# ORIGINAL ARTICLE

# The Feasibility, Reliability and Validity of the Malay McGill Quality of Life Questionnaire – Cardiff Short Form (MMQOL-CSF) in Malaysian Advanced Cancer Population

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#### **Summary**

Health-related quality of life (HRQoL) assessment is important in healthcare outcomes. This study aimed to determine the feasibility, reliability and validity of the Malay McGill Quality of Life Questionnaire – Cardiff Short Form (MMQOL-CSF) in advanced cancer population. Patients either completed the MMQOL-CSF alone or in addition to its long version. The study recruited 116 participants (average age = 44 years old). On average, MMQOL-CSF was completed in 5.4 minutes. Most domains showed evidence of reliability (Cronbach's  $\alpha$  = 0.76-0.92). Correlation with its long version was moderate to strong ( $r_s$  = 0.54-0.87). The MMQOL-CSF was a feasible, reliable and valid HRQoL instrument in this population.

Key Words: Health-related quality of life, Advanced cancer, MMQOL-CSF, Feasibility, Reliability,

Validity

#### Introduction

There now exists little doubt about the usefulness of health-related quality of life (HRQoL) measurement in healthcare settings across the world and this area has been subjected to numerous research studies over the past few decades. HRQoL stands as a vital medical outcome assessment especially for those suffering from advanced cancer who will subsequently require the specialised provision of palliative care. Universally, HRQoL has been accepted as a subjective, multidimensional and dynamic concept encompassing at least physical, social and psychological components of daily activities <sup>1-3</sup>. In addition, there is an increasing

recognition that dimensions such as existential well-being <sup>46</sup> or spirituality <sup>7.9</sup> should also be integrated into HRQoL instruments. This is particularly vital in studies of the terminally-ill.

While it is exteremely vital to measure HRQoL in individuals with non-curable diseases <sup>10</sup>, there is also little doubt that HRQoL is greatly dependent upon an individual's cultural experience <sup>11</sup>. Thus, there exists an overwhelming need to develop culturally-sensitive instruments to enable HRQoL comparisons across cultures <sup>12</sup>. Despite this, the majority of current tools have been developed and tested extensively in English-

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speaking countries. Although increasing efforts have been made towards development of cross-culturally adapted tools for use in non-English-speaking countries <sup>13-15</sup>, palliative-care-specific HRQoL instruments have been neglected.

The McGill Quality of Life Questionnaire (MQOL) possesses established use and psychometric properties as a result of wide testing in English-speaking countries such as in North America, United Kingdom and Australia 16-20. Recently it has been shortened to an 8item questionnaire by researchers in the UK, producing the McGill Quality of Life Questionnaire - Cardiff Short Form (MOOL-CSF) in an attempt to create a simple, least-burdening yet useful instrument for palliative care recipients. Expanding use of the MQOL in such population can be witnessed by efforts from Lo et al. 21, generating the Hong Kong version of the MQOL. Nevertheless, still very little is known about its performance in other Asian countries where the importance of palliative care services is also becoming more apparent <sup>22-24</sup>. Several cancer-specific instruments have already been cross-culturally adapted and validated in Asian countries 25, 26, but so far there is no published evidence of a Malay-version of the MQOL.

Therefore, the necessity for a comprehensive and yet practical HRQoL tool for use in Malaysia has prompted cross-cultural adaptation of the English MQOL and its short version (MQOL-CSF) into Malay. Nevertheless, its utility can only be confirmed after relevant psychometric properties for such instrument are established <sup>27, 28</sup>. This study aimed at determining the feasibility, reliability and validity of the newly-developed Malay MQOL-CSF (developmental stage not reported here) in the Malaysian advanced cancer population.

#### **Materials and Methods**

#### **Ethical approvals**

An official permission to conduct these studies in Malaysia was obtained through the Economic Planning Unit (EPU), Prime Minister Department in Kuala Lumpur after submission of the application letter and a detailed study proposal. In addition, letters were also sent to the Sabah Director of Health Services and the Director of Queen Elizabeth Hospital to inform them about the study and obtain their consents.

#### Study design and patient selection

Patients with advanced cancer were recruited from Queen Elizabeth Hospital, Kota Kinabalu, Sabah, Malaysia. Those patients who met the following inclusion criteria were enrolled into the study: male and female patients with advanced cancer; aged between 18-85 years, possessed reasonable ability of completing the questionnaire; and able to read and write Malay. The study was prospective and cross-sectional in design.

# Study instruments/questions Malay McGill Quality of Life Questionnaire (MMQOL)

This was the Malay adapted version of the original English MOOL 16; developed through an established iterative forward-backward translation procedure. It consists of 17 items (including a global HRQoL question) and an open-ended question allowing patients to report issues that have influence on their HRQoL. Five HRQoL domains are explored by the MMQOL: physical symptoms (items 1-3), physical wellbeing (item 4), psychological well-being (items 5-8), existential well-being (items 9-14) and support issues (items 15 and 16). The total score is derived from the mean of all five domains. The three physical symptoms listed by patients are those giving them the biggest problems and influencing their HROoL. The frame of reference for all questions is for "the past 2 days" (for in-patients) and for "the past 7 days" (for out-patients). The response categories are based on a numerical rating scale from 0 to 10 with anchor ends. There is also a final question (based on dichotomous 'Yes' or 'No' response choices) asking whether the patient has had any help in completing their questionnaire.

