



Quality of life in Malaysian children with epilepsy

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ABSTRACT

Background: Children with epilepsy (CWE) are at risk of impaired quality of life (QOL), and achieving a good QOL is an important treatment goal among CWE. To date, there are no published multiethnic QOL studies in Asia. Our study aimed to: i) investigate the QOL of multiethnic CWE in Malaysia as reported by both the child and parent; ii) determine the level of agreement between child-self report and parent-proxy report QOL; and iii) explore potential correlates of sociodemographic, epilepsy characteristics, and family functioning with QOL in CWE.

Methods: Cross-sectional study of all CWE aged 8–18 years old with at least 6 months' duration of epilepsy, minimum reading level of primary school education Year 1, and attending mainstream education. Quality of life was measured using the parent-proxy and child self-report of Quality of Life Measurement for Children with Epilepsy (CHEQOL-25) questionnaire. Total and subscale CHEQOL-25 scores were obtained. The levels of parent–child agreement were determined using intraclass correlation coefficients (ICC). Family functioning was assessed using the General functioning subscale (GF-12).

Results: A total of 115 CWE and their parents participated in the study. In general, Malaysian parents rated children's total CHEQOL-25 scores poorer than the children themselves [mean total parent score: 68.56 (SD: 10.86); mean total child score: 71.82 (SD: 9.55)]. Agreement between child and parent on the CHEQOL-25 was poor to moderate (ICC ranged from 0.31–0.54), with greatest discordance in the epilepsy secrecy domain (ICC = 0.31, $p = 0.026$). Parent and child were more likely to agree on more external domains: intrapersonal/social (ICC = 0.54, $p < 0.001$) and interpersonal/emotional (ICC = 0.50, $p < 0.001$). Malay ethnicity, focal seizure and high seizure frequency (≥ 1 seizure per month) were associated with lower CHEQOL-25 scores. There was a significant but weak correlation between GF-12 and parent–proxy CHEQOL-25 Total Scores ($r = -0.186$, $p = 0.046$).

Conclusion: Our results emphasize the importance to have the child's perspective of their QOL as the level of agreement between the parent and child reported scores were poor to moderate. Malaysian CWE of Malay ethnicity, those with focal seizures or high seizure frequency are at risk of poorer QOL.

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1. Introduction

Quality of life (QOL) is defined by the World Health Organization (WHO) as the 'individual's perceptions of their position in life in the context of the culture and value systems which they live, and in relation to their goals, expectations and concerns' [1]. Children with epilepsy (CWE) are at risk of impaired QOL, and achieving a good QOL is an important treatment goal among CWE [2]. A recent meta-analysis identified several clinical and psychosocial risk factors associated with QOL, including duration of epilepsy, seizure type, frequency, number

of antiepileptic drugs (AEDs), presence of additional comorbidity, parental anxiety, and family socioeconomic status [3]. However, there was also heterogeneity for certain risk factors due to methodological differences and only four out of the 21 studies included in the meta-analysis were from Asia.

Several generic QOL and epilepsy-targeted QOL instruments have been developed [2]. Each of these QOL scales is developed differently and thus, is not easily comparable with one another. Sadeghi et al. reviewed the available pediatric epilepsy QOL scales and developed a practical valuation system based on the WHO international classification of functioning to aid clinicians to select the most appropriate QOL scale on the basis of content [4]. While parental ratings are appropriate for assessing QOL in young or immature children who lack the necessary cognitive and linguistic skills, concerns have been raised regarding the reliance on parental reports alone in older children as they may have

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different perspectives about the impact of the illness on their lives [2]. Studies that incorporated child self-report QOL questionnaires have reported disagreement between parent-proxy and child ratings, with parental reports being generally lower compared with the child self-reports [5–7]. Thus, it is important to obtain information from both the child and parent to have a holistic picture of how epilepsy impacts the lives of CWE and their families.

Family functioning, which includes family cohesion and flexibility dimensions, plays a critical role in the adaptation of child and family with chronic illness. Families of CWE generally had more problems with family functioning than control groups, and family factors were associated with child psychopathology [8]. The relationship between family functioning and QOL is less well studied. In a study on adults with epilepsy, specific components of family functioning were associated with QOL [9]. Studies on children with new onset epilepsy found that better family functioning was associated with a more favorable QOL and protected against decline of the child's self-esteem [10,11]. Family functioning may be a modifiable risk factor; if family functioning is poor, then it is a risk factor; but if it is good, then it is a protective factor.

