

Validity and reliability of the Chinese parent proxy and child self-report health related quality of life measure for children with epilepsy (CHEQOL-25) in Malaysia

¹Su Woan Wo, ¹Pauline Siew Mei Lai, ²Lai Choo Ong, ³Wah Yun Low, ⁴Kheng Seang Lim, ²Chee Geap Tay, ⁵Chee Piau Wong, ⁶Ranjini Sivanesom

¹Department of Primary Care Medicine, University of Malaya Primary Care Research Group (UMPCR), ²Department of Pediatrics, ³Faculty of Medicine Dean's Office, ⁴Division of Neurology, Faculty of Medicine, University of Malaya, Kuala Lumpur; ⁵Jeffrey Cheah School of Medicine and Health Sciences, Monash University Malaysia, Selangor; ⁶Institute of Pediatrics, Hospital Kuala Lumpur, Kuala Lumpur, Malaysia

Abstract

Objective: To determine the validity and reliability of the Chinese parent proxy and child self-report health related quality of life measure for children with epilepsy (CHEQOL-25) in Malaysia. **Methods:** Face and content validity of the Chinese parent proxy and child self-report CHEQOL-25 was verified by an expert panel, and piloted in five children with epilepsy (CWE). The Chinese CHEQOL-25 was then administered to 40 parent proxies and their CWE (aged 8-18 years), from two tertiary hospitals, at baseline and 2 weeks later. **Results:** Forty parents and their CWE were recruited. Cronbach's alpha for each subscale ranged from 0.56-0.83. At test-retest, the interclass correlation for all items ranged from 0.68-0.97. Items 8 and 25 were removed as their corrected item-total correlation values were <0.3. Epilepsy severity, the number of anti-epileptic drugs taken daily, number of close friends and number of time spent with friends were found to be associated with the parent proxy CHEQOL-25 score. Duration of epilepsy, child's cognitive ability, number of close friends and number of time spent with friends were associated with child self-report CHEQOL-25. The parent proxy and the child self-report showed high to fair agreement on the "interpersonal/social" [Intraclass correlation coefficient (ICC)=0.670, p<0.001] and "epilepsy secrecy" subscale (ICC=0.417, p=0.048).

Conclusions: Our small study found that the Chinese CHEQOL-25 was a valid and reliable questionnaire to assess the quality of life of children with epilepsy from the parent prospective and child self-report when items 8 and 25 were removed.

INTRODUCTION

Childhood epilepsy is a complex pervasive neurobehavioral condition which significantly impacts on a child's psychosocial outcome.¹ Health related quality of life (HRQOL) is a subdomain of the more global construct of QOL², and assesses how a patient perceives their physical, psychological, interpersonal, and emotional well-being that is affected by their health condition and treatment.² Hence, HRQOL instruments have been increasingly used to identify dimensions that are important to children with epilepsy (CWE).¹

School going children as young as seven or eight years of age are now able to express their own opinions. They are able to perceive how their disease is progressing, and how treatment of their disease has affected their daily HRQOL.³ Parents

are also involved in the decision regarding their child's treatment, and its effectiveness.⁴ Therefore, both parent-proxy and child self-report HRQOL are equally important to provide information regarding their child's HRQOL.

To date, 11 HRQOL instruments have been developed and validated to assess the HRQOL of children with epilepsy (CWE).⁵⁻¹⁵ Some instruments only had the child self-report^{7,12}, some only had the parent proxy report^{8,10,11,13,15,16}, while others had both parent proxy and child self-reports.^{5,6,14} Previous studies showed that there is a high level of agreement between parent proxy and child self-report ratings on external life experiences, especially in the physical and social wellbeing of the child; where the parent was able to observe the conduct of their child. However,

Address correspondence to: Dr Pauline SM Lai, ¹Department of Primary Care Medicine, University of Malaya Primary Care Research Group, Faculty of Medicine, University of Malaya, 50603 Kuala Lumpur, Malaysia. Tel: +60379493920, mobile: +60192157079, email: plai@ummc.edu.my

parents were not able to accurately report their child's internal experience (such as their attitude towards epilepsy).¹⁷ Therefore, the combination of a parent proxy report and child self-report has the advantage of providing more information about a child's HRQOL.¹⁸

We selected the health related quality of life measure for children with epilepsy (CHEQOL-25) developed by Ronen¹⁴, as it had good psychometric properties and have been extensively validated worldwide.

Chinese is one of the six official languages of the United Nations, the official language in China and Taiwan, and spoken by approximately 1.3 billion people worldwide, including Malaysia.¹⁹ To date, the Chinese CHEQOL-25 has only been validated by Yam *et al.*⁴ in Hong Kong, China. There is a need to validate the Chinese CHEQOL-25 in Malaysia, as Malaysian Chinese, may be influenced by the cultural diversity that exists in Malaysia. Although Hong Kong does not use simplified Chinese like in Malaysia, the "Mandarin" or "Pu Tong Hua" that is spoken in Hong Kong is similar to that which is spoken in Malaysia.²⁰ In addition, the only difference between simplified and traditional Chinese characters is that simplified Chinese characters have fewer strokes, and are easier to write than traditional Chinese characters. This was the basis of why we selected to use the mandarin version of the CHEQOL-25 translated by Yam *et al.* Therefore, the aim of our study was to determine the validity and reliability of the parent proxy and child self-report CHEQOL-25 in Malaysia.

METHODS

Study design

This validation study was conducted from February 2012 to December 2014 in two tertiary hospitals in Malaysia.

