Indirect Costs of Epilepsy

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Health Dimensions of the Epilepsies

Panel 1: The Impact of Epilepsy on Patients,
Families, the Health Care System, and Society
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Overview

• Defining the impact of a disease
• What are ‘costs’?
• How are they measured?
• What do we know about them in epilepsy?
• How are they measured in other neurologic conditions?
• How might they be measured in the US epilepsy population?
Impact = Disease Burden = Opportunity Cost

• Opportunity Cost
  – the opportunity forgone as a result of having to use a resource
  – the value of the next-best alternative use of a resource
'COSTS'

Direct
- Medical
  - Health Care Provider Time
  - Medications
  - Facilities
  - Material and Equipment
- Non-medical
  - Transportation
  - Child Care
  - Patient and Care-giver Time
  - Education & Rehabilitation

Indirect
- Productive Activity
- Leisure Activity

Intangible (Quality of Life)
- Emotional Well-Being
  - Physical Function
  - Social Relations
  - Social Role Function
  - Cognitive Function
How are these Other Costs Measured?

- **Direct-Non Medical**
  - Market price of services rendered

- **Productivity & Time**
  - Human Capital Approach – sample-specific or age/gender specific wage-rates applied to hours lost d/t disease

- **Intangible**
  - Psychometric - ‘Quality of Life’ scales
  - Econometric - Quality/Disability Adjusted Life-Year

Who do we study?

- No Seizures
- Yearly
- Monthly
- Weekly

Seizure Frequency

Onset

Start AED1  Start AED 2  Start AED 3  Start AED 4  Start AED 5

Community Neurologists

Primary Care

Epilepsy Center
Unemployment Rates
Prevalent Samples

AED Withdrawal Study (UK) <11%
Epilepsy Support Groups (Europe) 23%
Community Primary Care (UK) 30%
Referrals for Surgery (US) 39%
Intellectual Co-Morbidity in Children

Onset < 5 yrs

Onset >= 5 yrs

Berg, 2008

IQ < 80

IQ >= 80

26%

74%
Special Education Services

Outcome 5 years after diagnosis

SF – No seizures since diagnosis
ER – Early Remission ( >3 yrs SF)
LR – Late Remission ( 1-3 yrs SF)
NR – No remission
INTR – Meets ‘intractable’ criteria

Berg, 2005
What do we Know about these Costs in Epilepsy in the US?

<table>
<thead>
<tr>
<th>Author/Year</th>
<th>Begley 2000</th>
<th>Yoon 2009</th>
<th>Ivanova 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sampling</td>
<td>Incident / Prevalent</td>
<td>Prevalent</td>
<td>Prevalent</td>
</tr>
<tr>
<td>Patient Source</td>
<td>US Epilepsy Centers</td>
<td>US Population</td>
<td>US Employer Database</td>
</tr>
<tr>
<td>Cases</td>
<td>1,168</td>
<td>2,837</td>
<td>758</td>
</tr>
<tr>
<td>Data Source</td>
<td>Patient Survey</td>
<td>Medical Expenditure Panel Survey (MEPS)</td>
<td>Medical &amp; Disability Claims</td>
</tr>
<tr>
<td>Non-Medical</td>
<td>Not Assessed</td>
<td>1.2 excess days of informal care annually ($99M in US)</td>
<td>Not Assessed</td>
</tr>
<tr>
<td>Productivity</td>
<td>Lost Earnings $4K-13K annual $105-295K lifetime</td>
<td>Not Assessed</td>
<td>49.5 annual work-loss days (vs. 14.5 in controls)</td>
</tr>
<tr>
<td>Patient &amp; Family Time</td>
<td>Not Assessed</td>
<td>Not Assessed</td>
<td>Not Assessed</td>
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Lifetime Direct vs. Indirect Costs for Prognostic Groups

- **84%** Indirect
- **16%** Direct

<table>
<thead>
<tr>
<th>Prognostic Group</th>
<th>Percentage of Sample</th>
</tr>
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<tbody>
<tr>
<td>Early Remission</td>
<td>61</td>
</tr>
<tr>
<td>Delayed Remission</td>
<td>15</td>
</tr>
<tr>
<td>Intractable</td>
<td>24</td>
</tr>
</tbody>
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*B* *indirect costs not assessed*
Quantifying Intangible Costs of Disease

Quality of Life

Perfect Health = 1.0

Death = 0

Years of Life

0

85

Disability-adjusted Life Years (DALYs)

Quality-adjusted Life Years (QALYs)
DALYs/1000 for Emerging Market Economies

DALYs/1000 pop.

DALYs/1000 for Emerging Market Economies

- Cancers = 19.0
- Depression = 8.0
- Stroke = 6.2
- Infectious/Parasitic
- Dementias
- HIV/AIDS
- Diabetes
- Drug Use
- Violence
- Multiple Sclerosis

Burden of Epilepsy EME Countries - Commission Estimate

Disability Weights from Literature
WHO GBD Disability Weights

Begley et al., 2007
How are they measured in other neurologic conditions?

- **Direct non-medical costs**
  - Rarely assessed
  - Calculated as use (usually yes/no) x avg. unit cost of service
  - Source of unit cost may be non-representative and obscure

- **Productivity costs**
  - Survey based
  - Categorical and continuous
  - Work hours/home production (expected - observed)
Migraine Disability Assessment

“On how many days in the past 3 months did you miss work or school”
1. did you miss work or school  .68
2. was your productivity at work or school reduced by half or more  .54
3. did you not do household work  .60
4. Was your productivity in household work reduced by half or more  .64
5. Did you mis family, social or non-work activities because of headache?”  .62

Total Reliability .80

Stewart, 2001
Migraine Severity & Productivity

Munkata, 2009
How might other costs be measured practically in the US epilepsy population?

• Modified Top-down approach
  – Develop respondent-based classification system
    • reliable & clinically valid
    • multi-dimensional (seizures & co-morbidities)
    • sensitive to full range of costs
  – Develop unit cost estimates for sub-groups
    • leverage existing populations surveys and community-based samples
    • use literature-based estimates with caution
  – Expand sampling frame to institutionalized persons