

Health-related quality of life in Malaysian children with epilepsy.

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Background: Children with epilepsy (CWE) are at risk of impaired health-related quality of life (HRQOL) and achieving a good HRQOL is an important treatment goal among CWE. To date there are no published multi-ethnic HRQOL studies in Asia. Our study aimed to: i) investigate the HRQOL of multi-ethnic 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 HRQOL; and iii) explore potential correlates of sociodemographic, epilepsy characteristics and family functioning with HRQOL 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. HRQOL was measured using the parent-proxy and child self-report of Health related 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 HRQOL lower than did the children themselves. 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's proxy CHEQOL-25 Total Scores ($r = -0.186$, $p = 0.046$). **Conclusion:** Our results emphasise the importance to have the child's perspective of their HRQOL as the level of agreement between the parent and child reported scores were poor to moderate. Psychosocial intervention for Malaysian CWE should be targeted at those of Malay ethnicity, those with focal seizures or high seizure frequency.