HEALTH RELATED QUALITY OF LIFE AND ACADEMIC ACHIEVEMENT IN CHILDREN WITH EPILEPSY

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FACULTY OF MEDICINE
UNIVERSITY OF MALAYA
KUALA LUMPUR

2018
HEALTH RELATED QUALITY OF LIFE AND ACADEMIC ACHIEVEMENT IN CHILDREN WITH EPILEPSY

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THESIS SUBMITTED IN FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

FACULTY OF MEDICINE
UNIVERSITY OF MALAYA
KUALA LUMPUR

2018
UNIVERSITY OF MALAYA
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HEALTH RELATED QUALITY OF LIFE AND ACADEMIC ACHIEVEMENT
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ABSTRACT

Epilepsy has a negative pervasive impact in the health related quality of life (HRQOL) of children with epilepsy (CWE) and their parents. Hence, the overall aim of this study was to explore the needs and challenges encountered by parents and their CWE, and to systematically review the impact of epilepsy on a child’s academic achievement. This study was divided into four phases: (1) the validation of the Malay and Chinese parent proxy and child self-report of the HRQOL measure for children with epilepsy (CHEQOL-25), (2) the validation of the Malay and Chinese general functioning subscale (GF-12), (3) the systematic review on the impact of epilepsy on academic achievement in children, (4) the needs and challenges of parents and their children in childhood epilepsy care. In phase 1 and 2, the Malay and Chinese versions of the CHEQOL-25 and GF-12 subscale were validated. These instruments were found to be valid and reliable to assess the HRQOL and family functioning of parents and their CWE in Malaysia, respectively. In phase 3, a search was conducted on five databases for articles published in English from 1980 till March 2015. Included were studies who recruited children (aged 5-18 years), with a diagnosis or newly/recurrent epilepsy, an intelligent quotient (IQ) of $\geq 70$ or attending regular school, with or without a control group, and studies which measured academic achievement using a standardised objective measure. Excluded were children with learning difficulties, intellectual disabilities (IQ<70) and other comorbidities such as attention deficits hyperactive disorder or autism. Twenty studies were included. The majority of the studies assessed “low achievement” whilst only two studies used the IQ-achievement discrepancy definition of “underachievement”. Fourteen studies (70%) reported that CWE had significantly lower academic achievement scores compared to
healthy controls, children with asthma or reported norms. The remaining six studies (30%) did not report any differences. CWE had stable academic achievement scores over time (2-4 years), even among those whose seizure frequency improved. Higher parental education and children with higher IQ, or had better attention or had a positive attitude towards epilepsy, were associated with higher academic achievement score. Older children were found to have lower academic achievement score. This systematic review highlights the need for early screening of learning problems and continued surveillance. In phase 4, purposive sampling was used to recruit CWE that were attending normal school and their parents. In-depth interviews were conducted in 18 parents (12 caregivers plus 3 pairs of caregivers) and 15 CWE. The experiences of parents and their child with epilepsy were divided into two time frames: “Experiences during their child’s first seizure” and “Experiences whilst growing up with epilepsy”. Parents’ main concerns and worries were their child’s physical health, psychological and emotional wellbeing, academic achievement and their child’s future. The children’s main concerns were restrictions imposed, their interpersonal relationship with peers, and being independent in the future. Parents reported that they needed epilepsy-related information, continuity of care, and parental support group. However, the children reported that their main need was independence and autonomy.

Keywords: health related quality of life, academic achievement, qualitative, children with epilepsy, parents
KUALITI HIDUP KESIHATAN DAN PENCAPAIAN AKADEMIK DI 
KALANGAN KANAK-KANAK DENGAN EPILEPSI

Abstrak

Epilepsi mempunyai kesan negatif atas kualiti hidup kesihatan kepada kanak-kanak dengan epilepsi (KDE) dan ibu bapa mereka. Oleh itu, matlamat keseluruhan kajian ini adalah untuk meneroka keperluan dan cabaran yang dihadapi oleh ibu bapa dan KDE mereka, dan untuk mengkaji semula secara sistematis kesan epilepsi kepada pencapaian akademik mereka. Kajian ini dibahagikan kepada empat peringkat: (1) pengesahan borang soal-selidik kualiti hidup kesihatan mengenai epilepsi proksi ibu bapa dan kanak-kanak lapor sendiri versi Bahasa Malaysia dan Bahasa Cina (CHEQOL-25), (2) pengesahan boring soal-selidik fungsi keluarga secara am versi Bahasa Malaysia dan Bahasa Cina (GF-12), (3) kajian sistematis mengenai kesan epilepsi kepada pencapaian akademik kanak-kanak, (4) keperluan dan cabaran ibu bapa dan anak-anak mereka dalam penjagaan epilepsy. Dalam fasa 1 dan 2, borang soal-selidik CHEQOL-25 dan GF-12 versi Bahasa Malaysia dan Bahasa Cina didapati sah dan boleh dipercayai untuk menilai kualiti hidup kesihatan kepada KDE dan fungsi keluarga ibu bapa di Malaysia. Dalam fasa 3, carian yang telah dijalankan ke atas lima pangkalan data untuk artikel yang diterbitkan dalam Bahasa Inggeris dari tahun 1980 sehingga Mac 2015. Termasuk adalah kajian yang merekrut kanak-kanak (berumur 5-18 tahun), dengan diagnosis atau epilepsi baru/berulang-ulang, yang menpunyai darjah pintar (IQ) daripada ≥70 atau menghadiri sekolah biasa, kajian dengan atau tanpa kumpulan kawalan, dan kajian yang mengukur pencapaian akademik menggunakan ukuran yang objektif yang seragam. Dikecualikan adalah KDE yang mengalami masalah pembelajaran, IQ<70 dan penyakit lain (defisit perhatian gangguan hiperaktif atau autism). 20 kajian telah dikumpulkan. Majoriti kajian dinilai "pencapaian rendah" whist hanya dua kajian

Kata kunci: kualiti hidup kesihatan, pencapaian akademik, kualitatif, kanak-kanak dengan epilepsi, ibubapa
ACKNOWLEDGEMENTS

Firstly, I would like to express my sincere gratitude to my beloved supervisors: Associate Professor Dr Pauline Lai Siew Mei, Professor Dr Low Wah Yun, and Professor Dr Ong Lai Choo for their continuous support. Their guidance helped me in all the time of research and writing of this thesis. I could not have imagined having better advisors and mentors for my study.

I would also like to thank all lecturers in the department of Primary Care Medicine, their constructive comments regarding my project. I thank my fellow postgraduate collegeus such as Renukha, Rinoa, Wen Ting, and Dr Julia sharing their experiences with me throughout this PhD journey.

My sincere thanks also goes to Professor Dr Lim Kheng Seang for the department of Medicine, Dr Tay Chee Geap and Associate Professor Anna Marie Nathan, from he department of Paediatrics, University Malaya Medical Centre, Dr Ranjini Sivanesom from Hospital Kuala Lumpur, Associate Professor Dr Wong Chee Piau from Sunway Medical Centre, as well as the nurses who helped me in recruiting patients for my study. I would like to thank all the parents and their children who took part in this study. Without their support it would be not possible to conduct this research.

I would like to thank my parents, my in laws, my sublings: Sushyan and Hungjune, and all my friends for supporting me throughout these years. Last but not the least, special thanks to my husband, Marcus Leong for his unconditional love, emotional support, and financial aid.
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<th>Abbreviation</th>
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<tbody>
<tr>
<td>ADHD</td>
<td>Attention deficit hyperactive disorder</td>
</tr>
<tr>
<td>AED</td>
<td>Number of antiepileptic drugs</td>
</tr>
<tr>
<td>AIC</td>
<td>Akaike’s information criterion</td>
</tr>
<tr>
<td>APSI</td>
<td>Adolescent Psychosocial Seizure Inventory</td>
</tr>
<tr>
<td>AS</td>
<td>Absence seizure</td>
</tr>
<tr>
<td>AVE</td>
<td>Average Variance Extracted</td>
</tr>
<tr>
<td>BECTS</td>
<td>Benign epilepsy with centro-temporal spikes</td>
</tr>
<tr>
<td>CAE</td>
<td>Childhood absence epilepsy</td>
</tr>
<tr>
<td>CBZ</td>
<td>Carbamazepine</td>
</tr>
<tr>
<td>CFA</td>
<td>Confirmatory factor analysis</td>
</tr>
<tr>
<td>CFI</td>
<td>Comparative fit index</td>
</tr>
<tr>
<td>CHEQOL-25</td>
<td>Health related quality of life measure for children with epilepsy</td>
</tr>
<tr>
<td>CHQ</td>
<td>Child Health Questionnaire</td>
</tr>
<tr>
<td>CMIN/DF</td>
<td>Chi-square/df ratio</td>
</tr>
<tr>
<td>CPS</td>
<td>Complex partial seizure</td>
</tr>
<tr>
<td>CS</td>
<td>Complex seizure</td>
</tr>
<tr>
<td>CT</td>
<td>Computerized tomography</td>
</tr>
<tr>
<td>CWE</td>
<td>Children with epilepsy</td>
</tr>
<tr>
<td>EEG</td>
<td>Electroencephalogram</td>
</tr>
<tr>
<td>EFA</td>
<td>Exploratory factor analysis</td>
</tr>
<tr>
<td>FAD</td>
<td>The McMaster Family Functioning Device</td>
</tr>
<tr>
<td>FES</td>
<td>Family Environment Scale</td>
</tr>
<tr>
<td>FLE</td>
<td>Frontal lobe epilepsy</td>
</tr>
<tr>
<td>GE</td>
<td>Generalized epilepsy</td>
</tr>
<tr>
<td>Abbr.</td>
<td>Description</td>
</tr>
<tr>
<td>-------</td>
<td>-------------</td>
</tr>
<tr>
<td>GF-12</td>
<td>General functioning subscale</td>
</tr>
<tr>
<td>GFI</td>
<td>Goodness of fit index</td>
</tr>
<tr>
<td>GS</td>
<td>Generalized seizure</td>
</tr>
<tr>
<td>HRQOL</td>
<td>Health related quality of life</td>
</tr>
<tr>
<td>IBE</td>
<td>International Bureau for Epilepsy</td>
</tr>
<tr>
<td>ICC</td>
<td>Intraclass correlation coefficient</td>
</tr>
<tr>
<td>IDI</td>
<td>In depth interview</td>
</tr>
<tr>
<td>IGE</td>
<td>Idiopathic generalized epilepsy</td>
</tr>
<tr>
<td>ILAE</td>
<td>International League Against Epilepsy</td>
</tr>
<tr>
<td>ILRE</td>
<td>Idiopathic localized related epilepsy</td>
</tr>
<tr>
<td>IOLE</td>
<td>Idiopathic occipital lobe epilepsy</td>
</tr>
<tr>
<td>IQ</td>
<td>Intelligence quotient</td>
</tr>
<tr>
<td>IQR</td>
<td>Interquartile range</td>
</tr>
<tr>
<td>ISOQOL</td>
<td>International Society for Quality of Life Research</td>
</tr>
<tr>
<td>KMO</td>
<td>Kaiser-Meyer-Olkin</td>
</tr>
<tr>
<td>MDI</td>
<td>Modification index coefficients</td>
</tr>
<tr>
<td>ML</td>
<td>Maximum likelihood</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic resonance imaging</td>
</tr>
<tr>
<td>PE</td>
<td>Partial epilepsy</td>
</tr>
<tr>
<td>PedsQL™</td>
<td>Pediatrics Quality of Life Inventory</td>
</tr>
<tr>
<td>PET</td>
<td>Positron emission tomography</td>
</tr>
<tr>
<td>PFA</td>
<td>Principal axis factoring</td>
</tr>
<tr>
<td>PGE</td>
<td>Primary generalized epilepsy with absence</td>
</tr>
<tr>
<td>PRO</td>
<td>Patient-Reported Outcomes</td>
</tr>
<tr>
<td>PS</td>
<td>Partial seizure</td>
</tr>
<tr>
<td>QOL</td>
<td>Quality of life</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomized controlled trial</td>
</tr>
<tr>
<td>RE</td>
<td>Rolantic epilepsy</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Description</td>
</tr>
<tr>
<td>--------------</td>
<td>-------------</td>
</tr>
<tr>
<td>RMSEA</td>
<td>Root-mean-square error of approximation</td>
</tr>
<tr>
<td>SES</td>
<td>Socioeconomic status</td>
</tr>
<tr>
<td>SGE</td>
<td>Symptomatic generalized epilepsy</td>
</tr>
<tr>
<td>SPECT</td>
<td>Single Photon Emission Computed Tomography</td>
</tr>
<tr>
<td>TLI</td>
<td>Tucker-Lewis index</td>
</tr>
<tr>
<td>UMMC</td>
<td>University Malaya Medical Centre</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
<tr>
<td>VPA</td>
<td>Valproate</td>
</tr>
</tbody>
</table>
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CHAPTER 1: INTRODUCTION

Epilepsy is the most common neurological condition in childhood and adolescence (Hirtz et al., 2007). During a seizure, a child may experience a sudden loss of consciousness, jerking, injuries, and bowel incontinence (G. M. Ronen, Streiner, & Rosenbaum, 2003). Due to the nature of epilepsy, and the unpredictability of seizure recurrence, epilepsy requires long-term treatment with medications. As a consequence, epilepsy has a negative pervasive impact in children with epilepsy (CWE), as well as in their parents (G. M. Ronen et al., 2003).

While doctors and parents are concerned as to how to prevent a seizure and the child from injury during a seizure, they may overlook a child’s learning, emotional, behavioral and social relationship with peers. Physical and social activities play a crucial role in a child’s healthy development (Carpay et al., 1997). Due to restrictions imposed by parents to avoid seizure occurrence (Wong & Wirrell, 2006), recent studies reported that CWE have significantly lower levels of functioning and well-being in physical, psychological, social, academic achievement and family functioning when compared to healthy controls, siblings, or reported norms (Kamath, Fayed, Goodman, Streiner, & Ronen, 2016; Kwong et al., 2016; Colin Reilly et al., 2014; Rodenburg, Wagner, Austin, Kerr, & Dunn, 2011; Sillanpää & Cress, 2009a). In addition, CWE have more adjustment problems than children with other chronic conditions such as asthma (J. K. Austin, Smith, Risinger, & McNelis, 1994).

Although children bear much of the burden of epilepsy, parents also suffer the negative consequences (G. M. Ronen et al., 2003) Parents of CWE experience stress from taking care of their CWE, as they are required to make decisions concerning the care and future of their child (G. M. Ronen et al., 2003). Mothers are usually at a higher risk for
psychological distress, such as depression and anxiety (Ferro & Speechley, 2009; Wood, Sherman, Hamiwka, Blackman, & Wirrell, 2008a). The more depressed the mother is, the higher the negative impact she has on the child’s health related quality of life (HRQOL), especially during the first two years after diagnosis (Ferro & Speechley, 2009). In addition, family functioning (McCusker, Kennedy, Anderson, Hicks, & Hanrahan, 2002), parental stress (Rodenburg, Meijer, Deković, & Aldenkamp, 2007), and parents’ anxiety about epilepsy (Yong, Chengye, & Jiong, 2006), have been found to be negatively associated with a child’s HRQOL. Therefore, parental adjustment is an important area to focus on to improve HRQOL in CWE (J. K. Austin & Caplan, 2007). Hence, the approach in epilepsy care has to be more holistic (J. K. Austin et al., 2015), and needs to include the parent’s and child’s views and experiences. Healthcare providers should provide interventions to improve the child’s HRQOL (Lew et al., 2006; McNelis, Johnson, Huberty, & Austin, 2005), parent’s mental health (Cushner-Weinstein et al., 2008), social support (Decker, Miller, & Buelow, 2016), and family functioning (Wagner et al., 2009).

Psychosocial and educational interventions can effectively treat mental health problems in CWE and their parents (Hagemann, Pfäfflin, Nussbeck, & May, 2016; Jantzen et al., 2009; Shore, Perkins, & Austin, 2008). By strengthening or reinforcing functional coping, parents can enhance their children’s psychological, social and emotional development (Wagner et al., 2009). This can be done by focusing on the parent’s personal investment as individuals, in the family as a whole, and in their understanding of the child’s medical, developmental and cognitive situation (Buelow, 2007). The majority of the psychosocial interventions developed were in the United States (Shore et al., 2008; Wagner, Smith, Ferguson, van Bakergem, & Hrisko, 2010), and in Europe (Jantzen et al., 2009). There is a paucity of data on studies on the development of psychosocial interventions in Malaysia. Therefore, the initial aim of this project was to
develop an intervention to improve psychosocial outcomes for CWE and their parents in Malaysia.

In order to measure the psychosocial outcomes of the intervention provided, we needed to measure the HRQOL, and family functioning of the CWE and their parents. A search of the literature found that there were no validated HRQOL or family functioning instruments that were validated in Malaysia. Hence, the first phase of the study was to validate these instruments.

However, it was not possible to perform a RCT to assess the effectiveness of the intervention. This was because we faced difficulty in recruiting CWE with normal cognitive function (who were able to fill up the HRQOL by themselves), despite enormous effort that was made to ensure successful recruitment from multiple sites. Secondly, an important issue raised while validating the questionnaires was that parents were concerned about how epilepsy would impact on their child’s academic achievement. A search of published literature revealed that this topic has never been reviewed systematically before. Hence, a systematic review was conducted to assess the prevalence of academic difficulties in CWE of normal intelligence, and its associating factors.

In addition, we found that there were a lot of unmet needs and challenges faced by parents and their CWE. Hence, we decided to perform a qualitative study to explore the experiences of parents and their CWE, and to identify the needs and challenges faced by these parents and children, and how these factors impact on their HRQOL, so that a psychosocial intervention can be developed to improve the child’s HRQOL in the future (McNelis, Buelow, Myers, & Johnson, 2007).
CHAPTER 2: LITERATURE REVIEW

2.1 Epileptic seizure and epilepsy

The brain is made up of millions of nerve cells that use electrical signals to control the body’s functions, senses and thoughts. If signals are disrupted, a person may experience an epileptic seizure (sometimes called a ‘fit’ or ‘attack’) (Fisher et al., 2014). A seizure is an event, and epilepsy is the disease involving recurrent unprovoked seizures (Fisher et al., 2014).

2.1.1 Definition of seizure

According to the International League against Epilepsy (ILAE), seizure is defined as “a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain. The term transient is used as demarcated in time, with a clear start and finish” (Fisher et al., 2014).

2.1.2 Definition of epilepsy

Epilepsy has traditionally been referred to as a disorder or a family of disorders, rather than a disease (Fisher et al., 2014). However, epilepsy is now called a “disease”, rather than a “disorder”. This is because a “disorder” implies a functional disturbance, which may not last long; whereas, the term “disease” may carry a longer lasting dysfunction of daily activities. In addition, the term “disorder” is poorly understood by the public and minimizes the serious nature of epilepsy. Therefore, ILAE and the International Bureau for Epilepsy (IBE) agreed that the word "disease" better describes the seriousness of epilepsy to the public (Fisher et al., 2014).
Now, epilepsy is defined as “a disease of the brain characterized by an enduring predisposition to generate epileptic seizures, and by the neurobiological, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure” (Fisher et al., 2014).

2.1.3 Operational (practical) clinical definition of epilepsy

According to the ILAE, an individual is defined to have epilepsy when he/she has two unprovoked seizures more than 24 hours apart. However, this definition has a few limitations. This definition does not allow the possibility of “outgrowing” epilepsy. Therefore, in 2014, the ILAE commissioned a second task force to develop a practical (operational) definition of epilepsy, designed for use by both doctors and patients. A person is considered to have epilepsy if they meet any of the following conditions in Table 2.1 (Fisher et al., 2014).

Table 2.1: Operational (practical) clinical definitions of epilepsy (Fisher et al., 2014)

- At least two unprovoked (or reflex) seizures occurring greater than 24 hours apart.
- One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
- Diagnosis of an epilepsy syndrome
  - Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years.
2.1.4 Seizure classification

The classification of seizure has been recently revised (Fisher et al., 2016). The first step in classifying the type of seizure to determine whether the seizures displayed are focal, generalized, or unknown (Figure 2.1).
Figure 2.1: Seizure classification for focal and generalized seizure (Fisher et al., 2016)
Focal seizure is defined as a seizure that is originating within networks that may be discretely localized or more widely distributed in one hemisphere of the brain (Berg et al., 2010). Focal seizure can be subdivided into motor or non-motor symptoms (Fisher et al., 2016).

Generalized epilepsy is defined as a seizure that is “originating at some part of the brain, then rapidly engaging, bilaterally distributed network” (Berg et al., 2010). Generalized seizures can be divided into motor and absence seizure (Fisher et al., 2016).

“Unknown onset” seizure is classified when the onset was missed or unnoticed. However, subsequent information may allow reclassification of the seizures as focal or generalized in onset (Fisher et al., 2016).

2.1.5 Etiology of epilepsy

Epilepsy has many possible causes. The three main causes of epilepsy are genetic, structural or metabolism, and unknown (Berg et al., 2010).

2.1.5.1 Genetic causes

“Genetic” does not mean “inherited”. Genetic causes in epilepsy means that epilepsy is caused by genetic mutation (Scheffer et al., 2016). Genetic epilepsy is defined as “the direct result of a known or presumed genetic defect(s) in which seizures are the core symptom of the disorder. Knowledge regarding genetic causes may derive from specific molecular genetic studies that have been well replicated and even become the basis of diagnostic tests (e.g., Dravet syndrome) or the evidence for a central role of a genetic component may come from appropriately designed family” (Berg et al., 2010).
2.1.5.2 **Structural or metabolic causes**

“Structural or metabolic” causes of epilepsy is a concept of etiology where lesions of the brain can be caused by stroke, brain trauma or infection, or a metabolic condition that has been found to be associated with the increase risk in developing epilepsy (Berg et al., 2010).

2.1.5.3 **Unknown causes**

“Unknown causes” of epilepsy is defined as the underlying cause of epilepsy that is not known and yet to recognized (Berg et al., 2010).

2.1.6 **Diagnosis of epilepsy**

Epilepsy can be diagnosed by obtaining a thorough medical history from the child, parents, or family members; and by performing an electroencephalogram test (EEG) to identify the cause of epilepsy (epilepsy etiology) and the type of seizure. Table 2.2 summaries the tests used to diagnose epilepsy syndromes.
### Table 2.2: Summary of the tests used to diagnose epilepsy syndromes

<table>
<thead>
<tr>
<th>Diagnostic test</th>
<th>Description</th>
</tr>
</thead>
</table>
| Electroencephalogram (EEG)                          | • To detect unusual brain activity that is associated with epilepsy  
• To determine seizure type and epilepsy syndrome. |
| Magnetic resonance imaging (MRI)                    | • To identity structural abnormalities  
• To be used when a patient has a focal onset on history (unless there is clear evidence of benign focal epilepsy)  
• To be used in patients who still have seizure after the initiation of antiepileptic drug |
| Computerized tomography (CT)                         | • To identify underlying gross pathology when MRI is not available or is contra-indicated  
• To determine whether a seizure has been caused by an acute neurological lesion or illness. |
| Positron emission tomography (PET)                   | • To locate the part of the brain that is causing seizures  
• To show the brain’s use of oxygen or sugar  
• To be used as a pre-surgical check-up in providing localisation information in some patients |
| Single Photon Emission Computed Tomography (SPECT)   | • To show how the brain functions (as opposed to MRI or CT scans which show brain structure)  
• To show the blood flow in the brain  
• Used only when seizures begin outside the temporal lobe and MRI scans do not show a structural abnormality. |
2.2 Epidemiology of epilepsy in children

Two of the most common terms used in epidemiology are incidence and prevalence.

2.2.1 Incidence of epilepsy

Incidence of a disorder is defined as the number of new cases in a population at a given duration (Last, 2001).

The incidence curve for epilepsy is j-shaped with the highest incidence of epilepsy occurring during the first few months of life (100/100,000) (Camfield, Camfield, Gordon, Wirrell, & Dooley, 1996; Hesdorffer et al., 2011; Olafsson et al., 2005). The incidence of epilepsy falls dramatically after the first year of life, and remains stable through the first 10 years of life, and falls further during adolescence in developed countries until age 60 (20/100,000) (Hesdorffer et al., 2011). Incidence rate begins to climb dramatically by age 80 (175/100,000).

In developed countries, 50% of epilepsy occur in childhood or adolescence (Olafsson et al., 2005). However, in Africa and South Africa, the peak incidence of epilepsy occurs in young adults, followed by the first 10 years of life (Rwiza et al., 1992). In Asia, incidence rates were only available from China and India (Mac et al., 2007) [See table 2.3]. The incidence of epilepsy in Asia were similar to those in developed countries (such as the United States of America and Europe), and lower than those from Africa and Latin America (Mac et al., 2007).
Table 2.3 Incidence of epilepsy globally

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Country</th>
<th>Study period/duration (years)</th>
<th>Incidence (per 1000 person-years) 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Banerjee et al. (2010)</td>
<td>India</td>
<td>2003-2008/5</td>
<td>27.0</td>
</tr>
<tr>
<td>Casetta et al. (2012)</td>
<td>Italy</td>
<td>1996-2005/10</td>
<td>57</td>
</tr>
<tr>
<td>Olafsson et al. (2005)</td>
<td>Iceland</td>
<td>1995-1999/5</td>
<td>56-130.2</td>
</tr>
<tr>
<td>Rwiza et al. (1992)</td>
<td>Tanzanian</td>
<td>1979-1988/10</td>
<td>120-190</td>
</tr>
<tr>
<td>W. Wang et al. (2002)</td>
<td>China</td>
<td>2000/1</td>
<td>28.8</td>
</tr>
</tbody>
</table>

2.2.2 Prevalence of epilepsy

On the other hand, prevalence is defined as the number of cases for a population at a single point in time (when the data were collected) (Katz, Wild, Elmore, & Lucan, 2014).

Globally, the prevalence of epilepsy ranges from 3.6 to 41.3% (Banerjee et al., 2010; Benamer & Grosset, 2009; Forsgren, Beghi, Oun, & Sillanpaa, 2005). In Asia, the prevalence of epilepsy ranges from 1.5 to 14.0 per 1000 (Mac et al., 2007) [Table 2.4]. In Malaysia, it is estimated that there are more than 200,000 people diagnosed with epilepsy. However, there is currently no information on the prevalence or the incidence of CWE in Malaysia (Manonmani & Tan, 1999).
<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Region/Country</th>
<th>Sample size</th>
<th>Children age (years)</th>
<th>Prevalence (in 1000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Al Rajeh et al. (2001)</td>
<td>Saudi Arabia</td>
<td>23700</td>
<td>0-9</td>
<td>6.5</td>
</tr>
<tr>
<td>C.-C. Chen, Chen, Yen, Chen, and Liou (2012)</td>
<td>Taiwan</td>
<td>37,947</td>
<td>0-19</td>
<td>5.97</td>
</tr>
<tr>
<td>Kwong, Chak, Wong, and So (2001)</td>
<td>Hong Kong</td>
<td>309</td>
<td>0-15</td>
<td>1.52</td>
</tr>
<tr>
<td>Lee, Low, Murugasu, and Raja (1997)</td>
<td>Singapore</td>
<td>96047</td>
<td>0-9</td>
<td>3.5</td>
</tr>
<tr>
<td>Malik, Akram, Tarar, and Sultan (2011)</td>
<td>Pakistan</td>
<td>92254</td>
<td>0-16</td>
<td>7.0</td>
</tr>
<tr>
<td>Russ, Larson, and Halfon (2012)</td>
<td>United States</td>
<td>91605</td>
<td>0-17</td>
<td>10.2</td>
</tr>
<tr>
<td>Waaler, Blom, Skeidsvoll, and Mykletum (2000)</td>
<td>Norway</td>
<td>38593</td>
<td>6-12</td>
<td>5.1</td>
</tr>
</tbody>
</table>
2.3 Impact of epilepsy on the health related quality of life in childhood epilepsy

HRQOL is a subdomain of quality of life (QOL) (Sadeghi, Fayed, & Ronen, 2014). HRQOL measures how a patient perceives their physical, psychological, interpersonal, and emotional well-being that is affected by their chronic illness and its treatment, whereas QOL which measures how an individual perceives his/her overall life (Sadeghi et al., 2014).

Previous studies found that side effects of AED (H. F. Chen, Tsai, Hsi, & Chen, 2016), psychological problems (such as anxiety and depression) (Endermann & Zimmermann, 2009), support from family (Ellis, Upton, & Thompson, 2000; Mahrer-Imhof et al., 2013), self-efficacy towards illness (Mahrer-Imhof et al., 2013), employment (Lim, Wo, Wong, & Tan, 2013), community support (Mahrer-Imhof et al., 2013) were factors impact HRQOL in adult with epilepsy. A few studies have been conducted to examine the impact of epilepsy on the quality of life in adult with epilepsy in Malaysia. Underemployment and psychological issues (such as low esteem) had negative impact on the HRQOL of adult with epilepsy (Neni, Latif, Wong, & Lua, 2010). Another study found that seizure control was also found to be a major concern in adult with epilepsy (Norsa'adah, Zainab, & Knight, 2013). Adult with better seizure control was found to have better QOL (Norsa'adah et al., 2013). A previous study found that adult with epilepsy who has sleep disturbance were more worried about their epilepsy and hence had negative impact on the HRQOL in adult with epilepsy (Hashim, Abdullah, Abdullah, Tharakan, & Musa, 2013).

Traditionally, the main goal in managing CWE focused only on seizure control and minimized adverse effects of antiepileptic drugs (AED) (G. M. Ronen et al., 2003). However, CWE were found to have compromised HRQOL (G. M. Ronen et al., 2003). These children were also found to have a higher risk of emotional, behavioral, social and
academic difficulties compared to healthy children (J. K. Austin, Huberty, Huster, & Dunn, 1999), children with asthma (J. K. Austin, Dunn, & Huster, 2000; J. K. Austin et al., 1999), and other chronic illnesses (Vickrey et al., 1994). Epilepsy variables, its comorbidities, and several mediating factors (such as family, child or community factors) can directly influence a child’s HRQOL, as shown in the conceptual model of the HRQOL in childhood epilepsy (Figure 2.2) (Lach et al., 2006; G. M. Ronen et al., 2010). To date, there is a paucity of date on the HRQOL of CWE in Malaysia.
Epilepsy and its comorbidity

Epilepsy variables
1. Age of onset
2. Duration of epilepsy
3. Number of antiepileptic drugs

Mediating factors

Family
1. Family functioning
2. Parental mental health
3. Resources: social support

Child
1. Age
2. Social skills
3. Academic achievement
4. Interpersonal relationships: restriction imposed and perceived stigma

Community
1. Health care service

Outcome

Health Related Quality of Life in children with epilepsy

Figure 2.2: A conceptual model of the Health Related Quality of Life (HRQOL) in childhood epilepsy
2.3.1 Epilepsy and its co-morbidities

Extensive research has examined the impact of epilepsy and its co-morbidities on HRQOL in CWE. In a systematic review on HRQOL in CWE, epilepsy variables [such as age of onset, duration of epilepsy, number of antiepileptic drugs (AED) and side effects of AED] and comorbidities (such as physical disabilities, cognitive impairment, mood disorders and behavioral problem) were found to have a negative impact on the HRQOL in CWE (D. Stevanovic, Tadic, & Novakovic, 2011). Other epilepsy variables such as seizure frequency, seizure severity, and seizure types were found to have inconsistent or no evidence on the HRQOL in CWE (Carson & Chapieski, 2016; Lagunju et al., 2009; Yong et al., 2006).

2.3.1.1 Epilepsy variables

(a) Age of onset

Children with an earlier onset of epilepsy onset have significantly poorer HRQOL (Baker, 1998; Clary, Vander Wal, & Titus, 2010; D. Y. Wu, Ding, Wang, & Hong, 2010; Yong et al., 2006). These children have lower emotional wellbeing, poorer social activities and interpersonal relationship with peers. This maybe because their parents tend to impose more restrictions on their daily activities as compared to their health siblings. Additionally, regular visits to hospital for follow-up and treatment may reduce social activities, and hence inhibit these children to develop social skills (Clary et al., 2010).

(b) Duration of epilepsy

A longer duration of epilepsy has been found to be associated with poorer HRQOL (Adewuya, 2006; Miller, Palermo, & Grewe, 2003; G. M. Ronen et al., 2010). These findings were as expected as a longer duration of epilepsy has been found to be associated with cognitive impairment (such as memory problems, executive dysfunction and
concentration). This then affects the learning and the ability to cope with stress, and lower HRQOL (Clary et al., 2010).

(c) Antiepileptic drugs

CWE who take a higher number of AED have significantly lower HRQOL (Adewuya, 2006; Miller et al., 2003; G. M. Ronen et al., 2010; D. Stevanovic, 2007). This may be because the use of a higher number of AED may indicate that the epilepsy is more severe (Lach et al., 2006). Additionally, a higher number of AED has been associated with more side effects (Benavente-Aguilar, Morales-Blanquez, Rubio, & Rey, 2004; Devinsky et al., 1999). Hence, clinical practice guidelines now recommend that epilepsy should be treated with one AED (where possible) to minimize side effects (Deckers et al., 2001). The use of newer AEDs such as topiramate, have been found to be associated with lesser side effects (Mikaeloff et al., 2003). CWE who were prescribed topiramate showed significant improvement in physical functioning (less fatigue), better self-esteem, less anxious, better memory and language ability, better social and behavioral domains, and hence improved in overall HRQOL (Jung, Kim, Hur, & Eom, 2011).

2.3.1.2 Co-morbidities

(a) Physical functioning

CWE experience fatigue (Elliott, Lach, & Smith, 2005; Galletti, Rinna, & Acquafondata, 1998), headache (Baker et al., 2008; Russ et al., 2012), sleeping problems (Ong, Yang, Wong, AlSiddiq, & Khu, 2010), or weight changes (Baker et al., 2008). As a result, CWE require excessive rest to recover after a seizure. This reduces their physical and social activities, and thus reduces their HRQOL (Galletti et al., 1998).
(b) **Cognitive impairment**

Cognitive impairment is often associated with childhood epilepsy due to underlying etiology, abnormal brain structure and epileptic activity (Chin et al., 2011). CWE may experience memory and/or information processing problems. They also lack the ability to concentrate and/or solve problems. One study found that attention and executive functions in children with new-onset epilepsy were significant more impaired compared with healthy controls, but less impaired compared with children with chronic epilepsy (Reuner, Kadish, Doering, Balke, & Schubert-Bast, 2016). Children with childhood absence epilepsy performed worse than healthy children in verbal skills and learning, even if their IQ scores fell within the normal range (Caplan et al., 2008; Conant, Wilfong, Inglese, & Schwarte, 2010). A previous systematic review showed that CWE had significantly lower memory score compared to controls and norms in a memory test (Menlove & Reilly, 2015). Early seizure onset, higher usage of AED, greater seizure frequency were found to be associated with memory impairment (Ijff & Aldenkamp, 2013; Menlove & Reilly, 2015). Recent study found that children have significantly higher risk of cognitive impairment when etiology of epilepsy was unknown or not classifiable (Reuner et al., 2016).

Cognitive impairment has a negative impact on the HRQOL in CWE (Raud, Kaldoja, & Kolk, 2015; Schraegle & Titus, 2016; Speechley et al., 2012). In one longitudinal study, CWE who had cognitive impairment at baseline, had significantly lower HRQOL scores compared to CWE without any cognitive impairment at baseline (Speechley et al., 2012). This maybe because CWE without any cognitive impairment could cope better with the stress associated with epilepsy (Clary et al., 2010).
(c) **Depression and anxiety**

Depression is a common psychiatric comorbid condition in children and adolescents with epilepsy. Depression was found to be significantly higher in CWE than healthy children: 23-33% in CWE versus 16% in healthy controls (Adewuya & Ola, 2005; Alwash, Hussein, & Matloub, 2000; D. W. Dunn, Austin, & Huster, 1999; Ettinger et al., 1998).

One of the predictive factors in depression in CWE is age. There was a significantly higher rate of depression in adolescents with epilepsy (12-18 years old) compared to children (aged 9-11 years) with or without seizure (Oguz, Kurul, & Dirik, 2002; Thome-Souza et al., 2004). Some studies reported that higher seizure frequency (Oguz et al., 2002), side effects of AED (Ramsey, Loiselle, Rausch, Harrison, & Modi, 2016; Sabbagh, Soria, Escolano, Bulteau, & Dellatolas, 2006), longer duration of epilepsy (Alwash et al., 2000; Oguz et al., 2002), and type of epilepsy (Schraegle & Titus, 2017; Thome-Souza et al., 2004; Titus, Kanive, Sanders, & Blackburn, 2008) were associated with a higher rate of depression in CWE. However, some studies did not find any association between these variable and depression (Caplan et al., 2005; D. W. Dunn et al., 1999; Oguz et al., 2002; Thome-Souza et al., 2004).

Family functioning was found to be significantly associated with depression in CWE. Higher family distress (D. W. Dunn et al., 1999), poorer proximal family factor (quality of parent-child relationship and parenting), poorer family relationships (Puka, Widjaja, & Smith, 2017), higher level of maternal anxiety and depression (Hodes, Garralda, Rose, & Schwartz, 1999; Shore, Austin, & Dunn, 2004), and lower parent confidence about managing a child’s discipline was associated with depression (J. K. Austin, Dunn, Johnson, & Perkins, 2004) Family functioning and parent-child relationship is related to
child psychopathology and can be explained using the expressed emotion theory (Hooley & Holly, 2006). Expressed emotion is defined as “the emotionally over-involved attitude that family members have toward a family member with a disorder” (Band, Barrowclough, & Wearden, 2014). Children displayed more emotional problems when their mothers were overly critical or emotional (Vostanis, Nicholls, & Harrington, 1994).

Anxiety disorders (e.g. panic attacks, obsessive compulsive disorders, generalized anxiety disorders etc.) affect 16-33% of CWE, compared to 16% in healthy controls (Alwash et al., 2000; Caplan et al., 2005; Ettinger et al., 1998; Williams et al., 2003). This may be due to the unpredictability of seizure and the inability to control seizures. A study in Korea found that anxiety had the most significant impact on the HRQOL in CWE, compared to the impact of depression and seizure frequency (S. H. Han, S. Lee, S. Eom, & H. D. Kim, 2016).

CWE who had lower verbal IQ score (Caplan et al., 2005), or were taking a higher number of AEDs (Adewuya & Ola, 2005; Ettinger et al., 1998; Oguz et al., 2002; Williams et al., 2003) were found to be more anxious. Some studies reported that older CWE who had better cognitive ability, and who emphasized more on peer relationship were found to have higher anxiety (D. W. Dunn et al., 1999; Oguz et al., 2002). However, some studies found that there was no association between age and anxiety in CWE (Ettinger et al., 1998; Oostrom, Schouten, Kruitwagen, Peters, & Jennekens-Schinkel, 2001; Williams et al., 2003). One study found that children with childhood absence epilepsy (CAE) had higher rates of anxiety compared to children with complex partial seizure (CPS) (D. W. Dunn & Austin, 2004).
In summary, the earlier onset (Baker, 1998; Clary et al., 2010; D. Y. Wu et al., 2010; Yong et al., 2006), or a longer duration of epilepsy (Adewuya, 2006; Miller et al., 2003; G. M. Ronen et al., 2010), a higher number of AED or side effects experienced from taking AED (Adewuya, 2006; Miller et al., 2003; G. M. Ronen et al., 2010; D. Stevanovic, 2007) were factors found to be associated with a lower HRQOL in CWE. In addition, physical disabilities associated with epilepsy (such as feeling fatigue after a seizure) (Galletti et al., 1998), cognitive impairment (such as poor executive functioning) (Reuner et al., 2016), mood disorders (such as anxiety and depression) (Adewuya & Ola, 2005; Alwash et al., 2000; D. W. Dunn et al., 1999; Ettinger et al., 1998), and were also found to be negatively associated with HRQOL in CWE.

2.3.2 Mediating factor

Mediating factors can be divided into three categories: family, child and community factors.

2.3.2.1 Family factors

(a) Family functioning

According to the McMaster family functioning model (Epstein, Baldwin, & Bishop, 1983), the core function of a family is to provide an environment that is appropriate for family members to grow physically, psychologically, socially and emotionally. A healthy family should be able to handle basic tasks (such as meeting the biological needs for the family of food and shelter), developmental tasks (such as encouraging the emotional growth of family members), and crisis tasks (such as solving problems during a family crisis). This can be established by effective communications, established family roles for every family member, and showing affection to each other (Epstein et al., 1983).
Family functioning has been consistently found to be a mediating factor of HRQOL in CWE and their parents. In a study conducted in the United States of America (USA), CWE who reported lower family activities and parent-child quality time were found to have lower HRQOL compared to healthy controls (Miller et al., 2003). Consistent with a Korean study on adolescents with epilepsy, family proximal (parent-child relationship), family distal (such as parental over control and parents depression) and family characteristics were significantly associated with behavioral problems in adolescents with epilepsy (S. H. Han et al., 2016).

(b) Parental mental health

Parents of CWE face a lot of challenges. They need to learn more about their child’s epilepsy, incorporate medications into their child’s daily routine, learn how to manage seizures, and bring their child regularly to the hospital for check-ups. Due to the unpredictable nature of childhood epilepsy, parents are uncertain about the future for their child and the family. Mothers are usually at a higher risk for psychological distress, such as depression and anxiety (Ferro & Speechley, 2009; Wood et al., 2008a). The more depressed the mother is, the higher the negative impact she has on the child’s health-related quality of life (HRQOL), especially during the first two years after diagnosis (Ferro & Speechley, 2009).

Parental depression and anxiety can affect the HRQOL in CWE (Yong et al., 2006). This may be because the parent’s attitude toward children can be influenced by their psychological conditions. If the parent anxiety towards their child’s epilepsy may increase the child’s worry towards seizure, and affect his or her psychosocial development. Therefore, it is important that parents learn to cope effectively to maintain the psychological well-being and family functioning.
(c) **Resources: social support**

Social support (such as help in daily activities, emotional support, and information support in childhood epilepsy care) is important in helping parents cope and care for their child with epilepsy (Carlson & Miller, 2017). Previous studies found that parents of CWE who have more social support had significantly lower levels of mental health problem (such as depression, anxiety and stress) (Rodenburg et al., 2007). Higher level of stress, depressive symptoms and anxiety were reported among parents with poor social support had poor parental adaptation (Akay et al., 2011). This may lead to poorer family proximal (parent-child relationship), which has negative impact on a child’s HRQOL (S. H. Han et al., 2016). Consistent with another study conducted on 152 parents of CWE, parents who actively searched for social support reported lower levels of depression and anxiety (Carlson & Miller, 2017).

