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Malay translation and validation of the quality of life after brain injury (QOLIBRI) questionnaire for individuals with traumatic brain injury

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Abstract

Background & Objectives: The Quality of Life after Brain Injury (QOLIBRI) is a health-related quality of life (QOL) questionnaire for individuals with traumatic brain injury (TBI). The aim of this study was to translate and validate the Malay version of QOLIBRI (M-QOLIBRI). *Methods:* One hundred sixty-two individuals with TBI participated in this cross-sectional and validation study. Internal consistency, concurrent-criterion validity, construct validity, and test–retest reliability were assessed with Cronbach's alpha, Spearman's correlation coefficient, confirmatory factor analysis, and intraclass correlation coefficient (ICC). *Results:* M-QOLIBRI was proven reliable, with an overall alpha value of 0.911 and an ICC value of 1.00. The t-test result showed insignificant differences between the first and second administration of M-QOLIBRI ($t = 1.897$, $p > 0.05$). No significant correlation existed between the M-QOLIBRI score and patients' age ($r = -.111$, $p > 0.05$) and time since injury ($r = -.117$, $p > 0.05$). Factor analysis was used to check for the validity of the instrument. The KMO value in this study was acceptable (0.786), which proved that the sample size was adequate.
Conclusions: This study demonstrated that M-QOLIBRI is a valid and reliable tool to assess the health-related QOL after brain injury of Malaysian population.

Keywords: Outcome assessment, quality of life, traumatic brain injury

INTRODUCTION

Traumatic brain injury (TBI) is one of the most common causes of long-term disability worldwide. It is defined as a change in brain function or other evidence of brain pathology caused by an external force.[1] Individuals suffering from TBI experience physical, cognitive, emotional, and behavioral effects, and the accompanying deficits can cause activity limitations and participation restrictions, resulting in a lifetime disability. Long-term disability in this population may reduce daily life function, social integration, leisure activities, and quality of life (QOL).[2,3]

The World Health Organization defined QOL as "individual perception of their position in their life in the context of culture and value system in which they live and in a relation of their goals, expectation, standard and concern".[4] This definition includes personal values, happiness, life satisfaction, and spiritual well-being.[5] Therefore, QOL can measure the negative impacts of the disease on the patients and the effectiveness of a rehabilitation program and can be used as a reference point in life when making a difficult decision.[6] However, generic instruments that measure QOL may not capture the particular problems typically experienced by those with a specific condition, such as TBI. By contrast, disease-specific health-related QOL (HRQOL) instruments are targeted to a specific health condition and should only contain relevant items to a specific disease; these questionnaires can thus be particularly relevant in clinical settings.[7,8]

The QOL After Brain Injury (QOLIBRI) instrument is a disease-specific tool for assessing the HRQOL of individuals with TBI.[9] Since 2010,

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QOLIBRI has been translated and validated in Asian countries[10,11], European countries[8,12,13,14,15], and Australia[16] and has been widely used in international studies.[17] This instrument has good psychometric properties and is reliable to measure the HRQOL of TBI populations.[8,9,15-20] This tool assesses six dimensions of HRQOL in accordance with six subscales (satisfaction: cognition, self, daily life and autonomy, and social relationships; feeling bothered: emotions and physical problems). QOLIBRI applies to individuals with TBI of all severities and at all time points after the injury.

QOLIBRI has been translated into several languages. Nevertheless, it has not been translated and validated for Malaysian population. The national language in Malaysia is Malay; therefore, a Malay version is more suitable for use in Malaysian population to evaluate TBI survivors' HRQOL better. This study aimed to translate the QOLIBRI questionnaire into the Malay language and investigate its main psychometric properties.

