# **ORIGINAL ARTICLE**

# Cross-cultural adaptation and validation of the Malay Adult cirrhosiS Knowledge Questionnaire (ASK-QM)

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#### ABSTRACT

Introduction: Cirrhosis is common in Malaysia, but no questionnaire in the local language (Malay) has been developed to assess patients' knowledge of this disease. This study aimed to adapt and validate the Malay Adult cirrhosiS Knowledge Questionnaire (ASK-QM).

Materials and Methods: ASK-QM was translated from English to Malay according to international guidelines. It was validated among cirrhotic patient who understand Malay language from two major liver centers in Klang Valley, Malaysia (University of Malaya and Hospital Selayang) from January 2021 to March 2022, at week 0 and 2. Patients with hepatic encephalopathy were excluded.

Results: 121 out of 132 patients with cirrhosis agreed to participate (response rate=91.7%). The overall median score of the ASK-QM was 54.5 [38.6-68.2] and the difficulty factor was 0.5 (range: 0.1-0.8 for each domain). Confirmatory factor analysis showed a good model fit with results of Comparative fit index (CFI) ranging from 0.836 to 1.000, whilst, the Tucker-Lewis index (TLI) ranged from 0.690 to 1.004 across all four domains. The root mean square error of approximation (RMSEA) value was reported from 0.000 to 0.100. For standardized root mean squared residual (SRMR) was from 0.008 to 0.015. Patients with tertiary education scored higher compared to those without (63.6 [45.5-77.3] vs 52.3 [36.4-63.6], p<0.05). The overall Kuder-Richardson (KR) coefficient was 0.761 indicating adequate internal consistency. Test-retest among 82 out of 121 patients (response rate=67.7%) demonstrated adequate reliability with eighteen out of 22 items having Wilcoxon signed-rank test values that were statistically not significant, p>0.005.

Conclusion: The ASK-QM was found to be a valid and reliable questionnaire for evaluating knowledge of liver cirrhosis amongst Malay-speaking adults.

#### **KEYWORDS**:

Cirrhosis, knowledge, questionnaire, adaptation, translation, validation study

#### INTRODUCTION

Liver cirrhosis is a condition of disruption of the liver parenchymal as a result of necrosis, regeneration, and diffuse fibrosis.<sup>1</sup> In 2019, liver cirrhosis was the 11th most common cause of death worldwide.<sup>2</sup> According to Global Burden of Disease, viral hepatitis B has been recognised as the main cause of chronic liver disease, including cirrhosis for the past 30 years.<sup>3</sup> This trend could be observed in Malaysia as well, where viral hepatitis B is still the main cause of liver cirrhosis, acute hepatitis-related death, and hepatocellular carcinoma.<sup>4,5</sup>

Knowledge about cirrhosis plays an important role in managing cirrhotic patients effectively.6 However, most studies showed that patients' knowledge about liver cirrhosis was still low.<sup>6-8</sup> Goldsworthy et al. reported that only 10% of cirrhotic patients were aware of the reason for the need for routine liver ultrasound and oesophageagastroscopy.7 Lack of patient knowledge regarding liver cirrhosis impacts a physician's clinical management, which may then leads to an increase in morbidity due to poor medication adherence and frequent re-hospitalizations.<sup>9-11</sup> An Australian study showed that many adults with viral hepatitis B were unaware of the risk of cirrhosis and hepatocellular carcinoma.<sup>12</sup> Patients with lower health literacy had significantly higher median Model for End-Stage Liver Disease (MELD) scores, which was linked to higher mortality and poorer outcomes.<sup>13</sup> In Malaysia, people who were older and had a lower education level or household income had a lower level of health literacy.<sup>14</sup>

To date, several questionnaires have been developed worldwide to evaluate patients' knowledge of liver cirrhosis.6,7,15,16 However, many of these questionnaires only assessed knowledge regarding clinical management and disease outcomes.<sup>67,15,16</sup> Hence, we developed and validated the Adult cirrhosiS Knowledge Questionnaire (ASK-Q) in English, which consisted of four domains: 1)selfunderstanding (5 items), 2)aetiology items), (5 3) complication (4 items), and 4) management of liver cirrhosis (8 items).17 The Kuder-Richardson coefficient was 0.760 indicated that the ASK-Q had good validity and reliability.<sup>17</sup> However, Malay is the national language of Malaysia, spoken by a most of its citizens, and spoken by the Austronesian family in Brunei. To date, not many questionnaires that assess the knowledge of liver cirrhosis exist in Malay. Hence, we aimed to cross-culturally adapt and validate the Malay version of ASK-Q to ensure it is both linguistically and culturally relevant for Malay-speaking

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populations, so that this questionnaire can be administered to a wider population around the Malay Archipelago.

