hospital Sultanah Aminah Johor Bahru, Malaysia*

Keywords: Autoimmune blistering disease, Quality of life, Malay

Abstract: Autoimmune blistering diseases (AIBD) represent a group of rare and chronic disorders with significant impact on quality of life (QoL). This study aimed to assess the validity and reliability of the Malay translation of the autoimmune bullous disease quality of life (ABQOL) questionnaire. This is a cross-sectional, questionnaire based study involving 75 patients with AIBD. The Malay version of ABQOL was produced by forward-backward translation of the original ABQOL. This was then administered to the recruited patients along with validated Malay versions of Dermatology Life Quality Index (DLQI) and Short Form Health Survey (SF-36) questionnaires. Validity was evaluated across a range of indices and reliability was assessed using internal consistency and test-retest methods. Internal consistency and test-retest reliability were high (Cronbach alpha= 0.940, r= 0.89). The Malay ABQOL had high correlation with the DLQI ($r=0.73$. $p<0.001$) and moderate correlation with the SF-36 ($r=0.50$, $p<0.001$). It also correlated moderately with PDAI and BPDAI disease severity scores ($r=0.47$, $p<0.001$, and $r=0.60$, $p= 0.002$). There was no significant difference in proportion of insensitive items between the ABQOL versus DLQI, and ABQOL versus SF-36. This study is limited by single study site with small sample size. We failed to include the whole spectrum of AIBDs. In conclusion, the Malay ABQOL is a valid and reliable tool for assessing QoL in AIBD patients.

1 INTRODUCTION

Autoimmune blistering diseases (AIBD) represent a group of rare and chronic condition which causes significant distress to those suffering from it. Clinical subtypes are dependent on the protein sites within the keratinocyte membrane and dermo-epidermal junction to which pathogenic auto-antibodies target. Regardless of subtype, AIBD cause enormous physical and psychological burden. (Sebaratnam *et al*., 2012)

Quality of life (QoL) assessment tools take into consideration patients' perspectives of their disease and treatment, their perceived need for health care, and their preferences for treatment and outcomes (Carr & Higginson, 2001). Being patient centred, aspects of patients' health status that are significant for the patient, but may not correlate with clinical severity can be better identified with the use of QoL assessment tools. In the past, QoL issues amongst patients have frequently been overlooked by clinicians due to various reasons, amongst which include time constrains and difficulty in interpreting as compared to laboratory parameters. However, this had begun to change as doctors and researchers started recognizing QoL as outcome measures in clinical trials (Renzi *et al.*, 2005). Over the past two decades, multiple attempts of evaluating AIBD's impact on quality of life (QoL) have been conducted in various parts of the world, mostly using generic and skin specific QoL questionnaires. Some of these include The Medical Outcome Study 36-item Short-form Survey (SF-36), Dermatology Life Quality Index (DLQI), Skindex and 12-item General Health Questionnaire (GHQ-12). Although all of these studies consistently reported negative QoL impact, the generic nature of these questionnaires may have limitations in capturing small changes affecting AIBD patients (Terrab *et al.*, 2005; Tabolli *et al.*, 2008; Paradisi *et al.*, 2012; Ghodsi *et al.*, 2012). This had led to the formulation of the Autoimmune Bullous Disease

Yap, E., Choon, S., Murrell, D., Tey, K. and P., S.
Validation of the Malay Version of Autoimmune Bullous Disease Quality of Life (ABQOL) Questionnaire.
DOI: 10.5220/0008150300400043
In *Proceedings of the 23rd Regional Conference of Dermatology (RCD 2018)*, pages 40-43
ISBN: 978-989-758-494-7

Quality of Life (ABQOL) questionnaire by the Australian panel of bullous experts, which is 17-item questionnaire looking at impact of autoimmune bullous disease on QoL (Sebaratnam *et al.*, 2013).
There is paucity of Malaysian data regarding AIBD impact on QoL which is partly contributed by the lack of validated AIBD-specific QoL instruments, particularly in the Malay language. Thus, the purpose of this study is to translate and adapt the ABQOL questionnaire into Malay and evaluate its validity and reliability in the Malaysian context.

2 METHODS

Patients Selection
Patients with histologically confirmed diagnosis of AIBD with self-professed proficiency in Malay language, at least 18 years old and able to give informed consent were recruited.

Translation of questionnaire
Permission to translate and use the ABQOL questionnaire was obtained from the authors who developed them.[8] The questionnaire was forward translated to Malay by a certified translation agency in Malaysia. The Malay questionnaire was then reviewed by a group of doctors who are proficient in the language to ensure cultural relevance. Following that, the translated questionnaire was given to a different translation agency which had no access to the original ABQOL to be back-translated. The back-translated version was then reviewed against the original by the original authors of the ABQOL. Discrepancies found between the forward and backward translations were resolved between the authors of the original ABQOL, principal investigator, and the 2 independent translation agencies.