# Malay McGill Quality of Life Questionnaire – Cardiff Short Form (MMQOL-CSF)

This 8-item questionnaire presents the exact content as the English MQOL-CSF. The global HRQoL item is retained, as well as the physical symptoms domain (items 1-3). Items 5 and 6 explore the psychological domain whereas the existential domain is represented by items 7 and 8. An open-ended question tapping on other aspects of life impacting upon HRQoL is also included in the last part of the instrument. Again, the frame of reference is for "the past 2 days" (for inpatients) and for "the past 7 days" (for out-patients). Scores given are based on a numerical rating scale from 0 to 10 with anchor ends.

## **Practicality Questions**

These are 5 items devised to determine the feasibility of the HRQoL assessment. Patients responded to questions on the average time taken to complete the MMQOL-CSF, its clarity, comprehensiveness and if there is any additional questions they want to be asked or if there is any unsuitable/difficult/distressing question(s) to answer.

#### General Health Question (GH)

This is a single item adapted from the generic questionnaire; Short Form-36 <sup>29</sup>. It asks the respondent about their general health status; which was rated on the response categories: "poor", "fair", "good", "very good" or "excellent". It was only used in the validity study (to demonstrate discriminant validity).

# Study procedure Feasibility study

Suitable out-patients who attended either the Palliative Care Clinic (PCC) or the Day Care Chemotherapy Unit (DCCU) were approached by the research assistant while awaiting consultation or receiving chemotherapy. Following a brief explanation about the study and an invitation to participate (verbally and via 'Patient Information Sheet'), patients who agreed to take part signed a written consent form. The Malay MQOL-CSF was then administered, followed by 5 practicality questions. The time taken to complete the form was recorded using a stopwatch. The research assistant was available to assist them by reading aloud the questions and/or record their responses if they so wished. Patients were finally thanked for their co-operation.

## Validity study

The validity study was conducted in the Palliative Care Unit (PCU) as well as in other in-patient wards in Queen Elizabeth Hospital. On the study day, all eligible in-patients were approached by the research assistant and explained the purpose of the study both verbally and through the 'Patient Information Sheet'. Patients who agreed to participate first signed the 'Written Consent Form'. Randomisation then followed, to determine whether they first complete the MMQOL ('study' group) or the MMQOL-CSF ('control' group). They were told to regard both questionnaires as two entirely separate instruments even though questions on the short form had originated from the original, long version. Lastly, patients answered the General Health

(GH) question. Again, the research assistant was available to assist them by reading aloud the questions and/or record their responses if they so wished. All patients were thanked for their participation in the study. Patients' demographic data were extracted from their medical case-notes and their most recent haemoglobin (Hb) level and white blood cell (WBC) count were also recorded.

#### Reliability study

Patients for this study were the same group of outpatients and in-patients recruited for the previous two studies as outlined above. The combination of their data was used to present the reliability results.

### Data processing and analysis

Prior to data analysis, all scores from both versions of instruments were transposed so that a score of 10 always represented the best HRQoL. SPSS version 10 for Windows was used to analyse all data. Nonparametric Mann-Whitney U test was used to test for significance in HRQoL mean scores. The probability of committing type I error was set at p < 0.05. For demographic characteristics, chi square test was used for categorical data whereas t-test was used for interval data (to compare the two groups of participant for the validity study only). Descriptive statistics were used to present most of the results for the feasibility study. The internal consistency reliability of the MMQOL-CSF and its subscales were determined by calculation of Cronbach's α for in-patients and out-patients separately. For the validity study, Spearman's rank correlation coefficient (rs) was used to examine the degree of association between MMOOL and MMOOL-CSF domains (criterion validity) and between MMQOL-CSF domains and General Health question (GH) (discriminant validity). In addition, convergent validity was established when item-domain correlation value exceeded 0.40 whereas divergent validity was confirmed when an item correlated stronger with its own domain than with other distantly-related domains. For 'known-group' validity, MMQOL-CSF median scores were compared between the groups that differed in Hb level or WBC count. Factor analysis (principal component analysis with varimax rotation) was conducted to confirm the construct validity of MMQOL-CSF by comparison with the MMQOL's construct.

#### **Results**

# Socio-demographic characteristics of study participants

#### Feasibility study

Over the 12-week study period, 74 patients attended the Palliative Care Clinic (PCC) for a total of 139 consultations while the Day Care Chemotherapy Unit (DCCU) was visited by 87 patients. Out of the total 161 patients, only 65 were approached (the rest did not meet the inclusion criteria) of whom 51 (78.5%) patients from both PCC (n=21) and DCCU (n=30) consented to participate in the study. The rest refused to participate due to various reasons such as feeling tired (n=9), did not understand the study (n=2) and other reasons (n=3). Table I shows the demographic characteristics of the study participants. The age of the participants ranged from 19 to 82 years, with a mean of 50.6 years. Majority of these out-patients were female, Chinese, married and were Christians. Most of them only had either primary or secondary education (n=33) and worked as supportive staffs or housewives (n=29). Their main cancer site was the gastrointestinal tract and many were receiving chemotherapy as their primary treatment (n=32).

