Predictors of health related quality of life for young people with epilepsy

by Allison Clarke and Christine Critchley
Acknowledgements

First, I would like to acknowledge the following organisations for their assistance in recruiting participants for this study:

- Epilepsy Australia
- Epilepsy Action (Australia)
- Epilepsy New Zealand
- Epilepsy Action (United Kingdom)
- Brainwave – The Irish Epilepsy Association
- Epilepsy Canada
Prevalence and Incidence

Epilepsy is the most common serious brain disorder worldwide and occurs across all age ranges, social classes and nationalities.

Australia’s prevalence for epilepsy for all age groups is approximately 100,330 cases (rate = 0.5%).

Australia’s prevalence for epilepsy for young people under 24 years is approximately 16,890 cases (rate = 0.25%).
Causes of Epilepsy

1. Injury from:
   - Brain trauma,
   - Infection,
   - Neurosurgery,
   - Toxic causes,
   - Stroke,
   - Prenatal Injury.

2. Tumour

3. Vascular Malformations

4. Genetic Abnormalities

BUT, over 50% of epilepsy cases have no known cause.
Treatment Options

- Anti-convulsant therapy (~70-80% achieve control)
- Alternate medical treatment such as Surgery, Vagal Nerve Stimulator, Ketogenic diet
- Medication management for prolonged seizures (e.g. Valium, midazolam)
- Limit triggers and manage lifestyle
- Counselling for the person with epilepsy and their family and carers
Aim

The aim of our study was to determine what were the best predictors of quality of life for young people with epilepsy.
Method (1)

N = 114 young people from a community sample, ranging in age from 10 to 24 years

Mean age = 17.92 years (SD = 3.90)
Mean duration of having epilepsy = 7.62 years (SD = 5.69)
Method (2)

Participants completed either a paper or Internet survey that included:
- demographic and medical history questions;
- Quality of life in Epilepsy for Adolescents (QOLIE-AD-48) scale;
- Hospital and Anxiety Scale (HADS);
- Concerns about seizures scale;
- Adolescent Coping Scale (ACS-SF); and
- General Function subscale from the Family Assessment Device (FAD).
## Demographics

<table>
<thead>
<tr>
<th>Category</th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>10-14</td>
<td>15-19</td>
</tr>
<tr>
<td>Survey Type</td>
<td>Paper</td>
<td>Internet</td>
</tr>
<tr>
<td>Resided in Australia</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Locality Type</td>
<td>Metropolitan</td>
<td>Regional</td>
</tr>
<tr>
<td>Integration Assistance</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

**Note:** DK - Unable to classify locality type
Seizure Types

Partial Seizures (Focal)
- Simple Partial
- Complex Partial

Generalised Seizures
- Absence
- Myoclonic
- Tonic-Clonic
- Tonic
- Atonic

Consciousness Lost (usually)
## Medical Characteristics (1)

<table>
<thead>
<tr>
<th>Category</th>
<th>0%</th>
<th>20%</th>
<th>40%</th>
<th>60%</th>
<th>80%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generalised Seizures</td>
<td>50.00%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partial Seizures</td>
<td></td>
<td>42.10%</td>
<td></td>
<td></td>
<td></td>
<td>57.90%</td>
</tr>
<tr>
<td>Seizures in Last Month</td>
<td></td>
<td></td>
<td>48.20%</td>
<td></td>
<td></td>
<td>51.80%</td>
</tr>
<tr>
<td>Lost Consciousness from a Seizure</td>
<td></td>
<td></td>
<td></td>
<td>28.10%</td>
<td></td>
<td>71.90%</td>
</tr>
<tr>
<td>Hospital Stay due to Seizure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>14.20%</td>
<td>85.80%</td>
</tr>
<tr>
<td>Other Chronic Illnesses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>27.90%</td>
</tr>
<tr>
<td>Other Chronic Illnesses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>72.10%</td>
</tr>
<tr>
<td>Other Chronic Illnesses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>NO</td>
</tr>
</tbody>
</table>
Thirty nine of the participants (34.80%) had at least one family member who had epilepsy. These family members included mothers, fathers, siblings, aunts, uncles, cousins, grandparents, great aunts, great uncles, and nieces.
Medical Characteristics (3)

