Cross-cultural adaptation of the Malay version of the parent-proxy Health-Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) in Malaysia

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Abstract

Article history:
Received 20 January 2015
Revised 25 February 2015
Accepted 26 February 2015
Available online 25 March 2015

Keywords:
Epilepsy
Children
Quality of life
Validation
CHEQOL-25 instrument
Malay

Purpose: We aimed to cross-culturally adapt the parent-proxy Health-Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) into Malay and to determine its validity and reliability among parents of children with epilepsy in Malaysia.

Methods: The English version of the parent-proxy CHEQOL-25 was translated according to international guidelines to Malay. Content validity was verified by an expert panel and piloted in five parents of children with epilepsy (CWE). The Malay parent-proxy CHEQOL-25 was then administered to 40 parents of CWE, aged 8–18 years from two tertiary hospitals, at baseline and 2 weeks later. Parents were also required to complete the Malay PedsQL™ 4.0 so that convergent validity could be assessed. Hypothesis testing was assessed by correlating the individual subscales in the parent-proxy CHEQOL-25 with epilepsy severity, the number of anticonvulsants, and the number of close friends.

Results: Participants from the pilot study did not encounter any problems in answering the final translated Malay parent-proxy CHEQOL-25. Hence, no further modifications were made. Cronbach’s α for each subscale of the Malay parent-proxy CHEQOL-25 ranged from 0.67 to 0.83. The intraclass correlation coefficient for all items at test–retest ranged from 0.70 to 0.94. Both the CHEQOL-25 and the PedsQL™ 4.0 showed good correlation in the social and emotional subscales (r = 0.598, p = 0.002 and r = 0.342, p = 0.031, respectively). The severity of epilepsy, higher number of antiepileptic drug(s), poorer cognitive ability of the child, lower number of close friends, and lesser amount of time spent with friends were significantly associated with poorer health-related quality of life.

Conclusions: The Malay parent-proxy CHEQOL-25 was found to be a valid and reliable instrument to assess parents’ perceived HRQOL of their CWE in Malaysia.

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1. Introduction

Health-related quality of life (HRQOL) is a subjective and multidimensional concept, which reflects on the individual’s perceived physical, psychological, interpersonal, and emotional functioning [1]. It has been increasingly used to measure a broader range of medical and treatment outcomes of a patient in clinical practice to point out areas of concern that are often overlooked by physicians, such as emotional and interpersonal skills [2]. For children, a suitable HRQOL instrument must accommodate the changes that occur through their development and should ask questions primarily about their physical appearance (e.g., having shiny hair), their activities (e.g., running and playing), and their social life (e.g., having a lot of friends) and less about being economically productive and self-sufficient [3]. By understanding the health condition and daily experiences of children, a suitable treatment can then be planned and
detrimental outcomes (such as side effects from medications) can be minimized [3].

Parent-proxy ratings of a child’s HRQOL have traditionally been used to provide information about their child’s well-being as their ratings have been reported to be more stable compared to a child’s self-report [4], and previous studies showed agreement (e.g., physical and social well-being) between these two ratings [5]. In addition, parents often play an important role in treatment decision-making as well as in the evaluation of the effectiveness of interventions [6].

To date, fourteen HRQOL instruments have been developed and validated to assess the quality of life of CWE [4,7–19]. We decided to culturally adapt the Health-Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) developed by Ronen et al. [4] for three reasons. Firstly, its psychometric properties were good [8]. Secondly, the CHEQOL-25 had the advantage of measuring the parent-proxy HRQOL in addition to the child’s self-report HRQOL [4]. Thirdly, this instrument was more applicable for administration in Asia as five items have been specifically modified by Yam et al. [6]: (1) the original version asked if CWE had any problems going away to camp. However, in Asia, children rarely went to “camps”. Hence, Yam et al. added the terms “extracurricular activities” and “sports” as these are activities that children in Asia perform; (2) the original version asked if CWE were “able to drive a car in the future”. This was modified by Yam et al. to if CWE were “able to go to university” as tertiary education was considered to be more important than learning how to drive a car in Asia; (3) the original version asked if CWE would “worry about their coping skills in teenage years”. This was changed by Yam et al. to if CWE would “worry if their epilepsy would be under control in the future”. This was because it may be difficult for CWE to anticipate their difficulties during their teenage years, which is a period that they have not yet experienced; (4) the statement whether CWE would be “treated well when they grow up” was changed to whether they would be “discriminated by other people when they grow up” as the latter statement was easier to understand; and (5) the statement if CWE felt “safe with their friends if they had a seizure” was changed to if CWE were “afraid that their teacher would find out about their epilepsy” as teachers play a significant role in a child’s life in Asia.

