

ORIGINAL ARTICLE

RELIABILITY AND VALIDITY OF THE MALAY VERSION OF PATIENT-CAREGIVER RELATIONSHIP QUESTIONNAIRE FOR OLDER ADULTS WITH DEMENTIA

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ABSTRACT

The quality of relationship between a person with dementia and a family caregiver has been identified as one of important factor in informal dementia care. Currently there is no validated questionnaire to measure the dyadic relationship in Malaysia. The aim of present study is to examine the reliability and validity of Quality of the Patient-Caregiver Relationship (QCPR) questionnaire in Malay version. A total of 70 patients with mild to moderate dementia and their caregivers were recruited from the psychogeriatric clinic, Universiti Kebangsaan Malaysia Medical Centre using a cross sectional study. The QCPR questionnaire was translated into Malay following the standard guidelines for cross-cultural adaptation of measure. The person with dementia and their caregiver completed the QCPR Malay version separately. Internal consistency and test-retest examined for reliability. Construct validity was tested with principal component factor analysis. The reliability of patient QCPR Malay version was good with Cronbach's alpha coefficients of 0.86 and intraclass correlation coefficients of 0.85. Item 11 was omitted from the caregiver QCPR Malay version due to its poor correlation with the corrected item-total score. The newly formed scale, 13 items caregiver QCPR Malay version, had satisfactory reliability (Cronbach's alpha 0.89 and intraclass correlation coefficients 0.91). Principal component factor analysis extracted 4 factors for patient version and 3 factors for caregiver version which explained 69.44% (patients' report) and 61.20% (caregivers' report) of the total variance of the scale. As a conclusion, both the patient (14 items) and caregiver (13 items) adapted QCPR Malay version is a reliable and valid tool to measure the quality of dyadic relationship between people with mild to moderate dementia and the caregiver.

Keywords: Informal care, dementia, caregiver, questionnaire, reliability, validity

INTRODUCTION

Globally in 2015, about 46.8 million people are living with dementia and the figure is estimated to double in every 20 years¹. The number of people living with dementia is 123,000 in 2015 and projected to be 261,000 in 2030 and 590,000 in 2050¹. Caregiving costs for people with dementia (PWD) are a major concern among healthcare providers^{2,3}. Most people with dementia are living in community and receive informal or family caregiving. Informal caregivers are people who provide regular care or supervision and usually involve family members, relatives, friends, neighbours and other unpaid individuals⁴. The majority of the primary informal caregivers for PWD are family members^{5,6}.

Informal caregiving for PWD is highly associated with negative effects including anxiety, social isolation, depression, fatigue and poorer physical health on the caregivers⁷⁻⁹. These detrimental

effects extended to physical, psychological and financial health of the caregivers. Extensive research to identify the predictors of caregiver burden had also been carried out¹⁰⁻¹³. Although researches focus on the negative aspects of caregiving, there are also reports on the positive aspect which motivates the caregivers. For some taking pride in their role in providing care can be rewarding and provides a sense of meaning¹⁴. Different motivation factors including affection, sense of obligation or duty like marital or filial obligation, cultural or norm had been identified among family caregivers in caring for PWD¹⁵.

Since dementia care is a dynamic process which involves continuous interaction and adjustment between the caregiver and care-recipient, the aspect of quality of relationship between this dyad should place an important aspect for evaluation. There are growing evidences using the quality of dyadic relationship to predict the psychological well-being for both the PWD and the caregivers¹⁵.

¹⁷. A specific tool identified as Quality of Carer-Patient Relationship scale (QCPR)¹⁸ has been developed to measure the quality of caregiver and care-recipient relationship. The QCPR questionnaire evaluates the quality of relationship irrespective of the kinship relationship between the informal caregiver and the care-recipient. Previous studies had successfully used QCPR to measure the quality of relationship between PWD and their caregiver¹⁹⁻²².

Currently, the growing number of people living with dementia in Malaysia has lead informal caregiving become a priority. Despite its importance, there is no culturally adapted questionnaire available to evaluate the quality of caregiving relationship in informal setting for older adults with dementia and their caregiver in Malaysia. Therefore, this pilot study aims to examine the reliability and validity of QCPR questionnaire in Malay language among dementia patient-caregiver dyads. This effort will provide local researchers and practitioners a tool to evaluate the quality of caregiving relationship in dementia care more effectively.