#### Validity study

Altogether, ten in-patient wards were involved in this 12-week validation study with a total of 65 patients (62.5%) consented participation out of 104 approached. Others declined participation on grounds of being tired (n=21), not being able to understand the study (n=13), feeling weak and sick (n=3) as well as for personal reasons (n=2). The majority of them came from the Palliative Care Unit (n=11). The mean age for all patients was 40.6 years (SD=13) and they ranged from 18 to 78 years old (median=42). Thirty-two patients (49.2%) completed the long version MMQOL first followed by the short form (referred to as 'study' patients) while 33 others (50.8%) did the reverse order. Help in completing the questionnaires were given to 41 patients (63.1%) in terms of either reading aloud the questions or circling the answers. Patients' demographic characteristics are shown in Table I in which no significant difference was found between the two groups of respondents, comprising of mainly the Kadazan-Dusun race.

# Reliability study

The study participants consisted of 51 out-patients and 65 in-patients who were recruited into the feasibility and validity studies, respectively. Table I summarises their demographic characteristics.

# Feasibility of the MMQOL-CSF Completion time

The average time taken for patients to complete the MMQOL-CSF was 5.35 minutes (SD=1.62), with no significant differences between PCC or DCCU patients (p > 0.05). The majority of patients completed the questionnaire in less than 10 minutes (98.0%). Thirty-six patients (70.6%) completed it in 5 minutes or less and help was given to 35 patients (mostly to read the questions aloud).

# **Practicality**

All the patients had agreed that the questions and instructions were either 'very clear' or 'clear'. Ninety-eight percent (n=50) agreed that the form was comprehensive. Only one patient mentioned that it was not comprehensive and that questions about 'family matters' should be added. There were no 'difficult, unsuitable or distressing' questions and almost one-third of the patients did not use the open-ended question. Interestingly, no missing data was recorded. Figure 1 illustrates details of these results.

# Validity of the MMQOL-CSF Criterion and discriminant validity

When comparisons were made between items in the short form and domains in the long version, strong correlations (r= 0.539-0.868) were observed for the analogous domains except for item 7 (burden/gift) in MMQOL-CSF (Table II). It showed stronger association with the psychological domain instead of the existential domain. However, investigation of similar relationships with the General Health question (GH) resulted in weak associations (r= 0.059-0.234) for all items in the short form questionnaire.

#### Convergent and divergent validity

Correlations between individual items in the MMQOL-CSF in relation to their respective domains were examined (Table III). All items correlated either moderately or strongly with their own domains (n=0.470-0.799) except for the items 6 (control over life) and 7 (burden/gift), which showed poor relationship (n=0.285). Again with the exception of existential items, the rest of the items correlated higher with their own domains in comparison to other domains. Both psychological and existential domains correlated the highest with the global HRQoL question (n=0.463-0.464).

## Known-group validity

The median values for HRQoL scores as measured on MMQOL-CSF were compared between groups of

patients with differing haemoglobin levels (Hb) and white blood cell (WBC) count. Patients with 'below normal' (< 13.5g/dL for males or <11.5g/dL for females) and 'normal' Hb levels (males: 13.5 – 18.0g/dL; females: 11.5 – 16.0g/dL) significantly differed in their physical symptoms, existential domain and total score. Higher scores were generally shown for patients with 'normal' level (Figure 2). The global HRQoL item and psychological domain scores were also better for the 'normal' group although they did not reach significance (p>0.05).

Similar trend was also observed for patients from various groups of WBC levels. Patients with normal WBC count (4-11mmol/L) had higher scores in all domains when compared to those having lower or higher WBC count (labelled 'abnormal'). Also, there were significant differences in their global HRQoL aspect, existential domain and total score. Figure 3 illustrates these findings.

## Construct validity by factor analysis

All items in the MMQOL initially loaded greater than 0.30 and were included in subsequent analyses. Four main factors emerged from the rotated component matrix that accounted for 69.1% of the total variance

(Table IV). These factors were clearly distinguished as 'physical symptoms domain' (on which the global HRQoL question and physical well-being item loaded highly as well), 'psychological domain', 'existential domain' and 'support domain'. However, item 14 (burden/gift) loaded higher on the support domain instead of on the existential dimension.

In comparison, MMQOL-CSF items supported 60.6% of the variance which produced only 2 main factors. The first factor was apparently the 'combination' of physical symptoms and psychological domains. The second factor was less apparent, in which the global HRQoL question and item 12 (control over life) loaded together. Additionally, item 14 (burden/gift) did not show high loading (only approaching 0.50) on any of the factors. A clear-cut existential domain was not observed (Table IV).

## Reliability of the MMQOL-CSF

The internal consistency of MMQOL-CSF dimensions were examined for both in- and out-patients by computing Cronbach's  $\underline{\alpha}$  value (Table V). In both groups,  $\underline{\alpha}$  values exceeded 0.70 for all the domains except for the existential domain (0.387-0.514).