#### MATERIALS AND METHODS

Cross-cultural adaptation of the Adult cirrhosiS Knowledge Questionnaire (ASK-Q) from English to Malay (ASK-QM)

The original English version of the ASK-Q which was developed and validated by our team, has been published and widely utilised in cirrhotic patient.<sup>17</sup> We have undertaken the task to translate into Malay language according to the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) guideline.<sup>18</sup> The production of a Malay version of ASK-Q followed a rigorous process involving forward and backward translation to ensure conceptual and cultural equivalence. The forward translation from English to Malay was conducted independently by a medical and nonmedical translator. The expert panel (consisting of four gastroenterologists/hepatologists and an academician with experience in the development and validation of questionnaires) reviewed and integrated the translations into a preliminary Malay version of ASK-Q. Similarly, backward translation from Malay to English was performed by another pair of medical and non-medical translators. Subsequently, a discussion of the expert panel, it resulted in a single culturally adapted Malay version of ASK-Q. The final version of the ASK-QM was pilot-tested among five Malay nativespeaking participants (60% men; 40% women) who were diagnosed with liver cirrhosis were asked to answer the ASK-QM. The aim was to assess the clarity, relevance, and content understanding of the ASK-QM. All participants completed the questionnaire without difficulty and mentioned that the statements were clear, easy to understand and culturally appropriate. The average time taken to complete the questionnaire was approximately eight minutes. Hence, no modifications were made and version 4 of the ASK-QM was used as the final questionnaire (Figure 1).

# Validation of the Malay Adult cirrhosiS Knowledge Questionnaire (ASK-QM)

The ASK-QM was then validated at two tertiary hospitals in Malaysia: University of Malaya Medical Centre, Kuala Lumpur, and Hospital Selayang, Selangor from January 2021 to March 2022. Patients who had liver cirrhosis with or without decompensation, aged ≥18 years old, who could understand Malay were recruited from the hepatology clinics, endoscopy rooms, or wards. Liver cirrhosis was diagnosed by imaging (ultrasonography or computed tomography scan), histopathology, or transient elastography (Fibroscan®). Causes of liver cirrhosis include chronic viral hepatitis (hepatitis B and C), alcoholic liver disease, non-alcoholic fatty liver disease (NAFLD), autoimmune hepatitis, methotrexate-related liver fibrosis, and cryptogenic liver cirrhosis. Sample size was calculated based on the recommended ratio of 5 participants to each item in the questionnaire, to perform factor analysis.<sup>19</sup> Since the ASK-QM has 22 items, the sample size required was 110 patients.

#### Patient characteristics

A baseline demographic form was used to collect patient demographic details such as age, gender, ethnicity, duration

of diagnosis, aetiology of liver cirrhosis, educational background, and severity of liver cirrhosis (using the Child-Pugh score).<sup>20</sup>

#### Malay Adult cirrhosiS Knowledge Questionnaire (ASK-QM)

The ASK-QM consists of four domains: self-understanding (5 items), aetiology (5 items), complications (4 items), and management of cirrhosis (8 items) with a total of 22 items. Each item had three options (yes, no and don't know). A correct response was awarded one point while 0 points was allocated for incorrect and "don't know" responses. The total score of each domain was calculated and converted to percentages (%). A higher score indicated higher knowledge of liver cirrhosis.

#### Procedure

Patients were recruited via convenience sampling. The purpose of the study was explained to patients using a participant information sheet. For those who agreed to participate, written informed consent was obtained. Patients were asked to fill the baseline demographic form and the ASK-QM at baseline. Two weeks later, the researcher contacted each patient via phone for a retest of the ASK-QM.

#### Ethical approval

The study was approved by the Medical Research Ethics Committee of the University Malaya Medical Centre (MREC ID NO: 2020827-9020) and National Medical Research Register (MERC ID NO: NMRR-20-3295-56800)

#### Data analysis

Data were analyzed using the Statistical Package for Social Sciences (SPSS) version 26 Armonk, NY: IBM Corp.) and SPSS AMOS version 23 (Armonk, NY: IBM Corp.). Since data were not normally distributed, non-parametric tests were used. Categorical variables were expressed as frequencies with percentages (%), whilst continuous data were presented as median with inter-quartile range. Non-parametric tests were used to analyse the data. Statistical significance was assumed at a p-value of <0.05.

#### Construct validity

The difficulty factor of the ASK-QM was calculated using the number of patients who answered the item correctly, divided by the total number of patients: 0.8-1.0 was classified as too easy, 0.3-0.8 as moderate, and  $\leq$  0.3 as too hard.21 An ideal questionnaire should have a difficulty factor ranging from 0.3 to 0.7.<sup>21</sup>

Confirmatory factor analysis (CFA) was conducted to assess the factor structure of ASK-QM. There are various criteria for the model of fit indices. Comparative fit index (CFI) ranges from 0 to 1. The cut-off point of good fit is 0.9, while > 0.95 indicates a perfect fit.<sup>22</sup> Tucker–Lewis index (TLI) values with > 0.90 could ruminate as a good fit, 0.80-0.90 a marginal fit, and <0.80 a poor fit.<sup>23</sup> For standardized root mean squared residual (SRMR) values: <0.08 is generally considered a good model fit.<sup>24</sup> The root mean square error of approximation (RMSEA) values of <0.05 are good, 0.05 to 0.08 are considered acceptable, and marginal results from 0.081 to 0.10, and > 0.1 is considered poor.<sup>25</sup>