Malay is a major language of the Austronesian family, the national language of Malaysia, Brunei, and Indonesia, and spoken by 270 million people. To date, there is no Malay-translated HRQOL instrument that has both parent-proxy rating and child self-report to assess the HRQOL of CWE. Therefore, we aimed to cross-culturally adapt and validate the Malay parent-proxy CHEQOL-25.

2. Material and methods

2.1. Design

This prospective study was conducted from February 2012 to February 2013 in two tertiary hospitals in Malaysia.

2.2. Population

Included were parents of CWE aged 8–18 years who could understand Malay. Excluded were parents whose children were <8 years of age as these younger children would not have been able to complete the child self-report by themselves.

2.3. Translation of the English parent-proxy CHEQOL-25 to Malay

Permission for translation was obtained from the original developer (via email on January 2012). License to use the instrument was purchased in August 2012. Translation of the English version of the parent-proxy CHEQOL-25 [6] to Malay was performed according to international guidelines [20](Fig. 1). A pilot study was conducted on five parents of CWE at a tertiary hospital to assess for face and content validity. Participants were invited to read the questions, to evaluate verbally if the items were difficult for them to comprehend, and to recommend items for deletion or modification. No further changes were made since no problems were reported.

2.4. Instruments used

2.4.1. Baseline demographic questionnaire

This instrument was used to collect parents’ baseline demographic information (such as age, ethnicity, educational level, occupation, and household income). In addition, their child’s demographic and clinical information (such as age, type of school, number of close friends, amount of time spent with friends, duration of epilepsy, health-care service usage, number of antiepileptic drug(s) taken, and epilepsy severity) was also collected. Epilepsy severity was assessed using the epilepsy illness severity score, which was determined based on the type of seizure, seizure frequency per year, number of antiepileptic medications, and observed side effects [21].

2.4.2. Parent-proxy Health-Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25)

This instrument was used to assess the parent-proxy ratings of their child’s HRQOL. It consists of 25 items with 5 subscales: interpersonal/social, present worries, future worries, intrapersonal/emotional, and epilepsy secrecy [4]. Parents were asked to fill out the CHEQOL-25 as a “surrogate informant” as they were instructed to fill the questionnaire based on what they thought their child would answer [22]. The CHEQOL-25 uses the alternative paired options of forced response whereby participants are asked to select the best statement from two options that most describes their child and then tick the degree to which they agree (e.g., sort of true or really true). Each item is scored on a scale of 1–4, and the sum of all items of the subscale is its total score (score range: 5–20). A higher score reflects a more positive perception in that domain.

2.4.3. The Pediatric Quality of Life Inventory™ (PedsQL™4.0)

This instrument was also used to assess the parent-proxy ratings of their child’s HRQOL so that the convergent validity of the parent-proxy CHEQOL-25 could be determined. It has both the parent-proxyreport and child self-report sections and was, therefore, a suitable choice for comparison with the parent-proxy CHEQOL-25. It has 23 items with 4 subscales: physical, emotional, social, and school. Both the parent-proxyreport and the child self-report used a 5-point Likert scale: never, almost never, sometimes, often, and almost always. Each item was reverse scored, and the total score of each subscale was calculated by the sum of all items and converted to percentage (score range: 0–100%) [23,24]. However, in order to compare the scores obtained from the PedsQL™ 4.0 with those from the CHEQOL-25, scores from the PedsQL™ 4.0 were then divided by five so that the score range of the PedsQL™ 4.0 would also range from 0 to 20. A higher score indicates a better HRQOL.

2.5. Data collection

Potential participants were screened, and the purpose of the study was explained. Informed consent was obtained. A baseline demographic questionnaire was used to collect the participants’ sociodemographic information as described above.

