Cross cultural adaptation and validation of the Malay Advance Care Planning Questionnaire

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Abstract

Background There is a growing interest among the developing countries on advance care planning (ACP) due to the reported benefits of planning ahead in the developed countries. Validated instruments in various languages have been developed to facilitate study on the views of public prior to its implementation. However, instrument to explore the views on advance care planning (ACP) in Malay has not been developed and validated yet, even though Malay is spoken extensively by approximately 220 million people in the Malay Archipelago. There is also a need for instrument in Malay language to facilitate the assessment of knowledge, attitude and practice (KAP) of Malaysians regarding advance care planning (ACP). Therefore, the purpose of this study is to cross-culturally adapt, and examine the internal consistency and reliability of the Malay Advance Care Planning Questionnaire (ACPQ-M) among the Malay speaking community dwellers.

Methods The ACPQ was translated according to international guidelines. This validation study was conducted from January to June 2018. Participants who were ≥21 years old, and able to understand Malay were recruited from an urban primary care clinic and a tertiary education institution in Malaysia. A researcher administered the ACPQ-M to participants via a face-to-face interview at baseline and two weeks later. Each interview took approximately 15-20 minutes.

Results A total of 222/232 participants agreed to participate (response rate=96.0%). Exploratory factor analysis and confirmatory factor analysis found that the ACPQ-M was a 4-factor model. The Cronbach’s α values for the four domains ranged from 0.674-0.947. Only 157/222 participants completed the test-retest (response rate=71%). At test-retest, quadratic weighted kappa values for all domains ranged from 0.340-0.674, except for two domains which ranged from -0.200-0.467.

Conclusions The ACPQ-M was found to be a 4-factor model, and a valid and reliable instrument to assess the KAP regarding ACP. This instrument can contribute to profound understanding of the KAP of Malaysians regarding ACP, and assist policy makers in determining the readiness for legislation of ACP in Malaysia.

Introduction

Advance care planning is a process which supports a person at various stages of life and health status
to understand and express their values, wishes and preferences toward future health care (1). Patients can record their preference of medical care and appoint a surrogate decision-maker ahead of time (2). Well implemented advance care planning policies have improved the quality of life of patients and their families (3, 4). This improvement may be contributed by the enhancement of patients’ sense of control over their medical care and the bonding between patients, families and health care professionals with advance care planning discussions (5, 6). Despite the known benefits, the uptake of advance care planning remains low (7) in countries which has legislation support such as the United States (8), United Kingdom (8) and Australia (9).

Advance care planning is currently not legislated in Malaysia although it is briefly described in the code of medical ethics (10). A study revealed that 76% of 56 patients undergoing haemodialysis in Malaysia have never heard of advance care planning (11). Another exploratory study performed on fifteen older Malaysians found that they were receptive to its concept, although they had no prior exposure to advance care planning (12). However, no in-depth work had been conducted in Malaysia to obtain further insights into their knowledge, attitude and practice towards advance care planning. Several instruments have been developed and validated to assess the views, knowledge, attitude and practice of advance care planning: the ‘Cultural values and belief scale’ (13), ‘The ethnicity and attitudes toward advance care directives questionnaires’ (14) and the ‘Asian American quality of life survey’ (15). These instruments were primarily tested and used in the United States (15), Korea (16), Japan (17) and Hong Kong (18). Recognition of the influence of culture and religion on individual’s preference for advance care planning has highlighted the need to consider a local instrument for assessment of knowledge, attitude and practice regarding advance care planning among the Malaysians (19).

The English version of the Advance Care Planning Questionnaire (ACPQ) was developed and validated to assess the knowledge, attitude and practice of advance care planning in Malaysia (20). This instrument was found to be a reliable instrument with adequate internal consistency to measure the four domains related to advance care planning: “feelings regarding advance care planning”, “justifications for advance care planning”, “justifications for not having advance care planning: fate
and religion” and “justifications for not having advance care planning: avoid thinking about death”.