Characteristic	n=121 (%)
Gender	
Male	72 (59.5)
Female	49 (40.5)
Median age in years, (IQR)	62.0, (55.5-69.0)
Ethnicity	
Malay	58 (47.9)
Chinese	41 (33.9)
Indian	18 (14.9)
Others*	4 (3.3)
Education level	
Primary	39 (32.2)
Secondary	55 (45.5)
Tertiary	27 (22.3)
Aetiology of liver cirrhosis **	
Viral hepatitis B	45 (35.2)
Viral hepatitis C	27 (21.1)
Non-alcoholic fatty liver disease	25 (19.5)
Alcoholic liver disease	13 (10.2)
Autoimmune hepatitis	8 (6.3)
Cryptogenic liver disease	5 (3.9)
Primary biliary cholangitis	4 (3.1)
Graft cirrhosis	1 (0.8)
Child-Pugh Class (Child-Pugh score)	
A (5-6)	65 (53.7)
B (7-9)	37 (30.6)
C (10-15)	19 (15.7)

#### Table I: Demographic and clinical characteristics of patients

• \* Filipino – 2 ; Indonesian – 2

• \*\* Some patients had more than 1 aetiology of liver cirrhosis.

Discriminative validity assesses if the questionnaire is able to discriminate between two distinct groups.<sup>26</sup> We hypothesized that patients with tertiary education would have higher knowledge scores compared to those patients without. Chi-square tests were used for individual items in each domain, while the Mann-Whitney U-test was used for continuous data (domain scores and total test scores).

#### Reliability

Reliability was assessed by evaluating the internal consistency of the ASK-QM. The response options in the ASK-QM was dichotomous (meaning that patients either answered the items correctly or incorrectly). Hence, Kuder-Richardson was used to calculate internal consistency.26,27 Kuder-Richardson values are classified as follows:  $\geq 0.80$ - high internal reliability,  $\geq 0.51$ -0.79- adequate internal reliability,  $\leq 0.50$ - unacceptable internal reliability.<sup>27</sup>

Kappa was used to assess the reliability of the ASK-QM at testretest for individual items, whilst the Wilcoxon signed ranked test was used for continuous data (domain scores and total test scores).<sup>28</sup> Kappa values can be classified as follows: >0.80 as a very good agreement; 0.61-0.80 as good agreement; 0.41-0.60 as moderate agreement; 0.21-0.4 as fair agreement and below as poor agreement.<sup>29</sup>

#### RESULTS

A total of 121 out of 132 patients with liver cirrhosis agreed to participate in the study (response rate = 91.7%). Majority were male (59.5%), completed secondary education (45.4%),

and had a median age of 62 years. The main aetiology of liver cirrhosis was viral hepatitis B (35.2%), followed by viral hepatitis C (21.1%) and non-alcoholic fatty liver disease (19.5%), with Child-Pugh class A (53.7%) scores (Table I).

#### Confirmatory factor analysis

CFA revealed that the CFI ranged from 0.836 to 1.000, whilst, the TLI ranged from 0.690 to 1.004 across all four domains. The RMSEA value was reported from 0.000 to 0.100. SRMR was from 0.008 to 0.015. CFI showed an adequate fit in the domains A (Self-understanding), B (Aetiologies), and D (Management) with a value of 0.845, 0.836, and 0.857 respectively. TLI showed mediocre fit in domains A, B, and D with values of 0.690, 0.671, and 0.799 correspondingly. Domain C (Complication) indicated a perfect fit for CFI (1.000) and TLI (1.004). Generally, SRMR indicated a good fit though across all domains (values of 0.015, 0.012, 0.008, and 0.014). RMSEA showed acceptable fit in domains A, C, and D (0.080, 0.000, and 0.042). Domain B indicated a poor fit with an RMSEA value of 0.100.

#### Validity

The overall difficulty factor of the ASK-QM was 0.5 (range: 0.1 to 0.8). A total of 9/22 (40.9%) items were "easy" (score $\geq$ 0.7) 11 out of 22(50.0%) items were "moderately easy" (scored between 0.3-0.7) and 2 out of 22(9.1%) items were "difficult" (score of <0.3). The overall total median score was 54.5 [38.6-68.2]. Patients had the highest median score in the domain of "self-understanding" (60.0 [40.0-80.0]), followed by "aetiology" (60.0 [40.0-80.0]), "complications" (50.0 [25.0-75.0]) and "management of cirrhosis" (50.0 [25.0-62.5]).

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Table II:

Domain	Items	Difficulty factor (n=121)	Total knowledge score (n=121) Median [IQR]	Tert	iary education (n=	27)	Sec	ondary education a below (n=94)	and	Chi2 Test/ Mann- Whitney U-test
				Mean ± SD	Median [IQR]	No. of Correct responses [n (%)]	Mean ± SD	Median [IQR]	No. of Correct responses [n (%)]	p-value
Self-understanding										
of liver cirrhosis	A1	0.4		$0.5 \pm 0.5$	1.0	15 (55.6)	$0.4 \pm 0.5$	0.0	38 (40.4)	0.163
	A2	0.5		$0.6 \pm 0.5$	1.0	15 (55.6)	$0.5 \pm 0.5$	0.0	49 (52.1)	0.753
	A3	0.7		$0.7 \pm 0.5$	1.0	18 (66.7)	$0.7 \pm 0.5$	1.0	68 (72.3)	0.567
	A4	0.7		$0.6 \pm 0.5$	1.0	15 (55.6)	$0.7 \pm 0.5$	1.0	68 (72.3)	0.098
	A5	0.5		$0.7 \pm 0.5$	1.0	19 (70.4)	$0.5 \pm 0.5$	0.0	45 (47.9)	0.038*
	Domain	0.6	60.0 [40.0-80.0]	$60.8 \pm 32.1$	60.0 [40.0-80.0]		57.0 ± 26.1	60.0 [40.0-80.0]		0.371
	score (%)									
Aetiologies of	B1	0.7		$0.7 \pm 0.4$	1.0	20 (74.1)	$0.7 \pm 0.4$	1.0	69 (73.4)	0.945
liver cirrhosis	B2	0.7		$0.7 \pm 0.4$	1.0	20 (74.1)	$0.7 \pm 0.5$	1.0	64 (68.1)	0.552
	B3	0.8		$0.8 \pm 0.4$	1.0	22 (81.5)	$0.7 \pm 0.4$	1.0	70 (74.5)	0.452
	B4	0.4		$0.4 \pm 0.5$	0.0	12 (44.4)	$0.4 \pm 0.5$	0.0	37 (39.4)	0.635
	B5	0.3		$0.3 \pm 0.5$	0.0	9 (33.3)	$0.3 \pm 0.5$	0.0	27 (28.7)	0.644
	Domain	0.6	60.0 [40.0-80.0]	61.4 ± 29.8	60.0 [40.0-80.0]		56.8 ± 26.2	60.0 [40.0-80.0]		0.277
	score (%)									
Complications	C1	0.7		$0.8 \pm 0.4$	1.0	22 (81.5)	$0.7 \pm 0.5$	1.0	61 (64.9)	0.102
of liver cirrhosis	5	0.6		$0.8 \pm 0.4$	1.0	21 (77.8)	$0.6 \pm 0.5$	1.0	53 (56.4)	0.044*
	ლ	0.3		$0.4 \pm 0.5$	0.0	10 (37.0)	$0.3 \pm 0.5$	0.0	31 (33.0)	0.695
	C4	0.7		$0.7 \pm 0.5$	1.0	18 (66.7)	$0.7 \pm 0.5$	1.0	61 (64.9)	0.865
	Domain	0.5	50.0 [25.0-75.0]	65.8 ± 27.9	75.0 [50.0-87.5]		54.8 ± 32.7	50.0 [25.0-75.0]		0.119
	score (%)	č						0		+
Management	10	0.1		$0.2 \pm 0.4$	0.0	4 (14.8)	0.1 ± 0.2	0.0	3 (3.2)	0.023*
of liver cirrhosis	77	<del>ر</del> .0		$0.1 \pm 0.5$	1.0	18 (66.7)	0.5 ± 0.5	0.0	46 (48.9)	0.104
	D3	0.6		$0.7 \pm 0.5$	1.0	19 (70.4)	$0.6 \pm 0.5$	1.0	57 (60.6)	0.356
	D4	0.7		$0.9 \pm 0.4$	1.0	23 (85.2)	$0.7 \pm 0.5$	1.0	67 (71.3)	0.145
	D5	0.3		$0.3 \pm 0.5$	0.0	9 (33.3)	$0.3 \pm 0.5$	0.0	26 (28.0)	0.588
	D6	0.4		$0.6 \pm 0.5$	1.0	16 (59.3)	$0.4 \pm 0.5$	0.0	34 (36.2)	0.032*
	D7	0.7		$0.7 \pm 0.4$	1.0	20 (74.1)	$0.7 \pm 0.5$	1.0	64 (68.1)	0.552
	D8	0.2		$0.2 \pm 0.4$	0.0	6 (22.2)	$0.2 \pm 0.4$	0.0	13 (13.8)	0.291
	Domain	0.4	50.0 [37.5-62.5]	53.2 ± 19.5	50.0 [37.5-75.0]		$41.4 \pm 17.6$	37.5 [25.0-50.0]		0.006*
	score (%)									
	Total	0.5	54.5 [38.6-68.2]	59.1 ± 21.9	63.6 [45.5-77.3]		$50.9 \pm 17.9$	52.3 [36.4-63.6]		0.034*
	Domain (%)									
<ul> <li>Note: #Chi2 test was</li> </ul>	used for cate	gorical varia	ables while the Manr	-Whitney U-test w	as used for continue	ous variables; *sta	tistically significa	nt at p<0.05.		