Population

Included were parent proxy and their CWE aged 8-18 years, who were attending regular school, who did not have mental or learning disability (as observed by their doctors or parents) and could read and understand Mandarin. Excluded were children less than 8 years of age as younger children would not be able to complete the child self-report by themselves, and have other comorbidities such as cerebral palsy or autism as these conditions may affect their overall quality of life.

Sample size calculation

It has been recommended that the number of participants required should be the number of items multiplied by 5-10 for each item to perform factor analysis. Since there are 25 items in the CHEQOL-25, we would need to recruit 125 participants. Enormous effort was made to ensure successful recruitment of the required number of participants from multiple sites. However, we failed to recruit this number, and this was added as a limitation. Therefore, a total of 40 CWE and their parents were recruited for this study.

Instruments used

Baseline demographic questionnaire

This instrument was used to collect the children's baseline demographic information (such as age, ethnicity, educational level, occupation, and household income). In addition, the children'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 anti-epileptic drug(s) taken, and epilepsy severity) were also collected. Epilepsy severity was assessed using the epilepsy illness severity score, which was determined based on type of seizure, seizure frequency per year, number of antiepileptic medications and observed side effects.²¹

The parent proxy and child self-report health related quality of life measure for children with epilepsy (CHEQOL-25)

We used the Chinese CHEQOL-25 translated and validated by Yam *et al.*^{4,22} Both the parent proxy and child self-report CHEQOL-25 consists of 25 items, with 5 subscales. The parent proxy CHEQOL had the "future worries" subscale, whereas the child self-report had the "quest for normality" subscale (Table 1).

The CHEQOL-25 uses the alternative paired options of forced response, whereby participants were asked to select the best statement from two options that most described their child, and then ticked the degree to which they agreed (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 (scores range: 5-20). A higher score reflects a more positive perception in that domain. Content validity was performed by an expert panel which consisted of a researcher experienced in the validation of instruments, a

Table 1: The subscales of the parent proxy and child self-report health-related quality of life measure for children with epilepsy (CHEQOL-25)

| Item number | Parent proxy | Child self-report |
|-------------|-----------------------|-----------------------|
| 1-5 | Interpersonal/social | Interpersonal/social |
| 6-10 | Present worries | Present worries |
| 11-15 | Future worries | Intrapersonal/emotion |
| 16-20 | Intrapersonal/emotion | Epilepsy secrecy |
| 21-25 | Epilepsy secrecy | Quest for normality |

paediatric neurologist and two psychologists. Face validity was performed in five parents and their children with epilepsy.

Data collection

Potential parent proxy and their CWE were screened, and the purpose of the study was explained. Informed consent was obtained from the parent proxy. A baseline demographic questionnaire was used to collect participants' socio-demographic information.

Participants were asked to complete the CHEQOL-25. This took approximately 30 minutes. The researcher then checked the questionnaires to ensure that all questions were answered. The CHEQOL-25 was re-administered to the same group of participants 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 was made to participants that they had received the questionnaire, as well as to remind them to send in their replies. In addition, participants were also questioned if any significant changes or events had occurred with their children, within the past two weeks, and all changes were documented.

Ethics approval was obtained: University Malaya Medical Centre Ethics Committee approval number: 896.10, and the Sunway Medical Centre Independent Research Ethics Committee approval number: 004/2012/ER.

Data analysis

Data entry and statistical analysis were conducted using the Statistical Package for the Social Sciences (SPSS) version 22.0. Descriptive statistics were calculated. Since data was not normally distributed, non-parametric tests were used.

Internal consistency was assessed using Cronbach alpha. Cronbach's alpha value of > 0.5 is considered as acceptable.^{23,24} Corrected item-total correlations were analyzed: values > 0.3 are considered as acceptable.²⁵ 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 intraclass correlation coefficient (ICC). 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".²⁶ The closer the ICC value is to 1.0, the better the reliability and the agreement: poor agreement: 0-0.2; fair agreement: 0.3-0.4; moderate agreement: 0.5-0.6, strong agreement: 0.7-0.8 and almost perfect agreement: > 0.8 .²⁷

The construct validity of the CHEQOL-25 was examined by testing whether the following factors affected quality of life: health care usage, the severity of epilepsy, the number of anti-epileptic drug(s) taken, the cognitive ability of the child, the number of close friends, and the amount of time spent with friends. This was analyzed using Spearman's rho (for continuous variables) and Man-Whitney U tests (for continuous and categorical variables).

RESULTS

Participants from the pilot study did not encounter any problems in answering the Chinese parent proxy and child self-report CHEQOL-25. Hence, no modifications were made. A total of 40 parents and their CWE were recruited (response rate=76.9%) (Figure 1). The demographic characteristic of parent proxy and their CWE are shown in Table 2.