METHODS

Malay translation of QOLIBRI

The translation process was conducted in five phases. First, the initial direct translation from the English version of QOLIBRI to the Malay language was performed by an independent bilingual translator from the Malaysian Institute of Translation and Books. Second, clinical experts in TBI management and rehabilitation evaluated and validated the content of the translated Malay version. These experts consisted of three rehabilitation physicians, four physiotherapists, and two occupational therapists. The corrections and changes made were documented. Third, the content validity was measured to ensure that every item in the instrument is relevant and represents the targeted construct for assessment purposes.

Fourth, the backward translation from the Malay version of QOLIBRI to the English language was performed by a language expert. Lastly, the same clinical experts were gathered again to compare the backward translation with the original questionnaire to ensure the similarity of the translated content. No other changes were made apart from the language. All the subscales and Likert scale remained the same.

The Malay translation of QOLIBRI (M-QOLIBRI) was then administrated to 35 patients with TBI in Malaysian population as a part of the pilot test. This administration was to ensure good comprehension of each question in the questionnaires among the TBI patients. The data were then analyzed using Cronbach's alpha to ensure the reliability of the M-QOLIBRI questionnaire.

Study population

A total of 162 patients with mild to severe TBI participated in this cross-sectional study. The study participants were recruited from three public hospitals. All the participants were recruited in accordance with the following inclusion criteria: i) confirmed diagnosis of TBI by the attending neurosurgeon or physician, ii) conscious, cooperative, and able to understand and answer the questionnaire, iii) aged between 18 and 65 years old at the time of questionnaire administration, and iv) time since the injury of at least 3 months. Participants were excluded if they had other neurological problems, current or preinjury psychiatric history (based on the available medical report), ongoing severe drug or alcohol addiction, and concomitant terminal illness or any other medical conditions that would negatively affect the QOL.

During the recruitment phase, 221 participants were screened in the medical rehabilitation specialist clinics in the three hospitals from January 2019 to November 2019. One hundred seventy-eight participants were eligible to participate after excluding 43 participants. Another 16 participants refused to participate due to time constraint, and only 162 participants provided written informed consent.

QOLIBRI

The QOLIBRI questionnaire consists of 37 items and is divided into 2 parts.[9] Part A concerns the level of life satisfaction, which consists of four domains: cognition, self, daily life and autonomy, and social relationships. Part B focuses on the discomfort and feeling bothered, consisting of two domains: emotions and physical problems. The Likert scale in part A is rated from 1 to 5, with 1 = "not satisfied at all" and 5 = "very satisfied." In part B, the Likert scale is also rated from 1 to 5, with 1 = "very bothered" and 5 = "not bothered at all." Therefore, the possible total score for QOLIBRI is between "0" and "100," where "0" is the worst QOL, and "100" is the best QOL.

Statistical analysis

The statistical analysis in this study was conducted

using IMB SPSS Statistics version 22.0 software. The total M-QOLIBRI score was measured similarly using the steps described in the original English version. The response was summed up and divided by the 37 questionnaire items to obtain the mean value of the score. The mean value was then subtracted to 1 and multiplied by 25 to acquire the score of M-QOLIBRI. A score of "0" depicted the worst QOL, and "100" was the best QOL.

For the process of M-QOLIBRI validation, factor analysis using principal component analysis (PCA) was utilized together with reliability test and test–retest reliability. The content validity index (CVI) was measured to ensure the validity of the questionnaire. The reliability test was performed using Cronbach's alpha to ensure that the questionnaire is reliable and can be implemented in Malaysian population. The process of determining test–retest reliability involved the use of the intraclass correlation coefficient (ICC) to measure the consistency of the patients' answers 2 weeks after the first administration. In addition, the t-test result was calculated to support the ICC score and ensure the reliability of M-QOLIBRI.

Ethical approval

The ethical approval for this research was obtained from the Institutional Review Board. The participants provided written informed consent.

RESULTS

Participants' characteristics

A total of 162 TBI patients participated in this study. One hundred thirty-eight of them (85.2%) were male, and the rest were female (18.4%). Most of the participants were married (51.9%), of Malay ethnicity (66.7%), and Muslim (67.9%). The participants' demographic and clinical characteristics are shown in Table 1. The majority of the participants acquired TBI from MVA (n=128, 79%). Most of the participants had severe TBI (n=128, 72.8%) and, physically, did not require the usage of walking aids to walk (n=114, 70.4%).