However, Malay language is extensively use in the malay archipelago especially in Malaysia, Brunei, and Indonesia, and spoken by approximately 220 million people (21). Therefore, this study aimed to cross-culturally adapt the English ACPQ to Malay (ACPQ-M) (20) and to determine its validity and reliability in assessing the knowledge, attitude and practice of Malaysians regarding advance care planning.

Methods
The cross cultural adaptation of the Advance Care Planning Questionnaire (ACPQ) from English to Malay consists of three parts: (1) translation, (2) validation, and (3) reliability testing.

Translation of the Advance Care Planning Questionnaire (ACPQ)
The English ACPQ was translated according to the Principles of Good Practice for the Translation and Cultural Adaptation Process (Figure 1) (22). No problems were encountered during the pilot test. Hence, version 4 of the ACPQ-M was used [Table 1].

Validation of the Malay Advance Care Planning Questionnaire (ACPQ-M)

Study design and setting
This validation study was conducted from January to June 2018 at an urban primary care clinic and a tertiary education institution in Malaysia.

Participants
Community dwellers who were ≥21 years and able to understand Malay were recruited. Community dwellers with mental illnesses such as dementia or psychosis were excluded.

Sample size calculation
The sample size was calculated based on rule of thumb of 10 participants per item to perform factor analysis (23, 24). The number of items in the ACPQ that could be validated was 16 as the items had a 5-point Likert-scale response (Table 1). Therefore, the total number of participants required was 16*10=160 participants.

Instruments used

The Malay Advance Care Planning Questionnaire (ACPQ-M)
The ACPQ-M consists of four sections and 60 items (29 items were measure on nominal scale, whilst 31 items were measured on a 5-point Likert scale). Participants are required to answer all the items in section A, B and C of the ACPQ-M. As for section D of the ACPQ-M, those who were in in favour of advance care planning were asked to answer the items in the domain “justifications for advance care planning”; while those who were not in favour of advance care planning were asked to answer the items in the domain “justifications for not having advance care planning: avoid thinking about death” and “justifications for not having advance care planning: fate and religion”.

**Procedure**

Eligible participants were approached, and the purpose of the study was explained to them using the participant information sheet. Written informed consent was obtained for those who agreed to participate. A researcher administered the ACPQ-M to participants via a face-to-face interview as this questionnaire contained some medical terms which may not be understood by the lay person. Each interview took between 10 to 20 minutes. The retest was performed two weeks later over the phone.

**Data analyses**

Data analyses were performed using the Statistical Package for Social Sciences (SPSS) version 23.0 (Chicago, Illinois, USA). As normality could not be assumed, the central tendency was described as median and interquartile range (IQR), whilst descriptive data was presented as number and frequency. Confirmatory factor analysis (CFA) was performed using Lavaan package in R software for statistical computing and graphics version 3.5.1 (R Foundation, Vienna, Austria) (25).

**Validity**

Face and content validity were verified by an expert panel (which consisted of two primary care physicians and three academic pharmacists). Flesch reading ease, to test the readability of the instrument was not applied to ACPQ-M because the computer calculated score was not developed and validated for use in Malay language (26).

Factor analysis was used to determine the construct validity. Exploratory factor analysis was performed to explore the dimensionality of the ACPQ-M by computing the percentage of total variance explained, the number of factors and factor loadings to determine the degree of agreement between
observed scores and latent variables (27). Bartlett’s test of sphericity was used to test for intercorrelations between all the variables within the correlation matrix (28). Sampling adequacies were determined using the Kaiser-Meyer-Olkin criterion and communalities of the variables. Kaiser-Meyer-Olkin, factor loading values and communalities of at least 0.6, 0.4 and 0.4, respectively, were deemed as having good construct validity (29).

Confirmatory factor analysis was conducted to verify the factor structure of the ACPQ-M (30). The factor structure was examined by computing the model fit indices such as comparative fit index, Tucker Lewis Index; standardised root mean square residual and root mean square error of approximation using diagonally weighted least square method for categorical variables (27).