METHODS

We conducted a cross-sectional study from August till December 2016 at Psycho-Geriatric Clinic, Department of Psychiatry, Universiti Kebangsaan Malaysia Medical Centre. All participants were recruited from the psycho-geriatric clinic based on the following criteria:

Inclusion Criteria

- Patient aged 60 years old and above, living in community with an active caregiver who lives with them or at least spent the daytime with them.
- Patient had a diagnosis of mild to moderate dementia or mild cognitive impairment by a geriatric psychiatrist according to DSM-5.
- Both the patient and caregiver were able to understand, speak or read in Malay language.
- Caregiver was willing to give written consent to participate.

Exclusion Criteria

- A history of psychosis, major mental health problem, severe physical condition or uncorrected sensory problem e.g. severe uncorrected impairment of vision or hearing.

Sampling Method

The sample size is calculated based on Gorsuch's rule of 5 suggestion on subjects-to-variable ratio²³.

The total items in this scale is multiplied by 5 and hence the required sample size for this study was 70 patient-caregiver pairs. Convenient sampling was used in this study. Both patient and the caregiver were explained about the purpose and procedure of the study and written informed consent was obtained before the interview begin. A face-to-face interview was conducted with patient to complete the QCPR questionnaire. The caregiver completed the QCPR as a self report questionnaire. This study was approved by the UKM Research Ethics Committee,Universiti Kebangsaan Malaysia (NN-102-2014).

Measure

Quality of Carer-Patient Relationship (QCPR)¹⁸

This is a 14 items scale measuring the quality of informal caregiving dyadic relationship for PWD. It measures both dimensions on the "warmth and affection" (items: 1,4,5,6,7,9,12 and 14) and the "absence of conflict and criticism" (item: 2,3,8,10,11 and 13) in a relationship. This scale can either be administered in a face-to-face interview or as a self completion questionnaire by the respondents. Both the PWD and caregiver perspective on the quality of dyadic relationship is measured in two different versions. Respondents are required to rate on a 5-point Likert-scale ranges from "totally disagree" to "totally agree". The total score ranges from 14 to 70. The median split with score of 42 was used to differentiate between a "better" (score >42) or "poorer" (score <42) relationship quality. The items on conflict and criticism are coded reversed so that a higher total score indicates a better quality of relationship. The internal consistency of the scale is 0.82.

Linguistic Validation of the QCPR

To minimize the risk of linguistic, cultural and both theoretical and practical understanding biases during the translation process, we engaged both subject-matter and linguistic experts to conduct the forward and backward translation. The English version of the QCPR was translated into Malay language by a local professional independant linguist and a bilingual clinical psychologist. A consensus meeting was held to discuss, compare and reconcile these two forward translations among both the translators and researchers and resulted in the production of first Malay version. The first Malay version was back translated by another bilingual professional linguist and a group of master clinical psychology students who were blinded to the original version of the questionnaire. The backward translated versions were compared with the original version item by item. To ensure content validity, cultural

appropriateness and linguistics comprehension, a second consensus meeting comprising of a multidisciplinary team of psychogeriatrician, clinical psychologist, geriatrician and linguistic experts were held which resulted in the production of second Malay version.