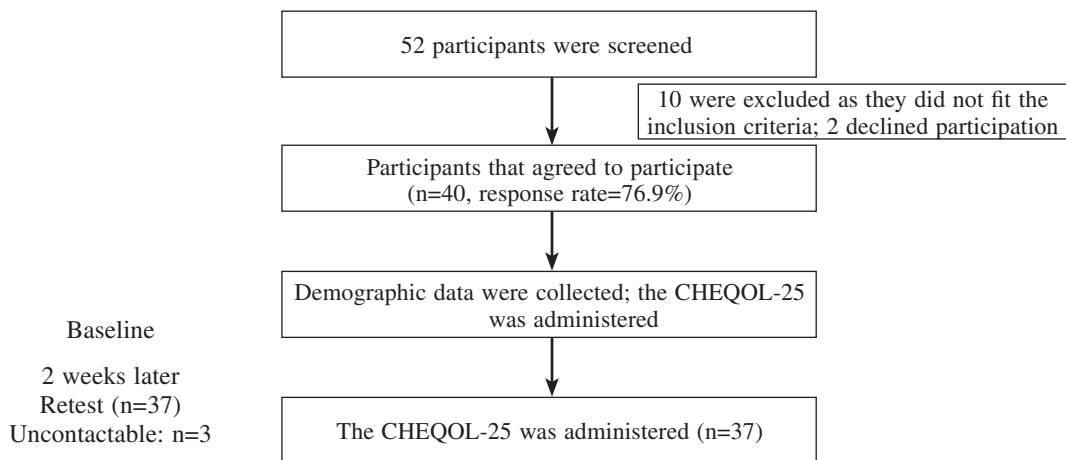


Figure 1. Flow of participants

Table 2: Demographic characteristic of parent proxy and their children with epilepsy

| | | N (%) (n=40) |
|---|-------------------------------------|--------------------------|
| Type of parent proxy | Mother | 35 (87.5) |
| | Father | 3 (7.5) |
| | Relative | 2 (5.0) |
| Mean age of parent proxy \pmSD (years) [range] | | 44.58 \pm 6.48 [32-58] |
| Mean age of their children with epilepsy \pm SD (years) [range] | Child (8-12 years) | 24 (60.0) |
| | Teenager (13-18 years) | 16 (40.0) |
| | | |
| Child's gender | Male | 30 (75.0) |
| | Female | 10 (25.0) |
| Level of education of the child | Primary (6 years of education) | 24 (60.0) |
| | Secondary (7-13 years of education) | 16 (40.0) |
| Mean duration of epilepsy \pm SD (years) [range] | | 6.8 \pm 4.7 [0.5-16] |
| Type of seizure | Absence | 3 (7.5) |
| | Generalized tonic-clonic | 23 (57.5) |
| | Partial | 14 (35.0) |
| Number of medication(s) taken daily | 0 | 4 (10.0) |
| | 1 | 22 (55.0) |
| | \geq 2 | 14 (35.0) |
| Mean score of epilepsy syndrome severity \pm SD [range] | | 5.57 \pm 1.53 [3-9] |
| Cognitive status | Normal | 30 (75.0) |
| | Mild learning disability | 10 (25.0) |
| Have not been admitted to hospital for epilepsy in the past 6 months | | 40 (100.0) |
| No. of times the child visited the doctor for epilepsy in the past 6 months | None | 25 (62.5) |
| | Once | 5 (12.5) |
| | \geq 2 | 10 (25.0) |
| | | |
| No. of close friends the child has | 0-2 | 8 (20.0) |
| | 3-5 | 13 (32.5) |
| | 6-10 | 5 (12.5) |
| | >10 | 14 (35.0) |
| | | |
| Amount of time per week spent in extracurricular activities with friends | None | 10 (25.0) |
| | Once | 8 (20.0) |
| | 2-3 times | 18 (45.0) |
| | \geq 4 times | 4 (10.0) |
| | | |