Comparative fit index and Tucker Lewis Index values of at least 0.95 and standardised root mean square residual value of ≤0.09 indicates goodness of fit (27). Additionally, root mean square error of approximation p-value of ≥0.05 also indicates acceptable level of model fit with the degree of fit being interpreted as such: root mean square error of approximation values <0.05 close fit, 0.05 to < 0.08 reasonably good, 0.08 to <0.10 mediocre, and ≥0.10 unacceptable (27, 31).

**Reliability**

Cronbach’s $\alpha$ was used to assess the internal consistency of the items in the ACPQ-M. Cronbach’s $\alpha$ values between 0.70–0.90 implied adequate internal consistency (32). Corrected item-total correlations were used to identify items which are inconsistent with other items in the ACPQ-M. Corrected item-total correlation values <0.2 were deemed as unacceptable (32).

Test-retest reliability was assessed using quadratic weighted Cohen’s kappa coefficient as the items for validation were measured as ordinal data on a 5 point Likert-scale (33). Kappa values can range from +1 to -1 (34). The value of +1 indicates complete inter-rater agreement for the categorical items, whereas -1 represents disagreement at the other end of the continuum. Kappa values can be interpreted as follows: <0 less than chance agreement, 0.01–0.20 slight agreement, 0.21–0.40 fair agreement, 0.41–0.60 moderate agreement, 0.61–0.80 substantial agreement and 0.81–1.00 almost perfect agreement (35).

Results
A total of 222/232 participants agreed to participate (response rate=96.0%). The majority were female (72.1%) and Malay (54.1%), with a median age of 29 years (IQR=12) [Table 2]. A total of 200 (90.1%) participants were in favour of advance care planning.

**Validity**

Exploratory factor analysis found that the ACPQ-M was a 4-factor model, which explained >50% of the total variance of each domain [Table 3]. Kaiser-Meyer-Olkin and factor loadings were >0.6 and >0.4, respectively. Communalities were >0.4 except for the item “I believed that the discussion of the topic of death was seen as “unlucky” and I tried to avoid discussing about it”. Bartlett’s tests of sphericity were significant for all domains (p<0.05).

Confirmatory factor analysis found that the Comparative Fit Index values for the four domains ranged from 0.985-1.000; while the Tucker Lewis Index values ranged from 0.956-1.000. The standardised root mean square residual values for the domains “feelings regarding advance care planning”, “justifications for advance care planning” and “justifications for not having advance care planning: fate and religion” were 0.021, 0.047 and 0.086, respectively. The p-value of root mean square error of approximation for the domains “feelings regarding advance care planning”, “justifications for advance care planning” and “justifications for not having advance care planning: fate and religion” were 0.088, 0.045 and 0.675, respectively. Standardised root mean square residual value and p-value of root mean square error of approximation for the domain “justifications for not having advance care planning: avoid thinking about death” were unable to be calculated probably due to inadequate data point or number of participants (df=0, n=8).

**Reliability**

The Cronbach’s α values for the four domains ranged from 0.674-0.947 (Table 4). The corrected item total correlation of all items was >0.2. The deletion of item ‘I believed that the discussion of the topic of death was seen as “unlucky” and I tried to avoid discussing about it’ in the domain “justifications for not having advance care planning: fate and religion” would increase the Cronbach’s α from 0.674 to 0.725.

Only 157/222 participants completed retest (response rate=71%), as the remaining participants were
either uncontactable (n=7) or refused to participate at retest (n=58). At test-retest, quadratic weighted kappa values for all domains ranged from 0.340-0.674; except for the domains “justifications for not having advance care planning: fate and religion” and “justifications for not having advance care planning: avoid thinking about death” which ranged from -0.200-0.467.