Participants were asked to complete the parent-proxy CHEQOL-25 and the parent-proxy PedsQL™ 4.0. This took approximately 30 min. The researcher then checked the questionnaires to ensure that all questions were answered. The parent-proxy CHEQOL-25 was readministered to the same group of parents 2 weeks later. Questionnaires were sent via express mail, and participants were asked to send their replies using the postage-paid return envelope. A follow-up telephone call was made to parents to ensure that they had received the questionnaire as well as to remind them to send in their replies. In addition, parents
were also questioned if any significant changes or events had occurred within the past two weeks, and all changes were documented. Ethics approval was obtained from the University Malaya Medical Centre Ethics Committee (approval number: 896.10) and the National Institutes of Health (Ministry of Health approval number: NMRR-12-425-12022).

Fig. 1. The translation process of the parent-proxy CHEQOL-25 from English to Malay. CHEQOL-25 = parent-proxy Health-Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) in Malaysia. Forward translation = translation of the document from English to Malay. Backward translation = translation of the document from Malay to English. The expert panel consisted of a pediatric neurologist, a researcher experienced in the validation of instruments, and two psychologists. Version 4 was sent to the original developer of the CHEQOL-25 for his comments. No further changes were made as he was satisfied with the forward and backward translation processes.

Baseline 65 participants were screened

Potential participants (n=44)

Participants that agreed to participate (n=40, response rate=90.1%)

Demographic data were collected; the CHEQOL-25 and the PedsQL 4.0 were administered

The CHEQOL-25 was re-administered (n=35)

Any significant changes that occurred within the past 2 weeks were documented

Fig. 2. Flow of participants.
2.6. Data analysis

Data entry and statistical analysis were conducted using Statistical Package for the Social Sciences (SPSS) version 21. Descriptive statistics were calculated. Since data were not normally distributed, nonparametric tests, the Mann–Whitney U test and Wilcoxon signed-rank test, were used.

Internal consistency was assessed using Cronbach’s α: <0.70 has inadequate internal consistency, 0.70–0.90 has adequate internal consistency, and >0.90 suggests redundancy of items [25]. Corrected item–total correlations were analyzed: values > 0.20 are considered as acceptable [26]. If removing an item increases Cronbach’s α significantly, excluding the item will increase the homogeneity of the subscale.

Test–retest reliability was analyzed using the intraclass correlation coefficient (ICC) and the Wilcoxon signed-rank test. The ICC is defined as “a measure of the relative similarity of quantities which share the same observational units of a sampling and/or measurement process” [27]. The closer the ICC value is to 1.0, the better the reliability and the agreement [28].

Spearman’s rho was used to assess convergent validity between the CHEQOL-25 and the PedsQL™ 4.0: <0.20 was “very weak”, 0.20–0.39 was “weak”, 0.40–0.59 was “moderate”, 0.60–0.79 was “strong”, and 0.80–1.0 was “very strong”. A p-value < 0.05 was considered as statistically significant.

Hypothesis testing was analyzed using Spearman’s rho and Wilcoxon signed-rank tests. The following factors were hypothesized to be negatively correlated with QOL: (a) the number of doctor visits and days hospitalized (as a measure for health-care use), (b) children with more severe epilepsy, (c) children taking a higher number of antiepileptic drugs, and (d) children with a learning disability. Interpersonal/social factors that were hypothesized to be positively associated with a better QOL were (e) children with more close friends and (f) children who spend more time per week with friends in extracurricular activities.

3. Results

Forty-four eligible parents of CWE were approached; four declined participation. Hence, 40 parents of CWE were recruited (response rate = 90.1%) (Fig. 2). The demographic characteristics of the parents and their CWE are shown in Table 1.

3.1. The psychometric properties

Cronbach’s α for each subscale ranged from 0.70 to 0.83 except for the present worries subscale (Cronbach’s α = 0.67). All items had a corrected item–total correlation value of >0.3 (Table 2).

Test–retest reliability was assessed in 35 (87.5%) parents after a 2-week interval as 5 parents were lost to follow-up. Twenty-four out of 25 items showed no significant difference at test–retest. The ICC for all items at test–retest ranged from 0.70 to 0.94 (Table 2).

