Epilepsy, co-morbidities and Quality of Life

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Aims of Presentation

- What is Quality of life [QOL]?
- What do we know about the impact of epilepsy on QOL?
- What are the co-morbidities of epilepsy?
- What do we know about the impact of epilepsy plus co-morbidities on QOL?
- What research questions are generated in respect of the above?
Interactions between epilepsy co-morbidities and QOL

QOL

Physical
- Daily functioning
  - Impaired ADL
    - SF and SS
    - AED effects
    - Injuries

Social
- Work
  - Social and family relations
  - Social functioning
    - Lost rates of marriage
    - Stigma and impact
    - Reduced social functioning
    - Under and unemployment

Psychological
- Cognitive
  - Cognitive factors
- Emotional
  - Well being
    - Low Self esteem
    - Loss of Control
    - Anxiety
    - Depression

ADL, activities of daily living

Baker GA. Clin Ther 1998;20:Suppl A;A2-A12
Definition of QOL

- Quality of life is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” The term “health-related quality of life” is generally used when referring to quality of life in the context of a person's health status.

- Relationship between QOL and Health status [often used interchangeably]

- QOL is multidimensional
Role of Epilepsy for QOL

- A clear relationship of QOL to Seizure Frequency

- Other weaker associations include:
  - Seizure type/combination
  - Seizure severity
  - Age of onset
  - Duration
  - AED effects
QOL by seizure frequency

Impact of Single Seizure on QOL

Dworetsky et al, Epilepsia 2000
Role of recent seizure frequency

Leidy et al, Neurology, 1999
**Perceived impact of uncontrolled seizures**

<table>
<thead>
<tr>
<th>Seizure activity:</th>
<th>None in last year</th>
<th>1+ per month</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Impacts a lot/some on:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship with family</td>
<td>13%</td>
<td>37%</td>
</tr>
<tr>
<td>Social activities</td>
<td>18%</td>
<td>55%</td>
</tr>
<tr>
<td>Ability to work</td>
<td>18%</td>
<td>45%</td>
</tr>
<tr>
<td>Overall health</td>
<td>21%</td>
<td>60%</td>
</tr>
<tr>
<td>Relationship with friends</td>
<td>11%</td>
<td>41%</td>
</tr>
<tr>
<td>Feelings of self</td>
<td>25%</td>
<td>55%</td>
</tr>
<tr>
<td>Plans for the future</td>
<td>24%</td>
<td>56%</td>
</tr>
<tr>
<td>Standard of living</td>
<td>16%</td>
<td>49%</td>
</tr>
</tbody>
</table>

Jacoby & Baker 1997
## QOL profile by epilepsy status

<table>
<thead>
<tr>
<th>Yrs since last Sz:</th>
<th>0-1</th>
<th>2-4</th>
<th>5-9</th>
<th>&gt;10</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Anxious</td>
<td>36</td>
<td>14</td>
<td>14</td>
<td>10</td>
</tr>
<tr>
<td>% Depressed</td>
<td>14</td>
<td>4</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>% Stigmatised</td>
<td>50</td>
<td>26</td>
<td>32</td>
<td>17</td>
</tr>
<tr>
<td>% Married</td>
<td>60</td>
<td>67</td>
<td>63</td>
<td>80</td>
</tr>
<tr>
<td>% Employed</td>
<td>34</td>
<td>48</td>
<td>70</td>
<td>68</td>
</tr>
</tbody>
</table>

Jacoby and Baker et al, Epilepsia 1996
Intractability, seizure freedom and QOL

<table>
<thead>
<tr>
<th>↓ SF of:</th>
<th>100%</th>
<th>75-99%</th>
<th>50-74%</th>
<th>0-50%</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>QOLIE-89</td>
<td>7.32</td>
<td>0.96</td>
<td>-0.20</td>
<td>-0.62</td>
<td>0.0004</td>
</tr>
<tr>
<td>QOLIE-89 MH</td>
<td>6.41</td>
<td>1.71</td>
<td>-2.09</td>
<td>-0.52</td>
<td>0.0003</td>
</tr>
<tr>
<td>QOLIE-89 PH</td>
<td>7.11</td>
<td>-0.67</td>
<td>-0.37</td>
<td>-1.07</td>
<td>0.002</td>
</tr>
<tr>
<td>QOLIE-89 CF</td>
<td>4.29</td>
<td>-0.16</td>
<td>-0.37</td>
<td>-0.12</td>
<td>NS</td>
</tr>
<tr>
<td>QOLIE-89 EP</td>
<td>7.26</td>
<td>3.04</td>
<td>1.86</td>
<td>0.57</td>
<td>0.0007</td>
</tr>
<tr>
<td>SF-36 MH</td>
<td>7.11</td>
<td>1.92</td>
<td>-3.53</td>
<td>-0.98</td>
<td>0.0008</td>
</tr>
<tr>
<td>SF-36 PF</td>
<td>3.66</td>
<td>-1.14</td>
<td>1.79</td>
<td>-0.98</td>
<td>NS</td>
</tr>
</tbody>
</table>

Birbeck et al, Epilepsia 2002
What are the common co-morbidities in epilepsy?

