Chinese translation of Attitudes of Older People to End of Life Issues Questionnaire

NPK Law RN, BN, MBA (Health Services Management), DN, JKH Luk RN, BN, MSc (Experimental Medicine) (UBC), FRCP (Edin, Glasg, Irel), FHKCP, FHKAM (Medicine), KC Choi BSc, PhD, CWH Chan RN, PhD

ABSTRACT

Objectives. To translate the Attitudes of Older People to End of Life Issues (AEOLI) questionnaire into a Chinese version and to establish its semantic equivalence, content equivalence, face validity, feasibility, and reliability.

Methods. The original AEOLI questionnaire was translated into Chinese using forward and backward translation based on the Brislin model. Semantic equivalence, content equivalence, face validity, reliability, and feasibility were established.

Results. The mean equivalence rating of the questionnaire was 90%, indicating that the Chinese version was a correct reflection of the English version. The content validity index was 0.83 indicating a high degree of agreement among the experts about its relevance. Face validity was assessed in 3 older persons living in nursing homes; the content of the Chinese AEOLI questionnaire reflected the concepts that the researcher intended to measure. The test-retest reliability was conducted in 50 older persons living in nursing homes; the weighted Kappa statistics were 0.61 to 1.00 (p<0.001), indicating moderate-to-excellent concordance.

Conclusion. The Chinese AEOLI questionnaire is a useful tool to examine the attitudes of older people towards end-of-life issues in the Chinese population.

Key words: Aged; Attitude; Homes for the aged; Translations

BACKGROUND

The proportion of older population (age ≥65 years) in Hong Kong is growing fast, amounting to over 900,000 (13% of total) in the 2011 Census. Around 70,000 of them live in residential care homes for the elderly (RCHEs). Many of them are frail, have multiple comorbidities and irreversible chronic medical illnesses, and are in the last phase of their lives.

End-of-life (EOL) care refers to the provision of physical, psychological, and spiritual care for people who have chronic illnesses or life-threatening diseases during the last phase of life, the duration of which varies from 6 months to 2 years. In Hong Kong, EOL care is not well-developed, particularly for non-cancer patients such as those with advanced dementia or other irreversible chronic diseases. Nearly all dying people are sent to the hospital, irrespective of their diagnosis, prognosis, age, and premorbid state. Advance care planning and advance directive are not commonly made, owing to many legal, social, cultural, and economic reasons.

Correspondence to: Dr James KH Luk, Department of Medicine and Geriatrics, Fung Yiu King Hospital, 9 Sandy Bay Road, Pokfulam, Hong Kong. Email: lukkh@ha.org.hk
Studies on the preferences for EOL care among Chinese older people in Hong Kong are lacking. The government and health care and social professionals do not have enough information about the attitudes and preferences of older people about EOL care. In a study in local RCHEs, 35% of older people preferred to die in RCHEs if they had a terminal disease or persistent vegetative state/irreversible coma, but the scale of such attitudes was not assessed.

The Attitudes of Older People to End of Life Issues (AEOLI) questionnaire was developed in the UK by a group of older people, academics, and clinical palliative care professionals. It deals with attitudes to, and preparations for, death, and preference of place of care. It has 27 items covering areas in decision making, pain, care, environment, living wills, euthanasia/physician-assisted suicide, ageism, psychological needs including religious/spiritual, quality versus quantity of life, and societal awareness. Each item scores from 1 to 5 points from ‘strongly agree’ to ‘strongly disagree’ using a 5-point Likert scale. The comprehensibility and the face validity were assessed by older people. The test-retest reliability was assessed using Cohen’s Kappa statistics for categorical variables; the Kappa value was >0.4. Its Cronbach’s alpha for internal consistency was 0.52 to 0.77. It has been used in different studies of EOL issues in older people.

A Chinese version of the AEOLI questionnaire is useful to understand the attitudes of the Chinese older people towards EOL including advance directive, advance care planning, enduring power of attorney for health care decision, ‘do not resuscitate’ order, use of life-sustaining treatment at EOL, and preference of place of death. This study translated the AEOLI questionnaire into a Chinese version and established its semantic equivalence, content equivalence, face validity, feasibility, and reliability.

METHODS

This study was approved by the Clinical Research Ethical Committee of the Chinese University of Hong Kong. Informed consent from each participant was obtained. The AEOLI questionnaire was translated into a Hong Kong Chinese version based on the Brislin model of translation, which involved 4 steps: English to Chinese forward translation, Chinese evaluation, blind back translation from Chinese to English, and comparison between the original and back-translated versions.