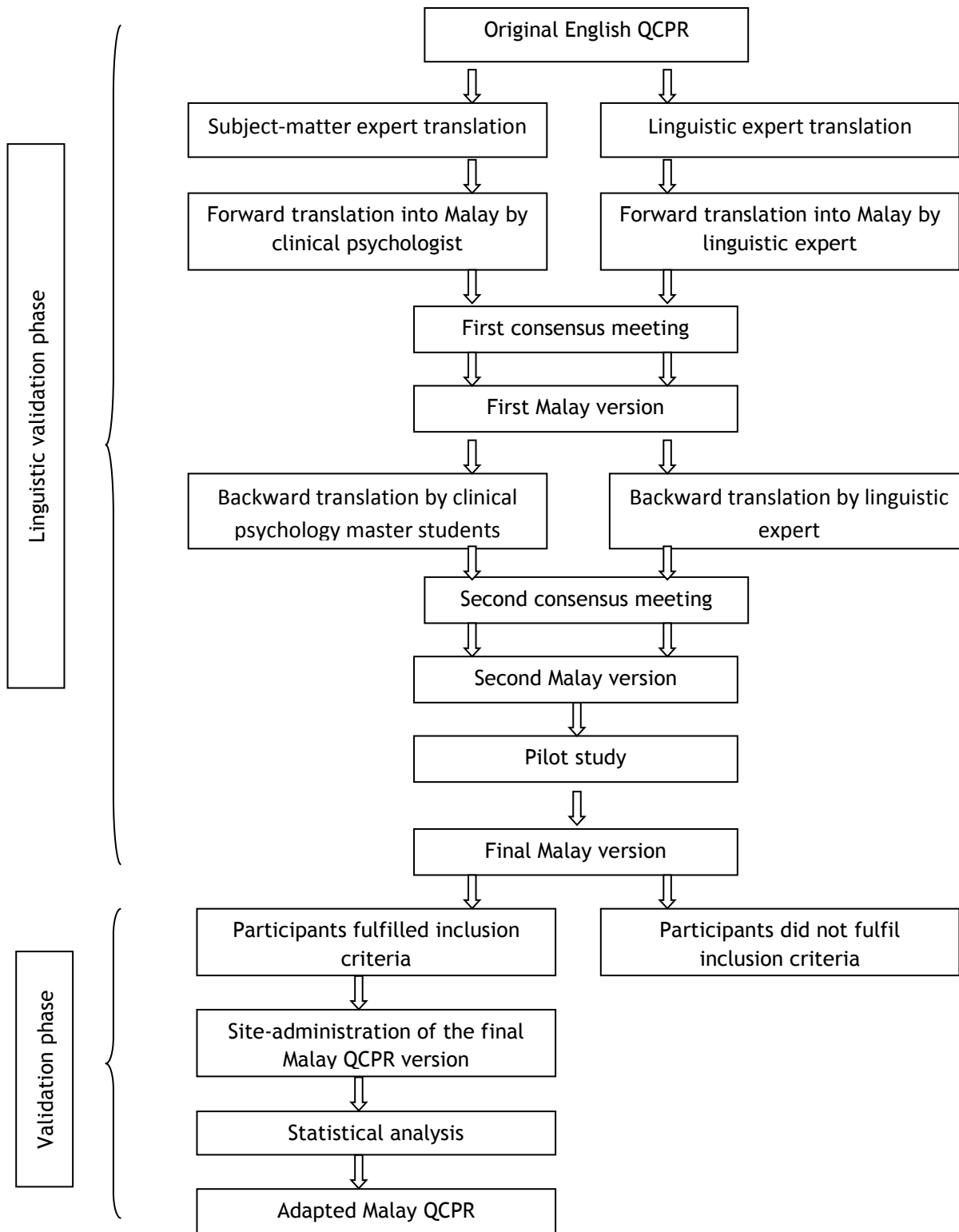
A pilot study on the second Malay version involved 15 native Malay-speaking patients with dementia and their caregivers. A face-to-face interview was conducted with patient whereas the caregiver completed the QCPR as a self report questionnaire. Both the patients and caregivers were inquired whether had any difficulty in understanding the questionnaire and their interpretation of all items. Besides, the participants were also encouraged to comment and suggest any alternatives if deemed necessary for each of the items. The feedback and comment obtained were reviewed and discussed by the researchers and necessary amendments were made to produce the final

Malay version for further psychometric assessment (Figure 1).

Statistical Analysis

Cronbach α coefficient was used to determine the internal consistency of the QCPR scale for both patient and caregiver responses. Cronbach α coefficient of ≥ 0.70 indicates a satisfactory internal consistency. Test-retest reliability was assessed after two weeks interval. Intraclass correlation coefficients (ICC) was used to evaluate the agreement. The ICC < 0.40 is considered as poor agreement, 0.41 to 0.60 is moderate agreement, 0.61 to 0.80 is good agreement and > 0.80 is excellent agreement²⁴. Construct validity was examined through principal component factor analysis with varimax rotation on both patient and caregiver responses. Kaiser-Meyer-Olkin (KMO) and Bartlett's test of sphericity were used to test for the appropriateness of factor analysis. The eigenvalue greater than 1 was used to determine the number of factors to extract.