Table I: Socio-demographic characteristics of the two groups of study patients

Socio-demographic	Feasibility study	Validity study (in-patients; n=65)				
characteristics	(out-patients; n=51)	Study	Control	p value†		
Age (years)		-				
Mean (SD)	50.6 (15.0)	40.7 (15.0)	40.5 (11.0)	0.973		
Median (range)	50.0 (19-82)	41 (18-78)	44 (18-59)			
Gender (%)						
Male	18 (35.3)	13 (40.6)	18 (54.5)	0.261		
Female	33 (64.7)	19 (59.4)	15 (45.5)			
Ethnicity (%)						
Kadazan-Dusun	12 (23.5)	15 (46.9)	16 (48.5)	0.224		
Chinese	20 (39.2)	-	1 (3.0)			
Bajau	4 (7.8)	3 (9.4)	4 (12.1)			
Murut	1 (2.0)	1 (3.1)	4 (12.1)			
Malay	-	-	1 (3.0)			
Others	14 (27.5)	13 (40.6)	7 (21.2)			
Marital status (%)						
Married	40 (78.4)	24 (75.0)	25 (75.8)	0.720		
Single	8 (15.7)	6 (18.8)	6 (18.2)			
Widowed	3 (5.9)	1 (3.1)	-			
Divorced	-	1 (3.1)	2 (6.1)			
Others	-	-	-			

Socio-demographic	Feasibility study	Validity study (in-patients; n=65)			
characteristics	(out-patients; n=51)	Study	Control	p value†	
Religion (%)					
Christian	26 (51.0)	16 (50.0)	20 (60.6)	0.456	
Islam	16 (31.4)	15 (46.9)	13 (39.4)		
Buddhist	7 (13.7)	1 (3.1)	-		
Others	2 (3.9)	-	-		
Primary cancer diagnosis (%)					
Breast	16 (31.4)	4 (12.5)	4 (12.1)	0.845	
Lung	1 (2.0)	-	1 (3.0)		
Prostate	-	1 (3.1)	-		
Gastrointestinal	19 (37.3)	2 (6.3)	3 (9.1)		
Gynaecological	2 (3.9)	5 (15.6)	4 (12.1)		
Pancreatic	1 (2.0)	-	1 (3.0)		
Bladder / renal	1 (2.0)	-	-		
Head & neck	5 (9.8)	8 (25)	7 (21.2)		
Others	6 (11.8)	12 (37.5)	13 (39.4)		
Current major treatment (%)					
Analgesia	13 (25.5)	3 (9.4)	5 (15.2)	0.101	
Anticancer drugs / chemotherapy	32 (62.7)	9 (28.1)	16 (48.5)		
Radiotherapy	2 (3.9)	8 (25.0)	2 (6.1)		
Others	4 (7.8)	12 (37.5)	10 (30.3)		

Footnotes: Study = patients completed MMQOL first. Control = patients completed MMQOL-CSF first. SD = standard deviation. † Chi square test for categorical data, t-test for interval data (for validity study only).

Table II: Correlations† between individual items in the MMQOL-CSF with domains in the MMQOL and General Health question (GH)

MMQOL	MMQOL-CSF items							
domains	Global	Global Item 1 Item 2 Item 3 Item 4 Item 5 Item 6 Item 7						
Global	0.796**	0.411**	0.580**	0.284 *	0.517**	0.479**	0.440**	0.331**
Physical Symptoms	0.379**	0.835**	0.862**	0.596**	0.546**	0.461**	0.401**	0.278**
Psychological	0.417**	0.397**	0.441**	0.349**	0.692**	0.868**	0.342**	0.427**
Existential	0.521**	0.273*	0.368**	0.278*	0.530**	0.542**	0.539**	0.394**
GH	0.201	0.240	0.234	0.168	0.070	0.114	0.110	0.059

Footnotes: † Spearman's rank coefficient ( $r_s$ ). Global = global HRQoL question. Items 1,2,3 = physical symptoms; items 4 (physical well-being), 5 (depressed), 6 (nervous/worried), 7 (feeling sad), 8 (afraid of future), 9 (meaningful life), 10 (life goals), 11 (worthwhile life), 12 (control over life), 13 (feeling good), 14 (burden/gift), 15 (impersonal/caring world) & 16 (support). \* significant at p < 0.05, \*\* significant at p < 0.01.

Table III: Correlations† between items and domains within the MMQOL-CSF

MMQOL	MMQOL-CSF items							
domains	Global	Global Item 1 Item 2 Item 3 Item 4 Item 5 Item 6 Item 7						
Global	1.000**	0.302*	0.428**	0.230*	0.431**	0.419**	0.425**	0.302*
Physical Symptoms	0.399**	0.741**†	0.799**†	0.470**†	0.537**	0.444**	0.436**	0.263*
Psychological	0.464**	0.455**	0.510**	0.396**	0.739***	0.739**†	0.330*	0.320*
Existential	0.463**	0.302*	0.470**	0.313*	0.433**	0.403**	0.285*†	0.285*†

Footnotes: † Spearman's rank coefficient ( $r_s$ ). Global = global HRQoL question. Items 1, 2, 3 = physical symptoms. Items 4 (depressed), 5 (feeling sad), 6 (control over life), 7 (burden/gift). \*\* significant at p < 0.01. † = corrected for overlap.