First, the AEOLI questionnaire was forward-translated by a bilingual geriatric nurse fluent in both Chinese and English who was aware of the intent of each item and the scale as a whole. Second, a native Chinese monolingual reviewer reviewed the translated questionnaire in terms of the Chinese grammar. Minor grammatical errors were corrected and 2 of the questions were rephrased, without changing the original meaning, to provide a more comprehensive understanding in Chinese. Third, the Chinese AEOLI questionnaire was back-translated into the original language by another registered nurse fluent in both English and Chinese who was unaware of the English version. Fourth, the back-translated version was compared with its original English version to evaluate the semantic equivalence by a native English-speaking translator. Any discrepancies were identified and whether the problem arose from the forward or backward translation was determined. If it was from the forward translation, the 4 steps were repeated. If it was from the backward translation, the part in question was further back translated. This process was repeated until maximum equivalence was achieved between the original English version and the back-translated version.

The language equivalence, cultural relevance, face and content validity of the Chinese AEOLI questionnaire were examined. The internal consistency and test-retest reliability of the translated version were tested. Each item of the questionnaire was assessed (including the concepts, grammar, wording, meaning, and format) to ensure conceptual and idiomatical equivalence. An expert panel consisting of 20 specialists in gerontology or palliative care assessed the semantic equivalence. Both the original and translated questionnaires’ items were compared, using a 4-point ordinal rating scale (1=not equivalent, 2= somewhat equivalent, 3=quite equivalent, and 4=extremely equivalent). Panel members could make their comments or suggestions on each item. Items rated as less than quite equivalent (<3) by more than 20% of respondents were amended. None of the items required further modification.

A committee comprising the researcher, one
bilingual senior medical officer, and one bilingual nursing professor reviewed the Chinese AEOLI questionnaire to reduce cultural bias and achieve better semantic equivalence. All translation discrepancies were discussed and resolved. This process aimed to determine whether the conceptual equivalence of the terms with the similar meaning in Chinese expressions had the same conceptual meanings in both cultures. No further amendment was made.

An expert panel of 2 professors, one consultant in geriatrics, 2 geriatric nurses, and one palliative care nurse evaluated the content equivalence and overall appropriateness for use in the study population. Discrepancies were analysed for translation misinterpretations. Changes were made to the translated version to ensure the questionnaire was valid and relevant to the local context in Hong Kong.

The content validity index (CVI) was assessed using a 4-point ordinal rating scale (1=irrelevant, 2=somewhat relevant, 3=quite relevant, and 4=extremely relevant). Panel members could make their comments or suggestions on each item. CVI was calculated based on the proportion of experts endorsing an item as content valid. A CVI of ≥0.8 indicates high content validity.

Face validity was assessed by 3 older persons (age ≥65 years) who were living in RCHEs and had secondary education to evaluate the content relevance and appropriateness of the questionnaire.

The Chinese AEOLI questionnaire was pilot-tested in 10 Cantonese-speaking older persons (age ≥65 years) living in RCHEs who were cognitively competent with an abbreviated mental test (AMT) score of ≥6. The duration of interview was estimated.

The reliability of the instrument was tested to prove its consistency in repeated measurements. 50 Cantonese-speaking older persons (age ≥65 years) living in RCHEs who were cognitively competent with an AMT score ≥6 were recruited. Weighted Kappa statistics were used to examine the test-retest reliability of the translated questionnaire. Kappa values of >0.8, >0.6, and >0.4 indicate excellent, substantial, and moderate concordance, respectively. The respondents were asked to comment on the questionnaire and identify any unclear items that were difficult to understand.

RESULTS

Translation
All the experts in the committee considered the Chinese AEOLI questionnaire (Table 1) to be culturally relevant for the older Chinese in Hong Kong. However, certain items in the English version had particular issues and required discussion before the Chinese version was finalised. In the Chinese culture, unlucky words such as death should be avoided. The expert panel was concerned that the word ‘death’ might provoke uncomfortable feelings or even emotional disturbances. Hence, direct translation of the word ‘die’ (死亡 in Chinese) in item 3 was avoided, and a more gentle Chinese term 離世 was used instead. In addition, living wills or advance directives are not commonly available in Hong Kong. Most older people in Hong Kong do not know what an advance directive is, and the rate of making advance directives is extremely low. The panel used the official translation of the Law Reform Commission for the term ‘living will’. The panel recommended that the interviewer explain living will beforehand. Moreover, only a few RCHEs in Hong Kong provide hospice care. Most of the RCHEs do not provide palliative care, and older residents are transferred to acute hospitals during their last days of life. Hence, the panel translated the word ‘hospice’ into the Chinese term meaning ‘palliative care hospitals or units’.

Semantic equivalence, content equivalence, and face validity
All items were rated as ‘quite equivalent’ or ‘extremely equivalent’ by ≥80% of the expert panel and committee members. The mean equivalence rate was 90%, indicating accurate translation. Some terms were modified without changing the original meaning. The CVI was 0.83 indicating a high degree of agreement among the experts about its relevance. Face validity confirmed that the content of the Chinese AEOLI questionnaire reflected the concepts that the researcher intended to measure.

Pilot study
The duration for each interview varied from 30 to 45 minutes. Respondents with better physical condition could respond faster. Those with hearing
or visual impairment needed more time to complete. All respondents were willing to discuss EOL issues with the researcher. Respondents gave no further comments, and no modification was required.