Study procedures
Medical records of recruited patients were reviewed to verify diagnosis of AIBD, duration of disease and treatment regimens. This was followed by a complete physical examination evaluating severity and stage of AIBD. All patients recruited were asked to fill up 3 patient-administered questionnaires. The questionnaires involved are the validated Malay translations of:

a. Dermatology Life Quality Index (DLQI) (Finlay & Khan, 1994)
b. The Medical Outcome Study 36-item Short-form Survey (SF-36) (Ware & Sherbourne, 1992)
c. Treatment of Autoimmune Bullous Disease Quality of Life (ABQOL) (Sebaratnam *et al.*, 2013)

Twenty-one out of the 75 patients recruited were required to return to the clinic 10-14 days after completion of the questionnaires for a repeat TABQOL questionnaire.

3 RESULT

Seventy-five patients with AIBD were recruited from May 2014 to January 2015. Mean age of patients was 54.7±15.6 years. Twenty four patients were male and 51 were female. There were 30 Malay patients, thirty Chinese patients, fourteen Indian patients and 1 patient of other race. Thirty-five patients had pemphigus vulgaris, seventeen had pemphigus foliaceous and 23 had bullous pemphigoid. Patients' responses to questions within the Malay ABQOL were illustrated in Figure 2. Effects of gender, age group, disease duration, autoimmune bullous disease (AIBD) subtypes and treatment grade on ABQOL scores were summarised in Table 1. Measures of validity and reliability of the Malay translation of ABQOL is summarised in Table 2.

Table 1: Effects of gender, age group, disease duration, autoimmune bullous disease (AIBD) subtypes and treatment grade on ABQOL scores

		ABQOL scores (IQR)	p-value
Gender	Male	12.5 (22.0)	0.941
	Female	11.0 (15.0)	
Age	<55	18.0 (17.0)	**p<0.001**
	>55	9.0 (14.0)	
Disease Duration	<6 months	21.0 (26.0)	**p=0.012**
	>6 months	10.5 (14.0)	
AIBD subtype	Pemphigus	15.5 (16.0)	**p=0.001**
	Pemphigoid	7.0 (8.0)	
Ethnic group	Malay	18.5 (15.0)	**p<0.001**
	Chinese	7.5 (10.0)	
	Malay	18.5 (15.0)	p=0.562
	Indian	17.0 (28.0)	
	Chinese	7.5 (10.0)	**p=0.025**
	Indian	18.5 (15.0)	

p-values generated using Mann-Whitney test

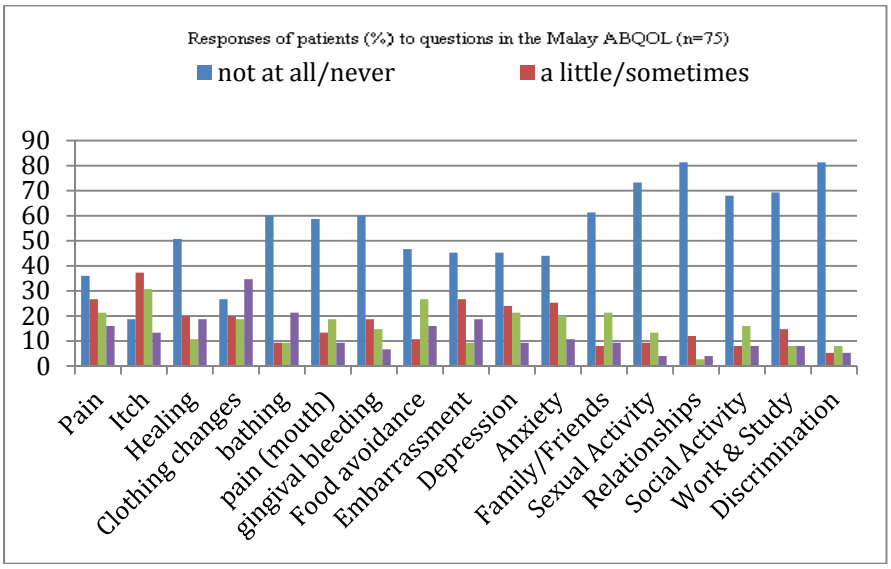

Figure 1 : Responses of patients (in percentage) to questions in the Malay ABQOL (n=75)

Table 2: Validity and reliability of the Malay translation of ABQOL

	Methods	Results
Face and content validity	Forward-backward translation, resolution of discrepancies by author and owner of the original questionnaire	Acceptable
Convergent validity	Correlation with PDAI Correlation with BPDAI Correlation with DLQI Correlation with SF-36	r= 0.47, p<0.001 r= 0.60, p=0.002 r= 0.73, p<0.001 r= -0.50, p<0.001
Discriminant validity (Fisher exact test)	DLQI SF-36	p= 0.758 p= 0.803
Internal consistency	Cronbach's alpha	α= 0.940, p<0.001
Test-retest reliability	ICC	r=0.89

4 DISCUSSION

A very high level of internal consistency and test-retest reliability was found, confirming findings of the English version of ABQOL (Sebaratnam *et al.*, 2013). The Malay ABQOL correlated highly with the DLQI but moderately with the SF-36. In both the pemphigus and pemphigoid group of patients, the ABQOL correlated moderately with disease severity. these results suggested that the degree to which patient's QoL was affected may not be dependent on clinical severity alone. Other factors contribute as well, including patient demographic characteristics, the natural history and site of skin disorders, and time to diagnosis (Tabolli *et al.*, 2008).