SD= Standard deviation

Table 3: The psychometric properties of the Chinese parent proxy CHEQOL-25

| Subscales | Items | Cronbach's α | Corrected item-total correlation | Cronbach's α if item is deleted | Test re-test reliability | | | | Intraclass Correlation Coefficient** | P-value |
|--------------------------|------------|---------------------|----------------------------------|--|--------------------------|--------|---------------|--------|--------------------------------------|---------|
| | | | | | Test (n=40) | | Retest (n=37) | | | |
| | | | | | Mean \pm SD | Median | Mean \pm SD | Median | | |
| Inter-personal/social | 1. | 0.825 | 0.604 | 0.797 | 3.22 (0.77) | 3.0 | 3.08 (0.76) | 3.0 | 0.853 | <0.001 |
| | 2. | | 0.470 | 0.845 | 3.05 (1.03) | 3.0 | 3.11 (0.94) | 3.0 | 0.794 | <0.001 |
| | 3 | | 0.660 | 0.779 | 3.17 (0.80) | 3.0 | 3.14 (0.79) | 3.0 | 0.927 | <0.001 |
| | 4. | | 0.675 | 0.777 | 3.15 (0.89) | 3.0 | 3.16 (0.87) | 3.0 | 0.961 | <0.001 |
| | 5. | | 0.746 | 0.753 | 3.03 (0.99) | 3.0 | 3.08 (0.93) | 3.0 | 0.920 | <0.001 |
| Present Worries | 6. | 0.662 | 0.655 | 0.499 | 3.03 (1.00) | 3.0 | 2.75 (0.98) | 2.0 | 0.832 | <0.001 |
| | 7. | | 0.347 | 0.646 | 2.47 (1.54) | 3.0 | 2.54 (1.10) | 2.0 | 0.941 | <0.001 |
| | 8. | | 0.254 | 0.673 | 3.25 (0.87) | 3.0 | 3.32 (0.82) | 3.0 | 0.875 | <0.001 |
| | 9. | | 0.331 | 0.650 | 2.80 (1.10) | 3.0 | 2.76 (1.06) | 3.0 | 0.953 | <0.001 |
| | 10. | | 0.524 | 0.555 | 2.63 (1.13) | 2.0 | 2.54 (1.07) | 3.0 | 0.912 | <0.001 |
| Future Worries | 11. | 0.818 | 0.514 | 0.809 | 3.10 (0.95) | 3.0 | 3.05 (0.88) | 3.0 | 0.871 | <0.001 |
| | 12. | | 0.725 | 0.756 | 3.10 (0.84) | 3.0 | 3.05 (0.78) | 3.0 | 0.898 | <0.001 |
| | 13. | | 0.709 | 0.750 | 2.95 (1.07) | 3.0 | 2.83 (1.04) | 3.0 | 0.890 | <0.001 |
| | 14. | | 0.648 | 0.771 | 3.00 (1.07) | 3.0 | 2.76 (1.01) | 3.0 | 0.930 | <0.001 |
| | 15. | | 0.642 | 0.819 | 2.8 (1.00) | 3.0 | 2.83 (0.96) | 3.0 | 0.919 | <0.001 |
| Intra-personal/emotional | 16. | 0.783 | 0.501 | 0.761 | 2.80 (1.00) | 3.0 | 2.59 (1.03) | 3.0 | 0.690 | <0.001 |
| | 17. | | 0.652 | 0.709 | 2.60 (1.12) | 3.0 | 2.62 (1.11) | 3.0 | 0.731 | <0.001 |
| | 18. | | 0.606 | 0.726 | 2.38 (1.12) | 3.0 | 2.24 (1.01) | 3.0 | 0.887 | <0.001 |
| | 19. | | 0.547 | 0.746 | 2.75 (0.98) | 3.0 | 2.89 (0.96) | 2.0 | 0.803 | <0.001 |
| | 20. | | 0.494 | 0.763 | 3.02 (0.88) | 3.0 | 2.84 (0.83) | 3.0 | 0.877 | <0.001 |
| Epilepsy secrecy | 21R# | 0.722 | 0.305 | 0.738 | 2.42 (0.90) | 2.0 | 2.35 (1.00) | 2.0 | 0.722 | <0.001 |
| | 22. | | 0.601 | 0.624 | 2.78 (1.00) | 3.0 | 2.75 (1.06) | 2.0 | 0.962 | <0.001 |
| | 23. | | 0.616 | 0.627 | 2.85 (0.86) | 3.0 | 2.81 (0.91) | 3.0 | 0.708 | <0.001 |
| | 24 | | 0.696 | 0.595 | 3.10 (0.87) | 3.0 | 3.03 (0.96) | 3.0 | 0.939 | <0.001 |
| | 25. | | 0.279 | 0.766 | 2.62 (1.10) | 3.0 | 2.65 (1.08) | 2.0 | 0.872 | <0.001 |

Note: # Items are reversed **p <0.001, SD= Standard deviation

Table 4: The psychometric properties of the Chinese Child self-report CHEQOL-25

| Subscales | Items | Cronbach's α | Corrected item-total correlation | Cronbach's α if item is deleted | Test re-test reliability | | | | Intraclass Correlation Coefficient*** | P-value |
|--------------------------|--------------|---------------------|----------------------------------|--|--------------------------|-------------|---------------|-------------|---------------------------------------|---------|
| | | | | | Test (n=40) | | Retest (n=37) | | | |
| | | | | | Mean \pm SD | Median | Mean \pm SD | Median | | |
| Inter-personal/social | 1. | 0.724 | 0.604 | 0.671 | 2.93 (0.94) | 3.0 | 2.70 (0.97) | 3.0 | 0.791 | <0.001 |
| | 2. | | 0.456 | 0.688 | 2.98 (0.97) | 3.0 | 3.10 (0.97) | 3.0 | 0.888 | <0.001 |
| | 3. | | 0.460 | 0.688 | 3.35 (0.83) | 3.0 | 3.16 (1.07) | 3.0 | 0.657 | <0.001 |
| | 4. | | 0.580 | 0.636 | 3.05 (1.06) | 3.0 | 2.92 (1.16) | 3.0 | 0.800 | <0.001 |
| | 5. | | 0.437 | 0.700 | 3.05 (1.10) | 3.0 | 2.97 (1.21) | 3.0 | 0.884 | <0.001 |
| Present worries | 6. | 0.562 | 0.312 | 0.567 | 2.27 (1.15) | 3.0 | 2.32 (1.20) | 3.0 | 0.912 | <0.001 |
| | 7. | | 0.362 | 0.491 | 1.47 (0.87) | 3.0 | 1.59 (0.96) | 2.0 | 0.878 | <0.001 |
| | 8. | | 0.184 | 0.580 | 3.15 (1.02) | 3.0 | 3.08 (1.06) | 3.0 | 0.840 | <0.001 |
| | 9. | | 0.341 | 0.495 | 1.97 (1.14) | 3.0 | 2.20 (1.22) | 3.0 | 0.846 | <0.001 |
| | 10. | | 0.542 | 0.542 | 0.368 | 1.80 (1.07) | 2.0 | 1.92 (1.09) | 2.0 | 0.778 |
| Intra-personal/emotional | 11. | 0.643 | 0.425 | 0.577 | 2.70 (0.97) | 3.0 | 2.57 (1.19) | 3.0 | 0.742 | <0.001 |
| | 12. | | 0.454 | 0.565 | 2.90 (0.93) | 3.0 | 3.08 (0.95) | 3.0 | 0.840 | <0.001 |
| | 13. | | 0.368 | 0.603 | 2.80 (0.99) | 3.0 | 2.65 (1.14) | 3.0 | 0.866 | <0.001 |
| | 14. | | 0.400 | 0.589 | 2.53 (1.10) | 3.0 | 2.60 (1.12) | 3.0 | 0.755 | <0.001 |
| | 15. | | 0.344 | 0.344 | 0.616 | 2.90 (1.05) | 3.0 | 2.89 (1.13) | 3.0 | 0.858 |
| Epilepsy secrecy | 16R#. | 0.689 | 0.451 | 0.564 | 2.78 (1.07) | 3.0 | 2.59 (1.04) | 3.0 | 0.854 | <0.001 |
| | 17. | | 0.412 | 0.456 | 2.98 (1.04) | 3.0 | 2.60 (1.17) | 3.0 | 0.689 | <0.001 |
| | 18R. | | 0.326 | 0.526 | 2.88 (1.05) | 3.0 | 2.59 (1.10) | 3.0 | 0.735 | <0.001 |
| | 19. | | 0.448 | 0.646 | 3.10 (0.96) | 3.0 | 2.97 (1.12) | 3.0 | 0.914 | <0.001 |
| | 20. | | 0.494 | 0.494 | 0.663 | 2.78 (1.03) | 3.0 | 2.84 (1.17) | 3.0 | 0.734 |
| Quest for normality | 21R# | 0.696 | 0.444 | 0.650 | 2.92 (1.16) | 2.0 | 3.05 (1.10) | 2.0 | 0.971 | <0.001 |
| | 22R#. | | 0.704 | 0.528 | 3.05 (1.04) | 3.0 | 2.95 (1.10) | 3.0 | 0.954 | <0.001 |
| | 23R#. | | 0.487 | 0.631 | 3.32 (1.00) | 3.0 | 3.05 (1.17) | 3.0 | 0.752 | <0.001 |
| | 24R#. | | 0.481 | 0.636 | 2.85 (0.95) | 3.0 | 2.81 (1.10) | 3.0 | 0.928 | <0.001 |
| | 25R#. | | 0.171 | 0.171 | 0.747 | 2.95 (0.98) | 3.0 | 2.95 (0.97) | 3.0 | 0.898 |