Recreability testing
The test-retest reliability was conducted in 12 men and 38 women aged 65 to 95 (mean, 84.1; standard deviation, 6.6) years. The weighted Kappa statistics ranged from 0.61 to 1.00 (p<0.001, Table 2), indicating moderate-to-excellent concordance.

DISCUSSION
The Chinese AEOLI questionnaire enables future researches of EOL care in Hong Kong. Knowing the older people’s attitudes towards EOL can give the government and society vital information about the
future plan of EOL in Hong Kong. Nonetheless, the original AEOLI questionnaire is from UK, and the UK health care system, particularly the EOL care support, differs from that in Hong Kong. The cultural issue can also affect the attitudes towards the EOL issues. Hence, the Chinese AEOLI questionnaire enables direct comparison of attitudes towards EOL issues between western and Chinese cultures.

The Chinese AEOLI questionnaire can potentially be used in all Chinese-speaking people in the world, irrespective of their dialects. Whether EOL attitudes differ among Chinese in different parts of China and the world can be examined. The Chinese AEOLI questionnaire was established using older people living in RCHEs. Theoretically, it can also be used in home-dwelling older people and enables comparison of older people living in RCHEs versus home.

There were limitations in this study. First, community-dwelling people were not included, whereas the original AEOLI questionnaire was tested on volunteers aged 55 to ≥75 years living in

<table>
<thead>
<tr>
<th>AEOLI questionnaire item</th>
<th>Weighted Kappa using Fleiss-Cohen weights (95% CI)</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>e1</td>
<td>0.86 (0.71-1.00)</td>
<td>&lt;0.001</td>
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<tr>
<td>e2</td>
<td>0.79 (0.62-0.96)</td>
<td>&lt;0.001</td>
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<tr>
<td>e3</td>
<td>0.99 (0.97-1.00)</td>
<td>&lt;0.001</td>
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<td>e4</td>
<td>0.94 (0.88-0.99)</td>
<td>&lt;0.001</td>
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<tr>
<td>e5</td>
<td>0.82 (0.61-1.00)</td>
<td>&lt;0.001</td>
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<tr>
<td>e6</td>
<td>0.93 (0.80-1.00)</td>
<td>&lt;0.001</td>
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<tr>
<td>e7</td>
<td>0.96 (0.91-1.00)</td>
<td>&lt;0.001</td>
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<td>0.95 (0.86-1.00)</td>
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<tr>
<td>e9</td>
<td>0.81 (0.59-1.00)</td>
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<tr>
<td>e10</td>
<td>0.61 (0.50-0.73)</td>
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<td>0.80 (0.72-0.89)</td>
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<tr>
<td>e12</td>
<td>0.61 (0.32-0.89)</td>
<td>&lt;0.001</td>
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<td>e13</td>
<td>0.89 (0.77-1.00)</td>
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<td>e14</td>
<td>0.78 (0.60-0.96)</td>
<td>&lt;0.001</td>
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<td>e15</td>
<td>0.87 (0.69-1.00)</td>
<td>&lt;0.001</td>
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<tr>
<td>e16</td>
<td>0.98 (0.94-1.00)</td>
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<td>0.94 (0.87-1.00)</td>
<td>&lt;0.001</td>
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<tr>
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<td>&lt;0.001</td>
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<tr>
<td>e19</td>
<td>0.64 (0.46-0.82)</td>
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<td>0.75 (0.43-1.00)</td>
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<td>0.97 (0.91-1.00)</td>
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<tr>
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<td>0.86 (0.77-0.96)</td>
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<td>e23</td>
<td>1.00 (1.00-1.00)</td>
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<td>0.97 (0.90-1.00)</td>
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<tr>
<td>e26</td>
<td>0.86 (0.75-0.97)</td>
<td>&lt;0.001</td>
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<tr>
<td>e27</td>
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the community who attended general practitioners in the UK. Nonetheless, the Chinese AEOLI questionnaire is expected to be applicable to home-dwelling older people. Some caution should be taken when interpreting and generalising the results, as this study was based on a relatively frail sample from the residential care home, and the extent of cultural influences on the attitude toward EOL care may vary between Chinese and western countries. Further testing of the Chinese AEOLI questionnaire using home-dwelling older people is needed. The Chinese AEOLI questionnaire was translated using Cantonese-speaking older people. The majority of the population in China speaks Mandarin and other dialects, and thus further tests are needed. Subjects were recruited from 10 out of 18 districts in Hong Kong to minimise selection bias. The psychometric properties of the AEOLI were not tested in this report and further studies are recommended.

CONCLUSION

The Chinese AEOLI questionnaire is a useful and reliable tool to measure attitudes of older people in Hong Kong towards EOL issues and hospice care. Further studies are needed to determine whether the questionnaire can be used in home-dwelling older people and non-Cantonese speaking Chinese populations. In addition, studies to test the psychometric properties of the questionnaire are recommended.

REFERENCES