Content Validity Index (CVI)

The measurement for CVI was conducted with nine clinical experts. Expert panels agreed that all items in M-QOLIBRI and the overall questionnaire do not require any changes and can be implemented on Malaysian population. The result showed excellent values, with the I-CVI values for all items higher than 0.79 (I-CVI = 0.89). Table 2 presents the CVI values for M-QOLIBRI.

Reliability of M-QOLIBRI from the Pilot Test

Thirty-five patients participated in this process, and the data were analyzed using Cronbach's alpha. α value was 0.911 for the overall M-QOLIBRI score (Table 3). Each domain reliability was considered good and acceptable, with an alpha value score above 0.7 for all domains. This result indicated that the M-QOLIBRI questionnaire is reliable and can be utilized to measure the level of QOL in Malaysian TBI patients.

Table 4 shows the mean scores of the 6 subscales in M-QOLIBRI 1) Cognitive, 2) Self, 3) Daily life and autonomy, 4) Social relationship, 5) Emotion, and 6) Physical. All the scales in M-QOLIBRI have a normal distribution which is in the range of +2. the 'Physical' subscale scored the least when compared to the others (M = 51.54, SD = 23.228), followed by 'Emotion' (M = 54.94, SD = 22.326). This shows that almost all participants were feeling bothered by their emotional and physical limitation status. All the other domains, (Cognitive, Self, Daily life and autonomy and Social relationship) have higher mean scores than the overall QOL mean score.

Test–retest reliability of M-QOLIBRI

The result demonstrated the good reliability of all domains in M-QOLIBRI. The overall M-QOLIBRI presented an ICC value of 1.000 (Table 5). The second test performed to verify the reliability was t-test. The M-QOLIBRI scores in the first and second administration (with an interval of 2 weeks) were calculated through paired sample t-test with α of .05. The result indicated that no significant difference existed between the first and second M-QOLIBRI scores, t (39) = –1.897, $p > .05$. The results are shown in Table 6.

Factor analysis

PCA was conducted for 37 items in M-QOLIBRI, forcing either 1 or 6 components. The factor rotation was set at promax, with a kappa value equal to 4. The Kaiser–Meyer–Olkin (KMO) test was performed in this study and showed a "middling" value (KMO = 0.786), implying an acceptable sample size. Bartlett's test of sphericity

Table 1: Demographic and clinical characteristic

Variable	N (162)	%	Mean (SD)
Age (years) (min-max = 18-65)			34.06 (11.604)
≤34 (18-34)	98	60.5	
≥35 (35-65)	64	39.5	
Gender			
Male	138	85.2	
Female	24	14.8	
Marital status			
Single	74	45.7	
Married	84	51.9	
Divorcee	4	2.5	
Race			
Malay	108	66.7	
Chinese	10	6.2	
Indian	42	25.9	
Others	2	1.2	
Religion			
Muslim	110	67.9	
Buddhism	6	3.7	
Hindu	38	23.5	
Others	8	4.9	
Occupational status			
Student	6	3.7	
Working	52	32.1	
Not working / retired	104	64.2	
Time since injury			
3 - 24 months	44	27.1	
>2 – 5 years	88	54.4	
>5 - 10 years	16	9.9	
above 10 years	14	8.6	
Severity of TBI			
Mild	16	9.9	
Moderate	28	17.3	
Severe	118	72.8	
Aetiology of TBI			
MVA	148	91.4	
Fall from height	4	2.5	
Others	10	6.2	
Using walking aids for ambulation			
Yes	48	29.6	
No	114	70.4	