Note: # Items are reversed ***p <0.001, SD= Standard deviation

Psychometric properties

Parent proxy health related quality of life measure for children with epilepsy (CHEQOL-25)

The Cronbach’s α for each subscale ranged from 0.662-0.825. All items had a corrected item-total correlation value of >0.3 , except items 8 and 25. Test-retest reliability was assessed in 37 (82.5%) parent proxies and their CWE after a 2-week interval, as 3 participants were lost to follow-up. Twenty-five items showed no significant difference at test–retest. ICC for all items at test-retest ranged from 0.690-0.962 (Table 3).

Child self-report health related quality of life measure for children with epilepsy (CHEQOL-25)

The Cronbach’s α for each subscale ranged from 0.562-0.724. All items had a corrected item-total correlation value of >0.3 , except items 8 and 25 (Table 4). Twenty-five items showed no significant difference at test–retest. ICC for all items at test-retest ranged from 0.657-0.971 (Table 4).

The *construct validity of the parent proxy and child self-report health related quality of life measure for children with epilepsy (CHEQOL-25)*

The severity of epilepsy, higher number of anti-epileptic drug(s), lower number of close friends,

Table 5: The construct validity of the parent proxy and child self-report CHEQOL-25

| Subscales | Factors associated with HRQOL | | | | | | | Mann-Whitney U test | |
|--------------------------|-------------------------------|-------------------|----------------------|-------------------------------|----------------------|-----------------------------------|-------------------|---------------------|---------|
| | Health care usage | Epilepsy severity | Duration of epilepsy | No. of anti-epileptic drug(s) | No. of close friends | Amount of time spent with friends | Cognitive ability | z-value | p-value |
| | Pearson correlation (r) | | | | | | | | |
| Parent-proxy | | | | | | | | | |
| Interpersonal/social | -0.282 | -0.481** | -0.131 | -0.335* | 0.394* | 0.416** | -1.824 | 0.069 | |
| Present worries | -0.126 | -0.024 | 0.222 | 0.051* | 0.105 | 0.047 | -1.235 | 0.224 | |
| Future worries | -0.101 | -0.273 | 0.041 | -0.256 | 0.157 | 0.135 | -1.573 | 0.122 | |
| Intrapersonal/emotional | -0.076 | -0.571** | 0.056 | -0.518** | 0.162 | 0.265 | -0.966 | 0.342 | |
| Epilepsy secrecy | 0.054 | 0.223 | -0.60 | 0.085 | 0.138 | -0.006 | -0.267 | 0.794 | |
| Child self-report | | | | | | | | | |
| Interpersonal/social | -0.223 | -0.285 | -0.335* | -0.057 | 0.371* | 0.378* | -1.192 | 0.246 | |
| Present worries | -0.030 | -0.139 | 0.072 | -0.112 | -0.256 | 0.067 | -0.960 | 0.346 | |
| Intrapersonal/emotional | -0.067 | -0.031 | -0.022 | 0.034 | 0.263 | 0.206 | -2.260 | 0.024* | |
| Epilepsy secrecy | 0.110 | -0.051 | -0.061 | -0.052 | 0.094 | 0.046 | -0.236 | 0.818 | |
| Quest for normality | 0.046 | 0.024 | -0.231 | -0.062 | 0.110 | 0.129 | -0.121 | 0.906 | |