2.3.2.2 Child’s age

(a) **Age**

Previous studies reported that older children with epilepsy have significant lower HRQOL scores in physical, psychological and social subscales (Benavente-Aguilar et al., 2004; Devinsky et al., 1995) compared with healthy controls (Schraegle & Titus, 2017). This may be because older children and adolescents place more emphasis on relationships with peers and would like to gain peer acceptance (Benson et al., 2015; Erikson, 1963).

(b) **Academic achievement**

Academic achievement in children is important as it affects future employment (Rodenburg et al., 2011; Sillanpää & Cress, 2009a). Previous studies found that academic problems are common in CWE (Ali, Tomek, & Lisk, 2014; Chambers et al., 2014; D. W. Dunn et al., 2010; Fastenau et al., 2004; Ibekwe, Ojinnaka, & Illoeje, 2007), as epilepsy
can cause cognitive impairment, attention deficit hyperactive disorder (ADHD), and learning disabilities (Fastenau, Shen, Dunn, & Austin, 2008). A previous study in 182 CWE with and without learning disability showed that CWE with learning disability have significantly lower QOL scores in interpersonal and emotional subscales compared to CWE without learning disability (Brabcová, Zárubová, Kohout, Jošt, & Kršek, 2015).

However, CWE of normal intelligence without comorbidities were also found to be at risk for academic underachievement (Rodenburg et al., 2011). In a recent population-based study on academic achievement in school-aged CWE found that cognitive impairment was not the only cause for difficulties with academic achievement (Colin Reilly et al., 2014).

(c) **Interpersonal relationship: Restrictions imposed**

Participation in extracurricular activities play a crucial role in a child’s healthy physical and emotional development (Carpay et al., 1997; Engel-Yeger, Zlotnik, Ravid, & Shahar, 2014; Kamath et al., 2016). Extracurricular activities such as sports, help children to build friendships, promote peer acceptance and improve fine or gross motor coordination (Guèvremont, Findlay, & Kohen, 2014; Merkel, 2013). In a population-based study, 11% of CWE experienced more than one serious injury, such as cut, fractures, broken teeth, concussions and others (C. S. Camfield & P. R. Camfield, 2015). This study found that most injuries occurred during normal daily activities, and parents of CWE also reported that these injuries were not easy to prevent (C. S. Camfield & P. R. Camfield, 2015).

Carpay and colleagues (1997) found that 83% of parents imposed at least one restriction on their child with epilepsy. Although some restrictions (e.g. supervision when
swimming) may be required (Bell, Gaitatzis, Bell, Johnson, & Sander, 2008), other restrictions were not required (e.g. avoiding physical activities). Imposing unnecessary restrictions may negatively impact on a child’s psychosocial function, autonomy development and HRQOL (Whitney et al., 2013; E. C. Wirrell, 2006). CWE who lack physical activities may have higher body mass index and lower bone mineral density (Wong & Wirrell, 2006).

(d) Stigma

Although the causes of stigma are complex, lack of public awareness about epilepsy has been considered to be an important determinant factor. Previous studies of public awareness, understanding, and attitudes towards epilepsy in developing countries such as China (Lai et al., 1990), Taiwan (Chung, Chang, Lai, & Lai, 1995), Saudi Arab (Alhazzani et al., 2016) had shown higher levels of stigma against epilepsy compared to developed countries such as United States (Caveness & Gallup, 1980) and Croatia (Bagic, Mastilica, & Bagic, 2012). In Malaysia, there is lack of public awareness towards epilepsy compared to other developed countries. Epilepsy is often considered as condition due to supernatural causes, such as possession (Neni et al., 2010). Previous studies have found that there is a frequent use of traditional treatment among the Chinese population in Malaysia (Lim, Tan, Lim, & Tan, 1999). The public awareness and understanding of a chronic illness is crucial because misconception and social misunderstanding may affect the quality of life of the patients more than the seizure itself.

Stigma has been found to be associated with mental health outcomes in CWE (Benson et al., 2015). According to Scambler and Hopkins (1986), there are two types of stigma associated with epilepsy: “enacted” and “felt” stigma. Enacted stigma refers to an individual’s experience of discrimination by others due to his or her epilepsy. For
example, being neglected in school or the workplace due to epilepsy. Felt stigma refers to an individual’s fear of unfair treatment by others after disclosure of one’s epilepsy. Felt stigma may be based on an individual’s own negative believes of one self. These individuals also believe that others will discriminate them, without any past experiences of enacted stigma (Quinn & Earnshaw, 2013).

Due to the development of self-identity and peer relationships during adolescence, enacted and felt stigma may have significant impact on their psychosocial health and self-esteem. A previous study found that most adolescents did not feel stigmatized (J. K. Austin et al., 2004). However, some adolescents (59%) did not reveal their epilepsy to others, and the majority (70%) never talked about epilepsy with their peers. These results showed that adolescents may not experience “enacted stigma”, but “felt stigma” may lead them to conceal their epilepsy to others (J. K. Austin et al., 2004). CWE who reported a greater need for information and support, more fear and worry related to having epilepsy, greater seizure severity, and younger age were significantly associated with greater stigmatization (J. K. Austin et al., 2004).

2.3.2.3 Community factor

A study on adults with epilepsy showed that community resources such as support groups, and counseling, were important to ensure better QOL (Paschal, Mitchell, Wilroy, Hawley, & Mitchell, 2016). To improve well-being of patient with epilepsy, nonprofit organization provides service to help individuals and caregivers to manage their seizure, to improve their overall health, to raise awareness about the risk of sudden unexpected death in epilepsy (SUDEP) and to increase epilepsy awareness to the community (such as school and local council). These organization are the Epilepsy Foundation (USA), The Canadian Epilepsy Alliance, Epilepsy Action (United Kingdom), China Association
Against Epilepsy, Epilepsy Australia, Epilepsy India, Japanese Epilepsy Association, and Slovenian League Against Epilepsy.

In Malaysia, Epilepsy Council of the Malaysian Society of Neurosciences and Malaysian Epilepsy Society have published consensus guideline on the management of epilepsy in Malaysia in the year 2017. The guidelines provide the updates for the use AED to all clinicians. All the recommendations in the guidelines were updated based on the most recent publications as well as the expert opinions of the panel (Council, 2017).

Family functioning (such as parent’s mental health and social support) (Carlson & Miller, 2017; Ferro & Speechley, 2009; Miller et al., 2003; Wood, Sherman, Hamiwka, Blackman, & Wirrell, 2008b), factors associated with a child (such as age, academic achievement, interpersonal relationship, attitudes towards epilepsy and stigma) (Joan K. Austin, MacLeod, Dunn, Shen, & Perkins, 2004; Benavente-Aguilar et al., 2004; C. Camfield & P. Camfield, 2015; Colin Reilly et al., 2014) and community resources (such as support group and counselling) (Paschal, Mitchell, Wilroy, Hawley, & Mitchell, 2016) have been consistently found to be mediating factors of HRQOL in CWE and their parents. Healthy family functioning is vital to provide an environment that would allow CWE and their family members to grow physically, psychologically, socially and emotionally (S.-H. Han, S.-A. Lee, S. Eom, & H.-D. Kim, 2016; Miller et al., 2003). Children who were older (Benavente-Aguilar et al., 2004), with lower academic achievement (Brabcová et al., 2015), who had more restriction in activities (Whitney et al., 2013), or who experienced stigma (Joan K. Austin et al., 2004) were found to be associated with a lower HRQOL. Parents of CWE who had more community support had significantly lower levels of mental health problems (such as depression, anxiety and stress) (Rodenburg et al., 2007).
2.4 Health related quality of life measurement

Generally, HRQOL can be assessed by “generic” or “disease/condition-specific” instruments (Harding, 2001).

“Generic” instruments assess a comprehensive array of domains (e.g. psychological and physical functioning) of HRQOL, irrespective of the underlying disorder. Generic HRQOL instruments have the advantage that the data acquired can be compared across demographic or clinical populations. However, these instruments lack the sensitivity to detect any specific-conditions related to a disease (G. M. Ronen et al., 2003). Examples of generic HRQOL instruments are the Child Health Questionnaire (CHQ) (Langraf, Abetz, & Ware, 1996) and the Pediatrics Quality of Life Inventory (PedsQL™) (Varni, Burwinkle, & Seid, 2006).

“Disease or condition-specific” HRQOL instruments were developed to examine the characteristics of HRQOL in a particular condition (Harding, 2001). As such, they are generally seen to be more relevant and sensitive in a specific disease. However, it is usually not possible to compare data from one disease-specific measure from another (G. M. Ronen et al., 2003).
2.4.1 Types of health related quality of life instruments

HRQOL can be reported by the child with epilepsy or by their parents/caregivers. The advantages and disadvantages of type of rates are listed in table 2.5.

Table 2.5: Type of raters for health related quality of life measurement

<table>
<thead>
<tr>
<th>HRQOL reported by</th>
<th>Definition</th>
<th>Advantage(s)</th>
<th>Disadvantage(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child self-report</td>
<td>Gaining a child’s responses such as feeling, attitudes, and value.</td>
<td>Child provides direct responses</td>
<td>- Child self-report can become inaccurate due to social desirability bias</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Child may have difficulty understanding or interpretation of questions that measure an abstract component (e.g. Personality)</td>
</tr>
<tr>
<td>Parent proxy</td>
<td>Parents who provides response on behalf of their child on their behalf</td>
<td>Parents provides useful and more concrete information as an observer (e.g. treatment outcome)</td>
<td>- Responses from proxies may be influenced by their subjective feelings about and experiences of caring for the child</td>
</tr>
</tbody>
</table>

It is important to determine who reports the HRQOL (Rothman et al., 2009). This was because there was an acceptable agreement in both parent proxy and child self-report in more observable domains such as physical functioning and interpersonal relationship. However, parent proxy and child self-report has lower agreement on the more abstract domains of HRQOL (van Empelen, Jennekens-Schinkel, van Rijen, Holders, & van Nieuwenhuizen, 2005; Yam et al., 2008). Parent proxy also tended to underestimate the HRQOL of their children (van Empelen et al., 2005; Yam et al., 2008). Therefore, both parent proxy and child self-report are potentially valid and need to be included in assessing HRQOL in CWE (Eiser & Morse, 2001).
2.4.2 Validation of instruments

A good instrument to assess HRQOL should be valid, reliable and, and to accurately measure data (Litwin, 1995).

Instruments need to be translated or culturally adapted before it can be used to assess an outcome measure. The process of validating an instrument can be divided into two phases: translation and cross cultural adaptation of the instrument, and its validation.

2.4.2.1 Translation and cross cultural adaptation of instruments

In 1999, the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) created a standardized guideline for the translation and cultural adaptation of instruments, to ensure conceptual equivalence and construct value equivalence (Wild et al., 2005) [Table 2.6].
Table 2.6: The International Society for Pharmacoeconomics and Outcomes Research (ISPOR) guideline for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures (Wild et al., 2005)

<table>
<thead>
<tr>
<th>Process</th>
<th>Definition</th>
<th>Key person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparation</td>
<td>Initial work, such as obtain permission from the instrument developer, that carried out before the translation work begins</td>
<td>Researcher or client who commissioning the translation of an instrument</td>
</tr>
<tr>
<td>Forward Translation</td>
<td>Translation of the original language of an instrument to the target language.</td>
<td>More than one native speakers of the target language and are fluent in the original language (to ensure conceptual and construct equivalent)</td>
</tr>
<tr>
<td>Reconciliation</td>
<td>Comparing and combining the forward translations (&gt;1) into a single forward translation.</td>
<td>Independent translator who should be a native speaker of the target language and fluent in the original language to carry out reconciliation</td>
</tr>
<tr>
<td>Back translation</td>
<td>Translation of the new language version back into the original language of an instrument to the target language.</td>
<td>The process usually involves more than one backward translators. For example: native speakers of the target language and are fluent in the original language, and without proper knowledge of the instrument</td>
</tr>
<tr>
<td>Back translation review</td>
<td>To compare the back-translated versions of the instruments with the original instrument. Any discrepancies between the original and the reconciled translated should be highlighted, and then revised in the process of resolving the issues.</td>
<td>Project manager and a key in-country consultant.</td>
</tr>
<tr>
<td></td>
<td>A project manager is the coordinator of the translation project, who provides oversight at each stage of the translation process.</td>
<td>A key in-country consultant is the main contact person managing the translation process who is a native speaker of the target language, fluent in the original language, reside in the target country. This person should also come from a relevant background and have experience in translating or managing the translation process</td>
</tr>
</tbody>
</table>
### Table 2.5 continued

<table>
<thead>
<tr>
<th>Process</th>
<th>Definition</th>
<th>Key person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harmonization</td>
<td>To compare the back-translated of multiple language versions with each other (if there is any) and the original instrument. All discrepancies should be highlighted and be resolved to ensure consistent approach to translation issues.</td>
<td>Project manager, back translator, or key in-country persons</td>
</tr>
<tr>
<td>Cognitive debriefing</td>
<td>A process to test the instrument on a small group of relevant person (such as patients or potential participants) or lay person to investigate the understandability, interpretation, and cultural relevance of the translation.</td>
<td>In-country consultant who is a native speaker of the target language, fluent in the original language, reside in the target country and preferably with experience in doing cognitive debriefing interview or qualitative interview.</td>
</tr>
<tr>
<td>Review of cognitive debriefing results and finalizaion</td>
<td>A meeting to compare the relevant person’s or lay person’s interpretation of the translation with the original version. Any discrepancies should be highlighted and amended.</td>
<td>Project manager and expert panel</td>
</tr>
<tr>
<td>Proof reading</td>
<td>The final review of the translation to check on the wording and grammar. Any typographic or error should be corrected.</td>
<td>Proof readers</td>
</tr>
<tr>
<td>Final report</td>
<td>A written report on the process of the translation.</td>
<td>Project manager</td>
</tr>
</tbody>
</table>
Once the instrument has been translated and culturally adapted, it is then validated.

2.4.2.2 Validation process

In order to determine the validity and its reliability of an instrument, the validity and reliability of an instrument has to be answered (Figure 2.3).

![Diagram of validation process]

**Figure 2.3: Process of validation of instruments**

(a) Validity

Validity of an instrument is defined as how the instrument measures what it is intended to measure (P. Liamputtong, 2013). Validity can be considered as a broad concept that can be divided into three main types: content, construct, and criterion validity (P. Liamputtong, 2013).
i  **Content validity**

Content validity is the extent to which the content of all the items in an instrument is measuring what it is intended to measure (Muijs, 2004). This can be achieved by an extensive search of literature and use of an expert panel.

Face validity refers to how an instrument appears. This can be assessed by administering the instrument to a small number respondents (pilot study), as well as by an expert panel.

ii  **Construct validity**

Construct validity refers to the ability of an instrument to measure a latent variable, which involves testing an instrument with a predefined hypothesis about the underlying construct. Construct validity can be assessed using factor analysis (Atkinson et al., 2011), convergent validity, and discriminative validity (Pallant, 2010).

Factor analysis allows researchers to condense a large set of variables items down to a smaller, more manageable number of dimensions or factors (Pallant, 2010). Factor analysis summarises the underlying patterns of correlation and groups closely related items into a factor. There are two types of factor analysis: exploratory and confirmatory. Exploratory factor analysis (EFA) is often used in the early stages of research to gather information about the interrelationships among a set of variables. Confirmatory factor analysis (CFA) is used to confirm specific hypotheses or theories concerning the structure underlying a set of variables (Pallant, 2010).

Convergent validity refers to the strong correlations between target instrument and another instruments that measure the same construct. For example, assessing a new
depression scale using another established depression scale such as the Beck Depression Inventory (Y. P. Wang & Gorenstein, 2013).

Discriminative validity refers to the ability of an instrument to distinguish between two groups of participants that have no relationship with each other (e.g. children with chronic illness versus healthy controls) (Jørgensen, Ris, Falla, & Juul-Kristensen, 2014).

(b) Reliability

Reliability of an instrument refers to the consistency or stability in measurement when repeated under similar conditions. The two most common indicators of reliability in an instrument are internal consistency and test-retest reliability (Pallant, 2010).

i Internal consistency

Internal consistency measures the average correlation among all items in an instrument (Ember & Ember, 2009). Items that measure the same underlying attributes would be highly correlated. Internal consistency can be measured by Cronbach’s coefficient alpha. Coefficients ranged from -1.0 to 1.0. The higher positive coefficient, the better the coefficients of association (Ember & Ember, 2009).

ii Test-test reliability

Test-retest reliability of an instrument is measured by administering the instrument to the same group of participants on two different points in time, and to examine the correlation between the two scores obtained. A higher test-retest correlation indicates a more reliable instrument (Pallant, 2010). An appropriate time interval to perform test-retest is between two to six weeks. This is because some variables (e.g. mood) can change over time and produce low test-retest reliability in an instrument (Pallant, 2010).
2.5 Gaps in literature

A search of published literature found that there are three areas where further studies are required. Firstly, there is no validated Malay or Chinese versions of a disease specific HRQOL instruments to assess HRQOL in CWE in Malaysia. There is also a lack of validated family functioning instruments in Malaysia.

Secondly, a search of published literature revealed that CWE of normal intelligence without comorbidities were also found to be risk for academic underachievement. This impact of epilepsy on academic achievement in CWE of normal intelligence ability without comorbidities never been reviewed systematically before. Hence, a systematic review was conducted to assess the prevalence of academic difficulties in CWE of, and its associating factors.

Lastly, little is known about the needs and challenges of CWE and their parents in childhood epilepsy care in Malaysia. In order to understand their real-life experiences, a qualitative approach is preferred as it gives a more in-depth perspective on how culture and religion play a role in affecting CWE and their parents in Malaysia, a multi-racial country, that may be different from other countries.

2.6 Overall aim

Therefore, the overall aim of this study was to examine the rationale, feasibility and validation of instruments that assessed the HRQOL and family functioning of CWE, to systematically review the impact of epilepsy on academic achievement in children with normal intelligence and without major comorbidities, and to explore the needs and challenges encountered by parents and their children in childhood epilepsy care, and how epilepsy affects the child’s HRQOL.
2.7 Research question

The research questions in this study were:

1. What is the validity of the CHEQOL-25 in CWE?
2. What is the validity of the GF-12 in family?
3. What is the impact of epilepsy on a child’s academic achievement?
4. What are the needs and challenges encountered by parents and their children in childhood epilepsy care, and how epilepsy affects the child’s HRQOL?

Therefore, this study is divided into four phases:

Phase 1: The validation of the parent proxy and child self-report of the health related quality of life measure for children with epilepsy (CHEQOL-25). This will be described in detail in chapter 3.

Phase 2: Validation of the family functioning instrument: the general functioning subscale (GF-12) from the family functioning device (FAD). This will be described in detail in chapter 4.

Phase 3: The impact of epilepsy on academic achievement in children with epilepsy: a systematic review. This will be described in detail in chapter 5.

Phase 4: Exploring the needs and challenges of parents and their children in childhood epilepsy care: a qualitative study. This will be described in detail in chapter 6.
A pilot study was conducted prior to the validation of the Malay and Chinese CHEQOL-25 and the RCT. We looked for potential participants in the adult and paediatric neurology clinics in UMMC; of whom only 50% had epilepsy for at least 6 months. Of these 50%, only 25-50% were between 8 to 18 years old; of whom 2-3 participants from each clinic had normal cognitive function. Hence, our recruitment rate was 1-3 participants per week. These same patients were asked to come back to the clinic for follow up after 3 months. This meant that the list of patients in both clinics were “repeated” after 3 months. At this point of time, we decided to look at other sites, such as Hospital Kuala Lumpur, Sunway Medical Centre, Hospital Kajang, Hospital Serdang, and Hospital Kebangsaan Malaysia to improve recruitment rates. The recruitment rates in Hospital Kuala Lumpur and Sunway Medical Centre were similar to UMMC. However, the doctors in Hospital Kajang, Hospital Serdang, and Hospital Kebangsaan Malaysia were not interested participate in this study. Despite these challenges, we decided to persist with the validation of the Malay and Chinese CHEQOL-25, which required 40 participants for each validation study. However, it was at this point of time that we realized that we could not continue with the RCT, which required a total of 160 participants.
### Table 3.1 Rate of recruitment of pilot study

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Pediatric neurology clinic (n=number of patient)</th>
<th>Adult neurology clinic (n=number of patient)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approximate number of patient/ clinic in UMMC</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Patients diagnosed with epilepsy</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>Child aged 8-18 years</td>
<td>10-12</td>
<td>4-6</td>
</tr>
<tr>
<td>Children attending normal school</td>
<td>6</td>
<td>2-3</td>
</tr>
<tr>
<td>Children who are able to answer CHEQOL-25</td>
<td>2-3</td>
<td>1-2</td>
</tr>
<tr>
<td>Total participants in 3-6 months</td>
<td>36</td>
<td>24</td>
</tr>
<tr>
<td>20% drop off rate</td>
<td>28-30</td>
<td>19-20</td>
</tr>
<tr>
<td>Hospital Kuala Lumpur</td>
<td>28-30</td>
<td>N/A</td>
</tr>
<tr>
<td>Sunway Medical Centre</td>
<td>14-15</td>
<td>N/A</td>
</tr>
<tr>
<td>Total number of participants multisite</td>
<td>70-75</td>
<td>19-20</td>
</tr>
</tbody>
</table>

Meanwhile, the validation of the Malay and Chinese GF-12 were conducted prior to the validation of CHEQOL-25, which involved parents of children with asthma and normal children from the community. We did not encounter any problems during the recruitment process.
CHAPTER 4: VALIDATION OF THE PARENT PROXY AND CHILD SELF-REPORT OF THE HEALTH RELATED QUALITY OF LIFE MEASURE FOR CHILDREN WITH EPILEPSY (CHEQOL-25)

For children, a suitable HRQOL instrument must accommodate the changes that occur through their development, and should primarily ask questions 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 (G. M. Ronen et al., 2003). 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 (G. M. Ronen, Rosenbaum, Law, & Streiner, 2001). 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 (G. M. Ronen et al., 2003).

This chapter will report on the validity of the parent proxy and child self-report of the health related quality of life measure for children with epilepsy (CHEQOL-25) in Malaysia will be reported.

4.1 Introduction

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 (G. M. Ronen et al., 2003) and previous studies showed agreement (e.g. physical and social wellbeing) between these two ratings (Eiser & Morse, 2001). In addition, parents often play an important role in the treatment decision
making as well as the evaluation of the effectiveness of interventions (Yam, Chow, & Ronen, 2005). Therefore, both parent-proxy and child self-report HRQOL are equally important to provide information regarding their child’s HRQOL.

To date, eleven HRQOL instruments have been developed and validated to assess the HRQOL of children with epilepsy (CWE) (Arunkumar, Wyllie, Kotagal, Ong, & Gilliam, 2000; Baars, Atherton, Koopman, Bullinger, & Power, 2005; Batzel, Dodrill, Dubinsky, & Queisser, 1991; Buck, Smith, Appleton, Baker, & Jacoby, 2007; Camfield, Breau, & Camfield, 2001, 2003; Carpay et al., 1997; Coda, Battistella, Bonivier, & Garofalo, 2001; Cramer et al., 1999; Goodwin, Lambrinos, Ferro, Sabaz, & Speechley, 2015; Hoare, Mann, & Dunn, 2000; G. M. Ronen, Streiner, Rosenbaum, & Canadian Pediatric Epilepsy, 2003; Sabaz et al., 2003). Some instruments only had a parent proxy report (Buck et al., 2007; Camfield et al., 2001, 2003; Carpay et al., 1997; Hoare et al., 2000; Sabaz et al., 2003) [Table 4.1], some only had the child self-report (Batzel et al., 1991; Coda A., 2001; Cramer et al., 1999) [Table 4.2], while three instruments contained both parent proxy and child self-reports [Table 4.3] (Arunkumar et al., 2000; R. M. Baars et al., 2005; G. M. Ronen et al., 2003).
Table 4.1: Health related quality of life instruments for children with epilepsy
(Parent proxy report)

<table>
<thead>
<tr>
<th>Instruments (Acronym)/ Country</th>
<th>Authors (Year)</th>
<th>No. of items</th>
<th>Validation age (years)</th>
<th>Description</th>
<th>Translated version</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Hague Restrictions in Childhood Epilepsy Scare (HARCES)/ Netherlands</td>
<td>Carpay et al. (1997)</td>
<td>10</td>
<td>4-16</td>
<td>To assess parent-reported disability due to restriction in CWE. Consist items on the amount of extra supervision needs, and special precautions taken, and specific restricted activities. Likert scale score of 1 to 4. Total score ranges from 10 (no disabilities) to 40 (most severe disability)</td>
<td>N/A</td>
</tr>
<tr>
<td>Impact of childhood illness scale: epilepsy/ UK</td>
<td>Hoare et al. (2000)</td>
<td>30</td>
<td>6-17</td>
<td>To assess the impact of epilepsy on CWE and the family Consists of four sections: impact of epilepsy and its treatment, impact of epilepsy on the child development and adjustment, parents, and family. Parents were asked to rate on frequency (Likert scale: rarely; sometimes; often) and importance (Likert scale: very important; sometime important; not important) on each item. Total score range from 0 to 120 with a higher scores indicates worse HRQOL.</td>
<td>Portuguese</td>
</tr>
<tr>
<td>Instruments (Acronym)/ Country</td>
<td>Authors (Year)</td>
<td>No. of items</td>
<td>Validation age (years)</td>
<td>Description</td>
<td>Translated version</td>
</tr>
<tr>
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</tr>
<tr>
<td>Impact of Pediatric Epilepsy Scale (IPES) or Impact of Child Neurological Disability (ICND)/ Canada</td>
<td>Camfield, (2001, 2003)</td>
<td>11</td>
<td>2-18</td>
<td>To assess the impact of childhood epilepsy on the family. Item on impact of epilepsy on academic achievement, activity participation, relationship with family, sibling, peers, self-esteem, and caregiver’s future hope. Likert scale score: 0-3. Total score: 0-33, higher score indicates higher impact. A visual analogue scale of 1-6 (poor-excellent) on rating a child’s overall HRQOL.</td>
<td>Chinese, Spanish</td>
</tr>
<tr>
<td>The Epilepsy in Learning Disabilities and Quality of Life (ELDQL)/ UK</td>
<td>Buck et al. (2007)</td>
<td>70</td>
<td>2-19</td>
<td>To assess HRQOL in CWE and disabilities. Four domains: behavior, seizure severity, mood, and side effects. A higher score indicated poorer HRQOL.</td>
<td>N/A</td>
</tr>
<tr>
<td>Quality of Life in Childhood Epilepsy Questionnaire (QOLCE)</td>
<td>Sabaz et al. (2003)</td>
<td>77</td>
<td>4-18</td>
<td>To assess HRQOL in CWE. 5 domains: physical function, emotional well-being, cognitive function, social function, and behavior. Likert scale score:0-6, total score: 0-100 point scale, a higher score indicates a better overall HRQOL.</td>
<td>Polish, Korean</td>
</tr>
<tr>
<td>Instruments (Acronym)/ Country</td>
<td>Authors (Year)</td>
<td>No. of items</td>
<td>Validation age (years)</td>
<td>Description</td>
<td>Translated version</td>
</tr>
<tr>
<td>-------------------------------</td>
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<td>-------------------</td>
</tr>
<tr>
<td>Impact of Pediatric Epilepsy Scale (IPES) or Impact of Child Neurological Disability (ICND)/ Canada</td>
<td>Camfield, (2001, 2003)</td>
<td>11</td>
<td>2-18</td>
<td>To assess the impact of childhood epilepsy on the family. Consist of item assessing impact of epilepsy on academic achievement, participation in activities, health, and relationship with family, siblings and peers, social activities, self-esteem, and caregiver’s future hope for their child. Likert scale score of 0 to 3. Total score range 0-33, with a higher score indicates higher impact. A visual analogue scale of 1-6 (poor-excellent) on rating a child’s overall HRQOL.</td>
<td>Chinese, Spanish</td>
</tr>
<tr>
<td>Instruments (Acronym)/ Country</td>
<td>Authors (Year)</td>
<td>No. of items</td>
<td>Validation age (years)</td>
<td>Description</td>
<td>Translated version</td>
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<tr>
<td>-------------------------------</td>
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<td>--------------</td>
<td>------------------------</td>
<td>-------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Adolescent Psychosocial Seizure Inventory (APSI)/USA</td>
<td>Batzel et al. (1991)</td>
<td>38</td>
<td>12-19</td>
<td>To assess psychosocial problems in adolescents with epilepsy. 8 domains include: family adjustment, emotional adjust, interpersonal, vocation outlook, school adjustment, adjust to seizure, management, and antisocial activity. Dichotomous variable: level 1 and 2 (absence of problem), level 3 and 4 (presence of problem)</td>
<td>Spanish</td>
</tr>
<tr>
<td>Quality of Life in Epilepsy Inventory for Adolescent (QOLIE-AD-48)</td>
<td>Cramer et al. (1999)</td>
<td>48</td>
<td>11-17</td>
<td>To assess HRQOL in CWE 8 domains: impact of epilepsy, memory, attitude towards epilepsy, physical functioning, stigma, health, behavior and social support. Likert scale score: 0-5. Total score: 0-100, a higher score indicates better HRQOL.</td>
<td>Portuguese, Chinese, Serbian, and Spanish</td>
</tr>
<tr>
<td>Epilepsy and Children Questionnaire (ECQ)/ UK</td>
<td>Coda et al. (2001)</td>
<td>61</td>
<td>7-16</td>
<td>To assess QOL and epilepsy knowledge Three domains: psychological, social, and scholastic functioning. Likert scale score of 1-5, a higher score indicate worst HRQOL.</td>
<td>Italian</td>
</tr>
</tbody>
</table>
Table 4.3: Health related quality of life instruments for children with epilepsy (parent proxy and child self-report)

<table>
<thead>
<tr>
<th>Instruments (Acronym)/ Country</th>
<th>Authors (Year)</th>
<th>No. of items</th>
<th>Validation age (years)</th>
<th>Description</th>
<th>Translated version</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health-Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25)/ Canada</td>
<td>G. M. Ronen et al. (2003)</td>
<td>25</td>
<td>6-15</td>
<td>To assess HRQOL in CWE 5 domains: interpersonal/social, intrapersonal/emotional, worries/concern, epilepsy secrecy and quest for normality Used alternative paired options of forced response, 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 indicates better HRQOL.</td>
<td>Chinese, Serbian, Czech</td>
</tr>
<tr>
<td>Quality of Life in Paediatric Epilepsy Scale (QOLPES)/ USA</td>
<td>Arunkumar et al. (2000)</td>
<td>20</td>
<td>0.4-12</td>
<td>To assess HRQOL in children and adolescent with epilepsy. Parents’ concerns including child's safety, and prospects for the future whilst children concern include social problem and side effect of medication. Likert scale score not reported.</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Table 4.4 continued

<table>
<thead>
<tr>
<th>Instruments (Acronym)/ Country</th>
<th>Authors (Year)</th>
<th>No. of items</th>
<th>Validation age (years)</th>
<th>Description</th>
<th>Translated version</th>
</tr>
</thead>
<tbody>
<tr>
<td>DISABKIDS- Epilepsy/ Europe</td>
<td>R. M. Baars et al. (2005)</td>
<td>47</td>
<td>4-7; 8-16</td>
<td>To assess HRQOL among CWE in conjunction with the DISABKIDS chronic generic module. Consist of the chronic generic module (37 items) and two epilepsy related module (10 items): Impact of epilepsy and perceived social stigma. Likert scale score of 1-5, total score of 0-100, a higher score indicates better HRQOL.</td>
<td>English, French, German, Dutch, Greek, and Swedish</td>
</tr>
</tbody>
</table>

Note: CWE= Children with epilepsy; HRQOL= Health related quality of life; USA= United States of America; N/A= Not applicable
We decided to culturally adapt the CHEQOL-25 (G. M. Ronen et al., 2003) for three reasons. Firstly, the CHEQOL-25 has both parent proxy and child self-report measure which the parent proxy can be used to complement the child self-report in assessing the HRQOL in CWE.

Secondly, among the three instruments which has both parent proxy and child self-report measure, the CHEQOL-25 has been modified, validated, and administered in Asia by Yam (2005), whilst the DISABKIDS-Epilepsy (R. Baars et al., 2005) has been translated to French, German, Dutch, Greek, and Swedish, and validated in Europe, which may not be suitable for administration in Asia.

Five items in the CHEQOL-25 were modified by Yam (2005) were: (1) Firstly, the original version asked if CWE had any problems going away to camp. However, in Asia, children rarely went to “camps”. Hence, Yam added the terms “extracurricular activities” and “sports”, as these are activities that children in Asia perform. (2) Secondly, the original item asked if CWE were “able to drive a car in the future”. This was modified by Yam 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) Thirdly, CWE were asked if they would “worry about their coping skills in teenage years”. This was changed by Yam 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 they have not yet experienced. (4) Fourthly, 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 is easier to understand. (5) Lastly, 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 (Table 4.4).

**Table 4.4 Original version versus modified version in CHEQOL-25**

<table>
<thead>
<tr>
<th>Original version (Ronen et al., 2003)</th>
<th>Modified version (Yam et al., 2005)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some epileptic children/adolescent have no problems going away to camp</td>
<td>Some epileptic children/adolescent may use the computer, play computer games, join camping or other sport activities.</td>
</tr>
<tr>
<td>Some children with epilepsy are able to drive a car in the future</td>
<td>Some children with epilepsy concern that they could not get into university because of the disease</td>
</tr>
<tr>
<td>Other kids with epilepsy are not worry about their coping skills in teenage years</td>
<td>Other kids with epilepsy believe that their seizures can still be controlled in the future</td>
</tr>
<tr>
<td>Some children with epilepsy are treated well when they grow up</td>
<td>Some children with epilepsy will not be discriminated by other people when they grow up</td>
</tr>
<tr>
<td>Some children with epilepsy feel safe with their friends if they had a seizure</td>
<td>Some children with epilepsy are do not mind if their teacher will find out that they have epilepsy</td>
</tr>
</tbody>
</table>

Lastly, the psychometric properties of the CHEQOL-25 were satisfactory: good internal consistency (Cronbach α = 0.71–0.92) and satisfactory test-retest reliability (range from 0.51 to 0.84) (Ma, Yam, Tsui, & Yau, 2006; G. M. Ronen, Streiner, D. L., Rosenbaum, P., 2003), whilst the Quality of Life in Paediatric Epilepsy Scale (QOLPES) developed by Arunkumar and colleagues (2000) did not report the psychometric properties of the instruments.

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, parents were not able to accurately report their child’s internal experience (such as their attitude towards epilepsy) (Eiser & Morse, 2001). Therefore, the
A combination of a parent proxy report and child self-report has the advantage of providing more information about a child’s HRQOL (Verhey et al., 2009).

Malay and Chinese are the two most common languages that are spoken by many people in Malaysia. 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 HRQOL instrument that has both parent proxy rating and child self-report to assess the HRQOL of CWE. Hence, there is a need to validate the Malay CHEQOL-25 in Malaysia.

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 (Gifford-Smith & Brownell, 2003). To date, the Chinese CHEQOL-25 has only been validated by Yam and colleagues (2005) in Hong Kong, China. Hence 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 (Bureau, 2012). 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 decided to use the mandarin version of the CHEQOL-25 translated by Yam et al (2005).
4.2 Cross cultural adaptation of the Malay parent proxy and child self-report Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) in Malaysia

4.2.1 Objective

To cross culturally adapt and validate the Malay parent proxy CHEQOL-25 in Malaysia.

4.2.2 Methods

4.2.2.1 Study design

This validation study was conducted from February 2012 to February 2013 in two tertiary hospitals: University Malaya Medical Centre (UMMC) and Hospital Kuala Lumpur (HKL), in Malaysia.

4.2.2.2 Participants

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

4.2.2.3 Sample size calculations

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. Hence, the minimum number of participants was 125.
4.2.2.4 Translation of the English Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) to Malay

Permission for translation was obtained from the original developer (via email on January 2012) [Appendix A]. License to use the instrument was purchased on August 2012 (Appendix B). Translation of the English version of the parent proxy CHEQOL-25 (Yam et al., 2005) to Malay was performed according to international guidelines (Cox et al., 2009) [Figure 4.1].

4.2.2.5 Pilot study

A pilot study was conducted on five parents and their CWE at a tertiary hospital to assess for face and content validity. Participants were invited to read the question and 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.

Forward translation performed by a psychology graduate (version 1a)  
Forward translation performed by a linguistic expert (version 1b)

Reviewed by the expert panel (version 2)

Backward translation by another psychology graduate (version 3a)  
Backward translation performed by a linguistic expert (version 3b)

Reviewed by the expert panel and the original author (version 4)

Pilot tested in 5 children with epilepsy

**Figure 4.1: The translation of the child self-report Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) from English to Malay**

Note: CHEQOL-25= Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) in Malaysia; Forward translation is that translation of the document from English to Malay; backward translation is the translation of the document from Malay to English; Expert panel consisted of a paediatric neurologist, a research who is expert in questionnaire validation and two psychologists
4.2.2.6 **Instruments used**

(a) *Baseline demographic questionnaire*

This instrument (Appendix C) 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 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 (J. K. Austin et al., 2000).

(b) *The Malay Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25): Parent proxy and child self-report form*

This instrument consists of two forms: the parent proxy (Appendix D) and the child self-report forms (Appendix E). The parent proxy form has 25 items with five subscales: interpersonal/social, present worries, future worries, intrapersonal/emotional, and epilepsy secrecy. The child self-report form also has 25 items, and shared the same subscales as the parent proxy CHEQOL-25 (interpersonal/social, present worries, intrapersonal/emotional, and epilepsy secrecy), except for with one subscale: quest for normality [Table 4.5]. (G. M. Ronen et al., 2003).

<table>
<thead>
<tr>
<th>Item</th>
<th>Parent-proxy Subscale</th>
<th>Child self-report Subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-5</td>
<td>Interpersonal/social</td>
<td>Interpersonal/social</td>
</tr>
<tr>
<td>6-10</td>
<td>Present worries</td>
<td>Worries</td>
</tr>
<tr>
<td>11-15</td>
<td>Future worries</td>
<td>Intrapersonal/emotional</td>
</tr>
<tr>
<td>16-20</td>
<td>Intrapersonal/emotional</td>
<td>Epilepsy secrecy</td>
</tr>
<tr>
<td>21-50</td>
<td>Epilepsy Secrecy</td>
<td>Quest for normality</td>
</tr>
</tbody>
</table>
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 for parent proxy items, or themselves for child self-report items, 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 (scores range: 5-20). A higher score reflects a more positive perception in that domain.

(c) *The Malay Paediatric Quality of Live Inventory™ (PedsQL™4.0)*

The Malay PedsQL 4.0 is a generic QOL (Varni et al., 2006) that has been validated in Malaysia (A. Ismail & Campbell, 2010). This instrument also has both the parent proxy-report (Appendix F) and the child self-report forms (Appendix G). Therefore, this is a suitable choice for comparison with the CHEQOL-25, so that the convergent validity of the CHEQOL-25 could be determined. It has 23 items with 4 subscales: physical, emotional, social and school. Both the parent proxy-report 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%) (Varni et al., 2006). However, in order to compare the scores obtained from the PedsQL 4.0 with the CHEQOL-25, scores from the PedsQL 4.0 were then divided by five, so that the range of the PedsQL 4.0 would also range from 0-20. A higher score indicates a better HRQOL.

4.2.2.7 Procedure

Potential participants were screened and the purpose of the study was explained (Appendix H). Informed consent was obtained (Appendix I). A baseline demographic
questionnaire was used to collect the parent’s and their children’s participants’ socio-demographic information, as described above.

Participants were asked to complete the CHEQOL-25 and the PedsQL 4.0. 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 parents to ensure 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 within the past two weeks, and all changes were documented.

4.2.2.8 Ethics

Ethics approval was obtained: University Malaya Medical Centre Ethics Committee approval number: 896.10 (Appendix J) and the National Institutes of Health, Ministry of Health approval number: NMRR-12-425-12022 (Appendix K).

4.2.2.9 Data analysis

Data entry and statistical analysis were conducted using Statistical Package for the Social Sciences (SPSS) version 21. Descriptive statistics were calculated. Normality was assessed using the Shapiro Wilk’s test. When data is not normally distributed, median and interquartile range (IQR) are reported instead of mean and standard deviation (Ghasemi & Zahediasl, 2012). Median is the central value of a set of data which is sorted in order and is not influenced by extreme values (outliers), IQR is the difference between the first and third quartiles (25th and 75th quantiles) (Ghasemi & Zahediasl, 2012). Since
normally could not be assumed, non-parametric was used. Continuous variables were reported as median and interquartile range; whilst categorical variables were reported as frequency and percentage. A p-value <0.05 was considered as statistically significant.

(a) **Validity**

Construct validity was assessed using hypothesis testing and was analyzed using Spearman’s rho and Wilcoxon Signed Rank tests (Weigle, 2002). The following factors were hypothesized to be negatively correlated with QOL: (a) number of doctor visits and days hospitalized (as a measure for health care use) (b) children with more severe epilepsy (c) children taking larger number of AED, and (d) children with some 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.

Convergent validity between the CHEQOL-25 and the PedsQL 4.0 were assessed using Spearman’s rho. Values <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 (Pallant, 2010).

(b) **Reliability**

Reliability was assessed using Cronbach alpha: values <0.70 has inadequate internal consistency, 0.70-0.90 has adequate internal consistency, >0.90 suggest redundancy of items (Pallant, 2010). Corrected item-total correlations were analysed: values >0.20 are considered as acceptable (Briggs & Cheek 1986). If removing an item increases Cronbach’s α significantly, excluding the item will increase the homogeneity of the subscale.
Test-retest reliability and parent-child level of agreement were analysed using intraclass correlation coefficient (ICC) and the Wilcoxon-Signed Rank test. 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” (Koch, 2004). The closer the ICC value is to 1.0, the better the reliability and the agreement (Weir, 2005).