- **Seizure Severity**
  - Low
  - > 1 Yr
  - DK
  - High

- **Medication Difficulties**
  - Never missed dose
  - Missed > 1 month
  - > 1 month and < 1 week
  - > 1 week

- **Other Traditional Treatments**
  - Yes
  - No

- **Complementary and Alternative Therapies**
  - Yes
  - No
Block 1 of Multiple Regression

Age

β = 0.14, r = 0.07

Health Related Quality of Life

Gender

β = 0.05, r = -0.06
Block 2 of Multiple Regression

- Epilepsy Duration: $\beta = 0.02, r = -0.03$
- Integration Aid: $\beta = 0.09, r = 0.17$
- Seizure in the Last Month: $\beta = 0.13, r = 0.08$

Health Related Quality of Life
Block 3 of Multiple Regression

- **Depression**
  - $\beta = -0.33^*, r = -0.60$

- **Anxiety**
  - $\beta = -0.32^*, r = -0.60$

- **Productive Coping**
  - $\beta = 0.11, r = 0.39$

- **Reference to Others Coping**
  - $\beta = -0.07, r = -0.02$

- **Non-Productive Coping**
  - $\beta = -0.19, r = -0.49$

- **Family Function**
  - $\beta = -0.06, r = 0.33$

* $p < 0.05$, ** $p < 0.001$
# Correlation Matrix of Block 3 Variables

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>A</th>
<th>PC</th>
<th>RO</th>
<th>NP</th>
<th>FF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression (D)</td>
<td>0.57**</td>
<td>-0.45**</td>
<td>0.40**</td>
<td>-0.46**</td>
<td></td>
</tr>
<tr>
<td>Anxiety (A)</td>
<td>-0.28*</td>
<td></td>
<td>0.60**</td>
<td>-0.47**</td>
<td></td>
</tr>
<tr>
<td>Productive Coping (PC)</td>
<td>-0.28*</td>
<td>0.47**</td>
<td>0.40**</td>
<td>0.43**</td>
<td></td>
</tr>
<tr>
<td>Reference Others Coping (RO)</td>
<td></td>
<td>0.47**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-productive Coping (NP)</td>
<td>0.60**</td>
<td>0.40**</td>
<td></td>
<td>-0.41**</td>
<td></td>
</tr>
<tr>
<td>Family Functioning (FF)</td>
<td>-0.47**</td>
<td>0.43**</td>
<td></td>
<td>-0.41**</td>
<td></td>
</tr>
</tbody>
</table>
Variables that did NOT predict

Gender, age, location, duration of illness, age of onset, seizure type, number of anti-convulsant medications, school integration assistance, other co-morbid conditions, traditional family structure and other family members with epilepsy.
Results

Anxiety levels were found to be elevated, with 34 participants (31.2%) demonstrating probable clinical levels of anxiety and a further 7 participants (6.4%) with probable clinical levels of depression based on the HADS scores.
Discussion

Anxiety and Depression are moderately correlated to health related quality of life whereas many medical and demographics factors were not.

Clinicians can promote better outcomes for young people with epilepsy by screening for anxiety and depression and treating it when it is found.

Given General Practitioners and Neurologists are often overseeing treatment of young people with epilepsy it is important that they screen for anxiety and depression and refer for treatment as required.
Thank you

The slides from this presentation are available from the Epilepsy ACT website: www.epilepsyact.org.au/. For more information about this study, please contact me at allison@optimalhealth.com.au.

For more information about epilepsy, please ring: Australian Epilepsy Helpline, 1300 852 853
Questions