*p <0.05 **p <.001

Table 6: The Chinese version of the parent proxy and child self-report CHEQOL-25 with previous validation studies

| | Chinese CHEQOL-25 (n=40) | Ronen ¹⁴ (n=381) | Ma ²⁸ (n=50) | Yam ²² (n=240) | Stevanovic ²⁹ (n=50) | Brabcova ³⁰ # (n=250) | Wo ³¹ (n=40) |
|-----------------------------|--------------------------------|--------------------------------|----------------------------|------------------------------|------------------------------------|-------------------------------------|----------------------------|
| Subscales | Mean ± SD [range] | Mean ± SD [range] | Mean ± SD [range] | Mean ± SD [range] | Mean ± SD [range] | Mean ± SD [range] | Mean ± SD [range] |
| Parent proxy | | | | | | | |
| Interpersonal/ social | 15.8±3.4 [6-20] | 15.2±4.0 [5- 20] | | 13.1±4.1 [5-20] | 15.0±4.1 [5-20] | | 15.4±4.0 [5-20] |
| Present worries | 14.2±3.4 [5-20] | 13.9±3.0 [5-20] | | 12.4±3.7 [6-20] | 13.1±3.1 [5-20] | | 13.1±3.2 [6-19] |
| Future worries | 14.9±3.8 [7- 20] | 15.3±3.6 [6-20] | | 12.7±3.8 [5-20] | 15.5± 4.5 [5-20] | | 14.0±4.1 [7-20] |
| Intrapersonal/ emotional | 13.4±3.8 [5-20] | 12.6±3.9 [5- 20] | | 10.8±3.3 [5-18] | 13.8±4.7 [5-20] | | 13.2±4.2 [5-20] |
| Epilepsy secrecy | 12.9±3.2 [5-20] | 14.1±3.2 [5-20] | | 11.5±3.7 [5-20] | 12.4±3.6 [5-20] | | 12.6±3.3 [5-20] |
| Child self-report | | | | | | | |
| Interpersonal/ social | 15.4±3.4 [8-20] | 16.2±4.0 [5- 20] | 15.8±3.9 [7-20] | 15.2±3.8 [7-20] | 14.4±4.6 [5-20] | 15.8±3.5 [5-20] | 15.3±3.2 [9-20] |
| Present worries | 10.7±3.8 [5-19] | 13.4±3.8 [5- 20] | 11.4±3.2 [6-10] | 12.07±3.7 [5-20] | 12.2±3.1 [5-20] | 10.9±3.3 [4-16] | 11.7±2.8 [5-17] |
| Intrapersonal/ emotional | 13.8±3.2 [6- 20] | 13.9±3.9 [5- 20] | 14.0±3.8 [5-20] | 13.4±3.6 [5-20] | 12.9± 4.3 [5-20] | 9.0±3.9 [4-16] | 12.6±3.2 [6- 20] |
| Epilepsy secrecy | 14.5±3.4 [7-20] | 15.7±3.96 [5- 20] | 14.7±3.7 [6-20] | 13.9±3.4 [5-20] | 12.6±4.3 [5-20] | N/A | 12.8±2.90 [6-20] |
| Quest for normality | 15.1±3.3 [8-20] | 16.1±3.2 [6- 20] | 16.9±3.3 [8-20] | 15.5±3.5 [5-20] | 14.1±2.7 [5-20] | 31.9±5.7 [15-40] | 15.7±3.0 [8-20] |

Note: SD= Standard deviation # The modified Czech version was a 4-factor structure: interpersonal/social consequences (items 1–5); worries and concerns (items 6, 7, 9, and 10); intrapersonal/emotional issues (items 11–14); and disclosure and normality (items 15–17 and 19–25).

and lesser amount of time spent with friends, were significantly associated with poorer score in the “interpersonal/social” subscale in the parent proxy CHEQOL-25. In addition, the severity of epilepsy and a higher number of anti-epileptic drugs daily were significantly associated with a lower score in the “intrapersonal/emotional” subscale (Table 5).

The duration of epilepsy, the higher number of close friends and a higher amount of time spent with friends were significantly associated with higher score in the “interpersonal/social” subscale in the child self-report CHEQOL-25

(Table 5). There was a significant difference in the “intrapersonal/emotion” subscale between children with normal cognitive ability and those with mild learning disability ($p=0.024$). The psychometric properties of Chinese parent proxy and child self-report CHEQOL-25 was compared with previous validation studies (Table 6). The number of participants recruited ranged from 40 to 381. The small sample size may be because the authors may have experienced similar difficulty in recruiting children with epilepsy with normal intelligence.

Level of agreement between parent proxy and their children with epilepsy in quality of life scores

The parent proxy and child self-report had a good level of agreement in the “interpersonal/social” (ICC= 0.670, $p < 0.001$) and “epilepsy secrecy” subscales (ICC=0.417, $p = 0.048$). The other subscales did not attain statistical significance.

DISCUSSION

The Chinese parent proxy and child self-report CHEQOL-25 was found to be a valid and reliable instrument to assess HRQOL in CWE in Malaysia.

The Cronbach’s α value for each subscale in the parent proxy and child self-report CHEQOL-25 exceeded 0.5, which was acceptable. Test-retest for both parent proxy and child self-report CHEQOL-25 showed that all ICC values exceeded 0.5, which indicates moderate agreement. This indicates that the Chinese parent proxy and child self-report CHEQOL-25 has achieved stable reliability.