4.2.3 Results

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. Forty-four eligible parents and their CWE were approached: four declined participation. Hence, 40 parents and their CWE were recruited (response rate=90.1%) [Figure 4.2]. The demographic characteristic of the parent and their CWE are shown in Table 4.6.
65 CWE were screened

21 were excluded if they did not fit the inclusion criteria

Potential CWE (n=44)

40 children who agreed to participate with parent consent (response rate=90.1%)

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

2 weeks later
Retest (n=35):
Uncontactable: n=4
CWE passed away: n=1

The child self-report CHEQOL-25 was administered (n=35)

Figure 4.2: Flow of participants for the Malay Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25)

Note: CWE= children with epilepsy; CHEQOL-25= Health Related Quality of Life Measure for Children with Epilepsy; PedsQL 4.0= Paediatric Quality of Life Inventory
Table 4.6: Characteristic of participants (parents and children) who involved in Malay version of CHEQOL-25 validation study

<table>
<thead>
<tr>
<th>Type of parent proxy</th>
<th>N (%) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>29 (72.5)</td>
</tr>
<tr>
<td>Father</td>
<td>11 (27.5)</td>
</tr>
</tbody>
</table>

| Median age of parent proxy (years) [IQR] | 44 [11.0] |

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>N (%) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Malay</td>
<td>32 (80%)</td>
</tr>
<tr>
<td>Indian</td>
<td>8 (20%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Median age of their children with epilepsy (years) [IQR]</th>
<th>14 [4.0]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child (7-12 years)</td>
<td>10 (25.0)</td>
</tr>
<tr>
<td>Teenager (13-18 years)</td>
<td>30 (75.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Child’s gender</th>
<th>N (%) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>27 (67.5)</td>
</tr>
<tr>
<td>Female</td>
<td>13 (32.5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of education of the child</th>
<th>N (%) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary (6 years of education)</td>
<td>10 (25.0)</td>
</tr>
<tr>
<td>Secondary (7-13 years of education)</td>
<td>27 (68.5)</td>
</tr>
<tr>
<td>Tertiary (≥ 14 years of education)</td>
<td>3 (7.5)</td>
</tr>
</tbody>
</table>

| Median duration of epilepsy (years) [IQR] | 5 [8.0] |

<table>
<thead>
<tr>
<th>Type of seizure</th>
<th>N (%) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Absence</td>
<td>1 (2.5)</td>
</tr>
<tr>
<td>Generalized tonic-clonic</td>
<td>18 (45.0)</td>
</tr>
<tr>
<td>Partial</td>
<td>20 (50.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of medication(s) taken daily</th>
<th>N (%) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>9 (22.5)</td>
</tr>
<tr>
<td>1</td>
<td>22 (55.5)</td>
</tr>
<tr>
<td>≥2</td>
<td>9 (22.5)</td>
</tr>
</tbody>
</table>

| Median score of epilepsy syndrome severity [IQR] | 4.5 [2.0] |

<table>
<thead>
<tr>
<th>Cognitive status</th>
<th>N (%) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal</td>
<td>28 (70.0)</td>
</tr>
<tr>
<td>Mild learning disability</td>
<td>12 (30.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Have not been admitted to hospital for epilepsy in the past 6 months</th>
<th>N (%) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>40 (100.0)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>No. of times the child visited the doctor for epilepsy in the past 6 months</th>
<th>N (%) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>9 (22.5)</td>
</tr>
<tr>
<td>Once</td>
<td>23 (57.5)</td>
</tr>
<tr>
<td>≥2</td>
<td>8 (15.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>No. of close friends the child has</th>
<th>N (%) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-2</td>
<td>6 (15.0)</td>
</tr>
<tr>
<td>3-5</td>
<td>12 (30.0)</td>
</tr>
<tr>
<td>6-10</td>
<td>13 (32.5)</td>
</tr>
<tr>
<td>&gt;10</td>
<td>9 (22.5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Amount of time per week spent in extracurricular activities with friends</th>
<th>N (%) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>4 (10.0)</td>
</tr>
<tr>
<td>Once</td>
<td>9 (22.5)</td>
</tr>
<tr>
<td>2-3 times</td>
<td>14 (35.0)</td>
</tr>
<tr>
<td>≥ 4 times</td>
<td>13 (32.5)</td>
</tr>
</tbody>
</table>

Note: IQR= interquartile range
4.2.3.1 **Construct validity**

The severity of epilepsy, higher number of anti-epileptic 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 interpersonal/social subscale in the parent proxy of CHEQOL-25. In addition, children who took a higher number of anti-epileptic drugs daily scored lower in the present worries subscale. Children who had learning difficulties had significantly lower score in the future worries subscale compared to those with normal cognitive ability (Table 4.7).

For the child self-report CHEQOL-12, the higher number of close friends and higher amount of time spent with friends were significantly associated with higher score interpersonal/social subscale. However, the epilepsy severity, number of AED taken, and cognitive ability did not show any significant relationship with the subscales (Table 4.7).
Table 4.7: Construct validity of the Malay parent proxy Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25)

<table>
<thead>
<tr>
<th>Subscales</th>
<th>Health care usage</th>
<th>Epilepsy severity</th>
<th>No. of anti-epileptic 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>Pearson correlation (r)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent proxy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal/social</td>
<td>-0.278</td>
<td>-0.343*</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>-2.238</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>
<tr>
<td>Child self-report</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal/social</td>
<td>-0.133</td>
<td>-0.205</td>
<td>-0.057</td>
<td>0.442**</td>
<td>0.441**</td>
<td>-1.824</td>
</tr>
<tr>
<td>Present worries</td>
<td>-0.155</td>
<td>-0.129</td>
<td>-0.051</td>
<td>0.179</td>
<td>0.147</td>
<td>-1.235</td>
</tr>
<tr>
<td>Future worries</td>
<td>-0.137</td>
<td>-0.071</td>
<td>-0.272</td>
<td>0.188</td>
<td>0.206</td>
<td>-1.573</td>
</tr>
<tr>
<td>Intrapersonal/emotional</td>
<td>-0.132</td>
<td>-0.112</td>
<td>-0.037</td>
<td>0.150</td>
<td>0.147</td>
<td>-0.966</td>
</tr>
<tr>
<td>Epilepsy secrecy</td>
<td>0.129</td>
<td>-0.064</td>
<td>-0.184</td>
<td>0.031</td>
<td>0.182</td>
<td>-1.146</td>
</tr>
</tbody>
</table>

Note: *p <0.05 **p <.001
4.2.3.2 Convergent validity

Both the parent-proxy and child self-report CHEQOL and the PedsQL 4.0 showed moderate to high correlation at the interpersonal/social and emotional subscales (r=0.598, p=0.002; r=0.342, p=0.031; r=0.589, p<0.001; r=0.597, p<0.001, respectively) [Table 4.8]. Parents rated the highest HRQOL score in the interpersonal/social subscale, followed by the future worries subscale, whilst CWE rated the highest HRQOL score in the quests for normality, followed by the interpersonal/social subscales.

<table>
<thead>
<tr>
<th>Subscales</th>
<th>CHEQOL-25 (n=40)</th>
<th>PedsQL 4.0#</th>
<th>Pearson rho correlation</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean ± SD [range]</td>
<td>Mean ± SD [range]</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Parent proxy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal/social</td>
<td>15.4±4.0 [5-20]</td>
<td>16.3±4.6 [5-20]</td>
<td>0.598</td>
<td>0.002**</td>
</tr>
<tr>
<td>Present worries</td>
<td>13.1±3.2 [6-19]</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Future worries</td>
<td>14.0±4.1 [7-20]</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Intrapersonal/emotional</td>
<td>13.2±4.2 [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>N/A</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td><strong>Child self-report</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal/social</td>
<td>15.3±3.2 [9-20]</td>
<td>16.3±4.6 [5-20]</td>
<td>0.589</td>
<td>&gt;0.001**</td>
</tr>
<tr>
<td>Present worries</td>
<td>11.7±2.8 [5-17]</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Intrapersonal/emotional</td>
<td>12.6±3.2 [6-20]</td>
<td>14.8±4.2 [3-20]</td>
<td>0.597</td>
<td>&gt;0.001**</td>
</tr>
<tr>
<td>Epilepsy secrecy</td>
<td>12.8±2.9 [6-20]</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Quest for normality</td>
<td>15.7±3.0 [8-20]</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
</tr>
</tbody>
</table>

#The PedsQL 4.0 has four subscales: physical, social, emotional and school. Hence, only social and emotional subscale can be compared with the parent proxy CHEQOL-25.
4.2.3.3 Reliability

The Cronbach’s α for each subscale in parent proxy CHEQOL-25 ranged from 0.70-0.87, except for the present worries subscale (Cronbach α=0.67). All items had a corrected item-total correlation value of >0.3 (Table 4.9).

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. ICC for all items at test-retest ranged from 0.70-0.94 (Table 4.9).
### Table 4.9: Reliability of the Malay parent proxy Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25)

<table>
<thead>
<tr>
<th>Sub-scales</th>
<th>Items</th>
<th>Corrected item-total correlation</th>
<th>Cronbach’s α if item is deleted</th>
<th>Cronbach’s α</th>
<th>Test re-test reliability Test (n=40) Mean score (SD) Median</th>
<th>Retest (n=35) Mean score (SD) Median</th>
<th>z-value</th>
<th>P-value</th>
<th>Wilcoxon Signed Rank test</th>
<th>Intraclass Correlation Coefficient**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inter- personal/social</td>
<td>1.</td>
<td>0.79</td>
<td>0.82</td>
<td>0.83</td>
<td>3.1 (0.9)</td>
<td>3.0</td>
<td>3.2 (0.7)</td>
<td>3.0</td>
<td>-0.277</td>
<td>0.782</td>
</tr>
<tr>
<td></td>
<td>2.</td>
<td>0.63</td>
<td>0.85</td>
<td>0.74</td>
<td>3.3 (0.9)</td>
<td>3.0</td>
<td>3.3 (0.7)</td>
<td>3.0</td>
<td>-0.277</td>
<td>0.782</td>
</tr>
<tr>
<td></td>
<td>3.</td>
<td>0.77</td>
<td>0.82</td>
<td>0.78</td>
<td>3.0 (1.0)</td>
<td>3.0</td>
<td>3.1 (0.9)</td>
<td>3.0</td>
<td>-0.054</td>
<td>0.957</td>
</tr>
<tr>
<td></td>
<td>4.</td>
<td>0.57</td>
<td>0.87</td>
<td>0.77</td>
<td>3.1 (1.1)</td>
<td>3.0</td>
<td>3.3 (0.9)</td>
<td>3.0</td>
<td>-0.758</td>
<td>0.488</td>
</tr>
<tr>
<td></td>
<td>5.</td>
<td>0.71</td>
<td>0.83</td>
<td>0.78</td>
<td>3.0 (1.0)</td>
<td>3.0</td>
<td>3.1 (0.9)</td>
<td>3.0</td>
<td>-0.378</td>
<td>0.705</td>
</tr>
<tr>
<td>Present</td>
<td>6.</td>
<td>0.56</td>
<td>0.49</td>
<td>0.67</td>
<td>2.7 (1.0)</td>
<td>3.0</td>
<td>2.5 (1.0)</td>
<td>2.0</td>
<td>-1.242</td>
<td>0.214</td>
</tr>
<tr>
<td>Worries</td>
<td>7.</td>
<td>0.50</td>
<td>0.64</td>
<td>0.67</td>
<td>2.2 (1.1)</td>
<td>2.0</td>
<td>2.3 (1.0)</td>
<td>2.0</td>
<td>-0.474</td>
<td>0.635</td>
</tr>
<tr>
<td></td>
<td>8.</td>
<td>0.58</td>
<td>0.63</td>
<td>0.71</td>
<td>3.5 (0.8)</td>
<td>4.0</td>
<td>3.4 (0.8)</td>
<td>4.0</td>
<td>-1.387</td>
<td>0.166</td>
</tr>
<tr>
<td></td>
<td>9.</td>
<td>0.42</td>
<td>0.57</td>
<td>0.72</td>
<td>2.5 (1.0)</td>
<td>2.5</td>
<td>2.6 (1.0)</td>
<td>3.0</td>
<td>-0.942</td>
<td>0.346</td>
</tr>
<tr>
<td></td>
<td>10.</td>
<td>0.40</td>
<td>0.59</td>
<td>0.70</td>
<td>2.3 (1.0)</td>
<td>2.0</td>
<td>2.3 (1.0)</td>
<td>2.0</td>
<td>-0.247</td>
<td>0.805</td>
</tr>
<tr>
<td>Intra- personal/emotional</td>
<td>11.</td>
<td>0.57</td>
<td>0.78</td>
<td>0.81</td>
<td>2.9 (1.1)</td>
<td>3.0</td>
<td>2.8 (1.0)</td>
<td>3.0</td>
<td>-0.165</td>
<td>0.869</td>
</tr>
<tr>
<td></td>
<td>12.</td>
<td>0.60</td>
<td>0.77</td>
<td>0.79</td>
<td>2.8 (1.1)</td>
<td>3.0</td>
<td>2.8 (1.0)</td>
<td>3.0</td>
<td>-0.119</td>
<td>0.905</td>
</tr>
<tr>
<td></td>
<td>13.</td>
<td>0.61</td>
<td>0.77</td>
<td>0.79</td>
<td>2.8 (1.0)</td>
<td>3.0</td>
<td>2.9 (1.0)</td>
<td>3.0</td>
<td>-1.897</td>
<td>0.058</td>
</tr>
<tr>
<td></td>
<td>14.</td>
<td>0.50</td>
<td>0.80</td>
<td>0.80</td>
<td>3.1 (1.1)</td>
<td>3.0</td>
<td>3.1 (1.0)</td>
<td>3.0</td>
<td>-0.333</td>
<td>0.739</td>
</tr>
<tr>
<td></td>
<td>15.</td>
<td>0.68</td>
<td>0.74</td>
<td>0.78</td>
<td>2.6 (1.1)</td>
<td>2.0</td>
<td>2.9 (0.9)</td>
<td>3.0</td>
<td>-2.405</td>
<td>0.016*</td>
</tr>
<tr>
<td>Quest for normality</td>
<td>16.</td>
<td>0.57</td>
<td>0.80</td>
<td>0.82</td>
<td>2.7 (1.1)</td>
<td>3.0</td>
<td>2.5 (1.0)</td>
<td>3.0</td>
<td>-0.549</td>
<td>0.583</td>
</tr>
<tr>
<td></td>
<td>17.</td>
<td>0.56</td>
<td>0.81</td>
<td>0.82</td>
<td>2.5 (1.2)</td>
<td>2.0</td>
<td>2.6 (0.9)</td>
<td>3.0</td>
<td>-1.413</td>
<td>0.158</td>
</tr>
<tr>
<td></td>
<td>18.</td>
<td>0.54</td>
<td>0.81</td>
<td>0.80</td>
<td>2.6 (1.2)</td>
<td>3.0</td>
<td>2.6 (1.0)</td>
<td>3.0</td>
<td>-0.552</td>
<td>0.581</td>
</tr>
<tr>
<td></td>
<td>19.</td>
<td>0.78</td>
<td>0.74</td>
<td>0.79</td>
<td>2.4 (1.0)</td>
<td>2.0</td>
<td>2.3 (1.0)</td>
<td>2.0</td>
<td>-0.486</td>
<td>0.627</td>
</tr>
<tr>
<td></td>
<td>20.</td>
<td>0.68</td>
<td>0.77</td>
<td>0.78</td>
<td>3.1 (1.0)</td>
<td>3.0</td>
<td>3.2 (0.9)</td>
<td>3.0</td>
<td>-0.172</td>
<td>0.863</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>21R#</td>
<td>0.36</td>
<td>0.69</td>
<td>0.70</td>
<td>2.2 (1.0)</td>
<td>2.0</td>
<td>2.1 (0.9)</td>
<td>2.0</td>
<td>-0.165</td>
<td>0.869</td>
</tr>
<tr>
<td>Secret</td>
<td>22.</td>
<td>0.44</td>
<td>0.67</td>
<td>0.68</td>
<td>2.5 (1.0)</td>
<td>3.0</td>
<td>2.5 (1.0)</td>
<td>2.0</td>
<td>-1.020</td>
<td>0.308</td>
</tr>
<tr>
<td></td>
<td>23.</td>
<td>0.67</td>
<td>0.56</td>
<td>0.61</td>
<td>2.5 (1.0)</td>
<td>3.0</td>
<td>2.5 (1.0)</td>
<td>3.0</td>
<td>-0.656</td>
<td>0.512</td>
</tr>
<tr>
<td></td>
<td>24.</td>
<td>0.48</td>
<td>0.65</td>
<td>0.63</td>
<td>3.1 (0.9)</td>
<td>3.0</td>
<td>2.7 (1.0)</td>
<td>3.0</td>
<td>-1.912</td>
<td>0.060</td>
</tr>
<tr>
<td></td>
<td>25.</td>
<td>0.58</td>
<td>0.69</td>
<td>0.69</td>
<td>2.3 (1.0)</td>
<td>2.0</td>
<td>2.2 (1.0)</td>
<td>2.0</td>
<td>-0.577</td>
<td>0.564</td>
</tr>
</tbody>
</table>

Note: # Items are reversed; *p < 0.05 **p < .001; SD= Standard deviation
The Cronbach’s α for each subscale in child self-report CHEQOL-25 ranged from 0.66-0.87. All items had a corrected item-total correlation value of >0.3 (Table 4.10).

Test-retest reliability was assessed in 35 (87.5%) children after a 2-week interval, as five 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 0.50-0.94 (Table 4.10).
Table 4.10: Reliability of the Malay child self-report Health related Quality of Life measure for Children with Epilepsy (CHEQOL-25)

<table>
<thead>
<tr>
<th>Subscales</th>
<th>Items</th>
<th>Cronbach’s α</th>
<th>Corrected item-total correlation</th>
<th>Cronbach’s α if item is deleted</th>
<th>Test (n=40)</th>
<th>Retest (n=35)</th>
<th>Test re-test reliability</th>
<th>Intraclass Correlation Coefficient*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mean score (SD)</td>
<td>Median</td>
<td>Mean score (SD)</td>
<td>Median</td>
</tr>
<tr>
<td>Interpersonal/ social</td>
<td>1.</td>
<td>0.80</td>
<td>0.69 (0.72)</td>
<td>3.1 (0.8)</td>
<td>3.0</td>
<td>3.1 (0.8)</td>
<td>3.0</td>
<td>0.66</td>
</tr>
<tr>
<td></td>
<td>2.</td>
<td>0.53</td>
<td>0.75</td>
<td>3.3 (0.8)</td>
<td>3.0</td>
<td>3.1 (0.8)</td>
<td>3.0</td>
<td>0.75</td>
</tr>
<tr>
<td></td>
<td>3.</td>
<td>0.67</td>
<td>0.72</td>
<td>3.0 (1.0)</td>
<td>3.0</td>
<td>3.1 (1.0)</td>
<td>3.0</td>
<td>0.57</td>
</tr>
<tr>
<td></td>
<td>4.</td>
<td>0.70</td>
<td>0.79</td>
<td>3.0 (1.1)</td>
<td>3.0</td>
<td>2.7 (1.1)</td>
<td>3.0</td>
<td>0.77</td>
</tr>
<tr>
<td></td>
<td>5.</td>
<td>0.61</td>
<td>0.70</td>
<td>3.0 (1.3)</td>
<td>4.0</td>
<td>3.2 (0.9)</td>
<td>4.0</td>
<td>0.77</td>
</tr>
<tr>
<td>Present Worries</td>
<td>6.</td>
<td>0.69</td>
<td>0.46 (0.49)</td>
<td>2.6 (1.2)</td>
<td>3.0</td>
<td>2.6 (1.1)</td>
<td>3.0</td>
<td>0.65</td>
</tr>
<tr>
<td></td>
<td>7.</td>
<td>0.38</td>
<td>0.64</td>
<td>1.6 (0.9)</td>
<td>1.0</td>
<td>1.7 (0.8)</td>
<td>2.0</td>
<td>0.50</td>
</tr>
<tr>
<td></td>
<td>8.</td>
<td>0.48</td>
<td>0.63</td>
<td>3.3 (1.0)</td>
<td>3.5</td>
<td>3.2 (1.0)</td>
<td>4.0</td>
<td>0.55</td>
</tr>
<tr>
<td></td>
<td>9.</td>
<td>0.45</td>
<td>0.58</td>
<td>2.2 (1.1)</td>
<td>2.0</td>
<td>2.6 (1.0)</td>
<td>2.0</td>
<td>0.77</td>
</tr>
<tr>
<td></td>
<td>10.</td>
<td>0.41</td>
<td>0.60</td>
<td>2.2 (1.1)</td>
<td>2.0</td>
<td>2.3 (1.0)</td>
<td>2.0</td>
<td>0.70</td>
</tr>
<tr>
<td>Intra-personal/ emotional</td>
<td>11.</td>
<td>0.71</td>
<td>0.57 (0.68)</td>
<td>2.4 (1.1)</td>
<td>2.0</td>
<td>2.7 (1.2)</td>
<td>3.0</td>
<td>0.76</td>
</tr>
<tr>
<td></td>
<td>12.</td>
<td>0.49</td>
<td>0.64</td>
<td>2.7 (1.1)</td>
<td>3.0</td>
<td>2.7 (1.1)</td>
<td>3.0</td>
<td>0.64</td>
</tr>
<tr>
<td></td>
<td>13.</td>
<td>0.56</td>
<td>0.67</td>
<td>2.6 (1.1)</td>
<td>3.0</td>
<td>2.6 (1.1)</td>
<td>3.0</td>
<td>0.76</td>
</tr>
<tr>
<td></td>
<td>14.</td>
<td>0.61</td>
<td>0.70</td>
<td>2.3 (1.1)</td>
<td>2.0</td>
<td>2.4 (1.1)</td>
<td>2.0</td>
<td>0.94</td>
</tr>
<tr>
<td></td>
<td>15.</td>
<td>0.40</td>
<td>0.61</td>
<td>2.7 (1.2)</td>
<td>3.0</td>
<td>2.5 (1.2)</td>
<td>3.0</td>
<td>0.66</td>
</tr>
<tr>
<td>Epilepsy Secrecy</td>
<td>16#.</td>
<td>0.66</td>
<td>0.47 (0.60)</td>
<td>2.5 (1.2)</td>
<td>3.0</td>
<td>2.6 (1.2)</td>
<td>3.0</td>
<td>0.78</td>
</tr>
<tr>
<td></td>
<td>17.</td>
<td>0.46</td>
<td>0.61</td>
<td>2.5 (1.2)</td>
<td>2.0</td>
<td>2.7 (1.2)</td>
<td>3.0</td>
<td>0.80</td>
</tr>
<tr>
<td></td>
<td>18#.</td>
<td>0.36</td>
<td>0.59</td>
<td>2.2 (1.0)</td>
<td>2.0</td>
<td>2.5 (1.0)</td>
<td>3.0</td>
<td>0.77</td>
</tr>
<tr>
<td></td>
<td>19.</td>
<td>0.68</td>
<td>0.64</td>
<td>2.7 (1.2)</td>
<td>3.0</td>
<td>2.8 (1.2)</td>
<td>3.0</td>
<td>0.70</td>
</tr>
<tr>
<td></td>
<td>20.</td>
<td>0.48</td>
<td>0.67</td>
<td>2.9 (1.1)</td>
<td>3.0</td>
<td>3.1 (1.0)</td>
<td>3.0</td>
<td>0.80</td>
</tr>
<tr>
<td>Quest for normality</td>
<td>21#.</td>
<td>0.70</td>
<td>0.36 (0.68)</td>
<td>2.2 (1.0)</td>
<td>3.0</td>
<td>3.1 (1.1)</td>
<td>4.0</td>
<td>0.78</td>
</tr>
<tr>
<td></td>
<td>22#.</td>
<td>0.44</td>
<td>0.66</td>
<td>2.5 (1.0)</td>
<td>3.5</td>
<td>3.2 (1.0)</td>
<td>3.0</td>
<td>0.77</td>
</tr>
<tr>
<td></td>
<td>23#.</td>
<td>0.37</td>
<td>0.57</td>
<td>2.5 (1.0)</td>
<td>4.0</td>
<td>3.2 (1.0)</td>
<td>4.0</td>
<td>0.67</td>
</tr>
<tr>
<td></td>
<td>24#</td>
<td>0.48</td>
<td>0.66</td>
<td>3.1 (0.9)</td>
<td>3.0</td>
<td>3.1 (0.8)</td>
<td>3.0</td>
<td>0.63</td>
</tr>
<tr>
<td></td>
<td>25#.</td>
<td>0.38</td>
<td>0.69</td>
<td>2.3 (1.0)</td>
<td>3.0</td>
<td>3.1 (1.0)</td>
<td>3.0</td>
<td>0.76</td>
</tr>
</tbody>
</table>

Note: # Items are reversed; *p <0.05 **p <.001; SD= Standard deviation
4.2.3.5 Comparison of the Malay parent proxy and child self-report Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) with previous studies

The mean and standard deviation of the CHEQOL-25 was compared with previous validations studies. Parents rated a higher HRQOL in the interpersonal/social and future worries (parent proxy form) compared to other studies (Table 4.11). Meanwhile, CWE rated a higher HRQOL in the interpersonal/social and quest for normality subscales compared to other studies (Table 4.11).

Table 4.11: Comparison of the Malay version of the parent proxy and child self-report Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) with previous validation studies

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent proxy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></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></td>
<td></td>
</tr>
<tr>
<td>Child self-report</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Epilepsy secrecy</td>
<td>12.8±2.9 [6-20]</td>
<td>15.7±3.96 [5-20]</td>
<td>14.7±3.7 [6-20]</td>
<td>13.9±3.4 [5-20]</td>
<td>12.6±4.3 [5-20]</td>
<td>N/A</td>
</tr>
</tbody>
</table>

#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); N/A= Not available
4.2.3.6 Level of agreement between parent proxy and their children with epilepsy in Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) scores

The parent proxy and child self-report had a good level of agreement in the “interpersonal/social” (ICC= 0.780, p<0.001) and “epilepsy secrecy” subscales (ICC=0.426, p=0.049). The other subscales did not attain statistical significance.

4.2.4 Discussion

The Malay version of the parent proxy and child self-report CHEQOL-25 were found to be valid and reliable instruments to assess the HRQOL among CWE and their parents who speak Malay in Malaysia, as the psychometric properties of these instruments were acceptable.

The Malay CHEQOL-25 was translated according to international guidelines (Cox et al., 2009) as per previous cultural adaptations of the CHEQOL-25 (D. Stevanovic et al., 2009; Yam et al., 2005). The cognitive debriefing from the pilot study indicated that the Malay parent proxy and child self-report CHEQOL-25 were easy to understand, indicating that our questionnaire had reached semantic and content equivalence to the English version.

4.2.4.1 Validity

Both the parent proxy and child self-report CHEQOL-25 and the PedsQL4.0 showed good correlation at the social and emotional subscales, indicating adequate convergent validity. Previous studies did not assess the convergent validity of the parent proxy CHEQOL-25; hence we are unable to make any comparisons.
The Malay parent proxy and child self-report CHEQOL-25 were found to have acceptable construct validity. Our findings concurred with previous studies (G. M. Ronen et al., 2003; Yam et al., 2005). 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.

4.2.4.2 Reliability

The Cronbach’s α value for each subscale ranged from 0.66 to 0.87, which was satisfactory, and our findinga were similar to previous studies. The only exception was the present worries subscales in both parent proxy and child self-report form which only had a Cronbach α value of 0.67 and 0.69 respectively. Previous studies also found a lower Cronbach α value in the present worries subscale (Brabcova et al., 2014; G. M. Ronen et al., 2003; D. Stevanovic et al., 2009; Yam et al., 2005). This may be because the questions asked in the present worries subscale covered many different aspect 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 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.

4.2.4.3 Comparison with previous studies

In the present study, parents and their CWE rated a higher HRQOL in the interpersonal/social, future worries (parent proxy form) and quest for normality (child self-report form), when compared to other studies (G. M. Ronen et al., 2003; D. Stevanovic et al., 2009; Yam et al., 2005). This may be because most of the 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. In addition, 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 (APA, 2002). As a result, parents perceived that their children have lesser worries for their future, whilst the children perceived higher HRQOL in their interpersonal relationship and quest for normality.

4.2.4.4 Level of agreement between parent proxy and their children with epilepsy

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 (D. Stevanovic et al., 2009; Verhey et al., 2009). In addition, a significant difference was noted in responses for the subscale on “epilepsy secrecy.”

4.2.4.5 Strength and limitation

Although we recruited participants from two tertiary hospitals, we were only able to recruit 40 participants, as our inclusion criteria 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 seizure that have normal cognitive ability. However, the strength of our study was that we performed assessed the convergent validity of the Malay parent proxy and child self-report CHEQOL-25, whereas previous studies did not.
4.2.5 **Conclusions**

The Malay parent proxy and child self-report CHEQOL-25 were found to be valid and reliable instruments to assess the perceived HRQOL of CWE in Malaysia.

4.3 **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**

4.3.1 **Objective**

To determine the validity and reliability of the Chinese parent proxy and child self-report CHEQOL-25 in Malaysia.

4.3.2 **Methods**

4.3.2.1 **Study design**

This validation study was conducted from February 2012 to December 2014 in two tertiary hospitals in Malaysia: UMMC and Sunway Medical Centre.

4.3.2.2 **Participants**

Included were parent proxy and their CWE aged 8-18 years, who were attending regular school, CWE 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 who were would not be able to complete the child self-report by themselves), and have other comorbidities such as cerebral palsy or autism.
4.3.2.3 **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, the minimum number of participants was 125.

4.3.2.4 **Instruments used**

(a) **Baseline demographic questionnaire**

This instrument (Appendix L) 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 (J. K. Austin et al., 1994).

(b) **The Chinese version of 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 (Yam et al., 2005; Yam, Ma, & Cherk, 2006). 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 (Bureau, 2012). 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. (Yam et al., 2005; Yam et al., 2006).

Both the parent proxy (Appendix M) and child self-report (Appendix N) CHEQOL-25 consists of 25 items, with five subscales. The parent proxy CHEQOL had the “future worries” subscale, whereas the child self-report had the “quest for normality” subscale (Table 4.2). 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 paediatric neurologist and two psychologists.

4.3.2.5 Pilot study

A pilot study was conducted on five parents and their CWE at a tertiary hospital to assess for face and content validity. Participants were invited to read the question and 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.
4.3.2.6 Procedures

Potential parent proxy and their CWE were screened, and the purpose of the study was explained (Appendix O). For those that agreed to participate, informed consent was obtained from the parent proxy (Appendix P). 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.

4.3.2.7 Ethics

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

4.3.2.8 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. Normality was assessed using the Shapiro Wilk’s test. Since normally could not be assumed, non-parametric was used. Continuous variables were reported as median and interquartile
range; whilst categorical variables were reported as frequency and percentage. A $p$-value $<0.05$ was considered as statistically significant.

(a) **Validity**

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).

In this study, convergent validity was not performed, as there was no validated Chinese generic QOL instrument that contained both parent proxy and child self-report.

(b) **Reliability**

Internal consistency was assessed using Cronbach alpha. Cronbach’s alpha value of $>0.5$ is considered as acceptable (Pallant, 2010). Corrected item-total correlations were analyzed: values $>0.3$ are considered as acceptable (Briggs & Cheek 1986). If removing an item increases Cronbach’s $\alpha$ significantly, excluding the item will increase the homogeneity of the subscale. Test-retest reliability and agreement between parent proxy and child self-report on QOL score, were analyzed using ICC. 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: $>0.8$ (Weir, 2005).
4.3.3 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.

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. A total of 40 parents and their CWE were recruited (response rate=76.9%) (Figure 4.3). The demographic characteristic of parent proxy and their CWE are shown in Table 4.12.
52 participants were screened

10 were excluded if they did not fit the inclusion criteria; 2 declined participation

Participants that agreed to participate (n=40, response rate=76.9%)

Demographic data were collected; the CHEQOL-25 was administered

2 weeks later
Retest (n=36):
Uncontactable:
n=3

The CHEQOL-25 was administered (n=37)

Figure 4.3: Flow of participants for Chinese Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25)

Note: CHEQOL-25= Health Related Quality of Life Measure for Children with Epilepsy
Table 4.12: Characteristic of participants (parents and children) who involved in Chinese version of CHEQOL-25 validation study

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of parent proxy</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>35 (87.5)</td>
</tr>
<tr>
<td>Father</td>
<td>3 (7.5)</td>
</tr>
<tr>
<td>Relative</td>
<td>2 (5.0)</td>
</tr>
<tr>
<td>Median age of parent proxy (years) [IQR]</td>
<td>44.0 [11.0]</td>
</tr>
<tr>
<td>Median age of their children with epilepsy (years) [IQR]</td>
<td>12.0 [3.0]</td>
</tr>
<tr>
<td>Child (7-12 years)</td>
<td>24 (60.0)</td>
</tr>
<tr>
<td>Teenager (13-18 years)</td>
<td>16 (40.0)</td>
</tr>
<tr>
<td>Child’s gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>30 (75.0)</td>
</tr>
<tr>
<td>Female</td>
<td>10 (25.0)</td>
</tr>
<tr>
<td>Level of education of the child</td>
<td></td>
</tr>
<tr>
<td>Primary (6 years of education)</td>
<td>24 (60.0)</td>
</tr>
<tr>
<td>Secondary (7-13 years of education)</td>
<td>16 (40.0)</td>
</tr>
<tr>
<td>Median duration of epilepsy [IQR]</td>
<td>5 [5.0]</td>
</tr>
<tr>
<td>Type of seizure</td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>3 (7.5)</td>
</tr>
<tr>
<td>Generalized tonic-clonic</td>
<td>23 (57.5)</td>
</tr>
<tr>
<td>Partial</td>
<td>14 (35.0)</td>
</tr>
<tr>
<td>Number of medication(s) taken daily</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>4 (10.0)</td>
</tr>
<tr>
<td>1</td>
<td>22 (55.5)</td>
</tr>
<tr>
<td>≥2</td>
<td>14 (35.0)</td>
</tr>
<tr>
<td>Median score of epilepsy syndrome severity [IQR]</td>
<td>5 [3.0]</td>
</tr>
<tr>
<td>Cognitive status</td>
<td></td>
</tr>
<tr>
<td>Normal</td>
<td>30 (75.0)</td>
</tr>
<tr>
<td>Mild learning disability</td>
<td>10 (25.0)</td>
</tr>
<tr>
<td>Have not been admitted to hospital for epilepsy in the past 6 months</td>
<td>40 (100.0)</td>
</tr>
<tr>
<td>No. of times the child visited the doctor for epilepsy in the past 6 months</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>25 (62.5)</td>
</tr>
<tr>
<td>Once</td>
<td>5 (12.5)</td>
</tr>
<tr>
<td>≥2</td>
<td>10 (25.0)</td>
</tr>
<tr>
<td>No. of close friends the child has</td>
<td></td>
</tr>
<tr>
<td>0-2</td>
<td>8 (20.0)</td>
</tr>
<tr>
<td>3-5</td>
<td>13 (32.5)</td>
</tr>
<tr>
<td>6-10</td>
<td>5 (12.5)</td>
</tr>
<tr>
<td>&gt;10</td>
<td>14 (35.0)</td>
</tr>
<tr>
<td>Amount of time per week spent in extracurricular activities with friends</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>10 (25.0)</td>
</tr>
<tr>
<td>Once</td>
<td>8 (20.0)</td>
</tr>
<tr>
<td>2-3 times</td>
<td>18 (45.0)</td>
</tr>
<tr>
<td>≥4 times</td>
<td>4 (10.0)</td>
</tr>
</tbody>
</table>

Note: IQR= interquartile range
4.3.3.1 Validity

The severity of epilepsy, a higher number of AED, lower number of close friends, 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 AED daily were significantly associated with a lower score in the “intrapersonal/emotional” subscale (Table 4.13).