Domain	Items	Kuder-	Corrected	Kuder-		est (N=121		R	etest (N=8;	2)	Kappa	Wilcoxon
	-	Richardson	item	Richardson	Mean	Median	No. of	Mean	Median	No. of	measurement	signed-
	_		knowledge	if Item	± SD		Correct	± SD		Correct	of agreement	ranked
			Total	deleted			responses			responses	value	test
			Correlation				[(%) u]			[u (%)]		p value
Self-understanding	A1	0.509	0.326	0.358	$0.4\pm 0.5$	0.0	53 (43.8)	0.4± 0.5	0.0	33 (40.2)	0.632	0.118
of liver cirrhosis	A2		0.255	0.409	$0.5\pm 0.5$	1.0	64 (52.9)	0.6± 0.5	1.0	49 (59.8)	0.431	0.082
	A3		0.270	0.400	$0.7\pm 0.5$							
	1.0	86 (71.1)	0.7±0.4	1.0	60 (73.2)	0.434	0.648					
	A4		0.240	0.420	0.7± 0.5	1.0	83 (68.6)	0.6± 0.5	1.0	48 (58.5)	0.168	0.216
	A5		0.163	0.474	0.5± 0.5	1.0	64 (52.9)	0.5± 0.5	0.0	39 (47.6)	0.245	0.719
Aetiologies of	B1	0.534	0.240	0.513	0.7± 0.5	1.0	89 (73.6)	0.7± 0.4	1.0	61 (74.4)	0.537	0.791
liver cirrhosis	B2		0.289	0.485	$0.7\pm 0.4$	1.0	84 (69.4)	0.7± 0.5	1.0	54 (65.9)	0.408	0.819
	B3		0.355	0.447	0.8± 0.4	1.0	92 (76.0)	0.6± 0.5	1.0	51 (62.2)	0.237	0.021*
	B4		0.356	0.441	$0.4\pm 0.5$	0.0	49 (40.5)	0.4± 0.5	0.0	34 (41.5)	0.268	0.853
	B5		0.260	0.502	0.3± 0.5	0.0	36 (29.8)	0.4± 0.5	0.0	34 (41.5)	0.288	0.054
Complications of	U U	0.585	0.426	0.467	$0.7 \pm 0.5$	1.0	83 (68.6)	0.7± 0.5	1.0	59 (72.0)	0.456	1.000
liver cirrhosis	0		0.494	0.405	$0.6\pm 0.5$	1.0	74 (61.2)	0.5± 0.5	1.0	42 (51.2)	0.192	0.486
	თ		0.360	0.519	0.3± 0.5	0.0	41 (33.9)	$0.5\pm 0.5$	0.0	37 (45.1)	0.096	0.243
	С 4		0.204	0.635	$0.7 \pm 0.5$	1.0	79 (65.3)	0.7± 0.5	1.0	58 (70.7)	0.396	0.286
Management of	5	0.351	030	0.375	0.1± 0.2	0.0	7 (5.8)	0.2± 0.4	0.0	16 (19.5)	0.213	0.007*
liver cirrhosis	D2		0.312	0.214	$0.5\pm 0.5$	1.0	64 (52.9)	0.5± 0.5	0.0	39 (47.6)	0.344	0.441
	D3		060.0	0.352	$0.6\pm 0.5$	1.0	76 (62.8)	0.6± 0.5	1.0	47 (57.3)	0.397	0.839
	D4		0.200	0.291	$0.7\pm 0.4$	1.0	90 (74.4)	0.6± 0.5	1.0	47 (57.3)	0.427	0.017*
	D5		0.012	0.390	0.3± 0.5	0.0	36 (29.8)	0.2± 0.4	0.0	14 (17.3)	0.277	0.078
	D6		0.187	0.295	0.4± 0.5	0.0	50 (41.3)	0.5± 0.5	1.0	43 (52.4)	0.347	0.124
	D7		0.198	0.291	$0.7\pm 0.5$	1.0	84 (69.4)	0.5± 0.5	1.0	42 (51.2)	0.309	0.001*
	D8		0.132	0.327	0.2± 0.4	0.0	19 (15.7)	0.2± 0.4	0.0	18 (22.0)	0.249	0.359
Note: *statistically si	ignificant	: at p<0.05										

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Fig. 1: Translation process of the Malay Asian cirrhosiS Knowledge Questionnaire (ASK-QM)

Patients with tertiary education had a significantly higher median score compared to those without (63.6 [45.5-77.3] vs 52.3 [36.4-63.6], p < 0.05) (Table II).

#### Reliability

The overall Kuder Richardson was 0.761, whilst the Kuder Richardson values for each domain ranged from 0.351 to 0.585 (Table III). Seven out of 22 items had corrected itemtotal correlations <0.2 (Table III).

A total of 82 out of 121 patients participated at the retest (response rate=67.7%). Thirty patients (24.8%) could not be contacted and nine patients (7.5%) declined participation. Kappa values at the test-retest ranged from 0.096 to 0.632. One out of 22 items (4.5%) was in good agreement, 6 out of 22 items (27.3%) were in moderate agreement, 12 out of 22

items (54.5%) were in fair agreement and 3 out of 22 items (13.6%) were in poor agreement. Eighteen out of 22 items had Wilcoxon signed-rank test values that were statistically not significant, p>0.005 (Table III).