Ethno-cultural differences may also play an important role in the perception and understanding of epilepsy and potentially has an impact on QOL of CWE. There are only 2 Asian studies from Hong Kong and South Korea that have assessed both parent-proxy and child self-report QOL in CWE [12,13]. It is not known if other ethnicities among Asian CWE can have an impact on their QOL. Malaysia is a developing country that has a multiethnic population which use the same universal government-based healthcare and education systems; and the Malaysian healthcare system, social services, and cultural outlook may differ from that of western and other developed Asian countries; hence, the data on QOL of CWE cannot be extrapolated from existing studies. In addition, there is a paucity of data among Asian CWE as to whether there are differences in the perception of epilepsy between the child and parent.

Hence, the objectives of this study were to: i) investigate the QOL of multiethnic CWE in Malaysia as reported by both the child and parent; ii) determine the level of agreement between child-self report and parent-proxy report QOL and iii) explore the potential correlates of sociodemographic, epilepsy characteristics and family functioning with QOL in CWE.

2. Method

2.1. Patient recruitment

This cross-sectional study was conducted at pediatric neurology clinics of 3 tertiary hospitals: Hospital Raja Permaisuri Bainun (HRPB), Ipoh; University Malaya Medical Centre (UMMC) Kuala Lumpur, and Institute of Paediatrics Hospital Kuala Lumpur (IPHL). Children aged 8–18 years old with at least 6 months' duration of epilepsy, minimum reading level of primary school education Year 1 and attending mainstream education were eligible for inclusion in this study. Exclusion criteria included children with specific learning impairment, physical impairment, visual impairment, hearing impairment, or any chronic diseases that could independently have an impact on QOL. The parents of the patient were then approached and were given patient information sheet with verbal explanation. Informed written consent was obtained. The parent and child completed the questionnaires independently in the language of their choice (Malay, English, or Mandarin). A total of 115 participants (both the parent and patient) were recruited over an 18-month period between January 2014 and June 2016: 58 were recruited from HRPB Ipoh, 38 from UMMC and 19 from IPHL. This study was approved by the ethics committee of University Malaya Medical Centre (Ethics Committee Reference Number: 1031.34) and the Malaysia Medical Research and Ethics Committee (NMRR ID: 13-988-17817).

2.2. Data collection

(i) Standardized data proforma forms were used to obtain:

- Clinical data including baseline demographic data and socio-demographic data (ethnicity, family income, parental occupation, parental level of educational attainment, and number of children in the family)
- Epilepsy history including seizure type and frequency, number of regular AEDs the patient was on, age of epilepsy onset, and duration of epilepsy.

(ii) Quality of Life Measurement for Children with Epilepsy (CHEQOL-25):

CHEQOL-25 which has also a validated Mandarin version is the only epilepsy-specific QOL instrument that has the additional advantage of measuring both child's QOL and parent-proxy rating [14,15]. The Malay version have been validated among Malaysian CWE with adequate internal consistency Cronbach's alpha and showed good psychometric properties [16,17]. The use of the QOL questionnaire in children with epilepsy (CHEQOL-25) authored by Dr. Gabriel Ronen et al., was made under licence from McMaster University, Hamilton, Canada.

The CHEQOL-25 consists of:

- Twenty-five items that yield 5 subscales: interpersonal/social, present worries and concerns, intrapersonal/emotional, epilepsy secrecy, quest for normality (child only) or future worries and concerns (parent only).
- Each item is scored on a scale of 1–4 and the sum of all items of the subscale will yield separate child self-report and parent-proxy report scores. These scores range from 5 to 20, with higher scores reflecting a more positive perception in that domain and indicating a better QOL.
- Either the mother or father was accepted as proxy raters as their responses have been reported to be similar with no significant differences [14].

(iii) 12-item general functioning subscale (GF-12) for family functioning

- The GF-12 is a subscale of the Family Assessment Device (FAD). The FAD is a 60-item self-report questionnaire developed to measure family functioning [18] and is free from cultural bias as assessed in different populations in different countries [19]. The GF-12 subscale is internally consistent in different populations and can be used to measure the overall family functioning as it correlates highly with all other FAD scales [20]. Mandarin [20] and Malay [21] translations are available. The cut-off score is 2 and any score above 2 will enable clinicians to identify problematic family functioning [18].

2.3. Statistical analysis

Statistical analyses were performed using Statistical Package for Social Sciences (SPSS) for Windows version v22.0 (SPSS Inc., Chicago, IL, USA).

To determine the level of agreement between parent-proxy and child self-report scores, intraclass correlation coefficients (ICC) were used. The closer the ICC value is to 1.0, the better the reliability and agreement with poor agreement: ≤ 0.4 ; moderate agreement: 0.41–

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