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 4.13). 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).
Table 4.13: Construct validity of the Chinese parent proxy and child self-report Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25)

<table>
<thead>
<tr>
<th>Subscales</th>
<th>Health care usage</th>
<th>Epilepsy severity</th>
<th>No. of anti-epileptic 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>Pearson correlation (r)</td>
<td>Wilcoxon Signed Rank test</td>
<td>z-value</td>
<td>p-value</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent proxy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal/social</td>
<td>-0.282</td>
<td>-0.481 **</td>
<td>-0.131</td>
<td>-0.335*</td>
<td>0.394*</td>
<td>0.416**</td>
</tr>
<tr>
<td>Present worries</td>
<td>-0.126</td>
<td>-0.024</td>
<td>0.222</td>
<td>0.051*</td>
<td>0.105</td>
<td>0.047</td>
</tr>
<tr>
<td>Future worries</td>
<td>-0.101</td>
<td>-0.273</td>
<td>0.041</td>
<td>-0.256</td>
<td>0.157</td>
<td>0.135</td>
</tr>
<tr>
<td>Intrapersonal/emotional</td>
<td>-0.076</td>
<td>-0.571 **</td>
<td>0.056</td>
<td>-0.518 **</td>
<td>0.162</td>
<td>0.265</td>
</tr>
<tr>
<td>Epilepsy secrecy</td>
<td>0.054</td>
<td>0.223</td>
<td>-0.60</td>
<td>0.085</td>
<td>0.138</td>
<td>-0.006</td>
</tr>
<tr>
<td>Child self-report</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal/social</td>
<td>-0.223</td>
<td>-0.285</td>
<td>-0.335*</td>
<td>-0.057</td>
<td>0.371*</td>
<td>0.378*</td>
</tr>
<tr>
<td>Present worries</td>
<td>-0.030</td>
<td>-0.139</td>
<td>0.072</td>
<td>-0.112</td>
<td>-0.256</td>
<td>0.067</td>
</tr>
<tr>
<td>Future worries</td>
<td>-0.067</td>
<td>-0.031</td>
<td>-0.022</td>
<td>0.034</td>
<td>0.263</td>
<td>0.206</td>
</tr>
<tr>
<td>Intrapersonal/emotional</td>
<td>0.110</td>
<td>-0.051</td>
<td>-0.061</td>
<td>-0.052</td>
<td>0.094</td>
<td>0.046</td>
</tr>
<tr>
<td>Epilepsy secrecy</td>
<td>0.046</td>
<td>0.024</td>
<td>-0.231</td>
<td>-0.062</td>
<td>0.110</td>
<td>0.129</td>
</tr>
</tbody>
</table>

Note: *p <0.05 **p <.001
4.3.3.2 **Reliability**

The Cronbach’s $\alpha$ for each subscale in parent proxy CHEQOL-25 ranged from 0.662-0.825. All items had a corrected item-total correlation value of >0.3, except items 8 and 25 (Table 4.14). 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 0.690-0.961 (Table 4.14).
Table 4.14: Reliability of the Chinese parent proxy Health Related Quality of Life Measure for Children with Epilepsy CHEQOL-25

<table>
<thead>
<tr>
<th>Subscales</th>
<th>Items</th>
<th>Cronbach’s α</th>
<th>Corrected item-total correlation</th>
<th>Cronbach’s α if item is deleted</th>
<th>Test re-test reliability</th>
<th>Intra-class Correlation Coefficient**</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Test (n=40)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mean ± SD</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inter-personal/social</td>
<td>1.</td>
<td>0.825</td>
<td>0.604</td>
<td>0.797</td>
<td>3.22 (0.77)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>2.</td>
<td>0.470</td>
<td>0.845</td>
<td></td>
<td>3.05 (1.03)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>3.</td>
<td>0.660</td>
<td>0.779</td>
<td></td>
<td>3.17 (0.80)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>4.</td>
<td>0.675</td>
<td>0.777</td>
<td></td>
<td>3.15 (0.89)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>5.</td>
<td>0.746</td>
<td>0.753</td>
<td></td>
<td>3.03 (0.99)</td>
<td>3.0</td>
</tr>
<tr>
<td>Present Worries</td>
<td>6.</td>
<td>0.662</td>
<td>0.655</td>
<td>0.499</td>
<td>3.03 (1.00)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>7.</td>
<td>0.347</td>
<td>0.646</td>
<td></td>
<td>2.47 (1.54)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>8.</td>
<td>0.254</td>
<td>0.673</td>
<td></td>
<td>3.25 (0.87)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>9.</td>
<td>0.331</td>
<td>0.650</td>
<td></td>
<td>2.80 (1.10)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>10.</td>
<td>0.524</td>
<td>0.555</td>
<td></td>
<td>2.63 (1.13)</td>
<td>2.0</td>
</tr>
<tr>
<td>Future Worries</td>
<td>11.</td>
<td>0.818</td>
<td>0.514</td>
<td>0.809</td>
<td>3.10 (0.95)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>12.</td>
<td>0.725</td>
<td>0.756</td>
<td></td>
<td>3.10 (0.84)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>13.</td>
<td>0.709</td>
<td>0.750</td>
<td></td>
<td>2.95 (1.07)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>14.</td>
<td>0.648</td>
<td>0.771</td>
<td></td>
<td>3.00 (1.07)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>15.</td>
<td>0.642</td>
<td>0.819</td>
<td></td>
<td>2.8 (1.00)</td>
<td>3.0</td>
</tr>
<tr>
<td>Intra-personal/emotional</td>
<td>16.</td>
<td>0.783</td>
<td>0.501</td>
<td>0.761</td>
<td>2.80 (1.00)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>17.</td>
<td>0.652</td>
<td>0.709</td>
<td></td>
<td>2.60 (1.12)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>18.</td>
<td>0.606</td>
<td>0.726</td>
<td></td>
<td>2.38 (1.12)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>19.</td>
<td>0.547</td>
<td>0.746</td>
<td></td>
<td>2.75 (0.98)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>20.</td>
<td>0.494</td>
<td>0.763</td>
<td></td>
<td>3.02 (0.88)</td>
<td>3.0</td>
</tr>
<tr>
<td>Epilepsy Secrecy</td>
<td>21R#</td>
<td>0.722</td>
<td>0.305</td>
<td>0.738</td>
<td>2.42 (0.90)</td>
<td>2.0</td>
</tr>
<tr>
<td></td>
<td>22.</td>
<td>0.601</td>
<td>0.624</td>
<td></td>
<td>2.78 (1.00)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>23.</td>
<td>0.616</td>
<td>0.627</td>
<td></td>
<td>2.85 (0.86)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>24.</td>
<td>0.696</td>
<td>0.595</td>
<td></td>
<td>3.10 (0.87)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>25.</td>
<td>0.279</td>
<td>0.766</td>
<td></td>
<td>2.62 (1.10)</td>
<td>3.0</td>
</tr>
</tbody>
</table>

Note: # Items are reversed  **p <0.001, SD= Standard deviation
The Cronbach’s α for each subscale in child self-report CHEQOL ranged from 0.562-0.724. All items had a corrected item-total correlation value of >0.3, except items 8 and 25 (Table 4.15). Twenty-five items showed no significant difference at test–retest. ICC for all items at test-retest ranged from 0.657-0.954 (Table 4.15).
Table 4.15 Reliability of the Chinese child self-report Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25)

<table>
<thead>
<tr>
<th>Subscales</th>
<th>Items</th>
<th>Cronbach’s α</th>
<th>Corrected item-total correlation</th>
<th>Cronbach’s α if item is deleted</th>
<th>Test re-test reliability</th>
<th>Intra-class Correlation Coefficient**</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal/social</td>
<td>1.</td>
<td>0.724</td>
<td>0.604</td>
<td>0.671</td>
<td>2.93 (0.94)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>2.</td>
<td>0.456</td>
<td>0.688</td>
<td>0.35 (0.83)</td>
<td>2.98 (0.97)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>3.</td>
<td>0.460</td>
<td>0.688</td>
<td>0.35 (0.83)</td>
<td>3.05 (1.06)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>4.</td>
<td>0.580</td>
<td>0.636</td>
<td>3.05 (1.10)</td>
<td>3.05 (1.10)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>5.</td>
<td>0.437</td>
<td>0.700</td>
<td>3.05 (1.10)</td>
<td>3.05 (1.10)</td>
<td>3.0</td>
</tr>
<tr>
<td>Present Worries</td>
<td>6.</td>
<td>0.562</td>
<td>0.312</td>
<td>0.567</td>
<td>2.27 (1.15)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>7.</td>
<td></td>
<td>0.362</td>
<td>0.491</td>
<td>1.47 (0.87)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>8.</td>
<td>0.184</td>
<td>0.580</td>
<td>3.15 (1.02)</td>
<td>3.05 (1.06)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>9.</td>
<td>0.341</td>
<td>0.495</td>
<td>1.97 (1.14)</td>
<td>2.0 (1.07)</td>
<td>2.0</td>
</tr>
<tr>
<td></td>
<td>10.</td>
<td>0.542</td>
<td>0.368</td>
<td>1.80 (1.07)</td>
<td>1.3 (0.97)</td>
<td>2.0</td>
</tr>
<tr>
<td>Intra-personal/emotional</td>
<td>11.</td>
<td>0.643</td>
<td>0.425</td>
<td>0.577</td>
<td>2.70 (0.97)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>12.</td>
<td></td>
<td>0.454</td>
<td>0.565</td>
<td>2.90 (0.93)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>13.</td>
<td>0.368</td>
<td>0.603</td>
<td>2.80 (0.99)</td>
<td>3.05 (1.06)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>14.</td>
<td>0.400</td>
<td>0.589</td>
<td>2.53 (1.10)</td>
<td>2.97 (1.12)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>15.</td>
<td>0.344</td>
<td>0.616</td>
<td>2.90 (1.05)</td>
<td>2.97 (1.12)</td>
<td>3.0</td>
</tr>
<tr>
<td>Epilepsy Secrecy</td>
<td>16R#.</td>
<td>0.689</td>
<td>0.451</td>
<td>0.564</td>
<td>2.78 (1.07)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>17.</td>
<td></td>
<td>0.412</td>
<td>0.456</td>
<td>2.98 (1.04)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>18R.</td>
<td>0.326</td>
<td>0.526</td>
<td>2.88 (1.05)</td>
<td>3.05 (1.10)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>19.</td>
<td>0.448</td>
<td>0.646</td>
<td>3.10 (0.96)</td>
<td>3.05 (1.10)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>20.</td>
<td>0.494</td>
<td>0.663</td>
<td>2.78 (1.03)</td>
<td>3.05 (1.10)</td>
<td>3.0</td>
</tr>
<tr>
<td>Quest for normality</td>
<td>21R#</td>
<td>0.696</td>
<td>0.444</td>
<td>0.650</td>
<td>2.92 (1.16)</td>
<td>2.0</td>
</tr>
<tr>
<td></td>
<td>22R#.</td>
<td></td>
<td>0.704</td>
<td>0.528</td>
<td>3.05 (1.04)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>23R#.</td>
<td>0.487</td>
<td>0.631</td>
<td>3.32 (1.00)</td>
<td>3.05 (1.17)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>24R#.</td>
<td>0.481</td>
<td>0.636</td>
<td>2.85 (0.95)</td>
<td>2.81 (1.10)</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>25R#.</td>
<td>0.171</td>
<td>0.747</td>
<td>2.95 (0.98)</td>
<td>2.95 (0.97)</td>
<td>3.0</td>
</tr>
</tbody>
</table>

Note: # Items are reversed   **p <0.001, SD= Standard deviation
4.3.3.3 Comparison of the Chinese parent proxy and child self-report Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) with previous studies

The psychometric properties of Chinese parent proxy and child self-report CHEQOL-25 was compared with previous validation studies (Table 4.16). 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.
Table 4.16 Comparison Chinese parent proxy and child self-report Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) with previous studies

<table>
<thead>
<tr>
<th>Subscales</th>
<th>Chinese CHEQOL-25 (n=40)</th>
<th>Ronen (G. M. Ronen et al., 2003) (n=381)</th>
<th>Ma (Ma et al., 2006) (n=50)</th>
<th>Yam (Yam et al., 2005; Yam et al., 2006) (n=240)</th>
<th>Stevanovic (D. Stevanovic et al., 2009) (n=50)</th>
<th>Brabcova #(Brabcova et al., 2014) (n=250)</th>
<th>Wo (Wo et al., 2015a, 2015b) (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subscales Mean ± SD [range]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent proxy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child self-report</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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).
4.3.3.4 Level of agreement between parent proxy and their children with epilepsy in Health Related Quality of Life Measure for Children with Epilepsy (CHEQOL-25) 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.

4.3.4 Discussion

The Chinese parent proxy and child self-report CHEQOL-25 were found to be a valid and reliable instruments to assess HRQOL among CWE and their parents who speak Mandarin in Malaysia.

4.3.4.1 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 (Brabcova et al., 2014; G. M. Ronen et al., 2003; Yam et al., 2005). In our study, 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 (Yamamoto & Holloway, 2010).

4.3.4.2 Reliability

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. Our findings were similar to the previous validation studies (Brabcova et al., 2014; Ma et al., 2006; G. M. Ronen et al., 2003; D. Stevanovic et al., 2009; Wo et al., 2015a, 2015b). 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 (Brabcova et al., 2014; Yam et al., 2006).

4.3.4.3 **Comparison with previous studies**

In our study, the psychometric properties of the CHEQOL-25 were similar to previous validation studies. 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 (Ma et al., 2006; D. Stevanovic et al., 2009; Wo et al., 2015a, 2015b). Parents rated a higher HRQOL in the “interpersonal/social” and “present worries”, subscales compared to other studies (G. M. Ronen et al., 2003; D. Stevanovic et al., 2009; Wo et al., 2015a, 2015b; Yam et al., 2006). However, the children in our study rated a higher HRQOL in the “present worries” compared to other studies (G. M. Ronen et al., 2003; D. Stevanovic et al., 2009; Wo et al., 2015a, 2015b; Yam et al., 2006). 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.

4.3.4.4 **Level of agreement between parent proxy and their children with epilepsy**

There was moderate to high agreement between the parent proxy and child self-report in the “interpersonal/social” subscale. There was a significant difference was noted in responses for the subscale on “epilepsy secrecy”. These findings were consistent with previous findings (Verhey et al., 2009; Wo et al., 2015a, 2015b). 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 (D. Stevanovic et al., 2011; Verhey et al., 2009). Parent-proxy ratings correlated well with
child self-reports in areas where the parent was able to observe the conduct of their child. As the information provided by parents-proxy can be used to supplement and validate a child self-reported HRQOL. Therefore, both parent-proxy and child self-report are equally important to assess a child's HRQOL (Erhart, Ellert, Kurth, & Ravens-Sieberer, 2009; Jiang et al., 2013).

4.3.4.5 **Strengths and limitations**

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.

4.3.5 **Conclusions**

Our small study found that the Chinese parent proxy and child self-report CHEQOL-25 were valid and reliable instruments 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.
CHAPTER 5: VALIDATION OF THE FAMILY FUNCTIONING INSTRUMENT: THE GENERAL FUNCTIONING SUBSCALE (GF-12) FROM THE MCMASTER FAMILY ASSESSMENT DEVICE (FAD)

Instruments to assess family functioning have been used by researchers interested in assessing the effectiveness of family interventions. This chapter will report on the validation of the General Functioning (GF-12) subscale in Malaysia.

5.1 Introduction

A number of family functioning instruments have been used in western countries, such as the McMaster Family Assessment Device (FAD) (Epstein et al., 1983), the Family Environment Scale (FES) (Moos, 1990), the PedsQL™ Family Impact Module (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004), the Family APGAR (Smilkstein, Ashworth, & Montano, 1982), the Self-report Family Inventory (SFI) (Beavers, Hampson, & Hulgus, 1990), and the Family Functioning Index (FFI) (Pless & Satterwhite, 1973). However, the only instruments that have been validated in Malaysia are the Malay PedsQL Family Impact Module (Rahman et al., 2011) and the Malay FES (Omar et al., 2010). To date, a search of published literature revealed that there is no validated instrument available in Chinese to assess parents’ perceived family functioning in Malaysia.

The Malay version of the FES was found to be culturally inappropriate for use in Malaysia. In the original FES, one question which aims to assess undesired expressiveness within the family: “family members are usually careful about what they say to each other” is not suitable for use in Malaysia as generally, most children speak respectfully (and hence carefully) to their elders. It does not mean that Malaysians do not
know how to express themselves. The overall internal consistency of the Malay version of the FES was also lower than the original FES (Omar et al., 2010). On the other hand, the Malay PedsQL Family Impact Module, showed good internal consistency and was similar to the original study (Rahman et al., 2011). However, this questionnaire was designed primarily to assess the impact of paediatric chronic health conditions on parents and their family. Therefore, it cannot be used to assess in a healthy population.

The GF-12 subscale from the Family Assessment Device (FAD) was selected as the instrument to assess family functioning in Malaysia as this instrument was found to be free from cultural bias when assessed in different populations and countries around the world (Shek, 2001). In addition, it can also be used as a standalone instrument to assess overall family functioning (Kazarian, 2010). It consists of 12 items, is short and simple to use.

The GF-12 subscale has been translated into more than 20 different languages like Armenian (Kazarian, 2010), Chinese (Shek, 2001), Spanish (Barroilhet, Cano-Prous, Cervera-Enguix, Forjaz, & Guillén-Grima, 2009), Italian (Roncone et al., 1998), Dutch (Wenniger, Hageman, & Arrindell, 1993), and French (Speranza et al., 2012). However, these studies did not perform a full psychometric assessment of the instrument such as confirmatory and exploratory factor analysis in addition to the usual psychometric analyses. The Malay version of the GF-12 has been translated by Sumari (2011). However, there is no published evidence that this instrument has been validated.

A typical Chinese family establishes a cultural sphere characterized by Confucianism, where hierarchy and a tightly knit family structure exists (Elliot & Gray, 2000). Due to acculturation (defined as a process where an individual needs to adopt similar beliefs,
values and lifestyle to adapt to a new cultural environment) (Crane, Ngai, Larson, & Hafen, 2005), Malaysian Chinese can be influenced by the cultural diversity that exists in Malaysia. For example, North American Chinese adopted a bicultural family system where the family members are familiar with both Western and Chinese culture. They are bilingual and communicate with each other in Chinese and English (Atwood & Conway, 2004). Similarly, Malaysian Chinese might adhere to a different family system and have a different viewpoint of family functioning from their counterparts in China.

5.2 Validation of the Malay General Functioning subscale (GF-12) subscale from the McMaster Family Assessment Device (FAD)

5.2.1 Objective

To determine the reliability and validity of the Malay version of the GF-12 subscale in Malaysia.

5.2.2 Methods

5.2.2.1 Study design

This validation study was conducted in the respiratory pediatric clinic in UMMC and the community from May 2012- June 2012.

5.2.2.2 Participants

The patient group consists of parents of children with chronic respiratory disease for more than 6 months. To determine if the GF-12 subscale could discriminate between families with children with or without chronic illness, caregivers of healthy children were recruited as controls. Participants were gender and age matched with the patient group. In both groups, caregivers of children who were mentally challenged, with other chronic
disease(s) and unable to read or understand Malay language were excluded. Hired
domestic helpers (acting as caregivers for the child) were also excluded.

5.2.2.3 Sample size calculation

In order to conduct factor analysis, the subject-to-variables ratio should be no lower
than five according to the rule of five in validation studies (Hatcher, 1994). There are 12
items in the GF-12. Therefore, the minimum number of participants required for this study
is 60 participants.

5.2.2.4 Instruments

(a) Baseline demographic questionnaire

This instrument (Appendix R) 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, and duration of asthma/respiratory disease).

(b) The Malay version of the General Functioning (GF-12) subscale

We used the Malay version of the GF-12 subscale was translated by Sumari (2011)
(Appendix S). Permission to use this instrument was obtained (Appendix T). It is a self-
administered instrument with a 4-point Likert scale, ranging from 1 (strongly agree) to 4
(strongly disagree) (Epstein et al., 1983). Participants were required to rate how well an
item described their families in general. Reversed score items (items 1, 3, 5, 7 and 11)
were transformed by subtracting them from 5. To score, all items were summed up and
the total score was divided by the number of items. Scores range from 1 (healthy) to 4
(unhealthy). A score of 2 and above indicates problematic family functioning (Epstein et
al., 1983)
5.2.2.5 Procedures

Caregivers were recruited from the Pediatric respiratory clinic, University of Malaya Medical Centre (patient group) or the community (control group), and the purpose of the study was explained (Appendix U). Informed consent was obtained (Appendix V). Prior to the main study, a pilot test was conducted on five caregivers. Baseline information such as demographic data and the child’s medical history were collected. For the patient group, the instruments were administered whilst the caregiver and child were waiting to see the doctor. Caregivers completed the questionnaire themselves, after instructions were given by the researcher. This took about 10 minutes. The completed questionnaire was checked by the researcher to ensure that all questions had been answered. The GF-12 subscale was re-administered to the same group of caregivers after 4 weeks. Questionnaires were sent via mail and participants were encouraged to send their replies using the postage return envelope. Telephone reminders were performed to increase response rates. Caregivers were questioned on any significant changes or events that occurred within the past four weeks and all changes were documented. This process was repeated with the control group in the community.

5.2.2.6 Ethics

Ethics approval (ref number: 914.33) from University Malaya Medical Centre and informed consent were obtained (Appendix W).

5.2.2.7 Data analysis

Normality was assessed using the Shapiro Wilk’s test. Since normally could not be assumed, non-parametric was used. Continuous variables were reported as median and interquartile range; whilst categorical variables were reported as frequency and percentage. A p-value <0.05 was considered as statistically significant.
(a) **Validity**

**i. Factor analysis**

A 3-step validation process using confirmatory (steps 1 and 3) and exploratory factor analysis (step 2) were conducted to test, explore and confirm the factorial structure of the questionnaire. Statistical analysis was conducted using the Statistical Package for Social Sciences (SPSS) version 20 (Chicago, IL, USA) and Analysis of Moment Structure (AMOS) version 21.0 (Chicago, IL, USA).

Firstly, a confirmatory factor analysis (CFA) was used to test the fit of the data to the original 3-factor subscale. Multiple fit indices include the chi-square/df ratio (CMIN/DF), comparative fit index (CFI), goodness of fit index (GFI), adjusted goodness-of-fit index (AGFI), Tucker-Lewis index (TLI), and the root-mean-square error of approximation (RMSEA). According to Hu and Bentler (1999), the model chi-square statistic should be used to determine the fit of each model to the observed data (Bollen, 1989). A CMIN/DF value close to 1.00 and a non-significant model chi-square (p>0.05) suggests a good model of fit. The CFI, GFI, AGFI, and TLI values greater than 0.90 indicate an adequate model of fit (Hu & Bentler, 1999). Value of RMSEA not greater than 0.70 is considered a sign of good fit. Akaike’s information Criterion (AIC) was used to compare models. The smaller the value between two models shows better fit. Modification index coefficients (MDI) were used to check any cross-loadings between the latent variables.

Secondly, an exploratory factor analysis (EFA) was conducted using the principal axis factoring (PFA) extraction method with iterated oblique rotation (Promax). If Kaiser-Meyer-Olkin measure of sampling adequacy (KMO) exceeds the recommended value of 0.6 and the Bartlett’s test of sphericity shows significant p-value, this indicates an adequate sample size for factor analysis. Items with factor loadings coefficient 0.30 or
greater and differences of at least 0.2 between the loadings on two factors were included in the component. In the extraction, only factors with eigenvalues more than one were accepted (Tabachnick & Fidell, 2007). Items that did not meet these criteria were removed from the analysis. The Catell’s scree plot was used to plot each of the eigenvalues of factors and check on the relative importance of each factor (Catell, 1966).

Thirdly, using the number of factors determined by EFA, a further CFA was conducted to confirm if the data supported the factor structure of the GF-12 subscale. The maximum likelihood (ML) estimation method was used. Average Variance Extracted (AVE) values were calculated, with AVE must be higher than 0.5 (Hair, Black, Babin, & Anderson, 2009). The AVEs for any two factors are greater than their squared correlation estimate, indicating good construct reliability and adequate convergent validity (Hair et al., 2009).

\[ ii \quad Discriminative\ validity \]

The Mann-Whitney U test was used to determine the discriminative validity of the scale.

\[ (b) \quad Reliability \]

Reliability of the subscale was assessed by calculating Cronbach’s \( \alpha \) value. Cronbach’s \( \alpha \) value \( \geq 0.70 \) to 0.90 indicates acceptable internal consistency. Corrected item-total correlation will be used if Cronbach’s \( \alpha \) value is less than 0.70. Item with corrected item-total correlations less than 0.30 will be removed (Pallant, 2010).
5.2.3 Results

A total of 73 caregivers were recruited: 38 (52.1%) caregivers of children with chronic respiratory disease (patient group) and 35 (47.9%) caregivers of healthy children (control group). The response rate was 90%. Demographic characteristics of caregivers are shown in Table 5.1. No significant differences were found between the two groups.
Table 5.1: Demographic characteristics of caregivers in the control and patient group

<table>
<thead>
<tr>
<th></th>
<th>No. (%)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Control (n=35)</td>
<td>Patient (n=38)</td>
<td></td>
</tr>
<tr>
<td><strong>Primary caregiver [n (%)]</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>28 (80.0)</td>
<td>31 (81.6)</td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>7 (20.0)</td>
<td>6 (15.8)</td>
<td></td>
</tr>
<tr>
<td>Relative</td>
<td>0</td>
<td>1 (2.6)</td>
<td></td>
</tr>
<tr>
<td><strong>Median age (year) [IDR]</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;29</td>
<td>3 (8.6)</td>
<td>2 (5.3)</td>
<td></td>
</tr>
<tr>
<td>30-39</td>
<td>22 (62.9)</td>
<td>27 (71.1)</td>
<td></td>
</tr>
<tr>
<td>40-49</td>
<td>9 (25.7)</td>
<td>8 (21.1)</td>
<td></td>
</tr>
<tr>
<td>&gt;50</td>
<td>1 (2.9)</td>
<td>1 (2.6)</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Malay</td>
<td>18 (51.4)</td>
<td>27 (71.1)</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>11 (31.4)</td>
<td>5 (13.2)</td>
<td></td>
</tr>
<tr>
<td>Indian</td>
<td>6 (17.1)</td>
<td>6 (15.8)</td>
<td></td>
</tr>
<tr>
<td><strong>Occupational status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time (≥30 hours/week)</td>
<td>31 (88.6)</td>
<td>28 (73.7)</td>
<td></td>
</tr>
<tr>
<td>Part time (&lt;30 hours/week)</td>
<td>0</td>
<td>3 (7.9)</td>
<td></td>
</tr>
<tr>
<td>Unemployed/retired</td>
<td>4 (11.4)</td>
<td>7 (18.4)</td>
<td></td>
</tr>
<tr>
<td><strong>Highest education level completed</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>9 (25.7)</td>
<td>16 (42.1)</td>
<td></td>
</tr>
<tr>
<td>Diploma/vocational training</td>
<td>6 (17.1)</td>
<td>14 (36.8)</td>
<td></td>
</tr>
<tr>
<td>Bachelor and higher</td>
<td>20 (57.1)</td>
<td>8 (21.1)</td>
<td></td>
</tr>
<tr>
<td><strong>Household income per month (RM)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1999</td>
<td>2 (5.7)</td>
<td>6 (15.8)</td>
<td></td>
</tr>
<tr>
<td>2000-2999</td>
<td>7 (20.0)</td>
<td>12 (31.6)</td>
<td></td>
</tr>
<tr>
<td>3000-3999</td>
<td>9 (25.7)</td>
<td>9 (23.7)</td>
<td></td>
</tr>
<tr>
<td>4000-4999</td>
<td>3 (8.6)</td>
<td>5 (13.2)</td>
<td></td>
</tr>
<tr>
<td>&gt;5000</td>
<td>14 (40.0)</td>
<td>6 (15.8)</td>
<td></td>
</tr>
<tr>
<td><strong>Child’s age median (year) [IDR]</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infant (6-12 months)</td>
<td>3 (8.6)</td>
<td>2 (5.3)</td>
<td></td>
</tr>
<tr>
<td>Toddlers (1-4 years)</td>
<td>13 (37.16)</td>
<td>10 (26.3)</td>
<td></td>
</tr>
<tr>
<td>Pre-schoolers (4-6 years)</td>
<td>4 (11.4)</td>
<td>9 (23.7)</td>
<td></td>
</tr>
<tr>
<td>School aged children (7-12 years)</td>
<td>9 (25.7)</td>
<td>11 (28.9)</td>
<td></td>
</tr>
<tr>
<td>Teenagers (13-16 years)</td>
<td>6 (17.1)</td>
<td>6 (15.8)</td>
<td></td>
</tr>
<tr>
<td><strong>Type of respiratory disease</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>NA</td>
<td>30 (78.9)</td>
<td></td>
</tr>
<tr>
<td>Chronic bronchitis</td>
<td>NA</td>
<td>7 (18.4)</td>
<td></td>
</tr>
<tr>
<td>Chronic cough</td>
<td>NA</td>
<td>1 (2.6)</td>
<td></td>
</tr>
<tr>
<td><strong>Duration of respiratory disease median (years) [range]</strong></td>
<td>N/A</td>
<td>4.7 [11.0]</td>
<td></td>
</tr>
</tbody>
</table>

Note: IQR= interquartile range
5.2.3.1 Validity

(a) Factor analysis

Based on the original questionnaire, the GF-12 subscale was supposedly to be a 1-factor general family functioning model. Using CFA, the fit statistic showed that the 1-factor model could not be maintained, as the test of model yielded: $\chi^2= 86.102$, df= 54, CIMN/DF=1.594, $p=0.004$, CFI=0.808, GFI=0.825, AGFI=0.747, and RMSEA=0.091, AIC=134.102.

EFA was then performed. KMO adequacy was 0.76 indicating that the sample size was adequate for factor analysis. The Bartlett’s test of sphericity was significant ($p<0.001$) indicated that the correlation between items were sufficient for EFA analysis. Item 2 (“In times of crisis we can turn to each other for support”) and item 4 (“Individuals are accepted for what they are”) were excluded because it had low factor loadings of less than 0.4. EFA showed that a 3-factor structure of the Malay version of the GF-10 subscale would explain a total of 54.1% of the variance (Table 5.2). The first factor which comprised of five items (items 1, 3, 5, 7 and 9) accounted for 31.5% of the variance. Its items were about making decisions and conflict resolution, and can be conceptualized as “effective communication”. The second factor which comprised of three items (items 6, 8 and 12) accounted for 12.9% of the variance. Its items were about the expression of feelings and accepting each other, and can be conceptualized as “expressiveness and acceptance”. The third factor which comprised of two items (items 10 and 11) which accounted for 9.7% of the variance. Its items were about how well members can get along, and can be conceptualized as “cohesiveness”.

Table 5.2 Factor loadings for the Malay version of the GF-12 subscale using the Promax Method

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor loadings</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Factor 1</td>
<td>Factor 2</td>
<td>Factor 3</td>
</tr>
<tr>
<td></td>
<td>(effective</td>
<td>(expressiveness &amp; acceptance)</td>
<td>(cohesiveness)</td>
</tr>
<tr>
<td></td>
<td>communication)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Planning family activities is difficult because we misunderstand each other#</td>
<td>0.733</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Making decisions is a problem for our family#</td>
<td>0.679</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. We avoid discussing our fears and concerns#</td>
<td>0.610</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. We cannot talk to each other about the sadness we feel#</td>
<td>0.557</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. There are lots of bad feelings in the family#</td>
<td>0.550</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. We can express feelings to each other</td>
<td>0.840</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. We confide in each other</td>
<td>0.676</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. We feel accepted for what we are</td>
<td>0.514</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. We are able to make decisions about how to solve problems</td>
<td></td>
<td>0.624</td>
<td></td>
</tr>
<tr>
<td>11. We don't get along well together#</td>
<td></td>
<td></td>
<td>0.589</td>
</tr>
<tr>
<td>4. Individuals are accepted for what they are</td>
<td></td>
<td></td>
<td>0.353**</td>
</tr>
<tr>
<td>2. In times of crisis we can turn to each other for support</td>
<td></td>
<td>-0.217**</td>
<td></td>
</tr>
</tbody>
</table>

Note: # items are reversed; **factor loading less than 0.4
Lastly, a CFA was used to test the fit of the 3-factor model. The fit analysis showed an adequate model of fit: Chi square/df= 1.234, p=0.129, CFI=0.957, GFI=0.911, AGFI=0.846, TLI=0.939 and RMSEA=0.0570, AIC= 85.501. Standardized factor loadings for other items were moderately and highly correlated to the general family functioning factor, with loadings from 0.452-0.827 (Figure 5.1).

Figure 5.1: The factor structure of the Malay version of the General Functioning subscale (GF-10) using Confirmatory Factor Analysis
(b) *Discriminative validity*

A lower score indicates better family functioning. The GF-10 subscale was not able to differentiate between caregivers of children with chronic respiratory illness from healthy children. The overall median family functioning score was not significantly different between the patient and control groups, 1.70 versus 1.60, \( p=0.890 \). The median across all three factors were not significantly different between the patient and control group: 1.80 versus 1.80, \( p=0.987 \); 1.59 (0.41) versus 1.44, \( p=0.579 \); 1.65 versus 1.52, \( p=0.518 \) respectively.

5.2.3.2 *Reliability (with items 2 and 4 removed)*

The overall Cronbach’s \( \alpha \) value GF-10 (with items 2 and 4 removed) subscale was 0.806. The Cronbach’s \( \alpha \) value for each of the three factors: effective communication, expressiveness and acceptance, and cohesiveness, was 0.754, 0.718, and 0.575, respectively. Corrected item-total correlations showed that all items were more than 0.30 (Table 5.3). Hence, all 10 items were retained.

Test-retest reliability was assessed in 62 participants after a 4-week interval. Participants from the patient and control groups were combined. All items showed high Spearman’s correlation coefficients (0.34-0.79; \( p<0.001 \)) at test-retest. Only item 6 was significantly different at retest (\( p=0.029 \)). This indicates that the GF-10 subscale has achieved stable reliability.

Demographic factors such as gender, age, ethnicity, child’s age, duration of a child’s asthma, employment status, educational level, and marital status were not found to be associated with the overall GF-10 score.
Table 5.3: Reliability of the Malay General functioning subscale (GF-10) [with items 2 & 4 removed]

<table>
<thead>
<tr>
<th>Items</th>
<th>Corrected item-total correlation</th>
<th>Cronbach’s α if item is deleted</th>
<th>Test (n=73)</th>
<th>Discriminant validity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Control (n=35)</td>
<td>Patient (n=38)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mean score (SD)</td>
<td>Median</td>
</tr>
<tr>
<td><strong>Factor 1: Effective communication</strong></td>
<td>0.478</td>
<td>0.627</td>
<td>1.78 (0.48)</td>
<td>1.80</td>
</tr>
<tr>
<td>1. Planning family activities is difficult because we misunderstand each other#</td>
<td>0.621</td>
<td>0.798</td>
<td>1.71 (0.83)</td>
<td>2.00</td>
</tr>
<tr>
<td>3. We cannot talk to each other about the sadness we feel#</td>
<td>0.307</td>
<td>0.809</td>
<td>1.97 (0.71)</td>
<td>2.00</td>
</tr>
<tr>
<td>5. We avoid discussing our fears and concerns#</td>
<td>0.491</td>
<td>0.788</td>
<td>1.71 (0.57)</td>
<td>2.00</td>
</tr>
<tr>
<td>7. There are lots of bad feelings in the family#</td>
<td>0.481</td>
<td>0.798</td>
<td>1.80 (0.58)</td>
<td>2.00</td>
</tr>
<tr>
<td>9. Making decisions is a problem for our family#</td>
<td>0.589</td>
<td>0.776</td>
<td>1.71 (0.67)</td>
<td>2.00</td>
</tr>
<tr>
<td><strong>Factor 2: Expressiveness &amp; acceptance</strong></td>
<td>0.495</td>
<td>0.607</td>
<td>1.51 (0.47)</td>
<td>1.44</td>
</tr>
<tr>
<td>6. We can express feelings to each other</td>
<td>0.403</td>
<td>0.797</td>
<td>1.40 (0.55)</td>
<td>1.00</td>
</tr>
<tr>
<td>8. We feel accepted for what we are</td>
<td>0.427</td>
<td>0.795</td>
<td>1.57 (0.50)</td>
<td>2.00</td>
</tr>
<tr>
<td>12. We confide in each other</td>
<td>0.554</td>
<td>0.781</td>
<td>1.54 (0.66)</td>
<td>1.00</td>
</tr>
<tr>
<td><strong>Factor 3: Cohesiveness</strong></td>
<td>0.543</td>
<td>0.544</td>
<td>1.56 (0.53)</td>
<td>1.52</td>
</tr>
<tr>
<td>10. We are able to make decisions about how to solve problems</td>
<td>0.396</td>
<td>0.798</td>
<td>1.54 (0.56)</td>
<td>2.00</td>
</tr>
<tr>
<td>11. We don't get along well together#</td>
<td>0.558</td>
<td>0.780</td>
<td>1.57 (0.61)</td>
<td>2.00</td>
</tr>
<tr>
<td><strong>Total score</strong></td>
<td>N/A</td>
<td>N/A</td>
<td>1.65 (0.36)</td>
<td>1.60</td>
</tr>
</tbody>
</table>

Note. # Items are reversed; SD= Standard deviation
5.2.3.3 Comparison of the Malay General functioning subscale (GF-10) [with item 2 and 4 removed] with previous studies

The psychometric properties of the GF-10 subscale validated in Malaysia were similar to other GF-12 subscale validated elsewhere (Table 5.4).
Table 5.4: Comparison of the General Functioning subscale (GF-10) [with item 2 and 4 removed] with previous validation studies

<table>
<thead>
<tr>
<th>Authors</th>
<th>Language / Country</th>
<th>n</th>
<th>Sample</th>
<th>Cronbach’s alpha</th>
<th>Test-retest reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Patient group [Mean (SD)]</td>
<td>Control group [Mean (SD)]</td>
</tr>
<tr>
<td>Present study</td>
<td>Malay/ Malaysia</td>
<td>73</td>
<td>Caregivers of children with chronic respiratory disease [1.68 (0.36)]</td>
<td>Caregivers of healthy children aged 1-16 [1.65 (0.40)]</td>
<td>0.806</td>
</tr>
<tr>
<td>Original study: Epstein et al (1983)</td>
<td>English/ Canada</td>
<td>294</td>
<td>Psychiatric adult patients &gt;18 years [2.6 (0.58)]</td>
<td>Community adults &gt;18 years [1.96, (0.53)]</td>
<td>0.920</td>
</tr>
<tr>
<td>Shek (2001)</td>
<td>Chinese/ Hong Kong, China</td>
<td>732</td>
<td>Adolescents with behavioural and emotional problems [2.45 (0.51)]</td>
<td>Healthy adolescents [2.28 (0.48)]</td>
<td>Not reported</td>
</tr>
<tr>
<td>Kazarian (2010)</td>
<td>Armenian/ Lebanon</td>
<td>558</td>
<td>None</td>
<td>Healthy adolescents [not reported]</td>
<td>0.80</td>
</tr>
<tr>
<td>Speranza et al. (2012)</td>
<td>French/ France</td>
<td>323</td>
<td>Relative(s) of psychiatric adult patients [2.30 (0.3)] &amp; medical adult patients and their relatives [2.10 (0.3)]</td>
<td>Healthy adults [1.8 (0.4)]</td>
<td>0.76</td>
</tr>
<tr>
<td>Barroilhet et al. (2009)</td>
<td>Spanish/ Spain</td>
<td>120</td>
<td>Adults with psychiatric [not reported] and medical illness [not reported]</td>
<td>Healthy adults [1.43 (0.33)]</td>
<td>0.86</td>
</tr>
<tr>
<td>Roncone et al. (1998)</td>
<td>Italian</td>
<td>261</td>
<td>Relative of patients with psychiatric [1.89 (0.40)]; &amp; medical problems [1.98 (0.47)]</td>
<td>Healthy adults [1.72 (0.47)]</td>
<td>0.76</td>
</tr>
<tr>
<td>Wenniger et al. (1993)</td>
<td>Dutch/ Dutch</td>
<td>233</td>
<td>Community adults &gt;18 years [1.68 (0.45)]</td>
<td>None</td>
<td>0.89</td>
</tr>
</tbody>
</table>

Note: SD= Standard deviation
5.2.4 Discussion

The Malay version of the GF-10 subscale was found to have 3-factor model and a reliable instrument for assessing general family functioning in Malaysia.

5.2.4.1 Validity

Factor analysis showed that the GF-12 subscale could not fit into the original 1-factor general functioning scale. Instead, the GF-10 subscale was now a 3-factor model, namely: effective communication, expressiveness & acceptance, and cohesiveness.

Item 2 “In times of crisis we can turn to each other for support” was removed. This may be because Malaysian caregivers perceive crisis as financial or monetary, and prefer not to turn to other family members for financial support. Perhaps in item 2, the word “crisis” could be substituted with the word “critical situation”. Item 4 “Individuals are accepted for who they are” was supposedly to measure perceived acceptance in the family (as with item 8 “We feel accepted for what we are”). However, item 4 did not perform as well. This may be because item 8 asks about “personal perception” whilst item 4 asks about “general opinion” on whether an individual should be accepted for what there are in a family. Perhaps item 4 could be modified to “My family members are accepted for what they are” to improve clarity.

The Malay version of the GF-10 subscale consists of three factors. The first (and main) factor (effective communication) explored communication between family members and their roles within the family. Items that belonged to this component included questions on family activity planning, discussing fears and concerns, resolving conflict and making decisions together. It is speculated that in a Malaysian family, communication refers to
the effectiveness and content of information exchanged among family members. Effective communication also enables family members to make decisions together.

The second factor (expressiveness and acceptance) explored how family members express themselves to each other within the family. These items include “we can express feeling to each other”, “family member feels accepted for what they are” and “we confide in each other. In the McMaster model of family functioning, “acceptance” was not included. This may be because the original model was developed in a western country that promotes an individual’s goals and the value of independence. However in Asian countries like Malaysia, the collectivist culture is more widely practiced. Malaysians are more interdependent on society members. There is a need to feel accepted and to accept others as they are.

The third factor explored “cohesiveness” among family members. These items include questions on how to solve problems together and how to get along well within the family. Cohesiveness in a family is defined as the emotional bonding among family members (Olson, Russell, & Sprengle, 1983). Cohesiveness is an important mediator of a formation, maintenance and closeness among the family members (Bollen & Hoyle, 1990). As a result, the family feels more united, which enables them to solve problems together.

Factor analysis revealed that the GF-10 subscale showed a similar structure to the McMaster Model of Family Functioning, indicating that this instrument can be used to assess overall family functioning. In addition, the GF-10 subscale was also able to assess acceptance and cohesiveness (which is an important component among Asians), which was not included in the McMaster Model of Family Functioning (Epstein et al., 1983).
Family functioning was found to be higher in parents of healthy children versus parents of children respiratory illness, however this difference did not reach statistical significance in our study. This may be due to our small sample size. Our findings were similar to two previous studies which assessed adult stroke (Bishop, Epstein, Keitner, Miller, & Srinivasan, 1986) and spinal cord injury (Evans, Bishop, Haselkorn, Hendricks, & Connis, 1991). A significant difference in family functioning was noted in studies between caregivers of patients with major depression and the community (Barroilhet et al., 2009; Bishop et al., 1986; Evans et al., 1991; Keitner et al., 1987). This may be because compared to physical illnesses, psychiatric illness is more unpredictable and often interrupted by relapses (McClellan & Cohen, 2007). As a result, caregivers experience more stress and difficulty adjusting to unpredictable events, and has worse family functioning.

5.2.4.2 Reliability

The Malay version of the GF-10 subscale showed adequate psychometric properties (internal consistency and test-retest correlation) when administered to Malaysian caregivers. These findings are similar to previous GF-12 subscale validation studies (Barroilhet et al., 2009; Epstein et al., 1983; Kazarian, 2010; Roncone et al., 1998; Shek, 2001; Smilkstein et al., 1982; Speranza et al., 2012; Wenniger et al., 1993).

5.2.4.3 Strengths and limitations

Our study has helped determine the actual factors on the GF-10 subscale. Results have also enabled researchers to assess family functioning, as well as identify issues or problems faced in a family who has children with chronic illness. Thus, effective psychosocial interventions and family counseling can be targeted to family who has low or unhealthy family functioning.
One of the limitations in the present study was that only 73 participants were recruited. When compared with other GF-12 validation studies, this seems small. This was because the present study only validated the GF subscale as a standalone instrument, whereas other studies validated the entire FAD which consisted of 60 items, and hence required a larger sample size. Convergent validity was also not performed in this study as there was no existing validated Malay family functioning instrument available in Malaysia during the period of study.

5.2.5 Conclusions

Although the Malay version of the GF-10 subscale did not show the same structure as the original general family functioning questionnaire, findings of the present study provided insight on dimensions that are applicable to Malaysian caregivers. With the removal of items 2 and 4, the Malay version of the GF-10 subscale was found to be a reliable and valid instrument to assess the general perceived family functioning among caregivers in Malaysia. Future studies should include an assessment of concurrent validity with related measures such as parental mental health and perceived social support.
5.3 Validation of the Chinese version of the General Functioning subscale (GF-12) from the Family Functioning Device

5.3.1 Objective

To determine the factorial validity and reliability of the Chinese version of the GF-12 subscale in Malaysia.

5.3.2 Methods

5.3.2.1 Study design

This validation study and has been conducted in Asthma and respiratory pediatric clinic in UMMC and the community from May 2012- June 2014.

5.3.2.2 Participants

The patient group consists of parents of children with chronic respiratory disease for more than 6 months. To determine if the GF-12 subscale could discriminate between families with children with or without chronic illness, caregivers of healthy children were recruited as controls. Participants were gender and age matched with the patient group. In both groups, caregivers of children who were mentally challenged, with other chronic disease(s) and unable to read or understand Chinese language were excluded. Hired domestic helpers (acting as caregivers for the child) were also excluded.

5.3.2.3 Sample size calculation

Sample size calculation has been described in detail as per section 5.2.2.3.
5.3.2.4 **Instruments**

(a) *Baseline demographic questionnaire*

The baseline demographic questionnaire has been described in detail as per section 5.2.2.4 (a).

(b) *The Chinese version of the General Functioning (GF-12) subscale*

We used the simplified Chinese version of the GF-12 subscale (Appendix X) that was translated and validated in Hong Kong adolescence with psychiatric problems versus healthy adolescence (Shek, 2001). Permission to use this instrument was obtained (appendix T). Face and content validity was tested in five parents who were asked to comment on the simplicity, clarity and relevance of the questions in the GF-12 subscale. Participants encountered no problems in answering the questionnaire.

5.3.2.5 **Procedures**

This has been described in detail in section 5.2.2.5.

5.3.2.6 **Ethics**

This has been described in detail in section 5.2.2.6.

5.3.2.7 **Data analysis**

Normality was assessed using the Shapiro Wilk’s test. Since normally could not be assumed, non-parametric was used. Continuous variables were reported as median and interquartile range; whilst categorical variables were reported as frequency and percentage. A p-value <0.05 was considered as statistically significant.
(a) **Validity**

i **Factor analysis**

CFA was used to test the fit of the data to the original 1-factor subscale. Multiple fit indices include CMIN/DF, CFI, GFI, AGFI, TLI, and RMSEA. A CMIN/DF value close to 1.00 and a non-significant model chi-square (p>0.05) suggests a good model of fit. The CFI, GFI, AGFI, and TLI values greater than 0.90 indicate an adequate model of fit (Hu & Bentler, 1999). Value of RMSEA not greater than 0.70 is considered a sign of good fit. AIC was used to compare models. The smaller the value between two models shows better fit. MDI was used to check any cross-loadings between the latent variables.

ii **Discriminative validity**

This has been described in detail in section 5.2.2.7.(a).ii.