MVA = motor vehicle accident, SD = standard deviation, TBI = traumatic brain injury

was significant ($p < 0.000$). The factor loading cutoff was set to > 0.30, and the eigenvalue was set to 1. In the one-factor solution, all items in M-QOLIBRI had a satisfactory loading value (> 0.40), except for the "Sex life" item in the social relationship domain. Some participants did not answer this question, but they did not exceed two-thirds of the total participants. The missing value was computed as "0." In the six-factor solution, the "Partner" item in the social relationship domain had the highest value (.891) of all items. In the Emotion domain, all items had a high value (>

Table 2: Values of the I-CVI and S-CVI of the M-QOLIBRI

M-QOLIBRI ITEM	Relevant (rating 3 or 4)	Not relevant (rating 1 or 2)	I-CVI*	Interpretation
PART A	9	0	1	Excellent
Q. A1	9	0	1	Excellent
Q. A2	9	0	1	Excellent
Q. A3	9	0	0.89	Excellent
Q. A4	8	1	1	Excellent
Q. A5	9	0	1	Excellent
Q. A6	9	0	1	Excellent
Q. A7	9	0	1	Excellent
PART B				
Q. B1	9	0	1	Excellent
Q. B2	9	0	1	Excellent
Q. B3	9	0	1	Excellent
Q. B4	9	0	1	Excellent
Q. B5	9	0	1	Excellent
Q. B6	9	0	1	Excellent
Q. B7	9	0	1	Excellent
PART C				
Q. C1	9	0	1	Excellent
Q. C2	9	0	1	Excellent
Q. C3	9	0	1	Excellent
Q. C4	9	0	1	Excellent
Q. C5	9	0	1	Excellent
Q. C6	9	0	1	Excellent
Q. C7	9	0	1	Excellent
PART D				
Q. D1	9	0	1	Excellent
Q. D2	9	0	1	Excellent
Q. D3	9	0	1	Excellent
Q. D4	8	1	0.89	Excellent
Q. D5	8	1	0.89	Excellent
Q. D6	9	0	1	Excellent
PART E				
Q. E1	9	0	1	Excellent
Q. E2	9	0	1	Excellent
Q. E3	9	0	1	Excellent
Q. E4	9	0	1	Excellent
Q. E5	9	0	1	Excellent
PART F				
Q. F1	8	1	0.89	Excellent
Q. F2	9	0	1	Excellent
Q. F3	9	0	1	Excellent
Q. F4	9	0	1	Excellent
Q. F5	9	0	1	Excellent
37 item		**S-CVI/ Ave	0.99	Excellent

Note: *I-CVI: item-level content validity index, **S-CVI/Ave: scale-level content validity index. Total number of experts, (n=9). M-QOLIBRI = Malay version of Quality of Life after Brain Injury

Table 3: The internal consistency of M-QOLIBRI

Domain	α-value	SD	Frequency
Cognitive	0.800	4.925	35
Self	0.762	4.345	35
Daily life and autonomy	0.700	4.804	35
Social relationship	0.726	4.445	35
Emotion	0.846	4.780	35
Physical	0.789	4.699	35
Overall	0.911	20.320	35

M-QOLIBRI = Malay version of Quality of Life after Brain Injury, SD = standard deviation

Table 4: Mean scores of each domain of the M-QOLIBRI

Domain	Mean	SD	Range
Cognitive	61.16	17.171	14 – 96
Self	64.42	16.193	14 – 96
Daily life and autonomy	61.11	17.569	18 – 96
Social relationship	64.56	19.104	21 – 100
Emotion	54.94	22.326	0 – 100
Physical	51.54	23.228	0 – 100
Total M-QOLIBRI	59.80	14.626	23-94

MQOLIBRI = Malay version of Quality of Life after Brain Injury, SD = standard deviation

Table 5: Test-retest intra-class correlation of M-QOLIBRI

Domain	ICC	95% Confidence Interval	
		Lower	Lower
Cognitive	1.000	.999	1.000
Self	1.000	1.000	1.000
Daily life autonomy	1.000	1.000	1.000
Social relationship	.992	.984	.996
Emotion problem	1.000	1.000	1.000
Physical problem	.998	.997	.999
Overall M-QOLIBRI	1.000	.999	1.000