#### DISCUSSION

The ASK-QM was culturally adapted and translated from the ASK-Q using ISPOR guidelines and was found to have adequate psychometric properties.<sup>30</sup> ASK-QM was a moderate to good fit model.<sup>22,25</sup> We were unable to compare our findings to the English ASK-Q or to any other previously developed questionnaires as CFA was not performed in these studies. CFA was used over exploratory factor analysis (EFA) because EFA is used during the initial stages of questionnaire development, especially the construct of the questionnaire

remains unclear. However, CFA was performed on the ASK-QM to confirm the model's fit in the target population.<sup>31</sup>

The overall difficulty factor of ASK-QM was 0.5. Our findings were similar to the ASK-Q (which also scored 0.5), indicating that the questionnaire was moderately easy for a patient to answer.<sup>32</sup> There were 2 items in ASK-QM categorized as "too hard", while ASK-Q only reported one item as "too hard". Therefore, the ASK-QM was an adequate and well-structured questionnaire, instead of being too difficult (which may overwhelm patients) or too easy (which would deter patient knowledge acquisition).<sup>33</sup>

The overall total knowledge median score [IQR] of ASK-QM was 54.5 [38.6-68.2], which was slightly lower than the English ASK-Q which had a median score [IQR] of 59.1 [45.6-68.2].<sup>17</sup> This could be attributed to the background educational level of the patients who answered the English ASK-Q, where more 48 patients (43.6%) had tertiary education, compared to 22.3% who answered the ASK-QM.<sup>17</sup> Our findings were similar to studies conducted by Volk et al. with a median score of 53% and Ramachandran et al. of 56%.<sup>6.15</sup>

ASK-QM was able to discriminate between patients with and without tertiary education. Our findings were similar with previous studies that showed that patients with higher education levels had higher levels of self-awareness of their general health and preventive care.<sup>34</sup> Several studies have also reported that higher education levels were associated with a greater knowledge of liver cirrhosis.<sup>17,35,36</sup>

Overall, the ASK-QM had adequate internal consistency (KR=0.761).<sup>27</sup> All domains showed adequate internal consistency except domain D (disease management) which had a KR value of 0.351. As a comparison, domain D in the ASK-Q scored 0.528. This could be due to patients guessing their answers, hence may reduce the internal consistency value.<sup>37</sup> Studies have suggested removing negative point biserial or adding item numbers could markedly improve KR value.<sup>38</sup> However, we decided to maintain the number of items in the ASK-QM as this questionnaire should mirror the ASK-Q, so that patients could have the option of answering the questionnaire in English or Malay.<sup>39</sup>

Eighteen out of 22 items were not significant at test-retest in the ASK-QM, indicating adequate reliability. On the other hand, the ASK-Q showed that 15/22 items were not significant. Similarly, patients also actively looked up information after the initial administration of the ASK-Q.<sup>17</sup> So we selected the duration of 2 weeks so as to minimise the chances of a patient learning new things or looking up information within this 2 week period, although we cannot prevent patients from doing so.<sup>40</sup>

The strength of our study was that the sample size was adequate, which allowed us to assess the psychometric properties of the ASK-QM. In addition, our study sample was obtained from two large gastroenterology/ hepatology centres, and was therefore more representative of the wider Malaysian population with liver cirrhosis. The ASK-QM had a good response rate, indicating that the questionnaire was easy to administer. However, one of the limitations of this study was that we administered the ASK-QM face-to-face at baseline and via the telephone at retest and that participants could have looked up the correct answers in between the test and retest. Telecommunication using phone calls at retest was used to increase the participation rate during the retest, especially during the COVID-19 pandemic.

#### CONCLUSION

The ASK-QM was found to be a valid and reliable questionnaire to assess patients' knowledge of liver cirrhosis among Malay-speaking adults in this country. As mentioned before, the outcome of cirrhosis is not only dependent on the treatment administered by the clinician. Patient adherence to clinic visits, endoscopy and imaging appointments, and compliance with medication will help improve outcomes and reduce hospitalisation. It is anticipated that the ASK-QM would facilitate such adherence and improve patient compliance with therapy.

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#### CONFLICT OF INTEREST

The authors declare they have no conflicts of interest.

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#### REFERENCES

- 1. Anthony PP, Ishak KG, Nayak NC, Poulsen HE, Scheuer PJ, Sobin LH. The morphology of cirrhosis. Recommendations on definition, nomenclature, and classification by a working group sponsored by the World Health Organization. J Clin Pathol 1978; 31(5): 395-414.
- 2. Asrani SK, Devarbhavi H, Eaton J, Kamath PS. Burden of liver diseases in the world. J Hepatol 2019; 70(1): 151-71.
- 3. Cheemerla S, Balakrishnan M. Global epidemiology of chronic liver disease. Clin Liver Dis (Hoboken) 2021; 17(5): 365-70.
- 4. Goh KL, Razlan H, Hartono JL, Qua CS, Yoong BK, Koh PS, et al. Liver cancer in Malaysia: epidemiology and clinical presentation in a multiracial Asian population. J Dig Dis 2015; 16(3): 152-8.
- Sarin SK, Kumar M, Eslam M, George J, Al Mahtab M, Akbar SMF, et al. Liver diseases in the Asia-Pacific region: a Lancet Gastroenterology & Hepatology Commission. Lancet Gastroenterol Hepatol 2020; 5(2): 167-228.
- Volk ML, Fisher N, Fontana RJ. Patient knowledge about disease self-management in cirrhosis. Am J Gastroenterol 2013; 108(3): 302-5.
- Goldsworthy MA, Fateen W, Thygesen H, Aldersley MA, Rowe IA, Jones RL. Patient understanding of liver cirrhosis and improvement using multimedia education. Frontline Gastroenterol 2017; 8(3): 214-9.
- 8. Hayward KL, Valery PC, Martin JH, Karmakar A, Patel PJ, Horsfall LU, et al. Medication beliefs predict medication adherence in ambulatory patients with decompensated cirrhosis. World J Gastroenterol 2017; 23(40): 7321-31.