(b) **Reliability**

This has been described in detail in section 5.2.2.7.(b).
5.3.3 Results

A total of 69 parents were approached and 62 parents were recruited (response rate: 89.9%). Thirty-two (51.6%) parents of children with chronic respiratory disease and 30 (48.4%) parents of healthy controls were recruited. No significant differences in the demographic characteristics were found between the two groups (Table 5.5). There were more boys in the patient group but this did not reach statistical significance. Although the majority of the patients had asthma, there was a huge variability in the duration of respiratory symptoms, ranging from 9 months to 15 years.
Table 5.5: Demographic characteristics of caregivers in the control and patient group in validation of Chinese General Functioning subscale (GF-12)

<table>
<thead>
<tr>
<th></th>
<th>Control (n=30)</th>
<th>Patient (n=32)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary caregiver [n (%)]</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>25 (83.3)</td>
<td>26 (81.2)</td>
</tr>
<tr>
<td>Father</td>
<td>5 (16.7)</td>
<td>6 (18.8)</td>
</tr>
<tr>
<td><strong>Median age (years) [IQR]</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;29</td>
<td>3 (10.0)</td>
<td>3 (9.4)</td>
</tr>
<tr>
<td>30-39</td>
<td>16 (53.3)</td>
<td>13 (40.6)</td>
</tr>
<tr>
<td>40-49</td>
<td>7 (23.4)</td>
<td>14 (43.8)</td>
</tr>
<tr>
<td>&gt;50</td>
<td>4 (13.3)</td>
<td>2 (6.2)</td>
</tr>
<tr>
<td><strong>Occupational status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time (≥30 hours/week)</td>
<td>23 (76.7)</td>
<td>19 (59.3)</td>
</tr>
<tr>
<td>Part time (&lt;30 hours/week)</td>
<td>1 (3.3)</td>
<td>3 (6.4)</td>
</tr>
<tr>
<td>Housewife</td>
<td>4 (13.3)</td>
<td>10 (31.3)</td>
</tr>
<tr>
<td>Retired</td>
<td>2 (6.7)</td>
<td>1 (3.0)</td>
</tr>
<tr>
<td><strong>Highest education level completed</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary school</td>
<td>3 (10.0)</td>
<td>1 (3.1)</td>
</tr>
<tr>
<td>High school</td>
<td>13 (43.3)</td>
<td>18 (56.3)</td>
</tr>
<tr>
<td>Diploma/vocational training</td>
<td>8 (26.7)</td>
<td>7 (21.9)</td>
</tr>
<tr>
<td>Bachelor and higher</td>
<td>6 (20.0)</td>
<td>6 (18.8)</td>
</tr>
<tr>
<td><strong>Household income per month (RM)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1999</td>
<td>3 (10.0)</td>
<td>3 (9.4)</td>
</tr>
<tr>
<td>2000-2999</td>
<td>13 (43.3)</td>
<td>5 (15.6)</td>
</tr>
<tr>
<td>3000-3999</td>
<td>5 (16.7)</td>
<td>9 (28.1)</td>
</tr>
<tr>
<td>4000-4999</td>
<td>2 (6.7)</td>
<td>5 (15.6)</td>
</tr>
<tr>
<td>&gt;5000</td>
<td>7 (23.3)</td>
<td>7 (31.3)</td>
</tr>
<tr>
<td><strong>Child’s gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>16 (53.3)</td>
<td>24 (75.0)</td>
</tr>
<tr>
<td>Female</td>
<td>14 (46.7)</td>
<td>8 (25.0)</td>
</tr>
<tr>
<td><strong>Child’s age median (years) [IQR]</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>N/A</td>
<td>20 (62.5)</td>
</tr>
<tr>
<td>Chronic bronchitis</td>
<td>N/A</td>
<td>12 (37.5)</td>
</tr>
<tr>
<td><strong>Type of respiratory disease</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>N/A</td>
<td>20 (62.5)</td>
</tr>
<tr>
<td>Chronic bronchitis</td>
<td>N/A</td>
<td>12 (37.5)</td>
</tr>
<tr>
<td><strong>Duration of respiratory disease median (years) [IQR]</strong></td>
<td>N/A</td>
<td>5.7 [5.0]</td>
</tr>
</tbody>
</table>

Note: IQR= Interquartile range
5.3.3.1 Validity

Using CFA, the results confirmed a good fit between the data and 1-factor structure of the Chinese version of the GF-12, as the test of model yielded: $\chi^2 = 54.912$, df = 50, CIMN/DF=1.098, p=0.294, CFI=0.991, GFI=0.880, AGFI=0.813, TLI=0.898 and RMSEA=0.040, AIC=110.912. Specifically, the AGFI was 0.813, suggesting that about 81.3% of the covariance of items (relationships between all items) could be explained by the factor structure. Standardized factor loadings for other items were highly correlated to the general family functioning factor, with loadings from 0.650 to 0.880 (Figure 5.2).
Figure 5.2: The factor structure of the Chinese version of the General Functioning (GF-12) subscale in Malaysia using Confirmatory Factor Analysis.
5.3.3.2 Discriminative validity

There was no difference in the GF-12 subscale scores between the patient and the control groups (1.82 versus 1.71), \( p=0.395 \).

5.3.3.3 Reliability

The overall Cronbach’s \( \alpha \) value of the Chinese version of the GF-12 subscale was 0.950. Corrected item-total correlations were more than 0.30 (Table 5.6). The deletion of any item did not improve the overall Cronbach’s \( \alpha \) of 0.950. Hence, all 12 items were retained.

Test-retest reliability was assessed in 56 (90%) participants after two weeks (Table 5.6). Six parents were lost in follow up: two parents (3.0%) were not contactable and four (6.5%) failed to complete the second set of questionnaires within the given period. All items showed moderate to high Spearman’s correlation coefficients (0.45 to 0.83; \( p<0.001 \)).
### Table 5.6 Reliability of the Chinese General Functioning subscale (GF-12)

<table>
<thead>
<tr>
<th>Item</th>
<th>Corrected item-total correlation</th>
<th>Cronbach’s α if item is deleted</th>
<th>Parents (n=62) at baseline (test)</th>
<th>Patient (n=32)</th>
<th>Discriminant validity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Control (n=30)</td>
<td>Patient (n=32)</td>
<td>Mann-Whitney U test</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mean (SD)</td>
<td>Median</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>1. Planning family activities is difficult because we misunderstand each other#</td>
<td>0.822</td>
<td>0.944</td>
<td>1.53 (0.63)</td>
<td>1.00</td>
<td>1.90 (0.77)</td>
</tr>
<tr>
<td>2. In times of crisis we can turn to each other for support</td>
<td>0.755</td>
<td>0.944</td>
<td>1.50 (0.51)</td>
<td>1.50</td>
<td>1.65 (0.70)</td>
</tr>
<tr>
<td>3. We cannot talk to each other about the sadness we feel#</td>
<td>0.686</td>
<td>0.948</td>
<td>2.03 (.85)</td>
<td>2.00</td>
<td>2.06 (0.84)</td>
</tr>
<tr>
<td>4. Individuals are accepted for what they are</td>
<td>0.728</td>
<td>0.945</td>
<td>1.53 (0.57)</td>
<td>1.50</td>
<td>1.65 (0.70)</td>
</tr>
<tr>
<td>5. We avoid discussing our fears and concerns#</td>
<td>0.651</td>
<td>0.948</td>
<td>1.90 (0.54)</td>
<td>2.00</td>
<td>2.19 (0.85)</td>
</tr>
<tr>
<td>6. We can express feelings to each other</td>
<td>0.864</td>
<td>0.941</td>
<td>1.77 (0.56)</td>
<td>2.00</td>
<td>1.97 (0.73)</td>
</tr>
<tr>
<td>7. There are lots of bad feelings in the family#</td>
<td>0.793</td>
<td>0.948</td>
<td>1.50 (0.57)</td>
<td>1.00</td>
<td>1.69 (0.82)</td>
</tr>
<tr>
<td>8. We feel accepted for what we are</td>
<td>0.723</td>
<td>0.945</td>
<td>1.50 (0.50)</td>
<td>1.50</td>
<td>1.65 (0.60)</td>
</tr>
<tr>
<td>9. Making decisions is a problem for our family#</td>
<td>0.756</td>
<td>0.944</td>
<td>1.73 (0.69)</td>
<td>2.00</td>
<td>1.84 (0.72)</td>
</tr>
<tr>
<td>10. We are able to make decisions about how to solve problems</td>
<td>0.806</td>
<td>0.943</td>
<td>1.76 (0.57)</td>
<td>2.00</td>
<td>1.81 (0.73)</td>
</tr>
<tr>
<td>11. We don’t get along well together#</td>
<td>0.822</td>
<td>0.942</td>
<td>1.50 (0.57)</td>
<td>1.00</td>
<td>1.72 (0.81)</td>
</tr>
<tr>
<td>12. We confide in each other</td>
<td>0.795</td>
<td>0.943</td>
<td>1.60 (0.56)</td>
<td>2.00</td>
<td>1.84 (0.85)</td>
</tr>
<tr>
<td>Total score</td>
<td>N/A</td>
<td>N/A</td>
<td>1.65 (0.46)</td>
<td>1.71</td>
<td>1.83 (0.63)</td>
</tr>
</tbody>
</table>

Note: # Items are reversed; SD= Standard deviation
5.3.3.4 Comparison of the Chinese General Functioning subscale (GF-12) with previous studies

The psychometric properties of the Chinese version of the GF-12 subscale validated in Malaysia were compared with other GF-12 subscale validated elsewhere (Table 5.7). Psychometric findings were similar among these studies.
Table 5.7: Comparison of the Chinese General Functioning subscale (GF-12) with previous studies

<table>
<thead>
<tr>
<th>Authors</th>
<th>Language/Country</th>
<th>n</th>
<th>Sample</th>
<th>Cronbach’s alpha</th>
<th>Test-retest reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present study</td>
<td>Chinese/Malaysia</td>
<td>62</td>
<td>Parents of children with chronic respiratory disease aged 1-17 [1.83 (.63)]</td>
<td>0.95</td>
<td>0.85</td>
</tr>
<tr>
<td>Original study: Epstein et al., (1983)</td>
<td>English/Canada</td>
<td>294</td>
<td>Psychiatric adult patients &gt;18 years [2.6 (0.58)]</td>
<td>0.920</td>
<td>0.71</td>
</tr>
<tr>
<td>Wo et al., (2012)</td>
<td>Malay/Malaysia</td>
<td>73</td>
<td>Caregivers of children with chronic respiratory disease [1.68 (0.36)]</td>
<td>0.806</td>
<td>0.82</td>
</tr>
<tr>
<td>Shek (2001)</td>
<td>Chinese/HK, China</td>
<td>732</td>
<td>Adolescents with behavioural and emotional problems [2.45 (0.51)]</td>
<td>Not reported</td>
<td>0.77</td>
</tr>
<tr>
<td>Kazarrian (2010)</td>
<td>Armenian/Lebanon</td>
<td>558</td>
<td>None</td>
<td>0.80</td>
<td>Not reported</td>
</tr>
<tr>
<td>Speranza et al. (2012)</td>
<td>French/ (France)</td>
<td>323</td>
<td>Relative(s) of psychiatric adult patients [2.30 (0.3)] and medical adult patients and their relatives [2.10 (0.3)]</td>
<td>0.76</td>
<td>0.88</td>
</tr>
<tr>
<td>Barroilhet et al. (2009)</td>
<td>Spanish/ (Spain)</td>
<td>120</td>
<td>Adults with psychiatric [not reported] and medical illness [not reported]</td>
<td>0.86</td>
<td>0.91</td>
</tr>
<tr>
<td>Roncone et al. (1998)</td>
<td>Italy/ Italian</td>
<td>261</td>
<td>Adult relative(s) of patients with psychiatric [1.89 (0.40)] and medical problems [1.98 (0.47)]</td>
<td>0.76</td>
<td>0.89</td>
</tr>
<tr>
<td>Wenniger et al. (1993)</td>
<td>Dutch/Dutch</td>
<td>233</td>
<td>Community adults &gt;18 years [1.68 (0.45)]</td>
<td>0.89</td>
<td>Not reported</td>
</tr>
</tbody>
</table>

Note: HK= Hong Kong; SD= Standard deviation
5.3.4 Discussion

The Chinese version of the GF-12 subscale was found to be a 1-factor model and a reliable instrument for assessing general family functioning in Malaysia.

5.3.4.1 Validity

CFA revealed that the Chinese version of the GF-12 subscale was consistent with a 1-factor model (Ridenour, Daley, & Reich, 1999), indicating that this instrument can be used to assess overall family functioning. These findings were different from the validation of the Italian version of the GF-12 subscale which found that their GF-12 subscale was a 4-factor model with the following domains: competence, emotional communication, and center-on-self. A possible explanation could be the way English speaking families behave as compared to Italian families. Generally, Italian families are more emotional, self-sacrificing, and protective over their family members as compared to English speaking families. In addition, Italian mothers tend to do all the family household chores, whereas English speaking families will have their chores divided among family members. Hence some modification of the GF-12 subscale was required for the Italian population (Roncone et al., 1998)

In our study, although family functioning was found to be higher in parents of healthy children versus parents of children respiratory illness, this difference did not reach statistical significance. This may be due to our small sample size. However, our findings were similar to other studies which assessed adult stroke (Bishop et al., 1986) and spinal cord injury (Evans et al., 1991). However, a significant difference in family functioning was noted in studies between caregivers of patients with major depression and the community (Barroilhet et al., 2009; Bishop et al., 1986; Evans et al., 1991; Keitner et al., 1987). There are several possible explanations for these discordant results. According to
(Rolland, 1999), key characteristics of the disease affect the family system and its adaptive functioning. Compared to physical illnesses, the course of psychiatric illness is unpredictable and often interrupted by relapses (McClellan & Cohen, 2007). As a result, caregivers experience more stress and difficulty adjusting to unpredictable events, giving rise to worse family functioning. Other variables such as the number and age of the siblings in a family could also influence family functioning, but this was not examined in our study.

5.3.4.2 Reliability

The Chinese version of the GF-12 subscale showed adequate psychometric properties (internal consistency and test-retest correlation). Our findings are similar to previous GF-12 subscale validation studies (Epstein et al., 1983; Kazarian, 2010; Roncone et al., 1998; Shek, 2001; Speranza et al., 2012; Wenniger et al., 1993).

5.3.4.3 Strengths and limitations

The strength of this study is that the Chinese GF-12 subscale can be used as a quick and effective tool to identify unhealthy family functioning in Malaysia. There were several limitations in our study. Although the rules for a validation study were met, the sample size in our study (n=62) was small compared to other GF-12 validation studies. This was because we only validated the GF-12 subscale as a standalone instrument, whereas other studies validated the entire FAD that consisted of 60 items (which required a larger sample size). Secondly, convergent validity was not performed given the lack of available Chinese validated instruments assessing family functioning in Malaysia during our study period. The GF-12 also failed to differentiate between families of children with chronic respiratory disease and healthy controls. Using the GF-12 on other population groups with physical or cognitive disability might yield different results. Future validation
studies of the GF-12 subscale should test the correlation of the GF-12 subscale with other variables related to family functioning such as parenting stress, to assess test for criterion-related validity (Rodenburg, Meijer, Deković, & Aldenkamp, 2005).

5.3.5 Conclusions

The Chinese GF-12 subscale was found to be a 1-factor model and a reliable instrument to assess the parents’ perceived family functioning of children with and without respiratory disease in Malaysia. Parents of children in both groups perceived good family functioning. No significant difference in family functioning was found between these two groups.
CHAPTER 6: THE IMPACT OF EPILEPSY ON ACADEMIC ACHIEVEMENT IN CHILDREN WITH NORMAL INTELLIGENCE AND WITHOUT COMORBIDITIES: A SYSTEMATIC REVIEW

Academic achievement is defined as the “knowledge attitude or skill developed in the school subject usually designed by test scores or by marks assigned by a teacher or by both” (Bray & Kehle, 2011; Woolfolk, 2007). Children with academic difficulties may exhibit “underachievement” or “low achievement”. Underachievement occurs when a child’s academic performance falls significantly below what is expected of the child’s intelligence quotient (IQ), whereas low achievement is when a child’s academic performance is below the population’s mean, and is independent of the child’s IQ (Puka, Khattab, Kerr, & Smith, 2015). The distinction between “underachievement” and “low achievement” is important, as the eligibility for special education is based on these definitions (C. Reilly & Neville, 2011). This chapter will report on the systematic review on the impact of epilepsy on academic achievement in children with normal intelligence and without comorbidities.

6.1 Introduction

Academic difficulty has been reported among children with epilepsy (CWE), even when these children have normal intelligence (i.e. an IQ≥70) (Fastenau et al., 2008; McNelis et al., 2005; Mitchell, Chavez, Lee, & Guzman, 1991), particularly in mathematics and reading (Fastenau et al., 2008; Jackson et al., 2013; Puka et al., 2015). However, studies on academic achievement in childhood epilepsy have relied on subjects recruited from clinical settings which tend to include CWE who have below average intelligence (an IQ<70) (Fastenau et al., 2008; McNelis et al., 2005; Colin Reilly et al., 2014). Therefore, the true prevalence of academic difficulties in CWE of normal
intelligence is not known. In a community based study conducted in the United States, CWE were found to have a high rate of school difficulties and grade repetition (Russ et al., 2012). If CWE are unable to progress as well as their peers in school, and tend to drop out of school earlier, it may impact on their social outcomes as they progress into adulthood (Sillanpaa, Jalava, Kaleva, & Shinnar, 1998). A study in the United Kingdom found that 31% of adults who had childhood epilepsy pursued higher education, compared to 48% of normal population (Chin et al., 2011). The same study showed the unemployment rate among adults with childhood epilepsy was 23% as compared with only 9% of the normal population (Chin et al., 2011).

Due to the nature of epilepsy as a disease, and the side effects of its treatment, CWE may have specific learning problems such as inattention and working memory that influence on classroom learning and academic achievement (C. Reilly & Neville, 2011). Although seizure variables (e.g. age of seizure onset, effects of antiepileptic drug) may affect academic achievement, study findings are conflicting (Aldenkamp, Weber, Overweg-Plandsoen, Reijs, & van Mil, 2005; Williams et al., 2001).

Family factors may also contribute to academic difficulties in CWE (Chambers et al., 2014; McNelis et al., 2005; Mitchell et al., 1991). Negative parenting such as harsh or inconsistent methods on how a parent disciplines a child, may deter a child from learning (Oostrom, Schouten, Kruitwagen, Peters, & Jennekens-Schinkel, 2003). A parent’s mental health may also affect the child. Greater parent’s anxiety may cause a child with epilepsy to withdraw from society and learning, as CWE usually internalize their anxiety and depression, thus making learning more difficult (D. W. Dunn et al., 2010). Mitchell and colleagues(1991) reported that encouragement from parents, as well as family
participation in promoting positive emotional and physical growth in CWE, may promote better academic achievement.

Child psychosocial and school factors may also have a significant impact on academic achievement. CWE who have negative attitudes toward their illness, have a low self-esteem, and poor motivation have poorer academic achievement (Austin, Huberty, Huster, & Dunn, 1998). These children will feel less positive about school as they are worried about how they will perform in examinations, are anxious when their teacher calls on them to answer questions (J. K. Austin, T. J. Huberty, G. A. Huster, & D. W. Dunn, 1998). McNelis and colleagues (2005) (McNelis et al., 2005) suggested that teacher’s involvement in assessing and monitoring CWE who are at risk for academic difficulties is important to help CWE success in academic achievement (McNelis et al., 2005).

A search of published literature revealed that to date, no systematic review has been performed on the impact of epilepsy on academic achievement in children with epilepsy and normal intelligence (IQ≥70). A literature review by Reilly et al in 2011 included studies which utilized both subjective (such as teacher’s reports) and objective measures of academic achievement, and recruited mixed population of children that attended normal as well as special education schools (C. Reilly & Neville, 2011).

6.1.1 Objective

To systematically examine published literature which focused on the academic achievement in CWE with normal intelligence (IQ>70) and without comorbidities, with respect to the prevalence of academic difficulties, and the possible factors associated with academic achievement.
6.2 Methods

6.2.1 Type of outcome

The types of patient outcome assessed were the scores of academic achievement based on standardized objective instruments in CWE.

6.2.2 Type of study

The type of study included were cross sectional and longitudinal studies.

6.2.3 Search strategies

The PRISMA guideline was used to guide our search strategy (Moher, Liberati, Tetzlaff, & Altman, 2009). A search was conducted on five databases: ERIC, PubMed, CINAHL, WoS, and PsycINFO for all studies assessing academic achievement in CWE, until March 2015. Medical Subject Headings (MESH) definitions of [“epilep*”, “seizure”] and [“child*”, “schoolchild*”, “school age*”, “preschool*”, “kid*”, “adoles*”, “teen*”, “boy*”, “girl*”, “paediatric*”, “school”, “primary school*”, “secondary school*”, “elementary school*”, “high school*”] was used to defined the study population. In addition, specific MESH definitions to describe outcomes such as [“academic”, “education”, “cogni*”, “achievement*”, “underachievement*”, “assessment*”, “low achievement*”].

6.2.4 Inclusion and exclusion criteria

Published articles which met the following criteria were considered for inclusion: cross sectional or longitudinal studies, in English (as we did not find any other study that published in other languages), conducted in children with a diagnosis or newly or recurrent epilepsy, aged 5-18 years, with an IQ ≥70 and attending regular school, with or without a control group, and which measured academic achievement using a standardised
objective instrument. A child was considered epileptic when diagnosed by a paediatric neurologist. Only studies published as full text article were included. Excluded were children with learning difficulties, intellectual disabilities (IQ<70) and other comorbidities such as attention deficit hyperactive disorder or autism. This is because these children may have learning difficulty. In addition, studies which reported on academic achievement measurement using unstandardized subjective instrument and article published only in abstract were excluded.

6.2.5 Data extraction

Two forms were used to extract data: the “Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies” (NIH, 2004) [Appendix Y] and a self-developed data extraction form [Appendix Z].

These forms were pilot-tested on five randomly-selected studies. Two pairs of reviewers (SWW/WYL and LCO/PSML) extracted data from each study. The two pairs then met to resolve any differences from the data extraction process. Due to substantial heterogeneity in the study design and outcomes measure of the articles reviewed, no attempt was made to summarize the data using meta-analysis.

6.3 Results

The number of studies which met the review inclusion criteria is shown in Figure 6.1.
Records identified through database searching (n=270)

Additional records identified through other sources (n=0)

Records after duplicates were removed (n=134)

Records screened (n=136)

Records excluded (n=106)
- Included children with other comorbidities (n=22)
- Included children with IQ <70 (n=20)
- Drug efficacy studies (n=29)
- Studies that did not use standardized objective instruments (n=12)
- Adults with epilepsy (n=13)
- Full text not available (n=10)

Full-text articles assessed for eligibility (n=30)

Studies included (n=20)

Excluded (n=10)
- Used subjective measures to assess academic achievement (n=3)
- Included children with IQ<70 (n=7)

Figure 6.1: Flow chart of the systematic review
6.3.1 Study characteristics of included studies

Out of 20 studies, 13 studies were conducted in the United States (J. K. Austin et al., 1998, 1999; Bailet & Turk, 2000; Caplan et al., 2006; Drewel, Bell, & Austin, 2009; Hermann et al., 2008; Jackson et al., 2013; Jones, Siddarth, Gurbani, Shields, & Caplan, 2010; Mitchell et al., 1991; Schoenfeld et al., 1999; Seidenberg et al., 1986; Williams et al., 2001; Williams, Sharp, Bates, Griebel, & et al., 1996), three in the Netherlands (Aldenkamp et al., 2005; Braakman et al., 2012; Overvliet et al., 2011), two in Brazil (Miziara et al., 2012; Tedrus, Fonseca, Melo, & Ximenes, 2009), one in Jamaica (Chambers et al., 2014), and one in Turkey (Gulgonen, Demirbilek, Korkmaz, Dervent, & Townes, 2000).

Fifteen studies were conducted at a single site (a public hospital) (Aldenkamp et al., 2005; Bailet & Turk, 2000; Braakman et al., 2012; Chambers et al., 2014; Gulgonen et al., 2000; Hermann et al., 2008; Jackson et al., 2013; Mitchell et al., 1991; Miziara et al., 2012; Overvliet et al., 2011; Schoenfeld et al., 1999; Seidenberg et al., 1986; Tedrus et al., 2009; Williams et al., 2001; Williams et al., 1996). The remaining 5 studies were conducted in more than one site: two were conducted in both a public and private hospital (J. K. Austin et al., 1998, 1999), one was conducted in a public hospital, private hospital and the community (Caplan et al., 2006; Jones et al., 2010), whilst one was conducted in a public hospital, private hospital and school (Drewel et al., 2009).

Sixteen were cross sectional studies (Aldenkamp et al., 2005; J. K. Austin et al., 1998; Braakman et al., 2012; Caplan et al., 2006; Chambers et al., 2014; Drewel et al., 2009; Gulgonen et al., 2000; Jackson et al., 2013; Mitchell et al., 1991; Miziara et al., 2012; Overvliet et al., 2011; Schoenfeld et al., 1999; Seidenberg et al., 1986; Tedrus et al., 2009; Williams et al., 2001; Williams et al., 1996), and four were longitudinal studies (J. K.
Austin et al., 1999; Bailet & Turk, 2000; Hermann et al., 2008; Jones et al., 2010) (Table 6.1 and Table 6.2, respectively).
Table 6.1 Cross sectional studies (n=16) which assessed the academic achievements of children with epilepsy

<table>
<thead>
<tr>
<th>Author(s) year</th>
<th>Setting</th>
<th>Population (sample size)</th>
<th>Control group</th>
<th>Instrument(s) used</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aldenkamp et al., 2005</td>
<td>Public hospital, The Netherlands</td>
<td>Children aged 6-12 years (n=176): PE (n=121); IGE (n=30); SGE (n=25)</td>
<td>Healthy controls (n=113)</td>
<td>Tempotest</td>
<td>Low achievement in CWE in comparison with healthy controls: Difference of 12 months in educational delay (mathematics and reading subscales) between the 2 groups. Children with PE had 14 months educational delay; whilst children with SGE had 26 months educational delay, compared to healthy controls. No educational delay was found in children with IGE.</td>
</tr>
<tr>
<td>Austin et al., 1998 (1998)</td>
<td>Public and private clinics, USA</td>
<td>Children aged 6-12 years (n=225): CWE (n=117)</td>
<td>Children with asthma (n=108)</td>
<td>CAT and ITBS</td>
<td>CWE had significantly lower achievement scores in reading and mathematics subscales than children with asthma.</td>
</tr>
<tr>
<td>Braakman et al., 2012 (2012)</td>
<td>Public hospital, the Netherlands</td>
<td>Children aged 6-16 years (n=50): children with FLE (n=50)</td>
<td>None</td>
<td>Tempotest</td>
<td>Low achievement in CWE in comparison of reference value, score &lt;80 indicates delay of academic achievement Children with FLE performed worse in reading and mathematics, which was significantly lower than the reference values on all subtests. Scores were lowest in participants with the highest seizure activity.</td>
</tr>
</tbody>
</table>
Table 6.1 continued

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Setting</th>
<th>Population (sample size)</th>
<th>Control group</th>
<th>Instrument(s) used</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caplan et al., (2006)</td>
<td>Public hospital, community services and private practices, USA</td>
<td>Children aged 5.1-16.3 years (n=149): children with CPS (n=93) &amp; PGE (n=56)</td>
<td>None</td>
<td>WIAT Screener</td>
<td>CWE demonstrated academic achievement within average range. There was no significant difference in academic achievement (reading, spelling, and mathematics) between children with CPS and PGE.</td>
</tr>
<tr>
<td>Chambers et al., (2014)</td>
<td>Public hospital, Jamaica</td>
<td>Children aged 7-12 years (n=66): children with GE and children with PE (n=33)</td>
<td>Healthy controls (n=33)</td>
<td>WRAT-3 math expanded</td>
<td>CWE did not score significant lower in mathematics compared to healthy controls.</td>
</tr>
<tr>
<td>Drewel et al., (2009)</td>
<td>Public clinics, private practices, and schools, USA</td>
<td>Children aged 8.5-15.1 years (n=173): children with GTCS, myoclonic or atonic (n=26), CPS or SPS (n=107) and AS (n=40)</td>
<td>None</td>
<td>WJR</td>
<td>Low achievement is defined as lower than expected mean (SD): 100(50)</td>
</tr>
<tr>
<td>Gulgonen et al., (2000)</td>
<td>Public hospital, Turkey</td>
<td>Children aged 6-14 years (n=42): children with IOLE (n=21)</td>
<td>Healthy controls (n=21)</td>
<td>WRAT-3, mathematics subscale only</td>
<td>There was no significant difference in mathematics between CWE and healthy controls. However, the performance in CWE was significantly inferior to healthy controls in the mental mathematics but not written mathematics.</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Setting</td>
<td>Population (sample size)</td>
<td>Control group</td>
<td>Instrument(s) used</td>
<td>Outcome</td>
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</table>
| Jackson et al., (2013) | Public hospital in USA | Children aged 8-18 years (n=166)  
Children with IGE: JME (n= 26) and CAE (n=11) and children with ILRE: BECTS (n=22) and FE (n=31) | Healthy controls (n=72) | WRAT-3 | Children with IGE performed significantly worse than healthy controls in spelling and mathematics, where mathematics showed the greatest discrepancies from healthy controls.  
Participants with ILRE scored significantly worse than healthy controls in mathematics.  
Participants with IGE scored significantly lower than ILRE participants only on tests of mathematics.  
Further analysis showed that all the sub-syndromes of IGE & ILRE (CAE, BECT, JME & FE) scored significantly lower in mathematics compared to healthy controls. Children with CAE had significant lower score in spelling compared to healthy controls. |
| Mitchell et al, (1991) | Public hospital in USA | Children aged 5-13 years (n=78) with: CWE (n=78) | None | PIAT | Academic underachievement defined as 0.5 SD below the expected score based on IQ level  
The percentage of CWE who were underachieving were greatest in general knowledge (50%), followed by reading comprehension (38%), mathematics (31%), spelling (32%) and reading (16%) |
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Setting</th>
<th>Population (sample size)</th>
<th>Control group</th>
<th>Instrument(s) used</th>
<th>Outcome</th>
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</thead>
<tbody>
<tr>
<td>Miziara et al., (2012)</td>
<td>Public hospital, Brazil</td>
<td>Children aged 7-13 years (n=71): children with BECTS (n=30)</td>
<td>Healthy controls (n=41)</td>
<td>SPT</td>
<td>The BECTS group had a significantly lower mean SPT score (composite of reading, mathematics, and writing subscales) than that of the healthy controls group.</td>
</tr>
<tr>
<td>Overvliet et al., (2011)</td>
<td>Public hospital, the Netherlands</td>
<td>Children aged 6.5-13 years (n=48) with: children with RE (n= 48)</td>
<td>None</td>
<td>Tempotest</td>
<td>Low achievement in CWE with scores of &lt;100 was considered to have an educational delay, &lt;50 indicates reading or mathematic deficits. Children with RE has significant impairment in reading (delay mean of 8.6 months in reading sentences and delay mean of 6 months in reading words) compared to mathematics (delay mean of 4.1 months). The finding indicated that RE is a language-related learning disorder but not a general learning disorder.</td>
</tr>
<tr>
<td>Schoenfeld et al., (1999)</td>
<td>Public hospital, USA</td>
<td>Children aged 7-16 years (n=84): children with CPS (n= 57)</td>
<td>Healthy controls (n=27)</td>
<td>WRAT-3</td>
<td>When IQ was used as covariance, children with CPS performed significantly worse than the healthy controls in academic achievement (reading, spelling and mathematics subscales).</td>
</tr>
</tbody>
</table>
Table 6.1 continued

<table>
<thead>
<tr>
<th>Author(s) and year</th>
<th>Setting</th>
<th>Population (sample size)</th>
<th>Control group</th>
<th>Instrument(s) used</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seidenberg et al., (1986)</td>
<td>Public hospital, USA</td>
<td>Children aged 7-15 years (n=122); children with GS (n=72) and children with PS (n=50)</td>
<td>None</td>
<td>WRAT and PIAT</td>
<td>Academic underachievement with cutoff of 1 SD below the expected score based on IQ level of CWE. CWE were making less academic progress than expected for their age and IQ level. Underachievement in CWE ranged from 10.1% - 33.3%. Academic deficiencies were greatest in mathematics, followed by spelling, reading, comprehension and word recognitions.</td>
</tr>
<tr>
<td>Tedrus et al., (2009)</td>
<td>Public hospital, Brazil</td>
<td>Children aged 8-11 years (n=69), children with BECTS without educational problem (n=31)</td>
<td>Healthy controls (n=38)</td>
<td>SPT</td>
<td>Low achievement in CWE in comparison with healthy control, using two categories: best 75% (superior or average) and lowest 25% (inferior). There was no significant differences on the mathematics subtest in children with BECTS compared to healthy controls. However, performance in reading and writing was frequently inferior for children with BECTS.</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Setting</td>
<td>Population (sample size)</td>
<td>Control group</td>
<td>Instrument(s) used</td>
<td>Outcome</td>
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<tr>
<td>Williams et al., (2001)</td>
<td>Public hospital, USA</td>
<td>Children aged 8-13 years (n=65): children with CPS (n=44) and GS (n=21)</td>
<td>None</td>
<td>WJR</td>
<td>Low achievement is defined as lower than expected mean (SD): 100(50)</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
<td>CWE demonstrated academic achievement within average range which was comparable to national norms.</td>
</tr>
<tr>
<td>Williams et al., (1996)</td>
<td>Public hospital, USA</td>
<td>Children aged 5.11-16.2 years (n=84): children with CPS or AS disorders: controlled CPS (n=22), controlled AS (n=22), uncontrolled CPS (n=21), and uncontrolled AS (n=19).</td>
<td>None</td>
<td>ITBS, Stanford 8, MAT 7, and CTBS 4</td>
<td>Low achievement in CWE in comparison with national norms.</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>Overall achievement scores for the sample has average range for reading (45%), mathematics (46%), language (50%), spelling (49%) and the basic battery (46%).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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<td></td>
<td>However, children with poor controlled seizures had significantly lower scores in reading compared to children with adequate seizure control.</td>
</tr>
</tbody>
</table>

PE, Partial epilepsy; IGE, Idiopathic generalized epilepsy; SGE, Symptomatic generalized epilepsy; USA, United States of America; CWE, Children with epilepsy; CAT, California Achievement Test; ITBS, Iowa Tests of Basic Skills; FLE, Frontal lobe epilepsy; CPS, Complex partial seizure; PGE, Primary generalized epilepsy with absence; WIAT, Wechsler Individual Achievement Test; WRAT-3, Wide Range Achievement Test-3; GE, Generalized epilepsy; SD, Standard deviation; GTCS, Generalised tonic clonic seizures; SPS, Simple partial seizure; AS, Absence seizure; WJR, Woodcock-Johnson Test of Achievement- Revised; IOLE, Idiopathic occipital lobe epilepsy; JME, Juvenile myoclonic epilepsy; CAE; childhood absence epilepsy; ILRE, Idiopathic localized related epilepsy; BECTS; Benign epilepsy with centro-temporal spikes; FE; Focal epilepsy; PIAT, Peabody Individual Achievement Test; SPT, School Performance Test; RE, Rolantic epilepsy; PS, Partial seizure; WRAT, Wide Range Achievement Test; Stanford 8, Stanford Achievement Test 8th edition; MAT 7, Metropolitan Achievement Test 7th edition; CTBS 4, Comprehensive Tests of Basic Skills 4th edition.
Table 6.2 Longitudinal studies (n=4) on academic achievement in children with epilepsy

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Study design, setting</th>
<th>Duration, number of times followed up</th>
<th>Population (sample size)</th>
<th>Instrument(s) used</th>
<th>Outcome</th>
</tr>
</thead>
</table>
| Austin et al., (1999) | Public and private clinics, USA | 4 years, at baseline and after 4 years | Children aged 12-17 years (n=194): CWE (n=98); controls: Children with asthma (n=96) | CAT, ITBS, and ISTEP | Twice as many CWE (44%) repeated at least one grade at school, as compared to children with asthma (22.5%).  
4 years later, CWE continued to perform significantly worse in all five achievement areas: composite, reading, mathematics, language and vocabulary) compared to children with asthma.  
Overall, children with either inactive or low-severity epilepsy had mean scores comparable to national norms.  
Those with high seizure severity had mean scores ranging from 3-5 points below national norms.  
No changes were found in academic achievement over time for either sample, even among those whose conditions improved.  
Although boys with high-severity epilepsy continued to have the lowest achievement scores, there was no trend for them to decline in achievement over time. |
<table>
<thead>
<tr>
<th>Author(s) year</th>
<th>Study design, setting</th>
<th>Duration, number of times followed up</th>
<th>Population (sample size)</th>
<th>Instrument(s) used</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bailet and Turk (2000)</td>
<td>Public clinics, USA</td>
<td>3 years, at baseline, after 1 year and 2 years</td>
<td>Children aged 8-13 years (n=113): children with IGE (n=77); controls: Children with migraine (n=13), and healthy controls (n=23)</td>
<td>WRAT-R</td>
<td>CWE had higher rates of grade retention (34%) and placement in special education (19%) compared with healthy controls. 4 years later, CWE scored significantly worse than healthy controls in all three academic subscales: reading, mathematics and spelling.</td>
</tr>
<tr>
<td>Hermann et al., (2008)</td>
<td>Public hospital, USA</td>
<td>2 years, at baseline and after 2 years</td>
<td>Children aged 8-18 years (n=62): children with newly onset epilepsy, without comorbidity: LRE (n=11) and IGE (n=13); controls: Healthy controls (n=38)</td>
<td>WRAT-3</td>
<td>CWE without comorbidity were no different from healthy controls. They were comparable and equivalent to healthy controls in all tested areas of academic achievement (reading, mathematics and spelling).</td>
</tr>
<tr>
<td>Jones et al., (2010)</td>
<td>Public hospital, private hospital and community, USA</td>
<td>2 years, at baseline and after 2 years at the 2nd year (lost to follow up: CWE (32%) and healthy controls (56%))</td>
<td>Children aged 7.6-16.1 years (n=82): children with CPS (n=31), CAE (n=25), and it was grouped into two groups: IQ below average (n=23) and average IQ (n=41); controls: Healthy controls (n=27)</td>
<td>WIAT screener</td>
<td>Academic achievement (reading, mathematic and spelling) was remarkable stability over the 2-year interval in all three groups. Among the CWE average IQ group with decreased seizure frequency at follow-up had a decline in mathematic score.</td>
</tr>
</tbody>
</table>

USA, United States of America; CWE, children with epilepsy; CAT, California Achievement Test; ITBS, Iowa Tests of Basic Skills; ISTEP, Indiana Statewide Test of Educational Progress; IGE, Idiopathic generalized epilepsy; WRAT-R, Wide Range Achievement Test Revised; LRE, Localized related epilepsy; WRAT-3, Wide Range Achievement Test 3; CPS, Complex partial seizure; CAE; childhood absence epilepsy; WIAT, Wechsler Individual Achievement Test.
Twelve out of 20 studies had a control group (Aldenkamp et al., 2005; J. K. Austin et al., 1998, 1999; Bailet & Turk, 2000; Chambers et al., 2014; Gulgonen et al., 2000; Hermann et al., 2008; Jackson et al., 2013; Jones et al., 2010; Miziara et al., 2012; Schoenfeld et al., 1999; Tedrus et al., 2009), whilst the remaining eight studies which did not have a control group, compared their academic achievement scores with normal means (Braakman et al., 2012; Caplan et al., 2006; Drewel et al., 2009; Mitchell et al., 1991; Overvliet et al., 2011; Seidenberg et al., 1986; Williams et al., 2001; Williams et al., 1996). Of the 12 studies that had a control group, nine studies used healthy children as controls (Aldenkamp et al., 2005; Chambers et al., 2014; Gulgonen et al., 2000; Hermann et al., 2008; Jackson et al., 2013; Jones et al., 2010; Miziara et al., 2012; Schoenfeld et al., 1999; Tedrus et al., 2009), whilst three studies used children with asthma or migraine as controls (Austin et al., 1998, 1999; Bailet & Turk, 2000).

Five out of 20 studies reported the response rates of their participants upon recruitment (range: 50.1%-97.0%) (Chambers et al., 2014; Drewel et al., 2009; Jackson et al., 2013; Mitchell et al., 1991; Miziara et al., 2012). However, only two studies performed a sample size calculation: (range: 42-220) (Aldenkamp et al., 2005; Chambers et al., 2014). Participants were followed up for two (Hermann et al., 2008; Jones et al., 2010), three (Bailet & Turk, 2000), and four years (J. K. Austin et al., 1999), respectively in the longitudinal studies.

6.3.2 **Low achievement and underachievement in children with epilepsy**

Out of 20 studies, only 18 studies assessed low achievement in CWE: 11 and four studies compared the expected mean score of CWE with controls (J. K. Austin et al., 1998, 1999; Bailet & Turk, 2000; Chambers et al., 2014; Gulgonen et al., 2000; Hermann et al., 2008; Jackson et al., 2013; Jones et al., 2010; Miziara et al., 2012; Schoenfeld et
al., 1999; Tedrus et al., 2009), and reported norms (Caplan et al., 2006; Drewel et al., 2009; Williams et al., 2001; Williams et al., 1996), respectively, whilst three assessed educational delay (Aldenkamp et al., 2005; Braakman et al., 2012; Overvliet et al., 2011).

Two studies assessed underachievement by using the IQ-achievement discrepancy definition cutoff score of 0.5 standard deviation (Mitchell et al., 1991) and 1.0 standard deviation (Seidenberg et al., 1986), below the expected IQ score. Underachievement in CWE ranged from 10-50% (Mitchell et al., 1991; Seidenberg et al., 1986).