ICC = intra-class correlation, M-QOLIBRI = Malay version of Quality of Life after Brain Injury

Table 6: Comparing between the first and second administration of M-QOLIBRI after 2 weeks apart

	Mean	SD	95% Confidence Interval		*t*	*dt*	Sig
			Lower	Upper			
First administration score	57.09	17.581	- .489	.016	-1.897	39	.065
Second administration score	57.33	17.841					

M-QOLIBRI = Malay version of Quality of Life after Brain Injury, SD = standard deviation

0.70), except for the "Anger and depression" item (0.399). Table 7 displays the factor loading with promax rotation of M-QOLIBRI.

DISCUSSION

Up to this date, no available Malay translated version of QOLIBRI can be implemented for the Malaysian TBI population. Given the fact that TBI is one of the main causes of major disabilities in our young adult population, a reliable and validated instrument to measure QOL is highly needed. Thus, this study has produced a Malay version of QOLIBRI, which has been proven valid and reliable to assess QOL in people with

Table 7: Factor loading with promax rotation of M-QOLIBRI

Domain	Item	Commu-nalities h2	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
Cognitive	Concentration	**.563**	**.486**	.375				
	Express yourself	**.513**					.650	
	Remember	**.549**	**.459**	.347				
	Plan and problem solve	**.600**		.756				
	Decision	**.723**		.790			.328	
	Find way	**.565**	**.422**	.311				
	Speed of thinking	**.578**	**.713**					
Self	Energy	**.441**	.427	**.304**				
	Motivation	**.525**	.309	**.522**				
	Self-esteem	**.575**		**.792**				
	Way you look	**.503**		**.603**				
	Achievement	**.522**	.489	**.339**				
	Self-perception	**.679**		**.438**			.501	
	Own future	**.477**	.403	**.383**				
Daily life autonomy	Independence	**.527**						**.688**
	Get out and about	**.589**						**.635**
	Domestic activities	**.685**					.488	**.347**
	Run personal financial	**.627**	.347					**.342**
	Participation work	**.543**	.618					
	Social and leisure activity	**.482**				.462		
	In charge of life	**.524**	.702					
Social relationship	Affection towards others	**.602**				**.603**		
	Family members	**.691**				**.472**		
	Friends	**.567**		.457		**.375**		
	Partner	**.777**				**.891**		
	Sex life	**.368**				**.552**		
	Attitudes of others	**.552**	.357			**.466**		
Emotions	Loneliness	**.602**			**.724**		.365	
	Boredom	**.623**			**.704**			
	Anxiety	**.785**			**.760**			
	Depression	**.733**			**.720**			
	Anger/ aggression	**.594**			**.399**			
Physical	Slow / clumsiness	**.596**			.357		**.662**	
	Other injuries	**.683**			.400		**.618**	
	Pain	**.501**	.699					
	See / hear	**.593**	.633				**.311**	
	TBI effects	**.577**	.576					

Note: factor loading > .30
M-QOLIBRI = Malay version of Quality of Life after Brain Injury, TBI = traumatic brain injury

TBI in Malaysia. The processes of translation and validation of the Malay version of QOLIBRI (M-QOLIBRI) were conducted in accordance with previous studies.[8,15,18]

The characteristics of the TBI patients who participated in this study are consistent with those in the literature, with the majority being males, TBI due to MVA, and a lower mean age of younger than 40 years old. Although the participants were only recruited from three hospitals, these are the main referral hospitals in Malaysia for acute TBI management and rehabilitation.