- **Psychological**
  - Anxiety
  - Depression
  - Low Self esteem
  - Reduced mastery
  - Felt stigma

- **Neuropsychological**
  - Impaired memory
  - Impaired learning
  - Impaired attention and concentration
  - Impaired speed of information processing
## Prevalence: Community sample

<table>
<thead>
<tr>
<th>Status</th>
<th>Seizure activity</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Status</td>
<td>None</td>
<td>&lt;1 a month</td>
<td>1+ a month</td>
</tr>
<tr>
<td>(n = 350) (%)</td>
<td>(n = 166) (%)</td>
<td>(n = 168) (%)</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not anxious</td>
<td>74</td>
<td>53</td>
<td>37</td>
</tr>
<tr>
<td>Borderline</td>
<td>13</td>
<td>18</td>
<td>19</td>
</tr>
<tr>
<td>Case</td>
<td>13</td>
<td>29</td>
<td>44</td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not depressed</td>
<td>84</td>
<td>71</td>
<td>62</td>
</tr>
<tr>
<td>Borderline</td>
<td>12</td>
<td>12</td>
<td>17</td>
</tr>
<tr>
<td>Case</td>
<td>4</td>
<td>10</td>
<td>21</td>
</tr>
</tbody>
</table>

Jacoby & Baker, 1996
Co-morbidities impact multiple aspects of patients’ self-reported health status
Role of depression for QOL

- 87 patients with TLE
- Variables examined:
  - Seizure-related
  - Demographic
  - Psychological
- QOLIE-89 scores predicted by:
  - Depression
  - Anxiety
  - ↓ seizure control
  - ↑ seizure severity
  - ↑ epilepsy duration
- Most variance explained by psychiatric morbidity

Loring et al, 2004
Role of non-clinical variables in QOL

- Anxiety and Depression
- ‘Burden of normality’
- Stigma, discrimination
- Resilience
  - ‘Cerebral reserve’
  - Outlook
  - Social capital
- Social support

References:
- Oyegbile et al, 2004
- Jacoby et al, 2001
- Hermann et al, 1990
- Michell et al, 1991; Suurmeijer et al, 2001; Fastenau et al, 2004
IBE Epilepsy and Cognitive Function Survey Results

- Nine IBE Chapters selected to participate
  - Austria
  - Denmark
  - Malta
  - Israel
  - Norway
  - Scotland
  - Ireland
  - Belgium
  - France

- 4,500 surveys distributed
- Data of 837 surveys from 9 countries analysed
Experience of cognitive impairment

Respondents indicating that they experienced difficulties “very much” or “moderately”

- Forgetting the way round familiar places: n = 17
- Impaired hand-eye coordination: n = 21
- Forgetting anniversaries, appointments and dates: n = 31
- Forgetting names of familiar people: n = 32
- Difficulty paying attention to a speech or news broadcast: n = 34
- Difficulty following instructions: n = 35
- Difficulty understanding something you have heard or read: n = 35
- Impaired ability to do mental arithmetic: n = 35
- Retaining a telephone number: n = 37
- Lethargy, sluggishness: n = 39
- Difficulties learning something new: n = 41
- Slowness of thought: n = 42
- Sleepiness, tiredness: n = 57

n = 837
Impact of cognitive impairment on work

n = 837

Belgium: 63%
France: 55%
Norway: 53%
Ireland: 51%
Austria: 46%
Scotland: 46%
Malta: 44%
Israel: 40%
Denmark: 37%
All Countries: 48%
What do we understand about the long-term impacts of epilepsy on QOL and co-morbidities?
Impact of childhood-onset epilepsy on QOL

- Population-based cohort of 245 children <16yrs, with active epilepsy.
- Followed from 1964 to 1997
- 91 survivors, 91 controls completed QOL questionnaires
- Mean age of epilepsy onset = 4.4yrs
- Mean age at FU = 41.5yrs
- 74 (81%) in remission at FU
- 61 off AEDS; 13 in remission on AEDs

Sillanpää et al, 2004
Long-term QOL Outcomes

- Marital status – rates lower cf. controls
- Offspring – rates lower cf. controls
- Employment – rates lower if on AEDs
- Driving – rates lower if on AEDs
- SES - lower if on AEDs

Conclusions:
- Having Epilepsy has substantial long-term impact, [even if Sz-free and off AEDs]
Questions generated

- How do we support people with epilepsy to minimise the impact of epilepsy and its treatment?

- How do we change societal attitudes towards epilepsy and reduce stigma – what kinds of intervention are effective?

- How do we identify who is at risk of developing co-morbidities and impaired QOL? [biomarkers, psychological and psychiatric risk factors, socioeconomic factors]

- How can we intervene to alter the risk of comorbidities and impaired QOL? [CBT, psycho-educational programmes more aggressive AED treatment - and what works?].
Considerations for future research

- What type of interventions? [CBT, psycho-educational, AED’s, antidepressant medication, surgery]

- Where is the evidence of the efficacy of intervention?

- What type of study? [RCT, observational, Longitudinal e.g. SANAD]

- Which groups? [children, elderly, LD]

- Multicentre or single centre?
Thank you for your attention