6.3.3 Academic difficulties in children with epilepsy

Fourteen out of 20 studies reported that CWE had academic difficulties compared to controls or reported norms (Aldenkamp et al., 2005; J. K. Austin et al., 1998, 1999; Bailet & Turk, 2000; Braakman et al., 2012; Drewel et al., 2009; Gulgonen et al., 2000; Jackson et al., 2013; Mitchell et al., 1991; Miziara et al., 2012; Overvliet et al., 2011; Schoenfeld et al., 1999; Seidenberg et al., 1986; Tedrus et al., 2009), 12 studies reported low achievement in CWE (Aldenkamp et al., 2005; J. K. Austin et al., 1998, 1999; Bailet & Turk, 2000; Braakman et al., 2012; Drewel et al., 2009; Gulgonen et al., 2000; Jackson et al., 2013; Miziara et al., 2012; Overvliet et al., 2011; Schoenfeld et al., 1999; Tedrus et al., 2009), whilst two studies reported underachievement in CWE (Mitchell et al., 1991; Seidenberg et al., 1986). The remaining six studies did not report any difference (Caplan et al., 2006; Chambers et al., 2014; Hermann et al., 2008; Jones et al., 2010; Williams et al., 2001; Williams et al., 1996).

Overall, the longitudinal studies found that CWE had stable academic achievement scores over time (J. K. Austin et al., 1999; Bailet & Turk, 2000; Hermann et al., 2008; Jones et al., 2010) [Table 6.2]. However, Austin and colleagues did not find an increase
in scores among those children whose seizure control had improved over time (J. K. Austin et al., 1999). Another study found a subgroup of children who showed a decline in their mathematics scores despite a decrease in seizure frequency on follow-up (Jones et al., 2010).

6.3.4 Academic domains measured in children with epilepsy

All the included studies assessed mathematics. Twelve studies showed CWE had significantly lower mathematics scores compared to controls or reported norm (Aldenkamp et al., 2005; J. K. Austin et al., 1998, 1999; Bailet & Turk, 2000; Braakman et al., 2012; Drewel et al., 2009; Gulgonen et al., 2000; Jackson et al., 2013; Mitchell et al., 1991; Miziara et al., 2012; Schoenfeld et al., 1999; Seidenberg et al., 1986), whilst the remaining eight studies did not find any significant differences (Caplan et al., 2006; Chambers et al., 2014; Hermann et al., 2008; Jones et al., 2010; Overvliet et al., 2011; Tedrus et al., 2009; Williams et al., 2001; Williams et al., 1996).

Of the 19 studies that assessed reading, 14 studies showed that CWE had significantly lower reading scores compared to controls or reported norm (Aldenkamp et al., 2005; J. K. Austin et al., 1998, 1999; Bailet & Turk, 2000; Braakman et al., 2012; Drewel et al., 2009; Gulgonen et al., 2000; Mitchell et al., 1991; Miziara et al., 2012; Overvliet et al., 2011; Schoenfeld et al., 1999; Seidenberg et al., 1986; Tedrus et al., 2009; Williams et al., 1996), whilst the remaining five studies did not find any significant difference (Caplan et al., 2006; Hermann et al., 2008; Jackson et al., 2013; Jones et al., 2010; Williams et al., 2001).

Of the 11 studies that assessed spelling, six studies showed that CWE had significantly lower spelling scores compared to control or reported norm (Caplan et al., 2006; Jackson et al., 2013; Jones et al., 2010; Overvliet et al., 2011; Tedrus et al., 2009; Williams et al., 2001; Williams et al., 1996).
et al., 2013; Mitchell et al., 1991; Schoenfeld et al., 1999; Seidenberg et al., 1986; Williams et al., 2001; Williams et al., 1996). Studies that measured other domains such as writing (Drewel et al., 2009; Miziara et al., 2012; Seidenberg et al., 1986; Williams et al., 1996), reading comprehension (Mitchell et al., 1991; Seidenberg et al., 1986), and general knowledge (Mitchell et al., 1991), found that CWE showed significantly lower scores compared to controls or reported norms.

6.3.5 **Instruments used to assess academic achievement**

Table 6.3: Instruments used to assess the academic achievement of children with epilepsy

<table>
<thead>
<tr>
<th>Instruments used</th>
<th>Number of studies</th>
<th>Purpose</th>
<th>Areas assessed</th>
<th>Age range</th>
<th>Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>California Achievement Test (CAT) (CTB, 1985)</td>
<td>2</td>
<td>A standardized test based on USA norm which measures academic achievement</td>
<td>Reading, Mathematics, Language, Vocabulary, Total composite score</td>
<td>Students from grade 2, 4-12 (7-18 years of age)</td>
<td>Scores are available in several formats: standard scores, percentile ranks, stanines, age and grade equivalents</td>
</tr>
<tr>
<td>Comprehensive Tests of Basic Skills, 4th edition (CTBS 4) (CTB, 1989)</td>
<td>1</td>
<td>A standardized test based on USA norm which measures academic achievement</td>
<td>Reading, Mathematics, Language, Vocabulary, Spelling, Total composite</td>
<td>Student from grade 1-12 (6-18 years of age)</td>
<td>Scores are available in several formats: standard scores, percentile ranks, stanines, age and grade equivalents</td>
</tr>
<tr>
<td>Indiana Statewide Test of Educational Progress (ISTEP) (CTB, 1992)</td>
<td>1</td>
<td>A standardized test that reports student achievement levels according to the Indiana Academic Standards in USA</td>
<td>Reading, Mathematics, Language, Vocabulary, Total composite</td>
<td>Student from grade 3-8 (8-14 years of age)</td>
<td>Scores are available in several formats: standard scores, percentile ranks, stanines, age and grade equivalents</td>
</tr>
<tr>
<td>Iowa Tests of Basic Skills (ITBS) (Hieronymus et al., 1986)</td>
<td>3</td>
<td>A standardized test based on USA norm which provides comprehensive assessment of student progress in academic achievement</td>
<td>Reading, Mathematics, Language, Vocabulary, Total composite score</td>
<td>Student from kindergarten to grade 12 (5-18 years of age)</td>
<td>Scores are available in several formats: standard scores, percentile ranks, stanines, age and grade equivalents</td>
</tr>
<tr>
<td>Instruments used</td>
<td>Number of studies</td>
<td>Purpose</td>
<td>Areas assessed</td>
<td>Age range</td>
<td>Scoring</td>
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<tr>
<td>Metropolitan Achievement Test, 7th edition (MAT 7) (Balow et al., 1993)</td>
<td>1 (Williams et al., 1996)</td>
<td>A standardized test based on USA norm which provides comprehensive assessment of student progress in academic achievement</td>
<td>Reading, Mathematic, Language, Vocabulary, Spelling, Total composite</td>
<td>Student from kindergarten to grade 12 (5-18 years of age)</td>
<td>Scores are available in several formats: standard scores, percentile ranks, stanines, age and grade equivalents</td>
</tr>
<tr>
<td>Peabody Individual Achievement Test (PIAT) (L. M. Dunn &amp; Markwardt, 1970)</td>
<td>2 (Mitchell et al., 1991; Seidenberg et al., 1986)</td>
<td>It is a criterion based survey of an individual’s scholastic attainment.</td>
<td>Reading, Reading comprehension, Mathematics, Spelling, General knowledge</td>
<td>Student from kindergarten to grade 12 (5-18 years of age)</td>
<td>The subtests and composite scores are calculated with derived scores indicating grade level equivalents and percentile ranking.</td>
</tr>
<tr>
<td>School performance Test (SPT) (LM, 1994; Stein, 1994)</td>
<td>2 (Miziara et al., 2012; Tedrus et al., 2009)</td>
<td>It used to obtain an objection evaluation of the fundamental abilities applied in school performance.</td>
<td>Reading, Writing, Mathematics</td>
<td>Student from kindergarten to grade 12 (5-18 years of age)</td>
<td>The total score is obtained by adding the scores of all the subtests, then classified according to age and educational level of the child. Performance is classified into superior (25% of students with the highest scores), average (students whose scores fall 25-75%) and inferior (25% of the students with lowest scores).</td>
</tr>
<tr>
<td>Instruments used</td>
<td>Number of studies</td>
<td>Purpose</td>
<td>Areas assessed</td>
<td>Age range</td>
<td>Scoring</td>
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<tr>
<td>Stanford Achievement Test, 8th edition (Stanford 8)</td>
<td>1</td>
<td>A standardized test based on USA norm which provides comprehensive assessment of student progress in academic achievement</td>
<td>Reading Mathemetic Language, Vocabulary Spelling Total composite</td>
<td>Student from kindergarten to grade 12 (5-18 years of age)</td>
<td>Scores are available in several formats: standard scores, percentile ranks, stanines, age and grade equivalents</td>
</tr>
<tr>
<td>Tempotest (de Vos, 1992, 1994)</td>
<td>2</td>
<td>A standardized Dutch short screening test for academic achievement</td>
<td>Reading Mathematics</td>
<td>Students from grade 3-8 (4-12 years of age)</td>
<td>Scoring using learning efficiency quotient, whereby 100% indicating no delay.</td>
</tr>
<tr>
<td>Wechsler Individual Achievement Test Screener (WIAT Screener) (Wechsler, 1992)</td>
<td>2</td>
<td>It measures academic achievement which shared the same normed and representative standardized sample as WISC-III, allowing for good comparison between IQ and achievement scores.</td>
<td>Basic reading Spelling Mathematics reasoning</td>
<td>Individuals aged 4-85 years</td>
<td>The scores are converted to standard scores (mean=100, SD=15). It provides age- and grade-based scores for the examinees.</td>
</tr>
<tr>
<td>Woodcock-Johnson Psychoeducational Battery – Revised (WJR) (Woodcock &amp; Johnson, 1989, 1990)</td>
<td>2</td>
<td>It is a test battery to assess academic achievement in children and adults</td>
<td>Reading Mathematics Written language</td>
<td>Individuals aged 2-90+ years</td>
<td>The scores are converted to standard scores (mean=100, SD=15). There is a total achievement score of overall performances</td>
</tr>
</tbody>
</table>
Table 6.3 continued

<table>
<thead>
<tr>
<th>Instruments used</th>
<th>Number of studies</th>
<th>Purpose</th>
<th>Areas assessed</th>
<th>Age range</th>
<th>Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wide Range Achievement Test (WRAT)/ WRAT-R Revised/ WRAT 3 (S Jastak &amp; Wilkinson, 1976; S. Jastak &amp; Wilkinson, 1984)</td>
<td>7 (Bailet &amp; Turk, 2000; Gulgonen et al., 2000; Hermann et al., 2008; Jackson et al., 2013; Schoenfeld et al., 1999; Seidenberg et al., 1986; Williams et al., 2001)</td>
<td>It is an individually screening test for academic achievement</td>
<td>Reading, Spelling, Mathematics</td>
<td>Individuals aged 2-95 years</td>
<td>For each subtest, raw scores (number of correct answer) of each subtest are converted to standard scores (mean=100, SD=15). There is no total composite score of overall performances across the three subtest.</td>
</tr>
<tr>
<td></td>
<td>1 (Chambers et al., 2014)</td>
<td>It is a group or individual screening test for non-verbal reasoning ability and achievement in reading and mathematics.</td>
<td>Mathematics, Reading, Non-verbal reasoning</td>
<td>Individuals aged 5-24, and individual with learning disability</td>
<td>For each subtest, raw scores (number of correct answer) of each subtest are converted to standard scores (mean=100, SD=15). There is no total composite score of overall performances across the three subtest.</td>
</tr>
</tbody>
</table>

Note: SD= Standard deviation
6.3.6 Factors associated with academic achievement

6.3.6.1 Demographic factors

The older the child, the lower the academic achievement score of the child (Mitchell et al., 1991; Seidenberg et al., 1986). There was no association found for gender (J. K. Austin et al., 1998, 1999; Miziara et al., 2012; Seidenberg et al., 1986; Williams et al., 2001; Williams et al., 1996) and socioeconomic status (Chambers et al., 2014; Williams et al., 2001) with academic achievement scores. However, a higher parental education was associated with a higher academic achievement score (Mitchell et al., 1991; Miziara et al., 2012) [Table 6.4].
Table 6.4: Demographic and socioeconomic status factors associated with academic achievement in children with epilepsy

<table>
<thead>
<tr>
<th>Factor</th>
<th>No. of studies (references)</th>
<th>Results</th>
</tr>
</thead>
</table>
| Gender                        | 6 (J. K. Austin et al., 1998, 1999; Miziara et al., 2012; Seidenberg et al., 1986; Williams et al., 2001; Williams et al., 1996) | Two studies reported that boys had significantly poorer academic achievement than girls (J. K. Austin et al., 1998, 1999)
|                               |                             | However, it was found that boys in the sample have more severe epilepsy than girls. The significant differences were only found between boys with “high severity” epilepsy and girls with “low severity” epilepsy. Therefore, gender was not a risk factor for academic achievement in CWE (J. K. Austin et al., 1999) |
| Age                           | 2 (Mitchell et al., 1991; Seidenberg et al., 1986) | Older children had significantly poorer academic achievement (Mitchell et al., 1991; Seidenberg et al., 1986) |
| Parents’ educational level    | 2 (Mitchell et al., 1991; Miziara et al., 2012) | Children whose parents had higher educational level had better academic achievement (Mitchell et al., 1991; Miziara et al., 2012) |
| SES                           | 2 (Chambers et al., 2014; Williams et al., 2001) | No association was seen between socioeconomic status and academic achievement (Chambers et al., 2014; Williams et al., 2001) |

Note: CWE=Children with epilepsy; SES= Socioeconomic status; SGE= Symptomatic generalized epilepsy; FLE= Frontal lobe epilepsy; BECTS= Benign epilepsy with centro-temporal spikes; RE= Rolantic epilepsy; IOLE= Idiopathic occipital lobe epilepsy; ILRE= Idiopathic localized related epilepsy; IGE= Idiopathic generalized epilepsy; GE= Generalized epilepsy; PE= Partial epilepsy; PGE= Primary generalized epilepsy with absence; PS= Partial seizure; GS= Generalized seizure; CS= complex seizure; CPS= Complex partial seizure; AS= Absence seizure;
6.3.6.2 Epilepsy/seizure related factors

Duration of epilepsy (Jones et al., 2010; Schoenfeld et al., 1999; Williams et al., 2001) and timing of seizure (Miziara et al., 2012) did not show any significant association with academic achievement. Studies that looked at the type of epilepsy (Aldenkamp et al., 2005; Bailet & Turk, 2000; Braakman et al., 2012; Chambers et al., 2014; Gulgonen et al., 2000; Hermann et al., 2008; Jackson et al., 2013; Miziara et al., 2012; Overvliet et al., 2011; Tedrus et al., 2009), epilepsy severity (J. K. Austin et al., 1998, 1999; Mitchell et al., 1991), age at seizure onset (Bailet & Turk, 2000; Jones et al., 2010; Miziara et al., 2012; Seidenberg et al., 1986; Williams et al., 1996), seizure type (Caplan et al., 2006; Drewel et al., 2009; Jones et al., 2010; Schoenfeld et al., 1999; Seidenberg et al., 1986; Williams et al., 2001; Williams et al., 1996), seizure control (Jones et al., 2010; Williams et al., 1996), seizure frequency (Bailet & Turk, 2000; Jones et al., 2010; Miziara et al., 2012; Schoenfeld et al., 1999; Seidenberg et al., 1986; Williams et al., 1996), EEG discharges (Aldenkamp et al., 2005; Bailet & Turk, 2000; Miziara et al., 2012), and the location of discharge (Aldenkamp et al., 2005; Bailet & Turk, 2000; Miziara et al., 2012) had mixed findings (Table 6.5).
Table 6.5: Epilepsy and illness related factors associated with academic achievement in children with epilepsy

<table>
<thead>
<tr>
<th>Factor</th>
<th>No. of studies</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of epilepsy</strong></td>
<td>10</td>
<td>Children with SGE (Aldenkamp et al., 2005), FLE (Braakman et al., 2012), BECT or RE (Miziara et al., 2012; Overvliet et al., 2011; Tedrus et al., 2009), IOLE (Gulgonen et al., 2000), and ILRE (Hermann et al., 2008; Jackson et al., 2013) had lower academic achievement score compared to healthy controls or norms. Children with IGE/GE and PE showed mixed results. Two studies showed that children with IGE scored significantly worse than controls in academic achievement (Bailet &amp; Turk, 2000; Jackson et al., 2013). However, two studies showed that children with IGE did not show educational delay compared to controls (Aldenkamp et al., 2005), and comparable academic achievement score compared to controls (Chambers et al., 2014). One study showed that children with PE had comparable academic achievement score compared to controls (Chambers et al., 2014). On the other hand, one study showed that children with PE scored significantly lower academic achievement than controls (Aldenkamp et al., 2005)</td>
</tr>
<tr>
<td><strong>Epilepsy severity</strong></td>
<td>3</td>
<td>Children who had more severe epilepsy had significantly lower academic achievement scores (J. K. Austin et al., 1998, 1999) No association was found between epilepsy severity and academic achievement (Mitchell et al., 1991)</td>
</tr>
<tr>
<td><strong>Duration of epilepsy</strong></td>
<td>4</td>
<td>No association was found between duration of epilepsy and academic achievement (Jones et al., 2010; Mitchell et al., 1991; Schoenfeld et al., 1999; Williams et al., 2001)</td>
</tr>
</tbody>
</table>
Table 6.5 continued

<table>
<thead>
<tr>
<th>Factor</th>
<th>No. of studies (references)</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at seizure onset</td>
<td>6 (Bailet &amp; Turk, 2000;</td>
<td>An earlier age of seizure onset was associated with poorer academic achievement in two studies (Schoenfeld et al., 1999; Seidenberg et al., 1986)</td>
</tr>
<tr>
<td></td>
<td>Jones et al., 2010;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Miziara et al., 2012;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Schoenfeld et al., 1999;</td>
<td></td>
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<tr>
<td></td>
<td>Seidenberg et al., 1986;</td>
<td>However, no association were found between age at seizure onset and academic achievement noted in four studies (Bailet &amp; Turk, 2000; Jones et al., 2010; Miziara et al., 2012; Williams et al., 1996)</td>
</tr>
<tr>
<td></td>
<td>Williams et al., 1996)</td>
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<tr>
<td>Seizure type</td>
<td>7 (Caplan et al., 2006;</td>
<td>There was no significant difference in academic achievement in children with PGE with absence compared to the norms (Caplan et al., 2006)</td>
</tr>
<tr>
<td></td>
<td>Drewel et al., 2009;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Jones et al., 2010;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Schoenfeld et al., 1999;</td>
<td>Children with PS (Seidenberg et al., 1986), GS (Drewel et al., 2009; Seidenberg et al., 1986), and CS (Drewel et al., 2009) had significantly lower academic achievement compared to the norms.</td>
</tr>
<tr>
<td></td>
<td>Seidenberg et al., 1986;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Williams et al., 2001;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Williams et al., 1996)</td>
<td>Children with CPS and AS showed mixed results. Four studies showed that children with CPS demonstrated academic achievement within average range compared to the norms(Caplan et al., 2006; Jones et al., 2010; Williams et al., 2001; Williams et al., 1996)</td>
</tr>
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<tr>
<td></td>
<td></td>
<td>However, one study showed that children with CPS performed significantly worse than controls in academic achievement (Schoenfeld et al., 1999).</td>
</tr>
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<tr>
<td></td>
<td></td>
<td>Two studies showed that children with AS demonstrated academic achievement within average range compared to the norms (Jones et al., 2010; Williams et al., 1996).</td>
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<tr>
<td></td>
<td></td>
<td>However, one study showed that children with AS had significantly lower academic achievement compared to the norms (Drewel et al., 2009)</td>
</tr>
<tr>
<td>Factor</td>
<td>No. of studies (references)</td>
<td>Results</td>
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<tr>
<td>-------------------------------</td>
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</tr>
</tbody>
</table>
| Seizure control              | 2 (Jones et al., 2010; Williams et al., 1996) | No association was found between seizure control and academic achievement in one study (Jones et al., 2010)  
However, one study showed that CWE with good seizure control have significant higher score in reading compared to CWE with poorly controlled seizure (Williams et al., 1996) |
| Seizure frequency            | 6 (Bailet & Turk, 2000; Jones et al., 2010; Mitchell et al., 1991; Schoenfeld et al., 1999; Seidenberg et al., 1986; Williams et al., 1996) | No association between seizure frequency and academic achievement in four studies (Bailet & Turk, 2000; Jones et al., 2010; Mitchell et al., 1991; Schoenfeld et al., 1999)  
However, one study showed that CWE who had decreased seizure frequency at follow-up had a decline in mathematic score (Jones et al., 2010)  
Another study also found that lifetime seizure frequency was significantly associated with poorer academic achievement (Seidenberg et al., 1986) |
| Timing of seizure occurrence | 1 (Miziara et al., 2012)    | Not association was found between timing of seizure occurrence and academic achievement in one study (Miziara et al., 2012)            |
| EEG discharges and the location of discharge | 3 (Aldenkamp et al., 2005; Bailet & Turk, 2000; Miziara et al., 2012) | No association between EEG abnormalities and academic achievement in two studies (Aldenkamp et al., 2005; Bailet & Turk, 2000; Miziara et al., 2012)  
However, one study found CWE with normal EEGs performed significantly better than CWE with abnormal EEGs (Bailet & Turk, 2000) |

Note: CWE=Children with epilepsy; SGE= Symptomatic generalized epilepsy; FLE= Frontal lobe epilepsy; BECTS= Benign epilepsy with centro-temporal spikes; RE= Rolanic epilepsy; IOLE= Idiopathic occipital lobe epilepsy; ILRE= Idiopathic localized related epilepsy; IGE= Idiopathic generalized epilepsy; GE= Generalized epilepsy; PE= Partial epilepsy; PGE= Primary generalized epilepsy with absence; PS= Partial seizure; GS= Generalized seizure; CS= complex seizure; CPS= Complex partial seizure; AS, Absence seizure; EEG= epileptiform;
6.3.6.3 Medication related factors

The number of antiepileptic drugs (Jones et al., 2010; Seidenberg et al., 1986), and type of treatment (no treatment, monotherapy or polytherapy) (Aldenkamp et al., 2005) were not found to be associated with academic achievement. However, the type of antiepileptic drug showed mixed results (Bailet & Turk, 2000; Miziara et al., 2012; Williams et al., 2001) [Table 6.6].

Table 6.6: Medication related factors associated with academic achievement in children with epilepsy

<table>
<thead>
<tr>
<th>Factor</th>
<th>No. of studies (references)</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of antiepileptic drug</td>
<td>3 (Bailet &amp; Turk, 2000; Miziara et al., 2012; Williams et al., 2001)</td>
<td>No association between type of antiepileptic drug and academic achievement in two studies (Miziara et al., 2012; Williams et al., 2001) One study found that CWE taking CBZ had better spelling score than CWE taking VPA (Bailet &amp; Turk, 2000)</td>
</tr>
<tr>
<td>Number of antiepileptic drug</td>
<td>1 (Jones et al., 2010; Seidenberg et al., 1986)</td>
<td>No association was found between number of antiepileptic drug and academic achievement in one study (Jones et al., 2010; Seidenberg et al., 1986)</td>
</tr>
<tr>
<td>Type of treatment (no treatment/monotherapy/polytherapy)</td>
<td>1 (Aldenkamp et al., 2005)</td>
<td>No association was found between type of treatment and academic achievement in one study (Aldenkamp et al., 2005)</td>
</tr>
</tbody>
</table>

Note: CWE=Children with epilepsy; CBZ= carbamazepine; VPA= valproate.
6.3.6.4 **Cognitive related factors**

The higher the IQ of the child (Chambers et al., 2014; Drewel et al., 2009; Mitchell et al., 1991; Williams et al., 2001) and the higher level of attention in school (Williams et al., 2001) were significantly associated with better academic achievement. However, thought disorders showed mixed results (Caplan et al., 2006) [Table 6.7].

**Table 6.7: Cognitive related factors associated with academic achievement in children with epilepsy**

<table>
<thead>
<tr>
<th>Factor</th>
<th>No. of studies (references)</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>IQ</td>
<td>5 (Aldenkamp et al., 2005; Chambers et al., 2014; Drewel et al., 2009; Mitchell et al., 1991; Williams et al., 2001)</td>
<td>A lower IQ level was associated educational underachievement (Aldenkamp et al., 2005; Chambers et al., 2014; Drewel et al., 2009; Mitchell et al., 1991; Williams et al., 2001)</td>
</tr>
<tr>
<td>Thought disorder</td>
<td>1 (Caplan et al., 2006)</td>
<td>Thought disorder was significant related to lower academic achievement with children with complex partial epilepsy (Caplan et al., 2006)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>However, there was no association between thought disorder and academic achievement in children with primary generalized epilepsy (Caplan et al., 2006)</td>
</tr>
<tr>
<td>Attention</td>
<td>1 (Williams et al., 2001)</td>
<td>Higher ability to pay attention to recall combinations of number/letters of increasing length immediately was significantly associated with better academic achievement in CWE (Williams et al., 2001)</td>
</tr>
</tbody>
</table>

Note: CWE=Children with epilepsy; IQ= Intelligence quotient
6.3.6.5 Child/family psychosocial related factors

The child’s positive attitude toward epilepsy was significantly associated with better academic achievement (J. K. Austin et al., 1998). No association was found between self-esteem (Williams et al., 2001) and peer difficulty (Drewel et al., 2009), with academic achievement. A “caring environment” showed mixed results (Chambers et al., 2014; Mitchell et al., 1991) [Table 6.8].

Table 6.8: Child/Family psychosocial related factors associated with academic achievement in children with epilepsy

<table>
<thead>
<tr>
<th>Factor</th>
<th>No. of studies (references)</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-esteem</td>
<td>1 (Williams et al., 2001)</td>
<td>No association was found between self-esteem and academic achievement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>in one study (Williams et al., 2001)</td>
</tr>
<tr>
<td>Peer difficulty</td>
<td>1 (Drewel et al., 2009)</td>
<td>No association was found between peer difficulty and academic achievement in one study (Drewel et al., 2009)</td>
</tr>
<tr>
<td>Attitude towards epilepsy</td>
<td>1 (J. K. Austin et al., 1998)</td>
<td>The child’s attitude toward epilepsy was significantly associated with academic achievement (J. K. Austin et al., 1998)</td>
</tr>
<tr>
<td>Caring environment</td>
<td>2 (Chambers et al., 2014; Mitchell et al., 1991)</td>
<td>No association was found between caring environment and academic achievement in one study (Chambers et al., 2014)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>However, a caring environment is significantly associated with better academic achievement in one study (Mitchell et al., 1991)</td>
</tr>
</tbody>
</table>
6.3.6.6 **School related factors**

No association was found between school self-concept and school adaptive functioning, with academic achievement (J. K. Austin et al., 1998) [Table 6.9].

**Table 6.9: School related factors associated with academic achievement in children with epilepsy**

<table>
<thead>
<tr>
<th>Factor</th>
<th>No. of studies (references)</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>School self-concept</td>
<td>1 (J. K. Austin et al., 1998)</td>
<td>No association was found between school self-concept and academic achievement in one study (J. K. Austin et al., 1998)</td>
</tr>
<tr>
<td>School adaptive functioning</td>
<td>1 (J. K. Austin et al., 1998)</td>
<td>No association was found between school adaptive functioning and academic achievement in one study (J. K. Austin et al., 1998)</td>
</tr>
</tbody>
</table>
6.4 Discussion

Our systematic review showed that the majority of the studies (70%) showed that CWE had significantly lower academic achievement scores than healthy controls or reported norms, whilst 30% reported no difference; which was similar to a previous review (C. Reilly & Neville, 2011). The previous review included a total of 15 studies (C. Reilly & Neville, 2011), whilst 20 studies were included in our present review. Although there were only eight studies (Aldenkamp et al., 2005; J. K. Austin et al., 1999; Bailet & Turk, 2000; Mitchell et al., 1991; Schoenfeld et al., 1999; Tedrus et al., 2009; Williams et al., 2001; Williams et al., 1996) that were included in both reviews, similar findings were obtained.

One third of the studies reviewed (35%) (Bailet & Turk, 2000; Chambers et al., 2014; Gulgonen et al., 2000; Hermann et al., 2008; Jackson et al., 2013; Schoenfeld et al., 1999; Seidenberg et al., 1986) used the WRAT to assess academic achievement, while others (Aldenkamp et al., 2005; J. K. Austin et al., 1998, 1999; Braakman et al., 2012; Caplan et al., 2006; Drewel et al., 2009; Jones et al., 2010; Mitchell et al., 1991; Miziara et al., 2012; Overvliet et al., 2011; Tedrus et al., 2009; Williams et al., 2001; Williams et al., 1996) utilized a variety of other instruments. Direct comparison between studies was difficult as each instrument assessed different outcome measures (e.g., educational delay, expected mean). Some studies measured academic achievement at or close to the time when epilepsy was diagnosed (Hermann et al., 2008; Jackson et al., 2013); whilst others assessed academic achievement in children who have been diagnosed with epilepsy for at least 6 months (Aldenkamp et al., 2005; J. K. Austin et al., 1998, 1999; Bailet & Turk, 2000; Braakman et al., 2012; Caplan et al., 2006; Chambers et al., 2014; Drewel et al., 2009; Gulgonen et al., 2000; Jones et al., 2010; Mitchell et al., 1991; Miziara et al., 2012; Overvliet et al., 2011; Schoenfeld et al., 1999; Seidenberg et al., 1986; Tedrus et al., 2009;
Williams et al., 2001; Williams et al., 1996). Lastly, academic difficulty could be due to other specific underlying impairment such as cognitive impairment (e.g., poor executive function), psychomotor impairment (e.g. lack of fine motor skill), or impairment of affective domains (e.g. attitudes towards epilepsy), which are important to promote learning (Woolfolk, 2007).

Most of the studies in our systematic review assessed “low achievement” rather than “underachievement”. This may be because low achievement may be less time consuming to evaluate compared to underachievement (Fletcher, Coulter, Reschly, & Vaughn, 2004). To assess underachievement, researchers would have to determine an appropriate cut off score (e.g., 1 or 1.5 standard deviation below the expected scores using the IQ-achievement discrepancy model), which may be difficult to perform as there are statistical limitations of psychometric cut offs (Fastenau et al., 2008; Fletcher et al., 2004). Therefore, assessing “low achievement” in CWE is more practical and pragmatic for future research. Children (regardless of type of disease) who are classified with underachievement or low achievement are eligible to be provided with special education services or educational support (Education, 2011). It is important to raise their performance with educational support so that they are not below average, but on par with their academic ability and potential (Ford & Moore, 2013).

Our systematic review found that children with higher IQ (Aldenkamp et al., 2005; Chambers et al., 2014; Drewel et al., 2009; Mitchell et al., 1991; Williams et al., 2001), who had better attention (Williams et al., 2001), and had a positive attitude towards epilepsy (J. K. Austin et al., 1998), as well as higher parental education (Mitchell et al., 1991; Miziara et al., 2012), were associated with higher academic achievement score. Older children were also found to have lower academic achievement score (Mitchell et al., 1991; Seidenberg et al., 1986). However, the number of studies that showed these
positive associations was small. Seizure characteristic have been studied but have yielded mixed results. Comparisons between studies was difficult partly due to the variability in definition of seizure types and indices of seizure severity For example, some studies measured seizure frequency using a lifetime seizure frequency (Miziara et al., 2012; Seidenberg et al., 1986), whilst others measured seizure frequency for the past one year (Jones et al., 2010). Lastly, most of the studies included did not investigate factors associated with academic achievement in a more holistic approach and using a structural equation model.

The high percentage of low achievement in CWE suggests that early screening of specific learning and behavioural problems, as well as early interventions should be developed and applied (Fastenau et al., 2008). The assessment of possible neuropsychological correlates of academic difficulties may help identify factors contributing to academic difficulties, and help with the development of individualized educational program and other educational plans, independent living needs and skills (Fastenau et al., 2009). Screening by an educational psychologist is important to identify CWE who require further assessment to determine their learning difficulties, which is often missed in school examinations or through a teacher’s observation in school. Screening may occur as early as at the time of epilepsy onset, or at the different stages of life, as children have different needs at the different stages of their life (G. M. Ronen et al., 2003). Given that older children showed poorer school achievement scores, screening for learning and behavioural problems are also important in adolescents as they transition to post-high school education and enter the workforce (G. M. Ronen et al., 2003). Through appropriate assessment, recommendation of interventions or educational support will then lessen the impact of such difficulties among CWE (C. Reilly & Fenton, 2013).
Attitudes of teachers and other education providers toward epilepsy can significantly influence’s school performance in CWE (J. K. Austin et al., 1998). CWE can be at an increased risk for academic problems if their teachers or parents do not understand their needs (Dantas, Cariri, Cariri, & Filho, 2001). Therefore, it is important that interventions to enhance a teacher’s awareness about epilepsy be developed. Although not all CWE require special education services, these students should be given opportunities to reach their full potential. It is also important for policy makers to ensure that schools are able to identify, evaluate, and reevaluate CWE who require special education and related services, to provide CWE a less restrictive and more interactive environment with other student. A discrimination-free environment where CWE should be encouraged to participate non-academic activities such as sports and special interest clubs, should be promoted.

In the present study, several research gaps were identified. Firstly, there are no published literature on interventions to improve academic achievement in CWE. Secondly, there is a lack of population based studies with an adequate sample size to comment accurately on the true prevalence of low achievement and underachievement in CWE. Thirdly, there is a paucity of studies particularly in Asia, as there is a lack of validated academic achievement instruments in Asian countries. Therefore, future studies on academic achievement in CWE should address these issues to better understand academic achievement in children with epilepsy.

6.4.1 Strengths and limitations

One of the limitations of our study was that we were not able to perform a meta-analysis. This was because the outcomes measured between studies were different and comparisons between studies were difficult.
However, the strength of our study was that we performed this systematic review according to the PRISMA guidelines, and that our search was conducted on five databases.

6.5 Conclusions

The majority of published literature found that academic achievement among CWE was lower than controls or reported norms. The high percentages of low achievement in CWE with normal intelligent and without any comorbidities, especially in the older age group, and the stability of scores even as seizure frequency improved, highlights the need for early screening of learning problems, and continued surveillance.
CHAPTER 7: EXPLORING THE NEEDS AND CHALLENGES OF PARENTS AND THEIR CHILDREN IN CHILDHOOD EPILEPSY CARE: A QUALITATIVE STUDY

Childhood epilepsy is one of the most common chronic illnesses which is associated with increased risk of poor HRQOL (D. Stevanovic et al., 2011). Psychosocial and educational interventions can effectively improve psychological and emotional well-being in CWE and their parents (Hagemann et al., 2016; Shore et al., 2008). By strengthening or reinforcing functional coping, parents can enhance their children’s psychological, social and emotional development (Wagner & Smith, 2006). However, whilst we were validating HRQOL and family functioning instruments to measure the psychosocial outcomes of the intervention provided, we found that there were unmet needs and challenges faced by parents and their CWE. Hence, a qualitative study was conducted to explore the needs and challenges faced by parents and their children in childhood epilepsy care.

7.1 Introduction

Epilepsy treatment goal is not just minimizing the seizures and adverse effects of drugs, it is important to meet the goal of improving the QOL in children successfully (G. M. Ronen et al., 2010). Parent’s coping capability and psychological well-being, which were influenced by culture and social belief, have a significant impact on their child’s HRQOL (G. M. Ronen et al., 2010). Needs and challenges of parents and their CWE can be assessed using qualitative and quantitative methods. To date, three quantitative studies examined the psychosocial needs among CWE using the Psychosocial Care Need Scales (Akbarbegloo, Valizadeh, Zamanzadeh, & Jabarzadeh, 2015; Rajalakshmi & Lalitha, 2014; Shore, Buelow, Austin, & Johnson, 2009). Psychosocial care needs (such as needs
for epilepsy related information and needs for support) were highest at the first three-months of epilepsy diagnosis for both parents and CWE. Worries about epilepsy and needs for information persisted after 24 months. However, using an instrument does not provided enough detail on the needs and challenges among CWE and their parents. Therefore, utilising qualitative methods would be a more suitable method to explore the needs and challenges among CWE and their parents (Cianchetti et al., 2015).

Qualitative research is particularly useful in understanding how an individual with epilepsy and their family bring meaning to their experience with epilepsy, how they manage their epilepsy and understand the changes in their health over time, and how they perceived care from health care providers (Benson et al., 2015; Benson, O’Toole, et al., 2016; McNelis et al., 2007; Mu, 2008; O'Toole et al., 2015). Several qualitative studies have been conducted to assess the needs and challenges in parents and their children with epilepsy (Table 7.1).
Table 7.1: A summary of qualitative study in parents and children with epilepsy

<table>
<thead>
<tr>
<th>Author (year)/Country</th>
<th>Sample</th>
<th>Study aims Qualitative methodology / analysis</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Desnous et al., (2013)/France</td>
<td>Parents with CWE aged 0-18 years (n=140)</td>
<td>To identify parents information needs on an education intervention / Semi-directive individual interviews/ Not reported</td>
<td>Parents’ main concern was side effects of antiepileptic drugs, how to ways to handle crisis during a seizure, trigger of seizure and knowledge about anatomy and physiology of the brain.</td>
</tr>
<tr>
<td>Murugupillai et al., (2016)/Sri Lanka</td>
<td>IDI: Parents with CWE (n=16) FGD: parents (n=16), school teacher (n=8) and public health staffs (n=10)</td>
<td>To identify parental concerns on childhood epilepsy care/ IDI and FGD/ Content analysis</td>
<td>Parents’ concerns were identified: CWE physical functioning, behavioral and cognitive functioning, psychological and emotional functioning, education of CWE, future of CWE, information about epilepsy treatment, and information about epilepsy.</td>
</tr>
<tr>
<td>Jones et al., (2014)/USA</td>
<td>Parents of CWE (n=22)</td>
<td>To identify parental concerns on their child’s struggle / IDI and FGD/ Content analysis</td>
<td>Parents were concern about their child’s epilepsy condition, children support in future education, and their child’s self-esteem.</td>
</tr>
<tr>
<td>Benson et al., (2016)/Ireland</td>
<td>Parents of CWE aged 6-16 years (n=34)</td>
<td>To explore the challenges encounter by parents of CWE in disclosing their child’s epilepsy to others / IDI/ Thematic analysis</td>
<td>Parents reported that they are working on maintaining normality in their child, had negative attitude towards epilepsy, perceived that others’ negative reactions to disclosure, grief on losing a ‘healthy child’ and having difficult to accept the diagnosis.</td>
</tr>
<tr>
<td>McNelis et al., (2007)/USA</td>
<td>CWE aged 7-15 years (n=11) and their parents</td>
<td>To explore concerns and needs of children with epilepsy and their parents/ FGD/ Thematic analysis</td>
<td>CWE requested doctors to discuss their epilepsy at their level and be equally informed as their parents. CWE developed misconceptions about epilepsy due to lack of information. Parents reported that they had problem dealing with healthcare providers and the used of healthcare system. They also struggled to understand epilepsy and the changes in family roles.</td>
</tr>
<tr>
<td>Author (year)</td>
<td>Sample</td>
<td>Study aims</td>
<td>Findings</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Mu (2008)/ Taiwan</td>
<td>Family with CWE aged 3-7 years old (n=7)</td>
<td>To investigate the family health–illness transition experience from the perspective of parents of children with epilepsy / IDI/ Thematic research</td>
<td>Family reported that epilepsy is an unacceptable illness. Therefore, family seldom talked about epilepsy. Parents of CWE coped by strengthening their parenting patterns by enhancing parental abilities, monitoring, and mastering the treatment and establishing a mutually respectful and accepting family environment.</td>
</tr>
<tr>
<td>Houston et al., (2000)/UK</td>
<td>CWE (n=25), children with asthma (n=10), and children with diabetes (n=10)</td>
<td>To compare the information needs CWE and children with asthma and children with diabetes / Not reported</td>
<td>CWE reported more unanswered questions and felt more excluded from discussions with doctors during their consultation compared to children with asthma and children with diabetes.</td>
</tr>
<tr>
<td>Hightower et al., (2002)</td>
<td>Children with epilepsy aged 9-12 years (n=8)</td>
<td>To explore the lived experience of school aged-children with epilepsy/ IDI/thematic analysis</td>
<td>CWE felt uncomfortable and feel upset for having seizures, dislike taking seizure medication. Their main source of social support was from their peers. CWE coped by participating in sports to have fun.</td>
</tr>
<tr>
<td>Moffat et al., (2009)/UK</td>
<td>CWE aged 7-12 years</td>
<td>To explore the perception of the impact of epilepsy has on their QOL / IDI and FGD / grounded theory approach</td>
<td>CWE reported medication issues such as tasted horrible, problem to swallow (pill stuck at throat and vomiting), number of medications taken daily, and side effects of (e.g. hair loss and gaining weight).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Most CWE reported that they were forgetful and worried about parents forgetting to give them their medication.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>CWE also reported on restrictions on activities. For example, they had to sleep in their parents’ bedroom as the mother did not trust the epilepsy bed monitor.</td>
</tr>
<tr>
<td>Author (year)</td>
<td>Sample</td>
<td>Study aims / Qualitative methodology / analysis</td>
<td>Main findings</td>
</tr>
<tr>
<td>--------------</td>
<td>--------</td>
<td>---------------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>Ronen et al., (1999)/Canada</td>
<td>CWE aged 6-10 years</td>
<td>To identify the different component of HRQOL in childhood epilepsy to develop a HRQOL specific measure/ FGD / Textual analysis</td>
<td>CWE reported that AED helped them to control their seizure. However, the side-effects of AED such as tiredness, was a barrier in their life. CWE also reported their caregivers were overprotective by imposing many restrictions (e.g. swimming).</td>
</tr>
<tr>
<td>Elliott et al., (2005)/Canada</td>
<td>CWE aged 7-18 years (n=49)</td>
<td>To explore how CWE with medically refractory epilepsy perceive the impact of epilepsy on their QOL/ IDI / content analysis</td>
<td>CWE reported physical problem and danger management problem. CWE reported that fatigue had negative impact on their academic achievement, physical activities. CWE reported that restriction of activities in and outside the home caused them inability to become independent. CWE reported fear of disclosure and stigma associated with having a seizure in front of peers.</td>
</tr>
<tr>
<td>Chiu et al., (2014)</td>
<td>CWE aged 14-17 years (n=11)</td>
<td>To understand how CWE adjust to their life after discontinued from AED / Content analysis</td>
<td>CWE reported that they perceived themselves as “normal”, and enjoyed life without restriction in term of social activities and diet from their caregivers. However, some CWE reported that their caregivers have conflicting attitudes towards “epilepsy-free” life style.</td>
</tr>
<tr>
<td>Author (year)/Country</td>
<td>Sample</td>
<td>Study aims / qualitative methodology / analysis</td>
<td>Findings</td>
</tr>
<tr>
<td>----------------------</td>
<td>--------</td>
<td>-----------------------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>Chen et al., (2010)/Taiwan</td>
<td>CWE aged 7-12 years (n=15)</td>
<td>To explore the experience of CWE / IDI / Thematic analysis</td>
<td>CWE used strategies to self-manage seizures which included resting and not taking part in strenuous/exciting activities. CWE reported memory problem due to medication. Fear of disclosure of epilepsy especially at school and either losing friends if they witnessed seizures or being teased.</td>
</tr>
<tr>
<td>McEwan et al., (2004)/UK</td>
<td>CWE aged 12-18 years (n=22)</td>
<td>To investigate QOL among adolescence with epilepsy / FGD / Thematic analysis</td>
<td>CWE reported that epilepsy had negative impact on their relationship with peers and autonomy development. CWE did not report problem in academic performance, however, they reported school related problem related to their relationship with teachers. CWE reported needs on epilepsy related knowledge and legislation (e.g. driving)</td>
</tr>
<tr>
<td>Benson et al., (2015)/Ireland</td>
<td>CWE aged 6–16 years (n=29)</td>
<td>To identify the barriers and facilitator of CWE to disclose their epilepsy diagnosis to others external to the nuclear family/IDI/thematic analysis</td>
<td>CWE reported having difficulty in disclosing their epilepsy to others. CWE were concern about epilepsy normalcy, reactions from other people, and the unique challenge that the invisibility of their condition denotes. They had difficulty in understanding and explaining their condition to others. CWE reported that their peers could not understand their condition when they tried to explain about epilepsy.</td>
</tr>
</tbody>
</table>

Note: CWE= Children with epilepsy, QOL= Quality of life; IDI= In depth interview, FGD= Focus group discussion, USA= United State of America, UK= United Kingdom; AED= Antiepileptic drugs
A few qualitative studies exploring the needs and challenges of people in epilepsy and family members have been conducted in Vietnam (Aydemir, Trung, Snape, Baker, & Jacoby, 2009) and Sri Lanka (Murugupillai et al., 2016). However, there is a paucity of information regarding the needs and challenges of CWE and their parents in Malaysia. Therefore, the main objective of this study was to explore the experiences of parents and their CWE and to identify the needs and challenges faced by these parents and children.