3.2. Construct validity

3.2.1. Convergent validity

The parent-proxy CHEQOL and the PedsQL™ 4.0 showed moderate to high correlation in the interpersonal/social and emotional subscales ($r = 0.598$, $p = 0.002$ and $r = 0.342$, $p = 0.031$, respectively) (Table 3). Parents rated the highest HRQOL score in the interpersonal/social subscale, followed by the future worries subscale.

3.2.2. Hypothesis testing

The severity of epilepsy, higher number of antiepileptic drug(s), poorer cognitive ability of the child, lower number of close friends, and lesser amount of time spent with friends were significantly associated with poorer scores in the interpersonal/social subscale. In addition, children who took a higher number of antiepileptic drugs daily scored lower in the present worries subscale. Children who had learning difficulties had significantly lower scores in the future worries subscale compared to those with normal cognitive ability (Table 4).

4. Discussion

The Malay version of the parent-proxy CHEQOL-25 was found to be a valid and reliable instrument to assess the HRQOL of CWE in Malaysia. Our instrument was translated according to international guidelines [20] as per previous cultural adaptations of the CHEQOL-25 [6,29]. The cognitive debriefing from the pilot study demonstrated that the Malay parent-proxy CHEQOL-25 was easy to understand, indicating that our questionnaire had reached semantic and content equivalence to the English version.

The Cronbach’s α value for each subscale exceeded 0.7, which was satisfactory. The only exception was the present worries subscale, which only had a Cronbach’s α value of 0.67. Previous studies also found a lower Cronbach’s α value in the present worries subscale [4,6,29]. This may be because the questions asked in the present worries subscale covered many different aspects of a child’s worry, such as “having to think about epilepsy before doing things”, “parents being worried...
that they will hurt themselves”, “inability to use the computer or play sports”, “worry about what might happen if they forget to take their medicines”, and “worry about being hurt during a seizure”. Test–retest analysis showed that ICC values exceeded 0.7, indicating that the Malay parent-proxy CHEQOL-25 achieved stable reliability.

Both the parent-proxy CHEQOL-25 and the PedsQL™ 4.0 showed good correlation in the social and emotional subscales, indicating adequate convergent validity. Previous studies did not assess the convergent validity of the parent-proxy CHEQOL-25, whereas previous studies did not.

Our participants rated a higher HRQOL score in the interpersonal/social and future worries subscales compared to other studies [4,6,29]. This may be because most children in our study (70%) had their seizures under control and were, therefore, able to perform more activities with their peers. As a result, they had lesser problems in making friends. The majority (75%) of the children in our study were also adolescents. Adolescents generally place more emphasis on gaining independence from their parents and would, therefore, make more effort to establish friendships with their peers [30]. As a result, parents perceived that their children have lesser worries for their future.

The Malay parent-proxy CHEQOL-25 was found to have acceptable construct validity. Our findings concurred with previous studies [4,6]. However, we did not find any association between health-care usage and the HRQOL as most of the children in our study had good seizure control.

Although we recruited participants from two tertiary hospitals, we were only able to recruit 40 participants as our inclusion criterion was to only have children with epilepsy with normal cognitive function. Hence, we could not perform factor analysis. We were also not able to perform discriminative validity as it was not feasible to recruit children with uncontrolled seizures that have normal cognitive ability. However, the strength of our study was that we assessed the convergent validity of the Malay parent-proxy CHEQOL-25, whereas previous studies did not.

### 5. Conclusions

The Malay parent-proxy CHEQOL-25 was found to be a valid and reliable instrument to assess parents’ perceived HRQOL of their CWE in Malaysia. Although Malay is the national language of Malaysia and the

### Table 3

Convergent validity of the Malay version of the parent-proxy CHEQOL-25 and comparison with previous validation studies.