Discussion

Main findings

The ACPQ-M was found to be a valid and reliable instrument to assess the knowledge, attitude and practice regarding advance care planning in Malaysia. The final version of the ACPQ-M consists of 4 sections and 60 items, of which 29 were measured on a nominal scale whilst 31 items were measured on a 5-point Likert scale.

Study on dimensionality using exploratory factor analysis showed that the ACPQ-M was a 4-factor model and a good model of fit. Our findings was similar to the original ACPQ (20). The four domains were “feelings regarding advance care planning”, “justifications for advance care planning”, “justifications for not having advance care planning: avoid thinking about death” and “justifications for not having advance care planning: fate and religion”. There was adequate sampling in all domains (Kaiser-Meyer-Olkin >0.6). Bartlett’s tests of sphericity were also significant for all domains which implied that the correlations between items were sufficient for factor analysis. Additionally, adequate amount of the variance can be explained by the underlying factors as indicated by the communalities >0.4 except for the item “I believed that the discussion of the topic of death was seen as unlucky and I tried to avoid discussing about it”. However, the factor loading for this item is >0.4. Hence, this item was retained as patients were able to understand the questionnaire without issue during validation of the English ACPQ, and we wanted the two versions to be the same (20).

Overall, the reliability of the ACPQ-M was satisfactory (ranged between 0.674-0.947). This was consistent with the reliability of English ACPQ (20). However, the test-retest reliability computed using quadratic weighted kappa was low for two domains: “Justifications for not having advance care planning: fate and religion” and “Justifications for not having advance care planning: avoid thinking about death”. We believed this to be attributed to the small number of participants (n=8) who were
not in favour of advance care planning. The kappa values for these two domains of the ACPQ-M were also lower than the original English ACPQ as more participants who were not in favour of advance care planning answered the English ACPQ (n=55) as opposed to the ACPQ-M (n=8) (20). In addition, the English ACPQ study recruited older participants (median age=68 years) when compared to the present study (median age=29 years) (20).

Limitations of the study
One of the limitations of the study was that convergent and discriminative validity were not performed. Convergent validity was not performed as there were no other validated instruments in Malay to assess the knowledge, attitude and practice during the period of our study. Discriminative validity was also not performed as it was not possible to identify participants who had high or low knowledge of advance care planning. In addition, the results of this study may not be generalisable as participants were only recruited from two urban sites.

Strength of the study
Despite the limitations, this study has validated the Malay Advance Care Planning Questionnaire and found that this tool had adequate psychometric properties. The tool can now be used to assess the knowledge, attitude and practice regarding advance care planning among Malaysians who are only able to understand Malay. Findings from the administration of this tool can assist policymakers to decide if Malaysians are ready for advance care planning to be legislated in Malaysia.

Conclusion
The ACPQ-M was found to be a 4-factor model, and a valid and reliable instrument to assess the knowledge, attitude and practice regarding advance care planning in Malaysia. This validated instrument can be used to assess the knowledge, attitude and practice of Malaysians regarding advance care planning, and to assist policy makers in determining the readiness for advance care planning in to be legislated in Malaysia.

Abbreviations
ACP
Advance care planning
ACPQ
Advance care planning questionnaire
ACPQ-M
Malay Advance care planning questionnaire
IQR
Inter-quartile range
KAP
Knowledge, attitude and practice

Declarations

Ethics approval and consent to participate
Ethics approval was obtained from the University Malaya Medical Centre Medical Ethics Committee prior to the study (MEC reference no. 20171118-5830).

Consent for publication
Not applicable.

Availability of data and materials
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests
The authors declare that there is no conflict of interest.

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Authors’ contributions
MKL, PSML, PSW, SO, FHMM conceived the study, participated in the design and reviewed the translated versions of the questionnaire; MKL was involved in data acquisition; MKL and PSML performed the analysis and interpretation of data; MKL drafted the manuscript; all authors read and approved the final manuscript.