7.1.1 Conceptual framework

To understand the needs and challenges of parent and their children with epilepsy, we used the: transaction of stress and coping theory: ABC-X model of family adaptation (McCubbin & Patterson, 1983) and the caregiving stress process model (Raina et al., 2004), Erik Erikson’s Psychosocial development (Erikson, 1963), and children's attitudes toward their epilepsy model (J. K. Austin et al., 2006) as the conceptual framework.

7.1.1.1 ABC-X model of family adaptation

To understand how a parent perceives stress and copes with the burden of daily care related to his/her child’s epilepsy, the ABCX model of family adaption was adapted (McCubbin & Patterson, 1983). Family adaptation is defined as a process a family response to demands of a stressors (such as a child with chronic illness), realize that adjustment strategies are needed within the family to restore family harmony, and lastly to improve family functioning. Stress results from an imbalance between demands and resources (Lazarus & Folkman, 1984). Family members become stressed when demands (A) exceed the family resources, or the ability to cope. Therefore, the interpretation of the stressful event is more important than the event itself. Stress (X) is appraised as involving the harm/loss that occurred, potential future threats and challenges. Then, family members will work out on how to deal with the situation and change the
undesirable conditions and to create a more positive environment. The resources including the internal (such as self-motivation, will power and inner strength) and external options (such as social support from friends, health care providers) (B). Coping (C) is conceptualized as efforts to manage stress (emotion focused coping and problem-focused coping)(Lazarus & Folkman, 1984). In general, stress and coping are interrelated in an ongoing process that balances demands, with the available resource (Lazarus & Folkman, 1984). Examining the parent’s stressors, resources, and coping style may provide evidence that affecting HRQOL of their CWE. The model is illustrated in Figure 7.1.
Figure 7.1: Adaptation of the ABC-X model in exploring the needs and challenges of children with epilepsy and their parents (McCubbin & Patterson, 1983)
A study reported that parenting a child with epilepsy can be a significant source of stress (Farrace, Tommasi, Casadio, & Verrotti, 2013). A previous qualitative study reported that parents who have negative attitudes towards epilepsy were physically exhausted and emotionally traumatized (Mu, 2008). One study also reported that parenting worries about their child’s epilepsy did not reduce overtime (Farrace et al., 2013). This was similar with a longitudinal study which parents’ needs of information about epilepsy remained high two years after their child diagnosis of epilepsy (Shore et al., 2009). Several studies reported that parental concern was the future of their CWE regarding further education, future employment, and being independent (Desnous et al., 2013; McEwan et al., 2004). Therefore, parental perceptions of their child’s functioning, epilepsy severity, and concern about future are the crisis-precipitating stressor (A).

Previous studies have frequently reported that social support is beneficial for parental adjustment (Rodenburg et al., 2007). Hence, social support is one of the resources (B) to reduce stress in parents of CWE. Another resource (B) is healthy family functioning. According to McMaster model of family functioning, a healthy is able to fulfil biological needs (such as food and shelter), to encourage the emotional growth of family members, and to solve problems during a family crisis (Epstein et al., 1983). Lastly, health care services play a very important role in helping parents to cope with their child epilepsy. Previous studies reported that parents hoped for more supportive doctors and nurses in childhood epilepsy care, such as how to handle a seizure and information about the side effects of AED (Jones et al., 2014; McNelis et al., 2007). Therefore, social support, family functioning and health care services are the family’s crisis-meeting resources (B).

There are two types coping strategies (C): problem-focused coping and emotional-focused coping (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Individual who adopted problem-focused coping would address the problem that was
causing distress, and seek a solution for it. Individual who adopted emotion-focused coping would try to reduce the negative emotions that were associated with the problem (Folkman et al., 1986).

7.1.1.2 Caregiving stress process model

The caregiving stress process model is a multidimensional model based on previous research and theory to assess the impact of informal caregiving process in caregiver’s health (Pearlin, Menaghan, Lieberman, & Mullan, 1981; Raina et al., 2004). Raina and colleagues (Raina et al., 2004) define stressors as the “problematic conditions and difficult circumstances experiences by caregivers” that affect the caregiver’s ability to adapt. This model consisted of five constructs: background and context, characteristic of child with chronic illness, caregiver’s intrapersonal factors; coping factors, and health outcomes (Figure 7.2).

![Caregiving stress process model](Attachment)

**Figure 7.2:** Adaptation of the Caregiver Stress Process Model (Raina et al., 2004) in exploring the needs and challenges of children with epilepsy and their parents
The first construct, background and context refers to the social and economic characteristic of the family. This includes parental education, occupation, and family income. Previous research have found that higher socioeconomic status was associated with fewer child behavioral problem (King, King, Rosenbaum, & Goffin, 1999), fewer caregiving burden (King et al., 1999), and better psychosocial and physical health (Sloper & Turner, 1993).

The child characteristics are refers to the child’s medical conditions which constitute to the caregiver’s burden (Raina et al., 2004). Previous study had showed that fewer behaviour problem in children was associated with higher caregiver self-efficacy and better psychological health (King et al., 1999).

Caregiver intrapersonal factor is defined as the caregiver’s internal state or self-efficacy (Raina et al., 2004). Caregiver self-efficacy was associated with higher perceived level of social support, better family functioning and higher use of effective stress management strategies (Carlson & Miller, 2017). Caregiver who has higher self-esteem and felt competent in managing their child’s treatment, have reported lower level of stress (Silver, Bauman, & Ireys, 1995). In contrast, caregiver who demonstrated learned helplessness experiences more depressive symptoms and poor adjustment. Long term worries and perception of vulnerability about the child’s future is associated with greater parental strain and burden (Ramaglia et al., 2007).

Coping factors consists of social support and coping strategies. Social support derived from the social relationship with caregiver’s friends and extended family (Carlson & Miller, 2017). Coping strategies such as problem focused and emotional focused
strategies, helped caregivers in response to stressful events (Folkman et al., 1986). Lastly, caregiver well-being are the psychological health and physical health (Raina et al., 2004).

7.1.1.3 Erik Erikson’s Psychosocial Development Theory

Child development refers to changes of growth that happens in children (Erikson, 1963). Study the child’s development theories enable us to gain better knowledge in understanding a child’s behaviour, ability and personality. The study of child developmental can be categorized into three main area: physical, cognitive and social-emotional development.

To answer the research questions, Erikson’s psychosocial theory (Erikson, 1963) was adopted. Erikson’s psychosocial theory emphasizes the social and emotional aspects of the formation of a health growth. According to Erikson, development occurs throughout life. There are eight psychosocial stages, with a crisis occurs at each developmental stages. Each crises involves a psychosocial needs of an individual conflicting with the expectations of society. Erikson proposed that a healthy personality can be built after the successful completion of crisis in each stages of development (Table 7.2).
Table 7.2: Eight stages of development and its crisis

<table>
<thead>
<tr>
<th>Stage</th>
<th>Psychosocial crisis</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>Trust versus mistrust</td>
<td>0-1.5 years (Infancy)</td>
</tr>
<tr>
<td>Two</td>
<td>Autonomy versus shame</td>
<td>1.5-3 years (Early childhood)</td>
</tr>
<tr>
<td>Three</td>
<td>Initiative versus guilt</td>
<td>3-5 years (Play age)</td>
</tr>
<tr>
<td>Four</td>
<td>Industry versus inferiority</td>
<td>5-12 years (School age)</td>
</tr>
<tr>
<td>Five</td>
<td>Ego identity versus role confusion</td>
<td>12-18 years (Adolescence)</td>
</tr>
<tr>
<td>Six</td>
<td>Intimacy versus isolation</td>
<td>18-40 years (Young adult)</td>
</tr>
<tr>
<td>Seven</td>
<td>Generativity versus stagnation</td>
<td>40-65 years (Adulthood)</td>
</tr>
<tr>
<td>Eight</td>
<td>Ego integrity versus despair</td>
<td>65 years and above (Maturity)</td>
</tr>
</tbody>
</table>

7.1.1.4 Model of Children's Attitudes toward their Epilepsy

Children’s attitude toward their health conditions was found to be an important factor on psychological adjustment (D. W. Dunn et al., 1999; LeBovidge, Lavigne, & Miller, 2005). Previous study suggested that children’s attitudes toward epilepsy are positively associated with positive self-concepts (J. K. Austin & Huberty, 1993), better coping capabilities (J. K. Austin, Patterson, & Huberty, 1991), and fewer behavioural problem (J. K. Austin et al., 1994).

In this model, family functioning, child’s worry about seizure, and child’s self-efficacy for seizure management were significant associated with the child’s attitudes towards epilepsy (J. K. Austin et al., 2006). Self-efficacy is defined as the child’s confidence in handling situation related to having seizure (J. K. Austin et al., 2006). There were four variables that associated with more child’s worry which include female gender, greater child psychosocial care needs, higher seizure frequency and poorer child’s self-efficacy for seizure management. In addition, CWE with greater psychosocial care needs in
children was found to have poorer self-efficacy for seizure management (J. K. Austin et al., 2006) [Figure 7.3].

**Figure 7.3:** Model of children's attitudes toward their epilepsy (J. K. Austin, Dunn, Perkins, & Shen, 2006)
7.2 Methods

7.2.1 Why qualitative research?

In view of the exploratory nature of the research question, qualitative methodology was applied to enable collection of in-depth information to understand and interpret the personal experiences of parents and their CWE, such as the exploration of what they know about epilepsy and how it feels to have epilepsy. These experiences were drawn on to explore the needs and challenges faced by parents and their CWE, as well as to identify the existing support/resources that would facilitate them in coping to care for a child with epilepsy. Lastly, we wanted to explore the needs of parents for a psychosocial intervention to improve on how to cope with their CWE.

7.2.2 Theoretical framework

The theoretical framework used in this study was the phenomenology approach. This method of analysis enables the researcher to understand, describe and interpret human behaviours (P. Liamputtong, 2013). Phenomenology can be analysed using the descriptive or the interpretive method. In our study, the descriptive phenomenology approach was employed.

7.2.2.1 Descriptive phenomenology

Descriptive phenomenology is a philosophically grounded approach, whereby researchers explore “things as they appear”, to achieve a rigorous and unbiased understanding of an individual’s experience (P. Liamputtong & Ezzy, 2005).
7.2.3 Study design

In-depth interviews (IDI) was used to explore and capture the “insider perspective” of parents and their CWE through the participants’ own words, feeling, thoughts, and experiences (Patton, 2002).

There are three methods of conducting an interview: informal conversational interviews, semi-structured interviews and standardized open-ended interviews (Patton, 2002). In our study, semi-structured interviews were adopted. It is an interview where researchers elicit information using a topic guide. However, participants are also allowed to elaborate on their answers.

7.2.4 Setting

Participants were recruited from the Paediatric (aged 8-18 years) and Adult Neurology (aged 15-18 years) Clinics, UMMC, Malaysia.

7.2.5 Duration of study

This study was conducted from December 2013 to June 2015.

7.2.6 Participants

Included were children aged 8-18 years, have been diagnosed with epilepsy for more than 6 months, controlled seizure (≤4 seizures in the past 6 months) and attending regular school. Excluded were children with learning difficulties, uncontrolled seizure (>4 seizures in the past 6 months), other chronic illness (e.g. cerebral palsy) and other comorbidities (e.g. ADHD, autism). Once the children were identified, then the parents were included to participate with consent.
7.2.7 Sampling

Purposive sampling based on the child’s age was used. CWE were divided into 2 main categories: children aged 8-12 years and adolescents aged 13-18 years. This was because adolescents may face different challenges from younger children and place more emphasis on peer relationship and independence (Erikson, 1963).

7.2.7.1 Sample size

The number of participants recruited ceased when thematic saturation occurred. Thematic saturation is defined where little new theme or data emerges from the data collected (P. Liamputtong, 2013).

7.2.8 Research instruments

7.2.8.1 Basic demographic form

A basic demographic form was used to collect parent’s 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, and duration of epilepsy) [Appendix C and L].

7.2.8.2 Topic guide

A topic guide for parents and their children were developed based on the ABC-X model conceptual framework (McCubbin & Patterson, 1983) [section 6.1.1.1] the caregiver stress process model (Raina et al., 2004) [section 6.1.1.2], the Erik Erikson’s psychosocial development theory (Erikson, 1963) [section 6.1.1.3], the model of children’s attitude towards their epilepsy (J. K. Austin et al., 2006) [section 6.1.1.4], literature review and the experience of the researcher team.
(a) **Topic guide for parents**

The topic guide for parents has three parts (Appendix AA). The first part of the topic guide consists of question on how parents felt during their child’s first seizure, the diagnosis of epilepsy, and how epilepsy has impacted on their life as well as their family’s life. The second part of the topic guide focuses on the support/resources available, and their needs in childhood epilepsy care. The third part focused on the how they coped when handling their CWE. Lastly, the topic guide asked parents thought what the health care providers or policy makers would do to them cope better in childhood epilepsy care.

(b) **Topic guide for children with epilepsy**

The first part of the topic guide for CWE was on how the child felt during their first seizure, when their epilepsy was diagnosed, and how epilepsy change has their life, as well as the family’s life (Appendix BB). The second part of the topic guide focused on the support or resources available and their needs in dealing with daily life challenges. The third part focused on how the children coped with epilepsy. Lastly, the topic guide focused on their attitude towards epilepsy.

### 7.2.9 Data collection

Parents and their CWE were approached when they are waiting to consult their doctor in the clinic. Purpose of the study was then explained (Appendix CC). For those who agreed to participate, inform consent was obtained (Appendix DD). Baseline demographic data was then collected and an appointment was arranged within one week after first session (collecting demographic information and building rapport) at their home within Klang Valley. The IDI could not be conducted at the clinic as the environment was not conducive. All IDI were conducted with parents and their CWE in their preferred
language: English, Malay, Chinese (by SWW) or Tamil (RS). Interviews were audio recorded, lasted from 30-60 mins for parents and 15-30 mins for children, respectively.

After the interview, initial impressions and thoughts about the parents and their CWE were recorded in a research diary. Any additional information from post-interview conversation were also included as field notes.

7.2.10 Ethics approval

Ethics approval was obtained from the University Malaya Medical Centre Ethics Committee approval number: 968.21. (Appendix EE).

7.2.11 Data management

All the interviews were transcribed verbatim by experienced transcribers. The transcript were checked by the interviewers (SWW and RS) and for accuracy. English, Malay and Chinese interviews were transcribed verbatim, whilst the Tamil interview was translated into English for analysis. Malay and Chinese interviews were not translated as the researcher (SWW) was familiar with these languages. Nvivo 10 (QSR International Pty Ltd. Version 10, 2012) for analysis and coding. Data analysis was facilitated by using Nvivo 10, a computer software program designed to manage text-based data.

7.2.12 Data Analysis

The IDI data was analysed using a thematic analysis which referred as “a method for identifying, analyzing analysis and reporting patterns (themes) within data” (Braun & Clarke, 2006). Thematic analysis also enable research to understand people’s everyday experience (Braun & Clarke, 2006). Thematic analysis is not bound to any pre-existing
theoretical framework. Therefore, it can be used within different theoretical frameworks (Braun & Clarke, 2006).

There are two approaches in thematic analysis: inductive and deductive approach. An inductive approach means the themes identified are strongly linked to the data set (Patton, 2002) (Patton, 1990). This approach is a process of coding the data without trying to fit into any pre-existing theoretical framework (Braun & Clarke, 2006). In contrast, a deductive approach, or the “theoretical thematic analysis” is driven by the researcher’s theoretical interest in the research area (Braun & Clarke, 2006). This approach provides a more detailed analysis of some aspects of the data and provides less rich descriptions of the overall data. Hence, using deductive approach of thematic analysis, researcher focuses only on particular feathered in coding the data that is relevant to the research theoretical framework (Braun & Clarke, 2006).

Data was analysed in three stages. Firstly, SWW coded each interview line by line to develop an initial list of codes (open coding), subsequent interviews were then coded using this list (a process of constant comparison) and new themes which emerged were added to the list (Braun & Clarke, 2006). During the second phase of analysis, open codes were organized and reorganized these codes conceptually or broader categories based on thematic similarities between open codes or “axial coding”. Throughout the coding process, codes were checked by researchers (SWW, PSML, WYL, and LCO) to ensure consistency of coding and consensus on axial coding. During the final selective coding phase of analysis, core categories and subcategories were organized within each conceptual domain and conceptually connected to one another, generating a theoretical representation of relationships among the concepts.
7.2.13 Reflexivity

Rigour or trustworthiness refers to the quality of the qualitative research. We have chosen to address rigour in this study using the criteria developed by Lincoln (1995). In the qualitative paradigm, credibility (internal validity), transferability (external validity), dependability (reliability) and confirmability (objectivity) were addressed.

In terms of credibility, prolonged fieldwork was used. An appointment was made during the patient’s visit to the doctor. A brief introduction of the research’s aims and background were obtained during the first meeting. Rapport was built. The IDI was conducted at participants’ home where they were at ease. Participant observation was also made during the visit.

Triangulation was performed by exploring the experiences of two groups of participants: CWE and their parents. We also adapted more than one theory to develop the topic guide. The credibility of the researcher (SWW) was achieved by attending qualitative workshop Peer review also ensured credibility. The three co-investigators (PL, WYL, and LCO) checked the data (quotes), and assigned themes or subthemes that were then compared with those of the investigator.

In terms of dependability, we integrated finding according to what we can see, as well as relying on theoretical and conceptual frameworks.

In terms of confirmability, we provide evidence that corroborated the finding. Findings or themes emerged from the analyses by providing quotes taken verbatim from the participants.
7.3 Results

A total of 15 families were interviewed (18 parents and 15 children). This was because three interviews involved both parents of the child. The demographics of the parents and their CWE are listed in Table 7.3 and Table 7.4, respectively.

The mean age of parents was 42.1 years, SD= 5.6 years (age range: 33-58 years). One parent was an occupational therapist and had previous experience in taking care of patients with epilepsy.
A total of eight boys and seven girls were recruited. The mean age of these children was 12.7 years, SD=1.7 (range: 8-17 years). The mean duration of epilepsy was 5.0, SD=3.5 years (range: 2-10 years). These children were diagnosed with idiopathic generalised epilepsy (n=8), childhood/juvenile absent epilepsy (n=6), and focal epilepsy (n=1).
Table 7.4: Characteristics of children with epilepsy (n=15)

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age (year)</th>
<th>Ethnicity</th>
<th>Gender</th>
<th>Type of epilepsy</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1</td>
<td>10</td>
<td>Indian</td>
<td>Girl</td>
<td>Idiopathic generalised epilepsy</td>
</tr>
<tr>
<td>C2</td>
<td>13</td>
<td>Malay</td>
<td>Boy</td>
<td>Idiopathic generalised epilepsy</td>
</tr>
<tr>
<td>C3</td>
<td>8</td>
<td>Chinese</td>
<td>Boy</td>
<td>Childhood absent epilepsy</td>
</tr>
<tr>
<td>C4</td>
<td>15</td>
<td>Indian</td>
<td>Girl</td>
<td>Idiopathic generalised epilepsy</td>
</tr>
<tr>
<td>C5</td>
<td>11</td>
<td>Chinese</td>
<td>Boy</td>
<td>Focal epilepsy</td>
</tr>
<tr>
<td>C6</td>
<td>12</td>
<td>Indian</td>
<td>Girl</td>
<td>Idiopathic generalised epilepsy</td>
</tr>
<tr>
<td>C7</td>
<td>9</td>
<td>Indian</td>
<td>Boy</td>
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7.3.1 Experiences of parents and their children with epilepsy

The experiences of parents and their children can be divided into two different time frames: “Experiences during child’s first seizure” and “Experiences whilst growing up with epilepsy”. The themes and subthemes are summarized in Table 7.5.
Table 7.5: Experiences of parents and children with epilepsy

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<td>Experiences whilst</td>
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7.3.1.1 Parents’ experiences during their child’s first seizure

Three themes emerged from: “Parents’ initial reactions”: “Emotional Reaction”, “Cause of epilepsy” and “Socio-cultural role in health seeking behaviour” (Table 7.5).

(a) Emotional reactions to child’s first seizure

All parents experienced negative emotional reactions when their child first had a seizure. They were upset, shocked, and worried. They thought that their child was going to die. A parent who was an occupational therapist did not think that his child was going to die, but felt sad because he realized that his child might have epilepsy.

That was the first time seizure, I don't know. I thought “What happened?” I thought, she couldn't breathe! I thought suddenly she just passed out and gone [died] already.”

43 years old, with a 15-year-old daughter with epilepsy

I feel very sad but I’m ready to accept [that he had seizure]. His mother, cannot accept... that her son had seizure.

46 years old, with a 13-year-old son with epilepsy

(b) Cause of epilepsy

In some families, some mothers blamed themselves for “causing” their child to have epilepsy. Additionally, there were some families where the in-laws blamed the mother for “causing” the child to have epilepsy. Some families also believed that epilepsy was a “supernatural” disease, caused by bad spirits.
I feel so sorry for him. I think he has epilepsy because of me. I took medication when I was pregnant.

58 years old, with a 16-year-old son with epilepsy

My husband’s family members are all vegetarian. So they blamed me because I am not a vegetarian, and said that I made my son to have epilepsy.

45 years old, with a 17-year-old boy with epilepsy

At first, I feel that he is not having a seizure. His EEG was normal. I thought that there was some sort of spirit that was disturbing him.

43 years old, with a 13-year-old son with epilepsy

When my son got his first seizure, my husband thought that it was caused by bad spirits.

44 years old, with an 11-year-old daughter with epilepsy

(c) Socio-cultural role in health seeking behaviour

Health seeking behaviour is defined as actions taken by an individual when seeking help to treat one’s health problem (Cornally & McCarthy, 2011). It can be further described by what facilitates the use of health care services, and what influences an individual to behave differently from others (MacKian, 2003).

At this stage, parents did not look for information actively, as they did not know that their child has epilepsy. Their main concern at this point of time was to find out what happened to their child, and to find a “cure” for their child’s seizure.
Some parents did not know what to do when their child has a seizure. They followed practices passed on by “old folks” such as putting a spoon inside the child’s mouth during a seizure.

*We used a spoon whenever our child had a seizure because we were afraid she would bite her tongue.*

*45 years old, with a 12-year-old daughter with epilepsy*

Some parents did not realize that their child was having a seizure. They thought that their child was unwell. Other parents only realized that their child had a seizure when the teacher informed them.

*We didn’t know that our son had a seizure. But when it occurred three times, we realized something was wrong... so we went to the hospital.*

*36 years old, with a 9-year-old son with epilepsy*

*I am very busy working so I did not know when his first seizure was. There were times when I called his name but he did not respond. Then, one day, his teacher called me and said that he had a seizure in school.*

*38 years old, with an 8-year-old son with epilepsy*

Most parents were aware that when their child was sick, and that their child needed medical care. Some parents sent their child to a healthcare institution, others sent to traditional healers, whilst one sought advice from a relative on what to do. In some families, parents disagreed on how the child should be cared for, as they had different health beliefs.
I had conflicts with my husband’s family. They believe in traditional healers. My mother in law asked me to bring my child to a temple. She also asked him to drink the “holy water” given by the priest.

45 years old, with a 17-year-old boy with epilepsy

...Initially, we went to a temple (traditional healer). But when the seizure became more and more frequent, I felt that something was wrong. I was so worried! I did not believe that traditional healer that much... then it dragged on for another half a year. I knew something was wrong! Seems like the brain has a problem. Without discussing with my husband, I brought him to a hospital to see a doctor.

44 years old, with an 11-year-old daughter with epilepsy

When she [my daughter] got her first seizure, I did not know that it was a seizure. Her face turned blue, so I quickly brought her to my aunt’s house. After a while she was still unconscious, so my aunt and I brought her to the clinic nearby.

54 years old, with a 12-year-old daughter with epilepsy

7.3.1.2 Experiences whilst growing up with epilepsy

Epilepsy is usually diagnosed several months after a child has their first seizure. This is because the diagnosis of epilepsy can only be obtained through a thorough clinical examination of the child with regards to seizure symptoms, triggers of seizure, family history, and an EEG examination. Usually by this stage, parents have gotten over their initial shock and may have found out more information about epilepsy. This section will discuss on parents’ experiences at the point of the diagnosis of epilepsy and its subsequent years.
Four themes were identified: “impact of epilepsy on the family”, “management of epilepsy care”, “parents’ needs” and “parents’ perceived impact of epilepsy on their child” (Table 7.5).

(a) **Impact of epilepsy on the family**

Epilepsy has both positive and negative impact on parents and the family. In some families, family members became more united. However, in some families, some parents developed health or mental health issues, and some parents were forced to give up their jobs to take care of their child with epilepsy.

In Malaysia, children who attend public schools will receive free medical treatment in public hospitals. We recruited all our participants from a public hospital. Hence, all our participants did not report any financial difficulties.

i  **The positive impact on the family**

Some parents reported that their child’s condition improved relationships between siblings, as they supported each other and thus grew closer.

*My eldest daughter helps me to take care of her [my daughter] when I am away. They are very close siblings. I think we [family members] are closer too because we try to solve our problems together.*

*45 years old, with a 12-year-old daughter with epilepsy*
The negative impact on the family

Some parents reported that they were having sleeping problems, as they were afraid that their child might have a seizure whilst sleeping. One parent developed hypertension as a result of stress, from the lack of sleep.

I couldn’t sleep at that time [when my child was first diagnosed with epilepsy]... As a result, my high blood pressure was very high... I went to see a doctor and he asked me to eat medication and relax.

38 years, with an 8-year-old son with epilepsy

All parents agreed that their experiences in handling their child with epilepsy improved over time. However, their fear that their child may have a seizure at any time still persisted, even several years after the diagnosis of epilepsy. Some parents became anxious and depressed, due to the stress in caring for their child with epilepsy.

I become anxious when my child screams. It is because when he gets a seizure attack, he screams... That’s why since then I cannot sleep at night if I hear him screaming... even if he is just playing and screaming with his sibling, I become anxious.

43 years old, with a 13-year-old son with epilepsy

I cannot control my tears... I am stressed taking care of everything... Sometimes I do not feel like doing anything and just sit on the sofa for the whole day... But my husband thinks I am faking it.

44 years old, with an 11-year-old son with epilepsy
All parents reported that they constantly worried for their child with epilepsy. They worry about their child’s health and their school performance. For parents who have adolescents with epilepsy, they worried about their child’s future, as to whether they will be able to live independently and to be able to have equal rights in future employment.

*We are worried that she won’t wake up anymore during her sleep. It is because she [our daughter] has seizure during sleep.*

54 years old, with a 12-year-old daughter with epilepsy

*I am worried about his future career. I’m worried that he cannot find a job due to his epilepsy. And he would not get equal treatment like others when he works in a company.*

45 years old, with a 17-year-old boy with epilepsy

(b) **Management of epilepsy care**

i  **Vigilance in caring for a child with epilepsy**

Parents are continuously watching out for any possible triggers of a seizure attack. All parents imposed restrictions on their child’s physical and social activities (such as sleepovers or planning for an overseas trip), as they were afraid that their child may have a seizure, and no one would know how to care of their child then.

*She was more sports inclined... but after that [seizure] she stopped all sport activity. She goes to school but the attack happens like 3-4 months once... We make sure that you know she eats properly and rests enough... I realized that no matter how much she wants to achieve, I had to stop her for trying too hard*

45 years old, with a 12-year-old daughter with epilepsy
We try to avoid overseas trips. Travelling locally is still okay because we can find a hospital.

45 years old, with a 10 years old son with epilepsy

ii Parents’ coping strategies

The caregiving process involves the care of self, and of others under your care (Raina et al., 2004). All parents reported that they needed to be strong emotionally and spiritually, so that they would have the strength to take care of their child who has epilepsy. Most parents discussed the value of faith in their lives, and how their belief in God has provided them the strength to care. When they felt that they could not handle a problem, they learned how to “let go”.

I prayed when I was upset. Praying makes me strong.

54 years old, with a 12-year-old daughter with epilepsy

I was very sad when my daughter was diagnosed with epilepsy. I cried, I cannot do anything right. I did not know what to do. After I cried... I surrender to God. Let God look after it.

38 years old, with a 15-year-old son with epilepsy

Parents coped with their problems using two different coping strategies: problem-focused coping and effective emotional-focused coping. Parents who used problem-focused coping would address the problem that was causing distress, and would seek a solution for it. Alternatively, parents who used effective emotion-focused coping would try to reduce the negative emotions that were associated with the problem, such as thinking positively, and seeking for emotional support.
We have to find our own information. We find it from the internet... search for anything related on how to take care of him, and how to overcome it [seizure].

43 years old, with a 13-year-old son with epilepsy

I talked to my neighbour when I was upset. She is a kind lady who listens to me all the time. We discussed about how to take care of our children. Sometimes, she taught me how to handle my son when he has fits... Otherwise, I will call my mother. We talked about anything. Although I did not tell her much about my problem, I feel much better after talking to her.

45 years old, with an 11 years old son with epilepsy

I went to see my family doctor whenever I feel unwell. We are like friends. He talked to me and listened to me. He told me to relax and everything is going to be alright.

38 years old, with an 8-year-old son with epilepsy

iii Disclosure of epilepsy

Disclosing to others that their child has epilepsy was not easy for most parents. This was due to the fear of stigmatization, concern that their child’s future would be affected, and worry that their child would not be treated equally by the school teacher.

Yeah. I don’t want to talk about her epilepsy with her school teacher, like she doesn’t want me to tell her teacher, because I can understand that the teacher might not give her the same opportunity [like other classmates]...

45 years old, with a 12-year-old daughter with epilepsy
Some parents were willing to disclose to others that their child has epilepsy. For parents who shared this information with others, they felt that a burden has been lifted off their shoulder. These parents received positive responses, help and social support from others. The disclosure of epilepsy also meant that others (such as school teachers and classmates) could help ensure the safety of the child during a seizure. In addition, it also brought parents in a similar situation together.

*I treat him [my son] like a normal person. I feel that some parents who have a child with epilepsy dare not tell others, or discuss with others, as they feel embarrassed. I think when we communicate with others, may be, others might tell you: “Oh! I have an idea, on how to take care of the child better”. After you have communicated with others, may be you can get better information!*

38 years old, with an 8-year-old son with epilepsy

*All teachers know [about my son’s epilepsy]. The teachers take care of him. Even if he did not tell us that he had a seizure, his friends would inform us.*

46 years old, with a 13-year-old son with epilepsy

(c) **Unmet parental needs**

i  **Need for epilepsy related information**

Once the initial shock regarding the first seizure passed, parents wanted more information regarding epilepsy. Most parents mentioned that when their child was first diagnosed with epilepsy, they did not know much about the disease, prognosis, or the side effects of AED. This may be because epilepsy is not a commonly known disease, and how to care for a child while he/she is having a seizure is not well known. Parents wanted doctors to provide them with sufficient information, and to demonstrate on how to care
for a child with seizure. Doctors ordered tests to confirm or exclude the diagnosis of epilepsy, and prescribed medications for the seizure.

*The doctors prescribed medicines, and told me to turn her to the side.....when she has a seizure. The doctor did not demonstrate how to care for my child... um... so I did not know what to do. Epilepsy is not like breast cancer where they have roadshows ... and nurses teach us how to do breast checking [self-examination]. If they have something like that [for epilepsy], that would be better.*

*43 years old, with a 15-year-old daughter with epilepsy*

*I get information my sister in law (who is a nurse) and from the doctors. I also look for more information from the internet. I think maybe it is better if the doctors can teach me how to treat my daughter during a seizure.*

*43 years old, with a 15-year-old daughter with epilepsy*

*Sometime, I can’t be patient, I search on the internet. Whatever it is, whatever method how to take care of my son. This is because the doctor doesn’t give any detail, you know?*

*43 years old, with a 13-year-old son with epilepsy*

Although doctors provide more information about epilepsy in subsequent visits, some parents feel that the information provided should be more understandable, and doctors should be more frank about the side effect of AED. Parents also demanded for the latest information related to epilepsy.
The doctor always tells me to be at ease about the side effect of antiepileptic medications! Be at ease. But I do feel that sometimes, the doctor should be frank. I know that all medications have side effects. But no one told me what the side effect of Epilim is...

38 years old, with an 8-year-old son of epilepsy

I hope that doctor can update us the latest information related to epilepsy. For example, you know, like new medicine to treat epilepsy.

45 years old, with a 12-year-old daughter with epilepsy

ii Need for continuity of care

As we recruited participants from a public hospital, parents were not given a choice on which doctor they would consult with at each follow-up visit. There was no continuity of care. Some parents were required to repeat the same information to different doctors about their child’s epilepsy at each visit. They became frustrated and tired.

The doctor has my son’s medical record, right? He does not need to ask the same thing again. But every time when he goes for a follow up, or is admitted to the hospital, the doctor would ask: how my son got a seizure, what was his symptoms... I think the doctor does not need to ask again because there is a record! [Raising her voice]

43 years old, with a 13-year-old son with epilepsy

iii Need for a parental support group

Some parents were aware of the importance of a parental support group. They wished to be informed about the availability of an existing epilepsy caregiver support group, hoping to share and exchange information with other parents whose child has epilepsy.
Because even if the doctor wants (to give more information about epilepsy), other patients are waiting outside... He is rushing... So, I am not satisfied. That’s why, we should at least have a community... so that all parents can share their problems... I don’t have anyone to share my problem with. My husband said it is fine to have a seizure. But what is the way to solve it? How to share?

43 years old, with a 13-year-old son with epilepsy

(d) Parents' perceived impact of epilepsy on their child

i  Physical changes

Most parents did not report any significant physical changes before and after their child was diagnosed with epilepsy. However, there was one parent who reported that her child experienced significant hair and weight loss due to the AED.

I wasn’t sure why this happened to her. She has significant hair loss and became so thin. So the doctor decreased her dosage.

54-year-old, with a 12-year-old daughter with epilepsy

ii  Emotional changes

While some parents did not find any emotional changes in their child, there were a few who noted that their child gets angry easily.

He gets angry easily and no one can stop him. Sometime he even threw things on the floor when he lost his temper.

58 years old, with a 16-year-old son with epilepsy
iii  Behavioural changes

Behavioural changes before and after their child was diagnosed with epilepsy was not obvious. Some parents reported that their child displayed some behavioural problems (such as stubbornness or being naughty). However, they did not observe that these behavioural problems were any different before and after the diagnosis of epilepsy. These parents felt that these problems were due to their child’s characteristic rather than the disease itself.

One parent reported that her child did not behave well, and was “hyperactive” in school.

*He is hyperactive, and like to “pick on” others. His actions not only annoy his friends in school, but also made me angry. When no one wants to speak with him, he will make annoying sounds to get your attention. I always have to go to school and meet his teacher.*

44 years old, with an 11-year-old son with epilepsy

iv  Academic achievement

All CWE attended school and were able to participate in school activities. Some parents reported no changes in their children school performance before and after the diagnosis of epilepsy. Other parents reported that epilepsy had a negative impact on their child’s school performance, as they missed school or examinations rather frequently, or they had problems with understanding what was taught in school.

*She had very bad seizure and was hospitalized for a week. She was absent from school for almost 3 weeks... she had to skip her major form 3 trial exam.*

43 years old, with a 15-year-old daughter with epilepsy
Teacher called me to bring him back from school when he had a seizure or when he was not feeling well. It happens 2-3 times a month.

40 years old, with a 14-year-old son with epilepsy

...After my daughter was diagnosed with epilepsy, she became so forgetful. Sometimes she said she cannot understand what the teacher is talking about in class...

32 years old, with a 12-year-old daughter with epilepsy

One parent mentioned that his child’s academic achievement improved since taking AED. The parent thinks that the medication improved the child’s condition and controlled the seizure. As a result, he was able to concentrate in school, and do well in his studies.

Before he was diagnosed with epilepsy, he did very badly in school. He cannot concentrate in class, no matter what we did to help him. He only started to talk when he was 6 years old. We thought he was a slow learner. Until he was diagnosed with epilepsy and started taking medications, he became better in learning... I think the medications helped him concentrate better.

45 years old, with a 17-year-old son with epilepsy

v Interpersonal relationships

Most parents thought that their child had no problems making friends. However, some parents reported that their child did not have any friends in school. They were teased, “called names”, and were bullied in school.
She doesn’t know why they don’t want to be friends with her. She said her friends will tease her... said that she has fits. I feel that she is less happy in school. Because of this...

54 years old, with a 12-year-old daughter with epilepsy

He said that in school, his friends teased and kicked him, but he does not want to tell us or his teacher. He said he is afraid that the boy would not want to be friends with him.

44 years old, with an 11-year-old son with epilepsy

7.3.2 The experiences of children with epilepsy

7.3.2.1 Experiences during their first seizure

Two themes emerged from the “Child’s initial reactions”: “Physical reaction” and “emotional reaction” (Table 7.5). CWE did not reported on health seeking behaviour as they were not well enough to do so.

(a) Children’s initial reactions

The child’s initial reactions on his/her first seizure were mainly described by children aged 11 years and above, as younger children did not know they were having a seizure, or were too young to recall their experiences. They just thought that they were sick, and would get better with medication.

I am not alone (I am not the only student who has a seizure). I have seen another student in my school having a seizure.

15-year-old girl with epilepsy
My mother said that I was sick and I have to eat (take) medications. The doctor said two years later I will be fine.

8-year-old boy with epilepsy

...I was only six years old when I had my first seizure. I cannot recall what happened during my first seizure.

15-year-old boy with epilepsy

i  Physical reaction

Fatigue and excessive tiredness was experienced by some children after their first seizure. Some children noted that their tiredness lasted for a couple of hours, whilst others were tired for the whole day. Some children were conscious, but felt like they were “stuck inside” their body during their seizure. A total of eight children in this study had generalized epilepsy. They lost consciousness or “went blank” during their seizure, thus they could not remember anything during a seizure.

When the seizure was over, I was so tired. I cannot talk much. I just wanted to sleep.

12-year-old girl with epilepsy

I can hear people (during my seizure). But I couldn’t move. My whole body was “stuck”. I could not move anywhere. Only my mind was thinking.

12-year-old girl with epilepsy
Emotional reaction

Most children felt shocked, upset and scared during or after their seizure.

I was not really afraid but I was shocked... (During my seizure).

12-year-old girl with epilepsy

At that moment (during seizure) I was scared, but after that I felt alright. I am scared that it will come again.

15-year-old girl with epilepsy

7.3.2.2 Experiences whilst growing up with epilepsy

Growing up with epilepsy is not easy for most children. They have to deal with the fact that a seizure can occur at any point of time. They also have to deal with the after effects of a seizure, with restrictions imposed by their parents on their physical and social activities, and with doubt about their future prospects.

Four themes emerged from the “Children’s experiences whilst growing up with epilepsy: “Impact of epilepsy on their family”, “Attitudes toward epilepsy”, “Child’s needs” and “Impact of epilepsy on the child” (Table 7.5).

(a) Impact of epilepsy on their family

i Family functioning

Most children did not report any significant changes on their family before and after their diagnosis of epilepsy.
“My parents treat my sister and I the same (after the diagnosis of epilepsy). Not much changes in (family) activities.”

12-year-old girl with epilepsy

ii Relationship with siblings

Some children did not report any significant changes on their relationship with their siblings after their diagnosis of epilepsy. Some children felt that their relationship with their siblings grew closer due to epilepsy.

“My brothers took care of me when my parents were not free. They can protect me.”

11-year-old girl with epilepsy

(b) Attitude toward epilepsy

Attitude towards an illness has a significant impact on the psychosocial adjustment of CWE (J. K. Austin et al., 2006). In our study, most children were of the opinion that they would be seizure free in the future. They did not worry too much about their future. Conversely, some children (especially the girls) thought that they would never be seizure free, and that epilepsy would hinder them in their pursuit of achieving their ambitions.