Table IV: Factor analysis (rotated component matrix) for both MMQOL and MMQOL-CSF

Items	Rotated component matrix								
	ı	MMQOL compone	MMQOL-CSI	MMQOL-CSF components					
	1	2	3	4	1	2			
Global	0.616	0.261	0.226	0.331	0.164	0.821			
1	0.740	0.286	0.142	0.068	0.838	0.072			
2	0.908	0.155	-0.002	0.122	0.818	0.303			
3	0.678	0.245	0.013	0.321	0.655	0.100			
4	0.581	0.111	0.449	0.070					
5	0.543	0.544	0.288	0.298	0.724	0.416			
6	0.222	0.849	0.063	0.204					
7	0.321	0.848	0.134	0.133	0.685	0.359			
8	0.287	0.800	0.188	-0.124					
9	0.243	0.107	0.540	0.519					
10	0.071	0.100	0.766	-0.013					
11	0.069	0.136	0.755	-0.133					
12	0.215	0.003	0.747	0.263	0.128	0.784			
13	-0.051	0.473	0.593	0.242					
14	0.314	0.281	-0.153	0.629	0.263	0.495			
15	0.119	0.048	0.116	0.823					
16	0.141	0.019	0.094	0.861					

Footnotes: Global = global HRQoL question. Items 1,2,3 = physical symptoms. Items 4 (physical well-being), 5 (depressed), 6 (nervous/worried), 7 (feeling sad), 8 (afraid of future), 9 (meaningful life), 10 (life goals), 11 (worthwhile life), 12 (control over life), 13 (feeling good), 14 (burden/gift), 15 (impersonal/caring world) & 16 (support). Support item 16 has been removed for this analysis from the MQOL.

Table V: Internal consistency reliability (Cronbach's  $\alpha$ ) of the MMQOL-CSF for two groups of advanced cancer sufferers

Domain	Patient type			
	Out-patient	In-patient		
Physical symptoms	0.761	0.780		
Psychological	0.914	0.840		
Existential	0.514	0.387		
Total Score	0.834	0.826		

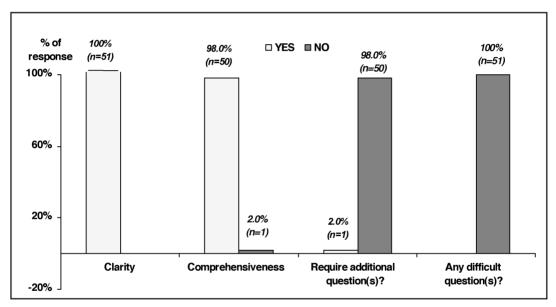


Fig. I: Responses on the practicality of the MMQOL-CSF

Footnotes: For questionnaire Clarity: "YES" = 'very clear' or 'clear'; "NO" = 'not clear' or 'very unclear'

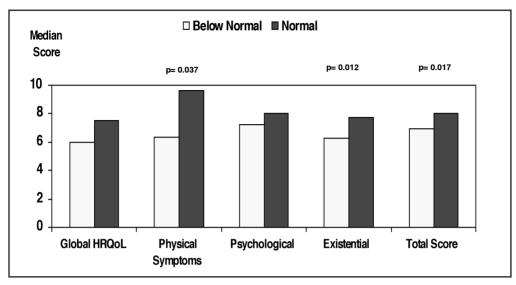


Fig. II: HRQoL median scores as measured by MMQOL-CSF for patients with different haemoglobin (Hb) levels

Footnotes: 'Below normal': Hb < 13.5g/dL (male) or Hb <11.5g/dL (female); 'Normal': Hb between 13.5 – 18.0g/dL (male) or Hb between 11.5 – 16.0g/dL (female). p< 0.05 = significant.

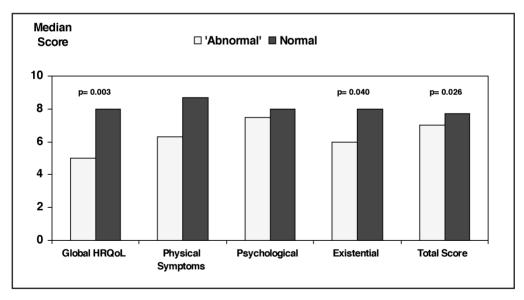


Fig. III: HRQoL median scores as measured by MMQOL-CSF for patients with different white blood cell (WBC) counts

Footnotes: 'Normal' WBC count : 4-11 mmol/L; 'Abnormal' WBC count : below or above 4-11 mmol/L. p< 0.05 = significant.

#### **Discussion**

The development and adaptation of a HRQoL instrument in another cultural setting will not be complete without preliminary testing of the tool's psychometric properties. As described by Guyatt *et al.* <sup>30</sup>, the pre-testing phase is essential to determine whether the instrument in question can perform as expected before it is implemented in any larger scale studies to produce valid interpretations.

The MQOL was first translated into Malay language and its short form, MMQOL-CSF was subsequently derived from that in another separate developmental stage not reported here. In this study, the MMQOL-CSF was preliminarily tested in a small sample of patients with advanced cancer in Malaysia. In view of its favourable performance in similar sample of patients in the United Kingdom <sup>17</sup> and Hong Kong <sup>21</sup>, it was anticipated to show robustness in the Malaysian culture as well.

The results indicated that MMQOL-CSF was a practical tool which can be completed in less than 10 minutes, far shorter than the expected completion time (15-20 minutes) for questionnaires intended for population of similar nature 10,30. Also from these results, one can be confident that the MMQOL-CSF is a clear and comprehensive HRQoL instrument (with no difficult or unsuitable questions), appropriate for use in Malaysian patients with advanced cancer. The fact that no missing was recorded also supported patients' acceptability towards this novel type of humanistic assessment since studies have been shown that sensitive and unacceptable questions can lead to missing data 31. These findings strengthened the arguments for the feasibility of MMQOL-CSF in this population.