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Tables

Table 1: The Malay Advance Care Planning Questionnaire (ACPQ-M)
| Section          | Description                                           | No of items | Domain                          | Type of data          |
|------------------|-------------------------------------------------------|-------------|---------------------------------|-----------------------|
| A                | Demographic information                              | 9           | Demographic information         | Nominal              |
| B                | Health Information                                   | 2           | Past medical history            | Nominal              |
| C                | Knowledge on advance care planning                   | 9           | Knowledge                       | Nominal              |
| D                | Issues regarding advance care planning               | 2           | Awareness                       | Nominal              |
|                  |                                                       | 5           | Previous experiences in last five years | Nominal              |
|                  |                                                       | 5           | Feelings regarding advance care planning | Likert               |
|                  |                                                       | 4           | Justifications for advance care planning | Likert               |
|                  |                                                       | 7           | Justifications for not having advance care planning | Likert               |
|                  |                                                       | 2           | Intentions to plan their advance care planning | Nominal              |
|                  |                                                       | 10          | Topics to discuss during advance care planning | Likert               |
|                  |                                                       | 4           | Recording of advance care planning | Likert               |
|                  |                                                       | 1           | Surrogate decision maker appointment | Nominal              |
| **Total**        |                                                       | **60**      |                                 |                       |

A total of 16 items using a 5-point Likert-scale for validation; items were not validated as the responses were descriptive

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**Table 2: Demographic characteristics and health status of participants**

| Demographic Characteristics                  | N (%)(n=222) |
|----------------------------------------------|--------------|
| Female                                       | 160 (72.1)   |
| Median age ± interquartile range (years) [range] | 29 ± 12 [22–73] |
| <40                                          | 117 (52.7)   |
| ≥40                                          | 105 (47.3)   |
| Ethnicity                                    |              |
| Malay                                        | 120 (54.1)   |
| Chinese                                      | 77 (34.6)    |
| Indian                                       | 23 (10.4)    |
| Others*                                      | 2 (0.9)      |
| Marital status                               |              |
| Single                                       | 132 (59.5)   |
| Married                                      | 88 (39.6)    |
| Divorced                                     | 1 (0.5)      |
| Widowed                                      | 1 (0.5)      |
| Level of education                           |              |
| Primary (completed 6 years of education)     | 2 (0.9)      |
| Secondary (completed 12 years of education)  | 33 (14.9)    |
| Tertiary (completed at least 15 years of education) | 187 (84.2)  |
| Religion                                     |              |
| Islam                                        | 120 (54.0)   |
|                        | N (%)  |
|------------------------|--------|
| **Religion**           |        |
| Buddhism               | 60 (27.0) |
| Christianity           | 21 (9.5)  |
| Hinduism               | 20 (9.0)  |
| Others**               | 1 (0.5)   |
| **Occupation**         |        |
| Employed               | 170 (76.6) |
| Unemployed             | 52 (23.4)  |
| **Personal monthly income** |    |
| <RM 1000 (<$250)       | 51 (23.0)  |
| RM1001-RM2000 ($251-$500) | 49 (22.1)  |
| RM2001-RM5000 ($501-$750) | 51 (23.0)  |
| RM3001-RM4000 ($751-$1000) | 30 (13.5)  |
| RM4001-RM5000 ($1001-$1250) | 9 (4.1)    |
| >RM5001 ($1251)        | 32 (18.9)  |
| **Living companions**  |        |
| Family (spouse, siblings, children) | 160 (72.1) |
| Friends                | 42 (18.9)  |
| Alone                  | 20 (9.0)   |
| **Self-rated health status** |    |
| Excellent              | 27 (12.2)  |
| Very good              | 79 (35.6)  |
| Good                   | 108 (48.6) |
| Poor                   | 8 (3.6)    |
| **Presence of co-morbidities** |         |
| Asthma / Chronic obstructive pulmonary disease | 12 (5.0)    |
| Hypertension           | 11 (4.8)   |
| Diabetes mellitus      | 10 (4.4)   |