I am not negative about that (being epileptic)... what is going to happen in the future...
I will go with the flow.

15-year-old girl with epilepsy

I do not like being epileptic. I have to take medications... I can’t go out with friends... I can’t imagine my life in the future.

15-year-old girl with epilepsy
i  Restrictions imposed on physical and social activities

All the children in our study were discouraged from participating in physical and social activities that were away from home. This was because their parents thought that participating in these activities would trigger a seizure, or that no one would know how to help them during a seizure. Some CWE also placed restrictions on themselves in order to avoid triggering a seizure. Generally, the teenagers in our study were unhappy when they were not allowed to go out with their friends. However, their parents allowed their friends to come over to their house. Despite the restrictions imposed, the participants did not think that their parents were over-protective. This was because they were aware that these restrictions were to keep them safe from any possible injury due to a seizure.

I know I cannot join too many extra-curriculum activities after my diagnosis. I cannot push too hard... If I get too tired (during sports), I have to stop or tell someone.

12-year-old girl with epilepsy

I do not like that my parents do not allow me to hang out with my friends other than home. But I have never argued with them. I have to accept it. It is for my own good.

17-year-old boy with epilepsy

ii  Self-efficacy in seizure management

Self-efficacy in this study is defined as how the child handling their epilepsy. Most children in our study did not actively look for information about epilepsy. Some children tried to find some information on the internet, but did not understand what they read. Knowledge about epilepsy was obtained from their parents.
I searched about epilepsy once on the internet and did not understand it.

15-year-old girl with epilepsy

I did not search about epilepsy. My mum tells me everything about epilepsy.

13-year-old boy with epilepsy

Most children in our study did not know the name or the dosage of the AED that they were taking. They also needed to be constantly reminded to take their medications. However, all the children in our study were aware of the importance of taking their medications to control their seizure, and they take it without complaining.

Mummy gives me medication every day. I just take it. I know it is good for me. Two years later (when I recovered) I can stop taking the medication.

8-year-old boy with epilepsy

Sometimes I remember to take my medicine but sometimes I don’t. But my mum will remind me to take my medicine.

15-year-old boy with epilepsy

iii Child’s coping strategies

Most children adopted problem solving and effective emotional coping strategies in dealing with challenges in life. Some children sought help from their siblings, whilst others shared their feeling with their close friends. Some children ignored their problems, hoping that they would go away.
When I was upset I talk to my sister. I can share everything with her. She takes care of me when my mum is away.

12-year-old girl with epilepsy

I sleep when I was upset. I cry too. No one knows. I don’t normally share with my friends. I just keep to myself. After that, I will be fine.

15-year-old girl with epilepsy

iv Disclosure of epilepsy

Some CWE selectively disclosed that they have epilepsy to people whom they trust. They did not want others to treat them differently. Whereas others did not want to disclose that they have epilepsy, if possible. The two main barriers identified were: stigma and “visibility of epilepsy”. Some CWE reported that experienced stigmatization. They were isolated socially, and viewed by others as ‘different’, ‘weird’, and ‘contagious’. One child reported that the “visibility of epilepsy” was a barrier in disclosing his condition to his peers. Epilepsy is only visible when a seizure occurs, or when a person is seen in public taking their medications. His peers did not believe that he had epilepsy, as he looked “normal”.

Only she (child’s best friend) knows about my epilepsy... She can be trusted... I would not tell others because I don’t want to feel different.

14-year-old girl with epilepsy
I used to be very close with my cousins until I was diagnosed with epilepsy 3 years ago. They no longer come near me during family functions. I tried to explain what epilepsy is all about and not contagious, but they refused to listen.

14-year-old girl with epilepsy

I did not tell my friends about my diagnosis because I look normal. I think they won't believe me and think that I am joking.

16-year-old boy with epilepsy

(c) Child’s needs

i Needs for development of independence and autonomy

Most adolescents in our study reported that they want to make their own decision about their life: such as driving, what they want to be in the future and whether to attend the national service course. One adolescent hopes that the doctor can communicate directly with her during consultation, and involve her in the decision making, together with her mother.

I want to serve national service end of this year. I don’t care if my parents wouldn’t let me go.

17-year-old with epilepsy

I think I am a better person to answer doctor’s question during follow-up, instead of just asking my mother. I hope the doctor can talk to me directly in person.

14-year-old girl with epilepsy
**Future and hope**

Most children in the study hope that they would be seizure free when they grow up. They want to be independent and to fulfil their dreams. However, some adolescents think that epilepsy would affect them in their future choice of study and career.

*I want to be a policeman after I graduate... I can do it if I work hard.*

16-year-old boy with epilepsy

**(d) Impact of epilepsy on the child**

The impact of epilepsy on the child can be categorised to five subthemes: “physical changes”, “emotional changes”, “behavioural changes”, “academic achievement” and “interpersonal relations with peers”.

**i Physical changes**

Most children did not report any significant physical changes due to epilepsy. However, some children reported that they get tired easily due to epilepsy, whilst one child reported significant hair and weight loss due to AED side effect.

*I feel tired easily. Most of the time I have low energy... I just want to go to sleep.*

15-year-old boy with epilepsy

*I am losing my hair lately. My mum said I am getting thinner than thinner. So I went to see doctor and doctor said have to cut down my medicine (dosage).*

12-year-old girl with epilepsy
ii  Emotional changes

Although majority of our children did not report any significant emotional changes due to epilepsy. Some children got upset easily whenever they think of their epilepsy whilst some children reported that they felt frustrated over restrictions imposed by their parents.

*I feel upset whenever I think of my health. I cannot do things that I really wanted to do.*

15-year-old girl with epilepsy

iii  Behavioural changes

All children did not report any significant behavioural changes due to epilepsy.

iv  Academic achievement

Some children had a negative impact on their academic achievement. Seizure can occur during or after school hours. Some children had a seizure during school resulting loss of consciousness. They experienced difficulties in concentrating on what was being taught in class. Some children had a seizure after school hours – e.g during their sleep. Hence, they were absent from school the following day. Other children thought that epilepsy did not have any significant impact on their academic achievement. Two children reported better academic achievement in school.

*I did not do well in school. Especially in Math. I cannot concentrate during class. I have to go home every time I have a seizure in school.*

15-year-old boy with epilepsy
I do not think epilepsy has anything to do with my study. I did not do well because I like to talk with my friends in class. If I work harder, I think I can improve myself.

16-year-old boy with epilepsy

Epilepsy motivated to do better in my study. I put extra effort in my study because I do not want epilepsy to slow me down.

17-year-old boy with epilepsy

I was so occupied with extra curriculum activities before I was diagnosed with epilepsy. Now I cannot go to badminton and swimming lessons, I have more time for myself, I can concentrate on my studies. Now I do better in school.

12-year-old girl with epilepsy

Interpersonal relationship

Some CWE have several close friends in school. They receive constant emotional and social support from their close friends whereas others did not want to make friends, and would rather be alone, or just hang out with one or two close friends that they could trust. However, a few children were bullied and isolated socially.

I make friends with all my classmates. My close buddies... There are five of us all together.

16-year-old boy with epilepsy

I have a close friend who is willing to take care of me when I am sick. I tell her everything. She cares about me.

14-year-old girl with epilepsy
Not all my classmates are my friends. Em... I don’t think I have any close friend

13-year-old boy with epilepsy

I had a seizure attack in school once. Since then, all my classmates like to tease me and call me awful names. So now... I do not have any friends in school.

12-year-old girl with epilepsy

7.4 Discussion

The study found that the experiences of parents and their child with epilepsy can be divided into two different time frames: “Experiences during their child’s first seizure” and “Experiences whilst growing up with epilepsy”.

7.4.1 Parents’ experiences during their child’s first seizure

7.4.1.1 Emotional reaction to child’s first seizure

All parents experienced negative emotional reactions. They were upset, shocked and worried that their children had seizure. Some parents were not willing to accept the fact that their child had a seizure, whilst some feared that their child may die. These initial reactions of parents during their child’s first seizure were consistent with previous studies and across cultures (Benson, Lambert, Gallagher, Shahwan, & Austin, 2016; Nguyen, Pertini, & Kettler, 2015; Smith et al., 2014; E. Wirrell & Turner, 2001). This can be explained by the five stages of grief model by Kübler-Ross (1969). The five stages of grief model can be applied to how parents accept a chronic illness in their child (Spiess, McLemore, Zinyemba, Ortiz, & Meyr, 2014).

The first stage is denial, where parents refuse to admit that their child has epilepsy. In this stage, parents may not comply with medical treatment but go for alternate medicine.
The second stage is anger. Anger is an emotional act in which parents blame themselves for causing their child to have seizure. The third stage is bargaining. It is a negotiative process where parents try to postpone or distance themselves from the real situation. They may refuse treatment and find ways to prove that their child does not have a seizure. The next stage is depression. Soon after the child has more seizures, parents start to feel that they have lost control. They feel depressed and sad. Depression may affects sleeping or eating patterns. Finally, after progressing through the four stages, parents start accepting the fact that they have a child with epilepsy.

7.4.1.2 Cause of epilepsy

Some mothers in the study blamed themselves and felt guilty for “causing” their child to have epilepsy. Our findings were similar to a previous study, where an African-American parent felt guilty that she “allowed” a parasitic infection to cause the onset of her child’s epilepsy (K. N. Wu et al., 2008). When a mother cannot protect their child from harm, maternal guilt may occur. Maternal guilt occurs when mothers think that they must fully devote themselves to their children and feel completely responsible for how their children develops (Wall, 2010). Mothers who believed they could not live up to either their own or social expectations for being a perfect mother to their children, were more prone to develop guilt and shame (Liss, Schiffrin, & Rizzo, 2013; Rotkirch & Janhunen, 2010). To overcome this, health care providers should educate mothers regarding epilepsy as a disease, so that they should not blame themselves for “causing” epilepsy to their child. If a parent feels guilty, they should talk to someone about their concerns.

Some parents believed that epilepsy was caused by bad spirits. Belief in spirit possession is common in Malaysia (Arulsamy, Goh, & Shaikh, 2014), especially among
rural folks (Neni et al., 2010). It is also common in Thailand (Saengpatrachai, Srinualta, Lorlertratna, Pradermduzzadeeporn, & Poonpol, 2010), China (Snape, Wang, Wu, Jacoby, & Baker, 2009), and Zambia (Stekelenburg et al., 2005).

7.4.1.3 **Socio-cultural role in health seeking behaviour**

Cultural practices and beliefs play a significant role in health seeking behaviour (Snape et al., 2009). If one believes that epilepsy is caused by the possession of “bad spirits”, then parents may seek health from traditional healers rather than from medical doctors (Abubakar et al., 2013; Shaikh & Hatcher, 2005; Webair & Bin-Gouth, 2013). Although the majority of participants believed that modern medicine was still the best treatment for epilepsy, traditional healers still played a salient role (Abubakar et al., 2013; Neni et al., 2010), especially when modern medicine is unable to cure the disease, or when there is no improvement to the condition (Abubakar et al., 2013; H. Ismail, Wright, Rhodes, & Small, 2005). In addition, some Chinese in Malaysia prefer traditional Chinese herbs for healing epilepsy (Lim et al., 1999). This is in contrast to western countries, where belief that epilepsy is caused by supernatural causes is less common (H. Ismail et al., 2005). Therefore, social-cultural factors play an important role in health seeking behaviour, and may directly attributed to the treatment gap between developed and developing countries. Providing education to the public to seek health from medical institutions is important. The greater the knowledge and awareness regarding epilepsy, and the effectiveness of the treatment of epilepsy would reduce treatment gap between developed and developing countries (Neligan & Sander, 2013).
7.4.2 Parent’s experiences whilst their child was growing up with epilepsy

(a) The positive impact on the family

As a result of the child’s epilepsy, family members grew closer. They would work together to solve problems. Parents showed their love for their child by sacrificing their time, sleep and job to look after their child. Some parents would plan family outings to a place where medical help was accessible in the event of an emergency. They would also bring their child who has epilepsy for swimming to have some fun, but will keep a close watch out that their child will not have a seizure then. Parents also learnt more about epilepsy, how to manage their child and how to cope with this new situation. Our findings were similar to a previous study where the positive impact on the family include becoming an expert about epilepsy and how to manage a child with epilepsy, giving more love and advocacy for their child with epilepsy, as well as recognizing the need to move on over time and live a healthier life (Smith et al., 2014). Older siblings would help to take care of their younger sibling who had epilepsy. Our findings concurred with a previous study where siblings accepting their brother or sister with epilepsy for who they are: “a strong family is about there for one another and getting through what life throws to you…” (Hames & Appleton, 2009).

(b) The negative impact on the family

Conversely, some parents reported that epilepsy had a negative impact on the family. Parents developed sleeping problems and high blood pressure, due to the stress of taking care of their child with epilepsy. These findings were consistent with previous studies where parents were not getting enough sleep (Smith et al., 2014), woke up at least three times per night (to check on their child), and on average only slept for four hours (Cottrell & Khan, 2005). Parents who perceived a higher epilepsy severity reported lower sleep quality, lower marital satisfaction, and lower maternal health (Cottrell & Khan, 2005).
However, another study reported that sleep quality was disrupted regardless of the epilepsy severity (Shaki, Goldbart, Daniel, Fraser, & Shorer, 2011). Ongoing sleep disturbance is associated with excessive daytime drowsiness, poor concentration in daily life, a higher risk of chronic illness (such as heart disease, kidney disease, high blood pressure, diabetes, and stroke) (Joshi, Lesser, Olsen, & O’Hara, 2016; Larson et al., 2012; Shaki et al., 2011).

Some parents experienced mental health problems such as depression and anxiety, which persisted even a few years after their child was diagnosed with epilepsy. Similarly, others also reported that their negative emotions had effected their child negatively (Akay et al., 2011; K. N. Wu et al., 2008). High levels of parental stress was found to be significantly associated with CWE behavioral problems: internalizing (e.g. anxiety, social withdrawal, and somatic complaints) and externalizing problems (e.g. aggression, bullying, hyperactive) (S. H. Han et al., 2016).

7.4.2.2 Management of epilepsy care

(a) Vigilance in caring for a child with epilepsy

Our findings showed that parents became more vigilant in caring for their child who has epilepsy. Parents imposed restrictions in physical activities that would trigger a seizure attack (e.g. swimming), and social activities (e.g. sleepover at a friend’s house) to ensure the safety of their child. During this process, parents had to reframe their role as a parent. Some parents had to lower their expectations on their child in terms of academic and sports achievement. The reframing of parental roles is a function of protecting their child and to promote their child’s development (Mu & Tomlinson, 1997). Our findings were similar to previous literature (Mu, 2008; Nguyen et al., 2015; Smith et al., 2014).
(b) Parent’s coping strategies

Parents coped using two different coping strategies: problem-focused coping and emotional-focused coping. Parents who used problem-focused coping would address the problem that was causing distress, and would seek a solution for it (e.g. seeking for epilepsy-related information). Parents who used emotion-focused coping would try to reduce the negative emotions that were associated with the problem, such as praying, thinking positively, and seeking for emotional support (e.g. emotional venting and talk to health care providers). This was consistent with the ABCX model (McCubbin & Patterson, 1983). Emotion-focused coping attempts to avoid or counteract negative emotions associated with the stressor, whilst problem-focused coping is an active attempt to solve the problem directly related to the source of stress (Lazarus & Folkman, 1984).

(c) Disclosure of epilepsy

Three strategies were adopted by parents with regards to the disclosure of epilepsy: concealment (do not disclose their child’s epilepsy to other people), selective disclosure (disclose to close people that can help their child), and voluntary disclosure (openly discuss about their child’s epilepsy to others). The majority of the parents in this study decided to conceal or selectively disclose the fact that their child has epilepsy. Parents who selectively disclosed their child’s epilepsy did this to selected significant others, like extended family, school teachers, or neighbours. Only a few parents decided to voluntary disclose this fact to others.

Epilepsy is a “concealable stigmatized disease” (Chaudoir & Fisher, 2010). Epilepsy is only visible when the person discloses their condition to others, or when a seizure occurs in the presence of others, or when taking medication in public (Chaudoir & Fisher, 2010). According to Scambler and Hopkins (Scambler & Hopkins, 1986), there are two
types of stigma associated with epilepsy: “enacted” and “felt” stigma. Enacted stigma refers to an individual’s experience of discrimination by others due to his or her epilepsy. For example, being neglected in school or the workplace due to epilepsy. Felt stigma refers to an individual’s fear of unfair treatment by others after disclosure of one’s epilepsy. Felt stigma may be based on the individual’s own negative beliefs of one self. These individuals also believe that others will discriminate them, without any past experiences of enacted stigma (Quinn & Earnshaw, 2013).

The barriers reported by our parents with regards to the disclosure of their child's epilepsy were similar to previous studies, which were fear of stigmatization (Jantzen et al., 2009), fear that their child with epilepsy would be treated differently in school, and concern that their child's future would be affected by stigmatization (Benson, O’Toole, et al., 2016; Mu, 2008). Although concealment or selective disclosure may protect their child from epilepsy-related stigma (Tröster, 1997), one study found that that individuals who concealed their medical condition had poorer psychosocial outcomes (Quinn & Earnshaw, 2013). This was because such silence may reinforce misunderstanding about epilepsy, and increase stigmatization. In addition, concealment and selective disclosure can increase the risk of physical harm to the child with epilepsy, as other people around the child may not know what to do during a seizure. Lastly, parents’ concealment has been significantly associated with a higher level of felt stigma in CWE (Ryu, Lee, Eom, & Kim, 2015), as CWE learn how their parents perceive epilepsy (Jacoby, Snape, & Baker, 2005).

The facilitators for parental disclosure in our study were similar to previous studies: disclosure to family members or teacher to ensure the child's safety when away from home, and encouraging reactions by others when parents discuss about epilepsy
(Gazibara, Nikolovski, Lakic, Pekmezovic, & Kisic-Tepavcevic, 2014; Roberts & Whiting, 2011). In contrast, a study conducted in Taiwan found that parents did not disclose epilepsy to school teacher because the parents thought that the school teacher would not know what to do during a seizure (Mu, 2008).

7.4.2.3 Unmet parental needs

(a) Epilepsy-related information

All of our parents reported that they needed more and updated epilepsy-related information, which was similar with a previous study (McNelis et al., 2007). They required help, assistance, and support from health care providers, regardless of the severity of epilepsy or how educated the parents were (Jones et al., 2014). Parents experienced many challenges in obtaining the correct information that would help them to understand their child’s diagnosis and treatment (S. A. Lewis, Noyes, & Mackereth, 2010; K. N. Wu et al., 2008).

Our parents also reported that they did not fully believe the doctor when he/she said that AED are safe to be given without ant side effects. A previous study has reported similar findings (McNelis et al., 2007).

(b) Continuity of care

All the parents in the study were recruited from a public hospital. In Malaysian public hospitals, parents unfortunately do not get to choose which doctor to see. Hence, they may not have the same doctor in their subsequent follow up. This resulted in some parents having to provide the child’s medical history and diagnosis at every consult. Parents felt lack of continuity of care prevented child from receiving optimal care (Ha & Longnecker, 2010). Continuity of care has been found to be beneficial as an ongoing doctor-patient
relationship builds over time. This can then lead to more in depth discussions, about important issues, between parents and their usual doctor (Freeman & Richards, 1994). Parents are also more satisfied with health service provided when continuity of care is in place (Cabana & Jee, 2004; Saultz & Albedaiwi, 2004).

(c) **Parental support group**

Our findings showed that parents needed of a social support group from other parents. Parent to parent support is helpful to families when the supporting parent is perceived as similar to the referred parent (Ainbinder et al., 1998). Parent support group is particularly useful as the common experience between parents enables understanding, acceptance of his/her thoughts and actions without judgement, and help in coping with difficult situations by sharing personal experiences and feedback. The support given between two parents is bi-directional, and is beneficial to both parties. Previous studies showed that parents of children with special needs who talked to other parents with similar experiences, made them feel “normal” about their situation (Ainbinder et al., 1998). Gaining ideas and information, such as practical parenting tips and linkages about their child with disability, from others who had similar experiences, may lead to better management of day-to-day challenges (Ainbinder et al., 1998; Singer et al., 1999). A qualitative study conducted in China revealed that parents who participated in a “parent to parent support” group, gained more moral support and encouragement than the community (McCabe, 2008; McWilliams, Reilly, McFarlane, Booker, & Heyman, 2016).

7.4.3 **Experiences during the child’s first seizure**

Should the first seizure occurred before the age of five, CWE were not able recall how they felt. For children who were able to recall their experience, they reported that they were shocked, upset, and scared as they did not know what was happening. No
comparison with other studies could be performed as there was no published literature on this topic.

7.4.4 Experiences of a child whilst growing up with epilepsy

7.4.4.1 A child’s attitudes toward epilepsy

Most of the CWE were not worried about their epilepsy, and believed that they would be seizure free in the future. As postulated by the model of children’s attitudes towards their epilepsy (J. K. Austin et al., 2006), a child’s attitude towards their epilepsy is governed by family mastery, a child’s worry about epilepsy, and a child’s self-efficacy for seizure management. Family mastery means that family members are able to work together to solve problems. A family with strong family mastery provides positive support to help the child to deal with their epilepsy. This includes maintaining regular family activities (such as outings and family gatherings), and taking precautions on any possible situation that may trigger a seizure. As a result, this decreases the child’s worry about epilepsy, and strengthens the child’s self-efficacy for seizure management.

Conversely, some girls in our study reported more worries and negative attitude towards epilepsy. They reported that they were worried about how epilepsy would affect their future. Our result was similar to a previous study (J. K. Austin & Caplan, 2007). This maybe because girls uses more emotional coping and tends to worry more compared to boys (Galambos, Leadbeater, & Barker, 2004).

(a) Restrictions imposed on physical and social activities

All the children in this study were unhappy with the restriction in physical and social activities that were away from home. These restrictions made them feel excluded or “different” from their peers which was similar to a previous study (Chiu et al., 2014).
Whilst one study reported that CWE feel overprotected by their parents (Sillanpää & Cress, 2009b), children in this study did not think that their parents were over-protective. This was because they were aware that these restrictions were to keep them safe from any possible injury due to a seizure.

(b) **Self-efficacy in seizure management**

The children in this study were passive in seeking for information about epilepsy by themselves, as they did not particularly want to know more about epilepsy. They were contented to leave their parents to seek for information regarding epilepsy, and to passively receive information from their parents. Some studies reported similar findings (Swarztrauber, Dewar, & Engel, 2003), while other study reported otherwise (Admi & Shaham, 2007; McEwan et al., 2004; McNelis et al., 2007). Younger children do not particular worry as they were cared for by their mothers. One possible explanation is that these children were not know how to ask question or they were not given a chance to ask question. Another explanation is that there was no age appropriate epilepsy information material (e.g. brochure) for these children. Hence, these children lost interest in seeking for epilepsy related knowledge. This is important to encourage CWE to be active in obtaining information because knowledge regarding epilepsy helps them understand the disease and treatment, and become independent in self-care in the future. They can use their knowledge to help them to become confident in managing their epilepsy in the future (S. A. Lewis et al., 2010).

(c) **Child’s coping**

Most children in this study has positive attitudes towards epilepsy. Thus, they adopted problem solving and effective emotional coping strategies in dealing with challenges in life. A positive attitude towards epilepsy has been found to be associated with positive
self-concepts, better coping capability and lesser behavioural problem (Funderburk, McCormick, & Austin, 2007). Some children sought help from their siblings, whilst others shared their feeling with their close friends. However, some children who have negative attitudes towards epilepsy tends to ignore their problems.

(d) Disclosure of epilepsy

Most children in this study reported concealment or selective disclosure to avoid possible peer rejection, as they wanted to pursue normalcy. Our findings were similar to previous studies (Benson et al., 2015; McEwan et al., 2004; McNelis et al., 2007). According to Erikson developmental theory, childhood and adolescence are critical periods for identity formation and self-definition (Erikson, 1963). During these periods, children and adolescents aim for normalcy and strive to gain peer acceptance (Benson et al., 2015).

7.4.4.2 Child’s needs

The children in this study were more concerned about gaining independence and wanting autonomy. Some children reported that they were worried when they thought about how epilepsy would affect their live in the future. For example, they were worried as to whether they were able to independent (e.g. employment). Our findings were similar to a previous finding (H.-J. Chen et al., 2010). Consistent with Erik Erikson psychosocial development theory (Erikson, 1963), growing children need for independence and autonomy.
7.4.4.3 Parents’ and child’s views on the impact of epilepsy on their child

Our study explored both the parents and child’s view. To date, only one qualitative study explored the concerns and needs of parents and their CWE (McNelis et al., 2007), but did not compare their views.

Previous studies showed that there was a high level of agreement between parent proxy and child self-report ratings on external life experiences, such as the physical and social wellbeing of the child; where the parent was able to observe the conduct of their child. However, parents were not able to accurately report their child’s internal experience (such as their attitude towards epilepsy) (Eiser & Morse, 2001). Our findings concurred with previous studies where the views of parents and their child with epilepsy were similar in the following areas: physical functioning (Labajo, Castarlenas, Miró, & Reinoso-Barbero, 2017), academic achievement (H.-J. Chen et al., 2010; McEwan et al., 2004) and bullying (Schroeder, Morris, & Flack, 2017).

The areas where the parent’s and child’s view differed were in functioning, behavioural changes and interpersonal relationship.

Parents reported that their child with epilepsy gets angry easily. However, none of the children in our study reported that they angered easily. Instead, the children reported that they were frustrated and upset due to the restrictions imposed by their parents. Anger is defined as a spontaneous feeling that occurs towards obstructive behavior (e.g. restriction imposed by parents) (Kazdin, 2000). Frustration is defined as an emotion that is felt by an individual during an attempt to achieve something that is difficult (Underwood, 1949). When a child does not know how to express their frustration, they may react by being...
angry, as perceived by their parents. In this case, the views of parents and their child did not differ. There was no prior literature to compare our findings.

Most parents and CWE did not report any significant behaviour changes due to epilepsy. Our findings contradicted with published literature which reported that children with epilepsy displayed more behavioural problems (Oostrom, van Teeseling, Smeets-Schouten, Peters, & Jennekens-Schinkel, 2005). This maybe because previous studies reported behavioural problem that were observed and rated by their parents (J. K. Austin et al., 2004) and teachers (D. W. Dunn, Austin, Caffrey, & Perkins, 2003). The children did not rate themselves in term of behavioural problems.

One parent reported that her 11-year-old child was too active, and hence, did not behave well in school. However, the child disagreed with his mother’s view. He did not feel that he was “overactive” or that he misbehaved in school. As for the children, they did not report any behavioural changes. This maybe because children may not understand the implications of their own behaviour (Herjanic et al., 1982). They may not be aware that their behaviour was “problematic”. Secondly, behavioural problems in a child (such as screaming and throwing tantrums) maybe a way of the child who lacks of the social or language skills to express himself/herself (Steffens & Bosch, 2003).

Our finding concurred with previous studies, which reported low agreement between parents and child regarding proper behaviour in school (Edelbrock, Costello, Dulcan, Conover, & Kala, 1986; Herjanic & Reich, 1982). Parents reported more school behaviour problems than their children. This study also found disagreement between parent’s and child’s view on interpersonal relationship. This finding was consistent with a previous study which reported that there was low agreement between mothers and
children in peer relationships (Herjanic & Reich, 1982). Most parents thought that their child had no problems making friends and have many friends. However, CWE in this study reported that they did not want to make friends, and would rather be alone, or just hang out with one or two close friends that they could trust.

7.4.5 Strengths and limitations

The strength of this study was that the views of parents and CWE regarding the needs and challenges in epilepsy care were explored. We are able to triangulate our data, and to explore with views were shared by both parent and child, and were not. Needs and challenges that are unique (e.g. socio-cultural belief in epilepsy) in Malaysia compared to other cultures were also identified.

One of the limitation of this study were that we recruited parents and their children with well controlled seizure that were diagnosed with: idiopathic generalised epilepsy, childhood absent epilepsy, focal epilepsy, and juvenile absence epilepsy. Therefore, there is lack of transferability to other CWE and with other co-morbidities: cognitive impairment, learning disabilities, conduct problems or psychological problems. Secondly, conveniece sampling was used to recruit participants. We finally recruited ten Indians, four Malays and four Chinese participants. Besides, there were imbalance of gender, ethnicity, and SES. Therefore, our participants were not representative of the Malaysian population.

7.5 Conclusions

Our study found that the experiences of parents and their child with epilepsy can be divided into two different time frames: “Experiences during their child’s first seizure” and “Experiences whilst growing up with epilepsy”. Parents’ main concerns and worries
were their child’s physical health (adverse effects of AED), psychological and emotional wellbeing, academic achievement and their child’s future. The children’s’ main concerns were restrictions imposed, their interpersonal relationship with peers, and being independent in the future. There were three main needs in parents: epilepsy-related information, continuity of care, and parental support group. In our study, the major needs in CWE was the need for independence and autonomy.
CHAPTER 8: DISCUSSION

Initially our aim was to develop a psychosocial intervention to improve the HRQOL of CWE and their parents. Therefore, several instruments such as the Malay and Chinese versions of the CHEQOL-25 to assess the HRQOL (chapter 4); and the Malay and Chinese versions of the GF-12 subscale to assess family functioning (chapter 5) were validated in Malaysia. However, these instruments were not used to assess the effectiveness of a psychosocial intervention to improve the HRQOL of CWE. This was because it was not possible to recruit sufficient CWE with normal cognitive function (who were able to fill up the HRQOL by themselves) to conduct a randomized controlled trial. Therefore, we modified the research project and changed its overall aim to the overall aim of this study was to examine the rationale, feasibility and validation of instruments that assessed the HRQOL and family functioning of CWE, to systematically review the impact of epilepsy on academic achievement in children with normal intelligence and without major comorbidities, and to explore the needs and challenges encountered by parents and their children in childhood epilepsy care, and how epilepsy affects the child’s HRQOL.

8.1 Health related quality of life measure for children with epilepsy in Malaysia

A valid and reliable HRQOL measure is an important outcome measure for CWE. The availability HRQOL measure such as the CHEQOL-25 in both Malay and Chinese versions helps professionals adopt a holistic approach and may increase their awareness of issues that concern CWE and their families in Malaysia. In our study, parents reported CWE reported adequate HRQOL score, highest score in interpersonal/social, future worries, present worries, intrapersonal/emotional, and lowest in epilepsy secrecy. This finding was consistent with our result in qualitative study (chapter 7). Some parents
reported that concealment or elective disclosal about their child’s epilepsy due to fear of stigmatization.

However, children in our study reported highest HRQOL in quest of normality, interpersonal/social, epilepsy secrecy, intrapersonal/ emotional, and lowest HRQOL in present worries subscales. This may be because the majority of children were protected and well taken care by their parents, they might not know much about their current medicial condition. Therefore, due to lack of awareness and knowledge, they were more worried about their epilepsy and the consequences after each seizure (e.g. remember to take medication in time, if they would get hurt when seizure happened).

Our study is important because, it demonstrated that the CWE without cognitive impairment, as young as eight years old is able to answer self-report CHEQOL-25 (chapter 4). We also found that parent-proxy ratings correlated well with child self-reports in areas where the parent was able to observe the conduct of their child, as the information provided by parents-proxy can be used to supplement and validate a child self-reported HRQOL. Therefore, both parent-proxy and child self-report of the CHEQOL-25 can used to assess a child's HRQOL in Malaysia.

8.2 Family functioning instrument in Malaysia

Researcher and clinician can assess family functioning in adults with or without chronic illness, using the Malay and Chinese GF-12 subscale. The GF-12 subscale can be used as standalone instrument of family functioning (chapter 5). This is because firstly, there was high correlations between the FAD total score and the GF-12 subscale scores (Speranza et al., 2012). Secondly, the GF-12 has been widely used. It has been translated and validated in different languages (such as Spanish and French). Recent studies showed
that cultural values and beliefs are factors to promote healthy family functioning and positive parenting outcomes (Delvecchio, Di Riso, & Salcuni, 2015). Further studies can examine the family functioning in across different cultural settings using the GF-12 subscale.

8.3 Academic achievement in children with epilepsy in Malaysia

Another important issue raised by parents were their concerns about how epilepsy would impact on their child’s academic achievement. Generally, Asian parents believe that academic achievement is an important goal in order for a child to succeed and be independent in the future (Bond, 2010). Our study found that in CWE of normal intelligence, the majority of published literature found that academic achievement was lower than controls or reported norms. Academic achievement of CWE was not solely affected by epilepsy related variables, rather, academic achievement was affected by the child’s attitude towards epilepsy, school-related factors, and the family’s adaptation to epilepsy (chapter 6). Parents and school teachers should work together to help CWE to cope with their school, to encourage them to succeed academically, and not to let epilepsy slow them down.

8.4 Needs and challenges encountered by parents and their children in childhood epilepsy care in Malaysia

The experiences of parents and their child with epilepsy were divided into two different time frames: “Experiences during their child’s first seizure” and “Experiences whilst growing up with epilepsy”. Similarly, another study which explored the experiences in caregivers of CWE also divided their participants into three categories: those diagnosed with epilepsy <1 year, those with epilepsy between 1-5 years, and those with epilepsy for >5 years. The authors postulated that caregivers of CWE diagnosed <1 year
would still be struggling to adjust to the diagnosis of epilepsy and the unpredictability of seizures. For CWE between 1-5 years, caregivers were uncertain about whether their child’s epilepsy would bring any positive impact to the family, whilst for CWE for >5 years, caregivers were more settled with the diagnosis of epilepsy but were worried about their child’s future (Smith et al., 2014). This illustrates that parents and their CWE have different needs and challenges at different points in time.

Some of our findings on the experiences of parents and their child with epilepsy were similar to previous studies (section 7.3.1, chapter 7). Our findings showed the factors that had an impact on the lives of parents and their child with epilepsy were: parental socio-cultural belief, attitudes towards epilepsy, social support from friends and family, family functioning, and community resources. These dimensions were also found to be congruent with the ABCX family adaptation model (McCubbin & Patterson, 1983), the caregiving process stress model (Raina et al., 2004) and, the children's attitudes toward their epilepsy model (J. K. Austin et al., 2006).

One unique finding from our qualitative study was the health seeking behaviour among parents of CWE (Chapter 7). Some parents believed that epilepsy was caused by “bad spirits”, hence they sought treatment from traditional healers rather than from medical doctors. They were also less likely to talk about epilepsy openly with their child, and hence influenced their child’s attitude towards epilepsy. Therefore, we proposed that socio-cultural factors should be added into the ABCX family adaptation model (McCubbin & Patterson, 1983), the caregiving process stress model (Raina et al., 2004), as well as the children's attitudes toward their epilepsy model (J. K. Austin et al., 2006).
8.5 Implications of our study findings

The Family Assessment Device (Epstein et al., 1983) was developed to assess the dimensions of the McMaster Family Functioning Model. It consists of six subscales and a general functioning subscale which assesses the overall level of family functioning. The FAD and the GF-12 have been translated into different languages and used in research studies across different cultures. Epstein and colleagues did not include socio-cultural factors in the McMaster Model of Family Functioning (Miller, Ryan, Keitner, Bishop, & Epstein, 2000).

In our qualitative study, when we explored the needs and challenges in CWE and their parents, we adopted the ABCX- family adaptation model. This model consists of family demands caused by epilepsy (stressors), family resources (social support), coping behaviours (problem-focused coping and emotional focused coping), and how a family deals with stressors (adjustment). The model proposes that when a stressor occurs, the family’s existing resources interact to influence family coping behaviours. These coping behaviours will then influence how the family deal with stressors.

We found that socio-cultural factors influence how parents deal with their child with epilepsy. For example, some parents believed that epilepsy (stressors) was caused by “bad spirits” (socio-cultural factor). Hence, they sought treatment (coping) from traditional healers (adjustment) rather than from medical doctors. This finding only emerged from the qualitative study. Additionally, recent studies also showed that cultural values and beliefs were factors that could promote healthy family functioning and positive parenting outcomes (Dejłvecchio, Di Riso, & Salcuni, 2015). Therefore, further studies should examine family functioning using the GF-12 subscale across different cultural settings.
In addition to medical treatment provided by doctors, childhood epilepsy may require a multidisciplinary team approach that involves other healthcare providers, such as developmental/child psychologists, pharmacists, nurses, counsellors, and educational psychologists to improve the HRQOL in CWE (Goldstein et al., 2004). It is important that healthcare providers recognize the needs and challenges of parents when their child is experiencing their first seizure, as well as when their child is diagnosed with epilepsy. Healthcare providers should tailor their communication to each parent’s needs for epilepsy-related information and its treatment, provide information about a child’s developmental milestone so that parents have a more realistic expectation of their child. Increasing parental epilepsy-related knowledge may increase their confidence in dealing with their child’s epilepsy. Healthcare providers should also provide child-friendly information to CWE, and to encourage children to ask questions related to their condition. Active health seeking behaviour would help CWE to understand their disease and treatment, and become independent to take care of themselves when they grow up. This may also strengthen the child’s self-efficacy for seizure management, and encourage a positive attitude towards epilepsy.

Our research findings can be used to develop a psychosocial intervention that addresses the needs and challenges of parents and their CWE in Malaysia. To date, most psychosocial interventions such as The Children’s Epilepsy Program (M. A. Lewis, Hatton, Salas, Leake, & Chiofalo, 1991), the FLIP & FLAP epilepsy program (Jantzen et al., 2009), and the Coping Openly and Personally with Epilepsy (COPE) (Wagner et al., 2010), have been developed in western countries. In Malaysia, a non-government organization (the Malaysian Society of Epilepsy) was set up to improve the QOL of patients with epilepsy, by providing patients with a support group, to educate the public on epilepsy, and to improve the welfare of people with epilepsy. However, our findings
showed that parents of CWE were not aware of this organization. There is currently no published data on any psychosocial intervention that has been developed and assessed for its effectiveness. Hence, we do not know whether the needs and challenges in parents and their CWE are met.

Children in this study reported tiredness after a seizure and side effects of AED have affected their academic achievement. To date, there is minimal information on how to help CWE in their academic performance in school (S. A. Lewis, Noyes, & Hastings, 2015). Therefore, parents, healthcare providers and school teachers should collaborate closely to understand CWE learning in school. Parents and researcher should work together to monitor how AED can affect their child’s learning. In addition, school teachers can refer a child with epilepsy to the educational psychologist for assessment on cognitive ability (IQ level) and learning styles. A detailed neuropsychological evaluation that assesses memory, language, attention span, and executive functioning by a neurologist can also help to understand a child’s learning impairment. When a child learning problems are identified, a suitable intervention can be developed. Interventions such as improve memory learning strategies using mnemonics, increase attention span by practicing attention break, increase sense of accomplishment in a child by setting short term goals and breaking difficult tasks down into simpler steps.

Lastly, future research should explore the needs and challenges of parents and their CWE who have uncontrolled seizure, have cognitive impairment (IQ<70), or other co-morbidities (such as ADHD, autism or learning disabilities). A qualitative study to explore the views of the remaining stakeholders such as health care providers and policy makers on childhood epilepsy care may also be conducted.
CHAPTER 9: CONCLUSIONS

The conclusions of this thesis can be divided into three phases. In phase 1, the Malay and Chinese parent proxy and child self-report CHEQOL-25 were found to be valid and reliable instruments to assess the perceived HRQOL of CWE in Malaysia.

The Malay version of the GF-10 subscale did not show the same structure as the original general family functioning questionnaire. When items 2 and 4 were removed from the Malay GF-10 subscale, it was found to be a reliable and valid instrument to assess the family functioning among caregivers in Malaysia. The Chinese GF-12 subscale was found to be a factorially valid and reliable instrument to assess the parents’ perceived family functioning of children with and without respiratory disease in Malaysia. The significance of the present study was that a validated and reliable GF-12 subscale can be used as a quick and effective tool to identify unhealthy family functioning. Parents of children in both groups perceived good family functioning. No significant difference in family functioning was found between these two groups.

In phase 3, the majority of published literature found that academic achievement among CWE was lower than controls or reported norms. The high percentages of low achievement in CWE with normal intelligent and without any comorbidities, especially in the older age group, and the stability of scores even as seizure frequency improved, highlights the need for early screening of learning problems, and continued surveillance.
In phase 4, the experiences of parents and their child with epilepsy can be divided into two different time frames: “Experiences during their child’s first seizure” and “Experiences whilst growing up with epilepsy”. Parents’ main concerns and worries were their child’s physical health (adverse effects of AED), psychological and emotional wellbeing, academic achievement and their child’s future. The children’s’ main concerns were restrictions imposed, their interpersonal relationship with peers, and being independent in the future. There were three main needs in parents: epilepsy-related information, continuity of care, and parental support group. In our study, the major needs in CWE was the need for independence and autonomy.
REFERENCES


LIST OF PUBLICATIONS AND PAPERS PRESENTED

PUBLICATIONS:


CONFERENCES:

1. 11th Asian Society for Pediatric Research (ASPR) from 15-18 April 2015, Osaka, Japan
   
   *Poster presentation* [Appendix JJ]
   
   Abstract title: 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

   *Oral presentation* [Appendix KK]
   
   Abstract title: In children with epilepsy, is there a difference between parent-proxy and child self-report on the health related quality of life?

2. Joint Scientific Meeting 9th ASPR Congress & 20th PSM Annual Congress (ASPR-PSM) 9-12 May 2013, Kuching, Malaysia
   
   *Oral presentation* [Appendix LL]
   
   Abstract tile: Parents Proxy health related quality of life measure of children with epilepsy: The reliability and validity of the Malay version in Malaysia

   
   *Oral presentation* [Appendix MM]
   
   Abstract title: The validation of the Chinese version of the General Functioning Subscale (GF-12) among parents of children with or without chronic respiratory disease in Malaysia

4. 24th Federation of Asian Pharmaceutical Association Congress (FAPA) 13-16 September 2012, Bali Nusa Dua, Indonesia
   
   *Oral presentation* [Appendix NN]
   
   Abstract title: The validation of the Malay version of the General Functioning subscale (GF-12) among primary caregivers of children with or without respiratory disease in Malaysia