The MMQOL-CSF has, undoubtedly, demonstrated its validity by measuring the intended facets in these patients. Evidence relating to this was demonstrated by the strong domain-domain correlation with the MMQOL - except for existential items (i.e. criterion validity) 32, 33 and was supported by convergent 34, divergent 35 and discriminant validity 36. This was in line with the results shown by the Korean versions of the WHOOOL instrument and its short form (WHOOOL-BREF) 37, suggesting that cross-culturally adapted short questionnaires also produce can psychometric properties. The instrument has also demonstrated its ability to differentiate between patients of differing clinical status based on their

biological Hb and WBC parameters (known-group validity) as shown by other established HRQoL tools  $^{\mbox{\tiny 38-}}$   $^{\mbox{\tiny 40}}.$ 

However, in spite of the favourable properties shown, the MMQOL-CSF's construct was not clearly evident from the factor analysis results. In theory, three main domains (physical symptom, psychological, existential) were expected but only two domains were produced by the MMOOL-CSF. Both physical symptoms and psychological domains loaded together while the second domain represented a relationship between the global HROoL question and item 12 (control over life) instead of the expected existential domain (items 12 and 14). In contrast, the original MMQOL produced encouraging results of four clear-cut domains although item 14 (burden/gift) loaded more on the support domain. This could be due to the truncation of 4 items out of the original 6 items that comprised the existential domain in the MMOOL-CSF; resulting in less evident association between items 12 (control over life) and 14 (burden/gift). The latter item particularly, may have been perceived differently in our Malaysian culture as revealed from its unpredictable loading pattern on the MMOOL. Similar with the Hong Kong study, item 12 (control over life) also did not load clearly on any factors while item 14 (burden/gift) correlated strongest with the psychological domain instead 21.

The internal consistency reliability results from the physical symptoms, psychological domains and total score in both in- and out-patients confirmed that they were reliable scales for group comparison i.e. possessing Cronbach's a values  $\geq 0.70^{-41}$ . However, cautions need to be exercised over the existential domain which consistently did not meet the required value for Cronbach's  $\underline{\alpha}$  despite some authors having suggested a coefficient of 0.5 as a sufficient level of reliability <sup>42</sup>.

The paramount importance of spiritual issues in relation to HRQoL in the terminally-ill population is well-recognised <sup>6, 9, 43</sup> and this can be witnessed by the increasing number of studies exploring its theoretical models and needs <sup>8, 44</sup>. The developers of the original MQOL have also demonstrated this importance through the strong association of its existential domain to overall HRQoL <sup>4</sup>. However, the findings from this study indicate that the existential domain in the MMQOL-CSF was rather unstable in terms of its reliability and validity results. Only the outcomes for known-group validity were favourable. Again, the explanation may lie in the

#### ORIGINAL ARTICLE

cultural differences in the Malaysian patients. As contended by McCahill *et al.* <sup>9</sup>, spiritual issues are appreciated differently in different cultures. In view of the importance of this existential domain in the original MQOL, this needs to be further re-examined.

Similar with other HRQoL studies <sup>45-47</sup>, difficulties in recruiting patients as a result of low literacy, poor physical status and aging were also experienced. In addition, more than half of the patients (in-patients=63.1%, out-patients=68.6%) needed help in reading aloud the questionnaire <sup>48</sup>. Although valid and reliable HRQoL information is still possible via this mode of administration <sup>35</sup>, future research should increase efforts to formulate different and more effective techniques for the less educated respondents. For example, Goh *et al.* <sup>49</sup> devised a taped version of the Functional Living Index – Cancer (FLIC) instrument to meet literacy problems in their Singapore study.

Limitations of the studies included the absence of testretest reliability and responsiveness data 30,50 as well as the failure to include a study and control group assessing the MMQOL-CSF at one time. The fact that Malaysia is a multiracial nation with people of numerous religions and cultures makes HRQoL research rather complicated. In other words, the impact of each different beliefs, religions and cultures could have greatly affected the results produced as demonstrated in many cross-cultural studies around the world 28, 51-53. Moreover, the main ethnic group represented here was the Christian Kadazan-Dusuns who are the natives of Sabah. This means that result generalisation from this study to the entire Malaysian population who are by majority Muslim Malays is still not possible at this stage.

#### Conclusion

Overall, evidence of the feasibility, validity and reliability of the MMQOL-CSF in Malaysian advanced cancer population have been demonstrated in this pretesting phase. Future studies should focus on the instrument's responsiveness as well as its test-retest reliability. In addition, the existential domain needs further revision in order to maintain the importance of this facet in this population. Needless to say, there should be more repeated studies in larger groups of patients in which, multicentre trials across the country can be considered. In order to generalise the results, the instrument should be administered to samples which would more adequately represent the general Malaysian population.

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# References

- Berzon R, Hays RD, Shumaker SA. International use, application and performance of health-related quality of life instruments. Qual Life Res 1993; 2: 367-68.
- Bowling A. Cancers. In: Bowling A (ed). Measuring Disease. Buckingham: Open University Press, 1995: 20-60.
- Testa M, Simonson D. Assessment of quality of life outcomes. New Engl J Med 1996; 384(13): 835-40.
- Cohen SR, Mount BM, Tomas JJN, Mount LF. Existential well-being is an important determinant of quality of life: Evidence from the McGill Quality of Life Questionnaire. Cancer 1996; 77: 576-86.