- 9. Hayward KL, Horsfall LU, Ruffin BJ, Cottrell WN, Chachay VS, Irvine KM, et al. Optimising care of patients with chronic disease: patient-oriented education may improve disease knowledge and self-management. Internal Medicine Journal.2017; 47: 952-5.
- Volk ML, Tocco RS, Bazick J, Rakoski MO, Lok AS. Hospital readmissions among patients with decompensated cirrhosis. Am J Gastroenterol 2012; 107(2): 247-52.
- 11. Tapper EB, Volk M. Strategies to Reduce 30-Day Readmissions in patients with cirrhosis. Curr Gastroenterol Rep 2017; 19(1): 1.
- Dahl TF, Cowie BC, Biggs BA, Leder K, MacLachlan JH, Marshall C. Health literacy in patients with chronic hepatitis B attending a tertiary hospital in Melbourne: a questionnaire based survey. BMC Infect Dis 2014; 14: 537.
- Martinez-Tapia A, Folterman C, Duarte-Chavez R, Bahirwani J, Chaput K, Martins N. S1009 Does the severity of model for endstage liver disease score correlate with poor health literacy among patients with cirrhosis? American Journal of Gastroenterology. 2020; 115: S514-S5.
- 14. Jaafar N, Perialathan K, Krishnan M, Juatan N, Ahmad M, Mien TYS, et al. Malaysian health literacy: scorecard performance from a national survey. Int J Environ Res Public Health 2021; 18(11): 5813
- 15. Ramachandran J, Woodman RJ, Muller KR, Wundke R, McCormick R, Kaambwa B, et al. Validation of knowledge questionnaire for patients with liver cirrhosis. Clin Gastroenterol Hepatol 2020; 18(8): 1867-73 e1.
- 16. Stelmach M, de Almeida Medeiros KA, Carvalho BJ, Pipek LZ, de Mesquita GHA, Nii F, et al. Instrument to evaluate the knowledge of patient with cirrhosis on his disease: construction and validity. BMC Gastroenterol 2021; 21(1): 83.
- Leung HK, Mahadeva S, Rajaram RB, Lai PSM. Development and validation of the Adult cirrhosiS Knowledge Questionnaire. Eur J Gastroenterol Hepatol 2023; 35(3): 333-41.
- Wild D, Grove A, Martin M, Eremenco S, McElroy S, Verjee-Lorenz A, et al. Principles of good practice for the translation and cultural adaptation process for Patient-Reported Outcomes (PRO) Measures: report of the ISPOR Task Force for Translation and Cultural Adaptation. Value Health. 2005; 8(2): 94-104.
- Pearson RH, Mundfrom DJ. Recommended sample size for conducting exploratory factor analysis on dichotomous data. Journal of Modern Applied Statistical Methods. 2010; 9(2): 359-68.
- Pugh RN, Murray-Lyon IM, Dawson JL, Pietroni MC, Williams R. Transection of the oesophagus for bleeding oesophageal varices. Br J Surg 1973; 60(8): 646-9.
- Patock J. Exam Scores: How to interpret your statistical analysis reprots university testing services, Arizona State University 2004.
- 22. Hu Lt, Bentler PM. Cut off criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. Structural Equation Modeling: A Multidisciplinary Journal. 1999; 6(1): 1-55.
- 23. Bentler PM. Comparative fit indexes in structural models. Psychological Bulletin. 1990; 107: 238-46.
- Pavlov G, Maydeu-Olivares A, Shi D. Using the standardized root mean squared residual (SRMR) to assess exact fit in structural equation models. Educational and Psychological Measurement 2021; 81(1): 110-30.