Items 8 and 25 were dropped from the parent proxy and child self-report CHEQOL-25 as these items showed low correlation with other items within the same subscale. This may be because item 8 asked about the ability of the child to use the computer, play computer games, go to a camp or play sports. All of the children in our study could use the computer, and answered this point positively. However, going to a camp or playing sports is not what they normally do. This then may have resulted in a low correlation with other items. Item 25 asked whether the child would be worried if he/she had seizure away from home, and nobody knew what to do about the seizure. This item had two parts and could have been interpreted as “would the child inform other people around him/her, so that they would know what to do in the event of seizure” or “would the child worry that nobody would know what to do in the event of a seizure when away from home”. Thus, item 25 may not fit into the subscale “epilepsy secrecy” of the questionnaire. Our findings (that items 8 and 25 did not correlate well with other items) was similar to two previous validation studies.^{4,30}

Both the parent proxy and child self-report CHEQOL-25 showed adequate construct validity. Factors found to be associated with a better parent proxy and child self-report CHEQOL-25 were children who had more close friends and who spent more time with friends. For the parent proxy, the more severe the child’s epilepsy, and higher number of antiepileptic drug taken daily

were associated with worse child’s HRQOL. For child self-report, duration of epilepsy and cognitive ability were associated with child’s HRQOL. Our findings concurred with previous studies.^{4,14,30} In the present studies, 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. Another reason could be that the parent proxies in our study were more worried that their children would not be able to perform well academically, as compared to being good in sports or using the computer (there is an item that assesses “inability to use the computer or play sports” in the present worries subscale). Asians generally place more emphasis on a child’s school performance (which is perceived as the key to succeed in life and social status), as compared to western countries.³²

In our study, the psychometric properties of the CHEQOL-25 were similar to previous validation studies (Table 6). The number of participants recruited ranged from 40-381. The small sample size may be because the authors may have experienced similar difficulty in recruiting children with normal intelligence.^{28,29,33} Parents rated a higher HRQOL in the “interpersonal/social” and “future worries”, subscales compared to other studies.^{4,14,29,31} However, the children in our study rated a higher HRQOL in the “quest for normality” This may be because the majority of children in our study (70%) had their seizures under control, and were therefore able to progress with their peers.

The parent proxy and child self-report showed lower agreement on the “present worries” and “intrapersonal/emotional”, but this did not reach statistical significance. Previous studies have shown that there was moderate to high agreement between the parent proxy and child self-report in the “interpersonal/social” subscale.^{18,29} In addition, a significant difference was noted in responses for the subscale on “epilepsy secrecy”. Overall, parents felt that they should keep their child’s epilepsy as a secret, whereas their child would be happy to tell their friends that they had epilepsy. There was less discrepancy in the external domains (“interpersonal/social” subscale), which was consistent with previous studies.^{18,34} Parent-proxy ratings correlated well with child self-reports in areas where the parent was able to observe the conduct of their child. This indicates that both parent-proxy and child self-report are equally important to assess a child’s HRQOL.

The strength of our study was that the level of agreement in parents and their CWE was

examined. We also recruited participants from two centers: a public hospital and a private hospital, which allowed us to recruit participants from different social demographic backgrounds. However, a limitation of our study was we managed to recruit only 40 participants. This was because our inclusion criterion was limited to CWE with normal cognitive function. Hence, we were not able to perform factor analysis (due to our small sample size) and discriminative validity (as it was not feasible to recruit children with uncontrolled seizure that had normal cognitive ability). Convergent validity was also not performed, as there was no validated Chinese generic QOL instrument that contained both parent proxy and child self-report when this study was conducted.

In conclusion, our small study found that the Chinese CHEQOL-25 was a valid and reliable questionnaire to assess the quality of life of children with epilepsy from the parent prospective and child self-report when items 8 and 25 were removed. HRQOL instruments that contain both the parent proxy and child self-report in measuring the child's HRQOL has the advantage that it can provide more information in both observable (such as social interaction with peers) and abstract concepts (such as quest for normality) on how CWE affected by the condition and its treatment.

ACKNOWLEDGEMENTS

This project was funded by the Postgraduate Research Fund (PG021-2012B) from the University of Malaya, Kuala Lumpur, Malaysia. 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.