- 5. Cohen SR, Mount BM, MacDonald N. Defining quality of life. Eur J Cancer 1996; 32A(5): 753-54.
- Clinch JJ, Dudgeon D, Schipper H. Quality of life assessment in palliative care. In: Doyle D, Hanks GWC, Macdonald N (eds). Oxford Textbook of Palliative Medicine. Oxford: Oxford University Press, 1998: 83-94.
- Holland J, Kash KM, Passik S, Gronert MK, Sison A, Lederberg M, et al. A Brief Spiritual Beliefs Inventory for use in quality of life research in life-threatening illness. Psycho-Oncol 1998; 7: 460-69.
- Hermann C. Spiritual needs of dying patients: A qualitative study. Oncol Nurs Forum 2001; 28(1): 67-72.
- 9. McCahill L, Ferrell BR, Virani R. Improving cancer care at the end of life. Lancet Oncol 2001; 2: 103-8.
- 10. Finlay IG, Dunlop R. Quality of life assessment in palliative care. Ann Oncol 1994; 5: 13-18.
- Johnson T. Cultural considerations. In: Spilker B (ed).
   Quality of Life and Pharmacoeconomics in Clinical Trials.
   2nd ed. Philadelphia: Lippincott-Raven, 1996: 511-15.
- Skevington S. Advancing cross-cultural research on quality of life: Observations drawn from the WHOQOL development. Qual Life Res2002; 11(2): 135-44.
- Alonso J, Prieto L, Anto J. The Spanish version of the Nottingham Health Profile: A review of adaptation and instrument characteristics. Oual Life Res 1994; 3: 385-93.
- 14. Chwalow A, Lurie A, Bean K, Parent du Chatelet I, Venot A, Dusser D, et al. A French version of the Sickness Impact Profile (SIP): Stages in the cross-cultural validation of a generic quality of life scale. Fund Clin Pharmacol 1992; 6: 319-26.
- Bonomi A, Cella D, Hahn E, Bjordal K, Sperner-Unterweger B, Gangeri L, et al. Multilingual translation of the Functional Assessment of Cancer Therapy (FACT) quality of life measurement system. Qual Life Res 1996; 5: 309-20.
- Cohen SR, Mount BM, Strobel MG, Bui F. The McGill Quality of Life Questionnaire: A measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. Palliat Med 1995; 9: 207-19.
- 17. Pratheepawanit N, Salek MS, Finlay IG. The applicability of quality-of-life assessment in palliative care: Comparing two individual quality-of-life measures. Palliat Med 1999; 13: 325-34.
- Annells M, Koch T. 'The real stuff': Implications for nursing of assessing and measuring a terminally ill person's quality of life. J Clin Nurs 2001; 10: 806-12.

- Stromgren A, Groenvold M, Pedersen L, Olsen A, Sjogren P. Symptomatology of cancer patients in palliative care: Content validation of self-assessment questionnaires against medical records. Eur J Cancer 2002; 38(6): 788-94.
- Secchi G, Strepparava MG. The quality of life in cancer patients: A cognitive approach. Eur J Intern Med 2001; 12: 35-42.
- Lo R, Woo J, Zhoc K, Li C, Yeo W, Johnson P, et al. Crosscultural validation of the McGill Quality of Life Questionnaire in Hong Kong Chinese. Palliat Med 2001; 15(5): 387-97.
- 22. Lim C. Overview of cancer in Malaysia. Jpnese J Clin Oncol 2002; 32(Suppl: \$37-42).
- 23. Suhatno. Palliative care in cervical cancer. Gan To Kagaku Ryoho 2000; 27(Suppl 2): 440-48.
- Laudico A. Development of cancer pain relief and palliative care in the Phillipines. Ann Acad Med Spore 1994; 23(2): 292-95.
- 25. Goh C, Tan T, Schipper H. Cross-cultural validation of quality of life assessment tools: Methodologies and results of English, Chinese and Malay translation of the Functional Living Index for Cancer (FLIC) in Singapore. In: Proceedings of the American Society of Clinical Oncologists 1994. Winnipeg, Canada; 1994: 455.
- Kobayashi K, Takeda F, Teramukai S, Gotoh I, Sakai H, Yoneda S, et al. A cross-validation of the European Organization for Research and Treatment of Cancer QLQ-C30 (EORTC QLQ-C30) for Japanese with lung cancer. Eur J Cancer 1998; 34(6): 810-15.
- 27. Bernhard J, Hurny CDT, Coates A, Gelber RD. Applying quality of life principles in international cancer clinical trials. In: Spilker B (ed). Quality of Life and Pharmacoeconomics in Clinical Trials. 2nd ed. Philadelphia: Lippincott-Raven, 1996: 693-705.
- 28. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: Literature review and proposed guidelines. J Clin Epidemiol 1993; 46(12): 1417-32.
- 29. Ware JJ, Sherbourne C. The MOS 36-Item Short Form Health Survey (SF-36)- conceptual framework and item selection. Med Care 1992; 30(6): 473-83.
- Guyatt G, Bombardier C, Tugwell P. Measuring diseasespecific quality of life in clinical trials. Can Med Assoc J 1986; 134: 889-95.
- Sprangers MAG, te Velde A, Aaronson NK. The construction and testing of the EORTC colorectal cancerspecific quality of life questionnaire module (QLQ-CR38). Eur J Cancer 1999; 35(2): 238-47.