- 25. Fabrigar LR, Wegener DT, MacCallum RC, Strahan EJ. Evaluating the use of exploratory factor analysis in psychological research. Psychological Methods 1999; 4: 272-99.
- 26. Sarmah HK, Hazarika BB. Determination of reliability and validity measures of a questionnaire. Indian Journal of Education and Information Management 2012; 1(11): 508-17.
- Ekolu SO, Quainoo H. Reliability of assessments in engineering education using Cronbach's alpha, KR and split-half methods. Global Journal of Engineering Education 2019; 21: 24-9.
- 28. McHugh ML. Interrater reliability: the kappa statistic. Biochem Med (Zagreb). 2012; 22(3): 276-82.
- 29. Viera AJ, Garrett JM. Understanding interobserver agreement: the kappa statistic. Fam Med 2005; 37(5): 360-3.
- 30. Cox E, Martin BC, Van Staa T, Garbe E, Siebert U, Johnson ML. Good research practices for comparative effectiveness research: approaches to mitigate bias and confounding in the design of nonrandomized studies of treatment effects using secondary data sources: the International Society for Pharmacoeconomics and Outcomes Research Good Research Practices for Retrospective Database Analysis Task Force Report--Part II. Value Health 2009; 12(8): 1053-61.
- 31. Worthington RL, Whittaker TA. Scale development research: A content analysis and recommendations for best practices. The Counseling Psychologist. 2006;34(6):806-38.
- 32. Johari J, Sahari J, Wahab DA, Shahrum Abdullah SA, Omar MZ, Muhamad N. Difficulty index of examinations and their relation to the achievement of programme outcomes. Procedia Social and Behavioral Sciences 2011;18:71-80.
- 33. Han K, Yi MY, Gweon G, Lee J-G, editors. Understanding the difficulty factors for learning materials: A qualitative study. Artificial Intelligence in Education; 2013 2013//; Berlin, Heidelberg: Springer Berlin Heidelberg.
- Raghupathi V, Raghupathi W. The influence of education on health: an empirical assessment of OECD countries for the period 1995–2015. Arch Public Health 2020; 78(1): 20.
- 35. Phisalprapa P, Tanwandee T, Neo B-L, Singh S. Knowledge, attitude, and behaviors toward liver health and viral hepatitisrelated liver diseases in Thailand. Medicine 2021; 100(51): e28308.
- 36. Majid B, Khan R, Junaid Z, Khurshid O, Rehman SH, Jaffri SN, et al. Assessment of knowledge about the risk factors of chronic liver disease in patients admitted in Civil Hospital Karachi. Cureus 2019; 11(10):e5945.
- 37. Jansen T, Rademakers J, Waverijn G, Verheij R, Osborne R, Heijmans M. The role of health literacy in explaining the association between educational attainment and the use of outof-hours primary care services in chronically ill people: a survey study. BMC Health Serv Res 2018;18(1):394.
- 38. Downing SM. Reliability: on the reproducibility of assessment data. Med Educ. 2004; 38(9): 1006-12.
- 39. Sharma H. How short or long should be a questionnaire for any research? Researchers dilemma in deciding the appropriate questionnaire length. Saudi J Anaesth 2022; 16(1): 65-8.
- 40. Wyse AE. How days between tests impacts alternate forms reliability in computerized adaptive tests. Educ Psychol Meas 2021; 81(4): 644-67.

## Appendix

# Soal Selidik Pengetahuan Sirosis Dewasa (ASK-QM). No. Siri\_\_\_\_

Sila tanda pada kotak yang berkenaan:

## A. Apakah yang anda faham dengan istilah "sirosis hati" (pengerasan hati)?

		Benar	Tidak Benar	Tidak Tahu
A1	Sirosis hati hanya boleh disembuh dengan ubat-ubatan.			
A2	Jangka hayat pesakit sirosis hati akan menjadi pendek setelah komplikasi berlaku.			
A3	Terdapat kerosakan kekal pada hati.			
A4	Anda tidak akan mengalami sebarang simptom jika sirosis hati masih di peringkat awal.			
A5	Sirosis hati boleh tersebar di kalangan ahli keluarga yang mempunyai kontak rapat dengan pesakit sirosis hati.			

#### B. Apakah sebab-sebab utama "sirosis hati"?

		Benar	Tidak	Tidak
			Benar	Tahu
B1	Pengambilan minuman beralkohol berlebihan untuk bertahun-tahun.			
B2	Lemak berlebihan yang terkumpul dalam hati (hati berlemak).			
B3	Jangkitan virus jangka panjang seperti Hepatits B atau C			
B4	Merokok secara berlebihan untuk bertahun-tahun.			
B5	Jangkitan virus jangka pendek seperti Influenza atau Hepatitis A.			

### C. Sirosis hati boleh menyebabkan komplikasi- komplikasi seperti berikut.

		Benar	Tidak Benar	Tidak Tahu
C1	Pembengkakan abdomen yang disebabkan oleh pengumpulan cecair berlebihan			
	di abdomen (asites).			
C2	Pembengkakan saluran darah (varises) pada perut atau usus.			
C3	Keliru atau mengantuk.			
C4	Kanser hati.			

#### D. Bagaimanakah sirosis hati dirawat oleh doktor anda?

		Benar	Tidak	Tidak
			Benar	Tahu
D1	Semua pesakit dengan sirosis hati perlu dirawat dengan diuretik (ubat yang			
	meningkatkan kadar buang air kecil) untuk mencegah pengumpulan cecair.			
D2	Propranolol dipreskrib untuk mengelakkan berlakunya pendarahan daripada			
	saluran darah yang bengkak (varises) pada esofagus (saluran makanan ke perut)			
	atau perut.			
D3	Hanya pemindahan hati boleh merawat sirosis hati.			
D4	Endoskop bahagian atas (satu skop dimasukkan ke dalam bahagian perut) dilakukan			
	untuk mengesan pembengkakan saluran darah (varises) pada esofagus			
	(saluran makanan ke perut) atau perut.			
D5	Untuk pesakit dengan asites, tiada pengawalan garam diperlukan.			
D6	Hati yang sihat boleh dipindahkan daripada seseorang yang baru meninggal dunia			
	kepada pesakit yang mempunyai sirosis hati.			
D7	Pemeriksaan ultrasound pada abdomen dilakukan untuk mengesan kanser hati.			
D8	Pemeriksaan ultrasound pada abdomen dilakukan untuk mengesan pengumpulan			
	cecair dalam abdomen (asites).			