DISCLOSURE

Conflict of interest: None

REFERENCES

- Ronen G, Streiner D, Rosenbaum P. Health-related quality of life in childhood epilepsy: Moving beyond 'seizure control with minimal adverse effects'. *Health Qual Life Outcomes* 2003;1(1):1-10.
- Sadeghi S, Fayed N, Ronen GM. Patient-reported outcome measures in pediatric epilepsy: a content analysis using World Health Organization definitions. *Epilepsia* 2014;55(9):1431-7.
- Ronen GM, Rosenbaum P, Law M, Streiner DL. Health-related quality of life in childhood disorders: A modified focus group technique to involve children. *Qual Life Res* 2001;10(1):71-9.
- Yam WK, Chow SM, Ronen GM. Chinese version of the parent-proxy health-related quality of life measure for children with epilepsy: Translation, cross-cultural adaptation, and reliability studies. *Epilepsy Behav* 2005;7(4):697-707.
- Arunkumar G, Wyllie E, Kotagal P, Ong HT, Gilliam F. Parent- and patient- validated content for pediatric epilepsy quality-of-life assessment. *Epilepsia* 2000;41(11):1474-84.
- Baars RM, Atherton CI, Koopman HM, Bullinger M, Power M. The European DISABKIDS project: development of seven condition-specific modules to measure health related quality of life in children and adolescents. *Health Qual Life Outcomes* 2005;3:70.
- Batzel LW, Dodrill CB, Dubinsky BL, et al. An objective method for the assessment of psychosocial problems in adolescents with epilepsy. *Epilepsia* 1991;32(2):202-11.
- Buck D, Smith M, Appleton R, Baker GA, Jacoby A. The development and validation of the Epilepsy and Learning Disabilities Quality of Life (ELDQOL) scale. *Epilepsy Behav* 2007;10(1):38-43.
- Camfield C, Breau L, Camfield P. Impact of pediatric epilepsy on the family: A new scale for clinical and research use. *Epilepsia* 2001;42(1):104-12.
- Carpay HA, Vermeulen J, Stroink H, et al. Disability due to restrictions in childhood epilepsy. *Dev Med Child Neurol* 1997;39(8):521-6.
- Coda A. B, P.A., Bonivier, C., et al. Quality of life and epilepsy in childhood: an Italian study. *Boll Lega It Epil* 2001;113:4.
- Cramer JA, Westbrook LE, Devinsky O, Perrine K, Glassman MB, Camfield C. Development of the quality of life in epilepsy inventory for adolescents: The QOLIE-AD-48. *Epilepsia* 1999;40(8):1114-21.
- Hoare P, Mann H, Dunn S. Parental perception of the quality of life among children with epilepsy or diabetes with a new assessment questionnaire. *Qual Life Res* 2000;9(6):637-44.
- Ronen GM, Streiner David L, Rosenbaum P, Canadian Pediatric Epilepsy Network. Health-related quality of life in children with epilepsy: development and validation of self-report and parent proxy measures. *Epilepsia* 2003;44(4):598-612.
- Sabaz M, Lawson JA, Cairns DR, et al. Validation of the quality of life in childhood epilepsy questionnaire in American epilepsy patients. *Epilepsy Behav* 2003;4(6):680-91.
- Camfield C, Breau L, Camfield P. Assessing the impact of pediatric epilepsy and concomitant behavioral, cognitive, and physical/neurologic disability: Impact of Childhood Neurologic Disability Scale. *Dev Med Child Neurol* 2003;45(3):152-9.
- Eiser C, Morse R. Can parents rate their child's health-related quality of life? Results of a systematic review. *Qual Life Res* 2001;10(4):347-57.
- Verhey LH, Kulik DM, Ronen GM, Rosenbaum P, Lach L, Streiner DL. Quality of life in childhood epilepsy: what is the level of agreement between youth and their parents? *Epilepsy Behav* 2009;14(2):407-10.
- Gifford-Smith ME, Brownell CA. Childhood peer relationships: social acceptance, friendships, and peer networks. *Journal of School Psychology* 2003;41(4):235-84.

20. Bureau CS. Official Language Devison. 2012; <http://www.csb.gov.hk/english/aboutus/org/scsd/1470.html>. Accessed 10.5.2016.
21. Austin JK, Smith MS, Risinger MW, McNelis AM. Childhood epilepsy and asthma: comparison of quality of life. *Epilepsia* 1994;35(3):608-15.
22. Yam WKL, Ma DKH, Cherk SWW. Factor structure and construct validity of the Chinese health-related quality of life measure for youth with epilepsy. *Epilepsy Behav* 2006;9(4):606-18.
23. Streiner DL, Norman GR. Health measurement scales: A practical guide to their development and use. 2nd ed. New York: Oxford University Press; 1995.
24. Sushil S, Verma N. Questionnaire validation made easy. *Eur J Sci Res* 2010; 46(2):172-8.
25. Briggs SRC, J.M. The role of factor analysis in the development and evaluation of personality scales. *Journal of Personality* 1986(54):38.
26. Koch GG. Intraclass correlation coefficient, in *Encyclopedia of Statistical Sciences*: John Wiley & Sons, Inc.; 2004.
27. Weir JP. Quantifying test-retest reliability using the intraclass correlation coefficient and the SEM. *J Strength Cond Res* 2005;19(1):231-40.
28. Ma KH, Yam KL, Tsui KW, Yau FT. Internal consistency and test-retest reliability of the Chinese version of the self-report health-related quality of life measure for children and adolescents with epilepsy. *Epilepsy Behav* 2006;9(1):51-7.
29. Stevanovic D, Tepavcevic DK, Jovic-Jakubi B, *et al*. Health-related quality of life measure for children with epilepsy (CHEQOL-25): Preliminary data for the Serbian version. *Epilepsy Behav* 2009;16(4):599-602.
30. Brabcova D, Krsek P, Kohout J, Zarubova J. Psychometric properties of the modified Czech version of the children self-report Quality-of-life Measure for Children with Epilepsy (CHEQOL-25). *Epilepsy Behav* 2014;33:31-8.
31. Wo SW, Lai PS, Ong LC, *et al*. 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. *Epilepsy Behav* 2015;45:118-23.
32. Yamamoto Y, Holloway S. Parental expectations and children's academic performance in sociocultural context. *Educ Psychol Rev* 2010;22(3):189-214.
33. Wo SW, Lai PSM, Ong LC, *et al*. Cross-cultural adaptation of the Malay version of the child self-report health-related quality of life measure for children with epilepsy (CHEQOL-25) in Malaysia. *Epilepsy Behav* 2015;51:124-6.
34. Stevanovic D, Tadic I, Novakovic T. Health-related quality of life in children and adolescents with epilepsy: A systematic review. In: Gadze ZP, ed. *Epilepsy in Children: Clinical and Social Aspects*: Intech; 2011.