<table>
<thead>
<tr>
<th>Subscales</th>
<th>CHEQOL-25 (n = 40)</th>
<th>Ronen (1) (n = 381)</th>
<th>Yam (2) (n = 40)</th>
<th>Stevanovic (3) (n = 50)</th>
<th>PedsQL™</th>
<th>Correlation r</th>
<th>p-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal/social</td>
<td>15.4 ± 4.0 (5–20)</td>
<td>15.2 ± 4.0 (5–20)</td>
<td>13.1 ± 4.1 (5–20)</td>
<td>15.0 ± 4.1 (5–20)</td>
<td>16.3 ± 4.6 (5–20)</td>
<td>0.398</td>
<td>0.002**</td>
</tr>
<tr>
<td>Present worries</td>
<td>13.1 ± 3.6 (6–19)</td>
<td>13.9 ± 3.0 (5–20)</td>
<td>12.4 ± 3.7 (6–20)</td>
<td>13.1 ± 3.1 (5–20)</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Future worries</td>
<td>14.0 ± 4.1 (7–20)</td>
<td>15.3 ± 3.6 (6–20)</td>
<td>12.7 ± 3.8 (5–20)</td>
<td>15.5 ± 4.5 (5–20)</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Intrapersonal/emotional</td>
<td>13.2 ± 4.2 (5–20)</td>
<td>12.6 ± 3.9 (5–20)</td>
<td>10.8 ± 3.3 (5–18)</td>
<td>13.8 ± 4.7 (5–20)</td>
<td>14.8 ± 4.2 (3–20)</td>
<td>0.342</td>
<td>0.031*</td>
</tr>
<tr>
<td>Epilepsy secrecy</td>
<td>12.6 ± 3.3 (5–20)</td>
<td>14.1 ± 3.2 (5–20)</td>
<td>11.5 ± 3.7 (5–20)</td>
<td>12.4 ± 3.6 (5–20)</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

N/A = not available.

** p > 0.001.
*p < 0.05.

The PedsQL™ 4.0 has four subscales: physical, social, emotional, and school. Hence, only social and emotional subscales can be compared with the parent-proxy CHEQOL-25.
majority of the population speaks Malay, there is still a sizable community of Chinese and South Indians residing in Malaysia. Hence, further studies should look into validating these other versions of the CHEQOL-25 to enable nationwide use of the instrument.

Acknowledgments

We would like to thank the nursing and clerical staff of the two hospitals under study for their assistance in the recruitment of participants. We would also like to thank all the participants who participated in our study.

This project was funded by the University of Malaya (research grant no: RG292/11HTM).

Conflict of interest

All authors declare that they have no conflict of interest.

References


Table 4

Hypothesis testing of the Malay version of the parent-proxy CHEQOL-25.

<table>
<thead>
<tr>
<th>Subscales</th>
<th>Health-care usage</th>
<th>Epilepsy severity</th>
<th>No. of antiepileptic drug(s)</th>
<th>No. of close friends</th>
<th>Amount of time spent with friends</th>
<th>Cognitive ability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>r</td>
<td>r</td>
<td>r</td>
<td>r</td>
<td>r</td>
<td>Wilcoxon signed-rank test</td>
</tr>
<tr>
<td>Interpersonal/social</td>
<td>−0.278</td>
<td>−0.345</td>
<td>−0.374</td>
<td>0.312</td>
<td>0.482**</td>
<td>−2.375</td>
</tr>
<tr>
<td>Present worries</td>
<td>−0.178</td>
<td>−0.367</td>
<td>−0.367</td>
<td>0.216</td>
<td>0.270</td>
<td>−1.471</td>
</tr>
<tr>
<td>Future worries</td>
<td>−0.142</td>
<td>−0.201</td>
<td>−0.222</td>
<td>0.096</td>
<td>0.258</td>
<td>−2.318</td>
</tr>
<tr>
<td>Intrapersonal/emotional</td>
<td>−0.188</td>
<td>−0.151</td>
<td>−0.263</td>
<td>0.090</td>
<td>0.304</td>
<td>−1.852</td>
</tr>
<tr>
<td>Epilepsy secrecy</td>
<td>0.031</td>
<td>−0.084</td>
<td>−0.064</td>
<td>0.078</td>
<td>0.122</td>
<td>−0.981</td>
</tr>
</tbody>
</table>

⁎ p < 0.05.

⁎⁎ p < 0.001.