PCA was adopted to validate M-QOLIBRI by following previous studies from Germany and Norway.[8,15] The result from one-factor loading indicated only two domains with an overall good fit item score (< 0.6). On the one hand, this result differed from that of the Norwegian study, with the first five domains showing an overall good fit. On the other hand, the study from Germany had a similar result to the Norwegian study, with the first five domains showing an overall good fit. The item score in the present study was weaker than those in the two other studies, although the present study presented a generally satisfying fit score for most items in the one-factor solution. Comparatively, this study had more items with a poor-fit score (score > 0.4).

Among the items with poor fit, the "Sex life" item in the "Social relationship" domain had the most undesirable score out of 37 items in the questionnaire (item score, 0.155). As a result, the present study portrayed a different finding from the Norwegian and German studies. The only explanation for this is that most participants, especially single and unmarried patients, did not complete the question. The sum of the factor loadings for the variable (communalities) in this study displayed a high value (more than 0.40), except for the "Sex life" item in the "Social relationship" domain (with a factor value of 0.368). This situation, however, was not observed in other studies. We speculated that this difference might be due to the unwillingness of most participants to answer the question on the satisfaction of their "Sex life." This question is considered a sensitive and private matter in the Malaysian cultural context. It is a taboo and culturally unacceptable for someone who is not legally married to discuss and talk about their sex life openly.

Nonetheless, the results from the present study and the Norwegian and German studies mentioned earlier presented some similarities. All the three studies showed a low score for the item "See/hear." The item with the highest score in the "Self" domain in our study and the Norwegian study was "self-esteem," and that with the lowest score was "energy." The other positive relationship domains were "Social relationship" with factor 4 and "Emotion" with factor 3. Although this study had more items with a poor-fit score, the result from the factor analysis showed that M-QOLIBRI is still a valid questionnaire.

The finding of this study verified that the M-QOLIBRI questionnaire is reliable and has good internal consistency. M-QOLIBRI showed a slightly higher ICC value than the QOLIBRI in a German study[15] and a Japanese study[11]. In this study, the test–retest reliability was excellent, both for the total score and for the individual domains of M-QOLIBRI (with an overall M-QOLIBRI ICC value of 1.000), except for two domains (0.992 for Social relationship and 0.998 for Physical problem). The Japanese study (overall QOLIBRI ICC = 0.90) showed excellent reliability with an ICC value of more than 0.75 (0.77–0.90). The lowest ICC value was for the "Physical problem" domain, which was similar to M-QOLIBRI with the lowest ICC score for "Physical problem". Different from the Japanese study, the German study (total QOLIBRI ICC = 0.91) showed the lowest ICC score for the "Emotion" (ICC = 0.72) domain. Apart from the "Emotion" domain, the rest of the domains showed an excellent ICC value (0.72–0.91).[15]

Lastly, a t-test was conducted to support the ICC test in ensuring the reliability of M-QOLIBRI. The findings in this study confirmed that no difference existed between the first and second administration of M-QOLIBRI. Thus, this instrument seems to be stable across time when no health changes occur. This result was similar to the result from an Israeli study[7,14], in which no significant differences were reported between two measurements. However, this result was different from that obtained by Siponkoski *et al*.[21], in which they reported having slight differences between the two measurements in the "Daily life and autonomy" and "Emotion" domains.

This study has some limitations. First, it did not consider the predictive factor that can or may influence the level of participants" QOL. Second, although the participants answered the questionnaire on their own, the presence of their carer nearby might have influenced them during the answering and understanding of the questions to some extent.

In conclusion, the translated Malay version of QOLIBRI (M-QOLIBRI) is ready to be

implemented in Malaysian population. The psychometric properties indicated that this Malay version of QOLIBRI is valid, consistent, and reliable. It can be used to understand the TBI survivors" level of QOL and, indirectly, the burden of TBI in this country. The M-QOLIBRI questionnaire is convenient and easy to understand. It also has the advantage of self-report without any help from family members or clinicians. The data obtained can assist clinicians to design a suitable rehabilitation treatment plan and use HRQOL as an indicator for health outcome in TBI survivors.

DISCLOSURE

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