Figure 1: Workflow of the translation, cross-cultural adaptation and validation process of the English QCPR to the adapted Malay QCPR



RESULTS

Participant Characteristics

Table 1 describes the socio-demographic characteristic of the participants. A total of 70 patients was recruited in this study. The patients age ranged from 61 to 89 with the mean of

77.27±6.85. MMSE score ranged from 10-25 with its mean of 18.03±4.22. Most of the participants were female (61.4%), Malay (55.7%), married (51.4%) studied up to primary level (47.1%) and with Alzheimer type of dementia diagnosis (48.6%). Meanwhile majority of the informal caregivers were patient’s children (65.7%).

Table 1 : Socio Demographic Characteristics of Participants

Variables	N=70	n (%)	Mean
Age			77.27 ± 6.85
MMSE			18.03 ± 4.22
Gender	Male	27 (38.6)	
	Female	43 (61.4)	
Race	Malay	39 (55.7)	
	Chinese	25 (35.7)	
	Indian	6 (8.6)	
Marital Status	Married	36 (51.4)	
	Widow	32 (45.7)	
	Single	2 (2.9)	
Education Level	No formal education	11 (15.7)	
	Primary	33 (47.1)	
	Secondary	20 (28.6)	
	Diploma and above	6 (8.6)	
Type of Dementia	Alzheimer	34 (48.6)	
	Vascular	25 (35.7)	
	Parkinson	4 (5.7)	
	Mild Cognitive Impairment	7 (10.0)	
Caregiver Relationship	Spouse	19 (27.1)	
	Children	46 (65.7)	
	Grandchildren	2 (2.9)	
	Sibling	3 (4.3)	

Reliability of the QCPR Malay Version

The patient QCPR Malay version scale had a satisfactory corrected item-total correlation with Cronbach’s alpha coefficient of 0.86. Nonetheless, item 11 of caregiver QCPR Malay version: “I blame my relative for the cause of my problem” was poorly correlated with the corrected item-total score. Thus, we suggested to omit item 11 from

the caregiver QCPR Malay version. After omitting item 11, all 13 items in the new caregiver QCPR Malay version gave a satisfactory corrected item-total correlation with Cronbach’s alpha coefficient of 0.89. Test-retest reliability was measured on a subset of 20 patient-caregiver dyads at two week interval. Excellent agreement was obtained with ICC of 0.85 for patients (14 items) and 0.91 for caregivers (13 items) (Table 2).

Table 2: Item-Total Correlation and Coefficient Alpha of QCPR Malay Version

Item	Patient - 14 items		Caregiver - 14 items		Caregiver - 13 items	
	Corrected Item-Total Correlation	Cronbach's alpha if item Deleted	Corrected Item-Total Correlation	Cronbach's alpha if item Deleted	Corrected Item-Total Correlation	Cronbach's alpha if item Deleted
Q1	0.53	0.85	0.68	0.86	0.67	0.88
Q2	0.60	0.85	0.55	0.87	0.57	0.88
Q3	0.38	0.86	0.58	0.87	0.61	0.88
Q4	0.55	0.85	0.48	0.87	0.43	0.89
Q5	0.59	0.85	0.69	0.86	0.70	0.88
Q6	0.59	0.85	0.52	0.87	0.56	0.88
Q7	0.61	0.85	0.67	0.86	0.64	0.88
Q8	0.58	0.85	0.59	0.87	0.59	0.88
Q9	0.73	0.84	0.39	0.88	0.38	0.89
Q10	0.25	0.87	0.52	0.87	0.52	0.89
Q11	0.34	0.86	0.19	0.89	-	-
Q12	0.75	0.85	0.69	0.87	0.72	0.88
Q13	0.45	0.86	0.68	0.86	0.67	0.88
Q14	0.61	0.85	0.57	0.87	0.61	0.88
Cronbach's Alpha	0.86		0.88		0.89	
Test-retest Reliability	0.85		0.90		0.91	

Validity of the QCPR Malay version

Principal component factor analysis was used to test the construct validity of QCPR for patient (14 items) and caregiver (13 items). KMO test values for both patients' and caregivers' response were 0.81 and 0.82 respectively. Barlett's test of sphericity of both responses were statistically significant (p<0.001). Both of this data ensured the adequacy for factor analysis. Four factors were extracted from the 14 items scale from patients' responses with eigenvalue greater than 1 which explained 69.44% of the total variance. As for caregivers' responses on the 13 items scale, three factors were extracted with the total variance of 61.20%.