* Murut (n=1), Punjabis (n=1); ** Sikhism (n=1)

Table 3: Exploratory factor analysis of the Malay Advance Care Planning Questionnaire (ACPQ-M)
| Domains (no. of items)                                | Items                                                                 | Factor loadings |
|------------------------------------------------------|----------------------------------------------------------------------|-----------------|
| Feelings regarding advance care planning             | Felt better to have expressed wished in advance if I had a heart attack or on a breathing machine | 0.931           |
| (5) (n = 222)                                        | Felt better to have expressed wished in advance if I had severe dementia | 0.916           |
|                                                      | Felt better to have expressed wished in advance if I had a stroke    | 0.913           |
|                                                      | Felt better to have expressed wished in advance if I had a road accident or in a coma  | 0.893           |
|                                                      | Felt better to have expressed wished in advance if I had cancer      | 0.889           |
| Justifications for advance care planning             | I am aware that I could possible lose my decision-making power as a result of becoming seriously ill or injured | 0.779           |
| (4) (n=200)                                          | I want to be able to make my own decision                            | 0.710           |
|                                                      | I hope to not burden my family with my medical treatment preferences | 0.705           |
|                                                      | There may be differences in opinions between my family members       | 0.685           |
| Justifications for not having advance care planning  | I believed that planning for my death would mean there is no hope for me | 0.851           |
| Fate and religion (4)                                | I will take it as it comes, as I have no control over my death       | 0.780           |
| (n=22)                                               | I felt that it was best to leave to fate or to God                    | 0.727           |
|                                                      | I believed that the discussion of the topic of death was seen as “unlucky” and I tried to avoid discussing about it | 0.446           |
| Justifications for not having advance care planning  | I do not want to think I will die or lose my memory                   |                 |
| Avoid thinking about death (3) (n=22)                | I cannot imagine myself in such a situation                           |                 |
|                                                      | I am currently healthy and there is no need to consider such decisions |                 |

Table 4: Reliability of the Malay Advance Care Planning Questionnaire (ACPQ-M)
| New domains               | Items                                                                                                                                 |
|--------------------------|---------------------------------------------------------------------------------------------------------------------------------------|
| (no. of items)           |                                                                                                                                         |
| **Feelings regarding advance care planning (5) (n = 157)** | Felt better to have expressed wished in advance if I had a heart attack or on a breathing machine  
Felt better to have expressed wished in advance if I had severe dementia  
Felt better to have expressed wished in advance if I had a stroke  
Felt better to have expressed wished in advance if I had a road accident or in a coma  
Felt better to have expressed wished in advance if I had cancer |
| **Justifications for advance care planning (4) (n = 149)** | I am aware that I could possible lose my decision-making power as a result of becoming seriously ill or injured  
I want to be able to make my own decision  
I hope to not burden my family with my medical treatment preferences  
There may be differences in opinions between my family members |
| **Justifications for not having advance care planning: Fate and religion (4) (n=8)** | I believed that planning for my death would mean there is no hope for me  
I will take it as it comes, as I have no control over my death  
I felt that it was best to leave to fate or to God  
I believed that the discussion of the topic of death was seen as “unlucky” and I tried to avoid discussing about it |
| **Justifications for not having advance care planning: Avoid thinking about death (3) (n=8)** | I do not want to think I will die or lose my memory  
I cannot imagine myself in such a situation  
I am currently healthy and there is no need to consider such decisions |

Figures
The English version of the ACPQ

Forward translation by a non-healthcare professional (version 1a)

Forward translation by a healthcare professional (version 1b)

Expert panel met to reconcile the two translations (version 2)

Backward translation by another non-healthcare (version 3a)

Backward translation by another healthcare professional (version 3b)

Reviewed by the expert panel (version 4)

Pilot tested in five participants

Figure 1

Translation of the Advance Care Planning Questionnaire (ACPQ) from English to Malay (20)