Unlike the results of the original authors, who had proven that the English ABQOL questionnaire is more sensitive than the DLQI and SF-36 in capturing the effects on QoL caused by changes in the clinical status (Sebaratnam *et al.*, 2013), we found all 3 tools equally good. There were 10 insensitive items in the Malay version of ABQOL, which is 3 items more compared to the original version of ABQOL. Questions pertaining to sexual activity, interpersonal relationships and workplace or school discrimination had the highest percentage of respondents with scores of zero (73.3%, 81.3% and 81.3% respectively). We felt the Asian culture may have played a role here. Sex and sexuality is not comfortably discussed amongst many Asians (Nicolosi *et al.*, 2004). Besides, many Asians emphasises the importance of family harmony and interpersonal relationships, and the high value of education and hard work. Saving face – the ability to preserve the public appearance of the patient and family for the sake of community propriety is extremely important to most Asian groups (Kramer *et al.*, 2002). This may have accounted for the low scores of these questions.

5 CONCLUSION

The Malay version of AABQOL is a valid and reliable tool in measuring impact of AIBD on patient's quality of life (QoL).

ACKNOWLEDGEMENT

We would like to thank Persatuan Dermatologi Malaysia (PDM) for awarding a grant for this research.

REFERENCES

Carr, A.J., Higginson, I.J., 2001. Are quality of life measures patient centred? *BMJ (Clinical research ed.)* 322, 1357–60. doi:10.1136/bmj.322.7298.1357

Finlay, A.Y., Khan, G.K., 1994. Dermatology Life Quality Index (DLQI) - A simple practical measure for routine clinical use. *Clinical and Experimental Dermatology*, *19,* pp. 210–216. doi:10.1111/j.1365-2230.1994.tb01167.x

Ghodsi, S.Z., Chams-Davatchi, C., Daneshpazhooh, M., Valikhani, M., Esmaili, N., 2012. Quality of life and psychological status of patients with pemphigus vulgaris using Dermatology Life Quality Index and General Health Questionnaires. *Journal of Dermatology, 39*, pp. 141–144.

Kramer, E.J., Kwong, K., Lee, E., Chung, H., 2002. Cultural factors influencing the mental health of Asian Americans. *Western Journal of Medicine, 176*, pp. 227–231.

Nicolosi, A., Jr., E.D.M., Villa, M., Glasser, D.B., 2004. A population study of the association between sexual function, sexual satisfaction and depressive symptoms in men. *Journal of affective disorders*, *82*, pp. 235–243. doi:http://dx.doi.org/10.1016/j.jad.2003.12.008

Paradisi, A., Cianchini, G., Lupi, F., Di Pietro, C., Sampogna, F., Didona, B., Pagliarello, C., Tabolli, S., Abeni, D., 2012. Quality of life in patients with pemphigus receiving adjuvant therapy. *Clinical and Experimental Dermatology*, *37*, pp. 626–630. doi:10.1111/j.1365-2230.2011.04282.x

Renzi, C., Tabolli, S., Picardi, A., Abeni, D., Puddu, P., Braga, M., 2005. Effects of patient satisfaction with care on health-related quality of life: A prospective study. *Journal of the European Academy of Dermatology and Venereology, 19*, pp. 712–718. doi:10.1111/j.1468-3083.2005.01301.x

Sebaratnam, D.F., Hanna, A.M., Chee, S.N., Frew, J.W., Venugopal, S.S., Daniel, B.S., Martin, L.K., Rhodes, L.M., Tan, J.C.K., Wang, C.Q., Welsh, B., Nijsten, T., Murrell, D.F., 2013. Development of a quality-of-life instrument for autoimmune bullous disease: The autoimmune bullous disease quality of life questionnaire. *JAMA Dermatology, 149*, pp. 1186–1191. doi:10.1001/jamadermatol.2013.4972

Sebaratnam, D.F., McMillan, J.R., Werth, V.P., Murrell, D.F., 2012. Quality of life in patients with bullous dermatoses. *Clinics in Dermatology*, *30*, pp. 103–107. doi:10.1016/j.clindermatol.2011.03.016

Tabolli, S., Mozzetta, A., Antinone, V., Alfani, S., Cianchini, G., Abeni, D., 2008. The health impact of pemphigus vulgaris and pemphigus foliaceus assessed using the Medical Outcomes Study 36-item short form health survey questionnaire. *The British journal of dermatology, 158,* pp. 1029–34. doi:10.1111/j.1365-2133.2008.08481.x

Terrab, Z., Benchikhi, H., Maaroufi, A., Hassoune, S., Amine, M., Lakhdar, H., 2005. [Quality of life and pemphigus]. *Annales de dermatologie et de venereologie* , *132*, pp. 321–328.

Ware, J.E., Sherbourne, C.D., 1992. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Medical care, 30*, pp. 473–83. doi:10.1097/00005650-199206000-00002