Table 3 shows the items loading after rotated by varimax method. From the patient's report, Factor 1 was loaded by eight items (1,4,5,6,7,9,12 and 14) that was corresponded to warm and affection domain. The remaining three extracted factors formed the critic and conflict domain of QCPR. Factor 2 (item 3 and 8) described the annoyance and avoidance, factor 3 (item 2 and 10) illustrated the conflict in opinions and factor 4 (item 11 and 13) on lack of appreciation. As for the caregiver's report, the warm and affection domain was represented by Factor 1 (item 5,6,12 and 14) and Factor 3 (item 1, 4,7 and 9) whereas Factor 2 described on the conflict and criticism domain was loaded with five items (2,3,8,10 and 13).

DISCUSSION

This pilot study was conducted to examine the reliability and validity of QCPR in Malay language

among older adults with mild to moderate dementia and their caregiver. Findings from the patient QCPR Malay version indicated a satisfactory reliability which is consistent with the original version¹⁸. Moreover the excellent agreement achieved in test-retest reliability in this study clearly indicated the negligible measurement error.

The results of factor analysis demonstrated that the QCPR Malay version for patient group yielded four factors which were higher than the two domains stated in the original study¹⁸. Nonetheless, if investigated closely, these results were still conformed to the original scale. For the 'warm and affection' domain, the items loaded on factor 1 corresponded perfectly in it. As for the factor 2, item 3 "There is a big distance in the relationship between my relative and myself" and item 8 "My relative often annoys me" was actually corroborated with the avoidance and annoyance in a relationship. For factor 3, item 2 "My relative and I often disagree" and item 10 "My relative and I often impose our opinions on each other" symbolizing the conflict of opinions and lastly for factor 4, item 11 "I blame my relative for the cause of my problems" and item 13 "My relative does not appreciate enough what I do for him/her" representing the accusation dimension in a relationship. These 3 factors were actually representing the overall conflict and criticism within a relationship from a broader perspective.

Table 3: Loading factors from principal component analysis with varimax rotation

Items	Patient's Factor (14 items)				Caregiver's Factor (13 items)		
	1	2	3	4	1	2	3
1	0.68						0.48
2			0.59			0.76	
3		0.88				0.61	
4	0.68						0.74
5	0.64				0.71		
6	0.78				0.77		
7	0.71						0.53
8		0.56				0.68	
9	0.77						0.63
10			0.89			0.71	
11				0.86	-	-	-
12	0.75				0.65		
13				0.66		0.55	
14	0.77				0.78		
% of Variance	40.72	11.86	9.19	7.67	44.66	8.65	7.89

As for the caregiver QCPR Malay version, by omitting the item 11, the newly formed 13 items caregiver QCPR Malay version has satisfactory reliability and constructs validity. Item 11 “I blame my relative for the cause of my problem” was poorly correlated with the corrected item-total score. This could be due to cultural differences between the western and eastern world. For majority of the Asian caregivers, filial responsibility and cultural obligation are the important motivation in caregiving²⁵. Hence blaming the care-recipient of the cause of one’s problem does not seem to be valid in this context as the strong belief in filial values and cultural commitment to care for aging parents appeared to be the most prevalent coping strategy^{26,27}.

Despite factor analysis extracted three factors on the 13 items caregiver QCPR Malay version, the overall domains are still consistent with the original scale. Both Factor 1 and 3 were corroborated with the “warm and affection” domain whereby Factor 2 fits into the “conflict and criticism” domain of the original scale¹⁸.

One of the major limitations in this study was the subjects were recruited from a single hospital in urban area which might not be representing the whole dementia population especially those residing in rural area. Hence future studies comprising both urban and rural population shall be conducted for review and comparison. Besides, this study only manage to recruit participants with mild to moderate dementia, hence future study should include people with severe dementia as this may affect differently on the relationship as the disease progress.

CONCLUSION

The adapted Malay QCPR questionnaire for both the patient (14 items) and caregiver (13 items) version is a valid and reliable scale to evaluate the quality of dyadic relationship between people with mild to moderate dementia and their caregiver living in community. Thus, QCPR questionnaire in Malay version will be useful tool for Malay speaking older adults with dementia and their caregiver.

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