#### ORIGINAL ARTICLE

- Schag CAC, Ganz PA, Heinrich RL. Cancer Rehabilitation Evaluation System - Short Form (CARES-SF): A cancer specific rehabilitation and quality of life instrument. Cancer 1991; 68: 1406-13.
- Gandek B, Ware Jr J, Aaronson N, Apolone G, Bjorner J, Brazier J, et al. Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: Results from the IQOLA Project. J Clin Epidemiol 1998; 51(11): 1171-78.
- 34. Bjordal K, de Graeff A, Fayers PM, Hammerlid E, van Pottelsberghe C, Curran D, et al. A 12 country field study of the EORTC QLQ-C30 (version 3.0) and the head and neck specific module (EORTC QLQ-H&N35) in head and neck patients. Eur J Cancer 2000; 36: 1796-1807.
- Sharp LK, Knight SJ, Nadler R, Albers M, Moran E, Kuzel T, et al. Quality of life in low-income patients with metastatic prostate cancer: Divergent and convergent validity of three instruments. Qual Life Res 1999; 8: 461-70.
- 36. Stockler MR, Osoba D, Corey P, Goodwin P, Tannock IF. Convergent, discriminative, and predictive validity of the Prostate Cancer Specific Quality of Life Instrument (PROSQOLI): Assessment and comparison with analogous scales from the EORTC QLQ-C30 and a trial-specific module. J Clin Epidemiol 1999; 52(7): 653-66.
- 37. Min S, Kim K, Lee C, Jung Y, Suh S, Kim D. Development of the Korean versions of WHO Quality of Life scale and WHOQOL-BREF. Qual Life Res 2002; 11: 593-600.
- 38. Cella DF, Tulsky DS, Gray G, Sarafian B, Linn E, Bonomi A, et al. The Functional Assessment of Cancer Therapy Scale: Development and validation of the general measure. J Clin Oncol 1993; 11(3): 570-79.
- Ganz PA, Schag CAC, Lee JJ, Sim MS. The CARES: A generic measure of health-related quality of life for patients with cancer. Qual Life Res 1992; 1: 19-29.
- Ferrans CE. Development of a quality of life index for patients with cancer. Oncol Nurs Forum 1990; 17(3 Suppl): 15-21.
- Nunnally J. Psychometric Theory. 2nd ed. New York: McGraw-Hill Book Company; 1978.
- Sigurdardottir V, Bolund C, Brandberg Y, Sullivan M. The impact of generalized malignant melanoma on quality of life evaluated by the EORTC questionnaire technique. Qual Life Res 1993; 2: 193-203.

- 43. Thomson J. The place of spiritual well-being in hospice patients' overall quality of life. Hosp J 2000; 15(2): 13-27.
- Kellehear A. Spirituality and palliative care: A model of needs. Palliat Med 2000; 14: 149-55.
- 45. Kaasa S, Hjermstad M, Jordhoy M, Wisloff F, Loge J. Compliance in quality of life data: A Norwegian experience. Stat Med 1998; 17: 623-32.
- Bernhard J, Cella D, Coates A, Fallowfield L, Ganz P, Moinpour C, et al. Missing quality of life data in clinical trials: Serious problems and challenges. Stat Med 1998; 17: 517-32.
- 47. Fuh J-L, Wang S-J, Lu S-R, Juang K-D, Lee S-J. Psychometric evaluation of a Chinese (Taiwanese) version of the SF-36 health survey amongst middle-aged women from a rural community. Qual Life Res 2000; 9(6): 675-83.
- 48. Cohen SR, Mount BM, Bruera E, Provost M, Rowe J, Tong K. Validity of the McGill Quality of Life Questionnaire in the palliative care setting: A multi-centre Canadian study demonstrating the importance of the existential domain. Palliat Med 1997; 11: 3-20.
- 49. Goh C, Lee K, Tan T, Wang T, Tan C, Wong J, et al. Measuring quality of life in different cultures: translation of the Functional Living Index for Cancer (FLIC) into Chinese and Malay in Singapore. Ann Acad Med Spore 1996; 25(3): 323-34.
- Deyo RA. Measuring functional outcomes in therapeutic trials for chronic disease. Controlled Clin Trials 1984; 5: 223-40.
- 51. Cella D, Llyod S, Wright B. Cross-cultural instrument equating: Current research and future directions. In: Spilker B (ed). Quality of Life and Pharmacoeconomics in Clinical Trials. 2nd ed. Philadelphia: Lippincott-Raven, 1996: 707-14.
- 52. Anderson R, McFarlane M, Naughton M, Shumaker S. Conceptual issues and considerations in cross-cultural validation of generic health-related quality of life instruments. In: Spilker B (ed). Quality of Life and Pharmacoeconomics in Clinical Trials. 2nd ed. Philadelphia: Lippincott-Raven, 1996: 605-12.
- 53. Bullinger M, Power M, Aaronson N, Cella D, Anderson R. Creating and evaluating cross-cultural instruments. In: Spilker B (ed). Quality of Life and Pharmacoeconomics in Clinical Trials. 2nd ed. Philadelphia: Lippincott-Raven, 1996: 659-67.