Studies of Epilepsy Epidemiology in Demographic Sites (SEEDS)

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Specific Aims

• prevalence of active convulsive epilepsy (ACE) in resource poor countries
  – easiest to identify
  – associated with most stigma
  – associated with most mortality
  – can be controlled with inexpensive anti-epileptic drugs

• attributable fraction of preventable risk factors for ACE
  – particularly preventable causes e.g. parasitic diseases

• magnitude and risk factors for mortality in epilepsy

• magnitude and risk factors of the treatment gap
SEEDS

• In Demographic Surveillance System (DSS) sites within the INDEPTH Network
• Strength of the DSS framework
  – Regular census → accurate denominator
  – Geographically defined populations
  – Infrastructure for efficient and prolonged follow-up
• Nested within on-going census in the DSS
Study Sites

- 12 INDEPTH sites expressed interest
- 5 DSS sites chosen for
  - endemicity of parasitic risk factors
    - Neurocysticercosis
    - Toxocara sp
    - Toxoplasmosis
    - Onchocerciasis
    - Malaria
- cost and logistical
<table>
<thead>
<tr>
<th>HDSS Site</th>
<th>Country</th>
<th>Population</th>
<th>Census per yr</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agincourt</td>
<td>South Africa</td>
<td>84,000</td>
<td>1</td>
</tr>
<tr>
<td>Ifakara</td>
<td>Tanzania</td>
<td>93,000</td>
<td>3</td>
</tr>
<tr>
<td>Iganga/Mayuge</td>
<td>Uganda</td>
<td>68,000</td>
<td>3</td>
</tr>
<tr>
<td>Kilifi</td>
<td>Kenya</td>
<td>260,000</td>
<td>2</td>
</tr>
<tr>
<td>Kintampo</td>
<td>Ghana</td>
<td>130,000</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>685,000</strong></td>
<td></td>
</tr>
</tbody>
</table>
Ongoing surveillance of a well defined population, with personal identifiers mapped in a demarcated study area – Demographic Surveillance System

Survey in each DSS site

Study A: Prevalence of Active Convulsive Epilepsy (ACE)

Identify cases for case-control study

Study B: Identification of risk factors for the development of ACE

Identify cases accessing and using treatment

Study C: Identification of magnitude and risk factors for the treatment gap

Identification of cohort to be followed up for 3-4 years

Study D: Calculation of risk ratio for death

Deaths

Study E: Identification of risk factors for death
Surveys to estimate prevalence of ACE

Stage I
Census team
2 item tool
History of convulsions
High sensitivity

Stage II
Epilepsy field team
10 item tool
Possible ACE identified
High specificity

Stage III
Clinical exam
Diagnosis of ACE
Classification
Confirmation
Survey tools

• Questionnaires based on those used in international studies

• Terminology – derived from FGD
  Pre-tested outside the study areas
  Refined by field workers during training

• Forward translation into vernacular and independent back translation into English

• Reliability: questions repeated in Stages I & II
3-stage method

STAGE I
- Eligible population (current census)
  - Survey Arm
  - Validation Arm
  - Screened in Stage I

STAGE II
- Positive
  - Pop. Sample; = 5,000*
  - Positive

STAGE III
- Positive
  - Positive
  - Positive

Positive
Negative
## Summary of ACE prevalence

<table>
<thead>
<tr>
<th>Site</th>
<th>Population</th>
<th>Cases of ACE</th>
<th>Cases fulfilled definition of residency</th>
<th>Crude prevalence (95% CI)</th>
<th>Adjusted prevalence (95% CI)</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kilifi</td>
<td>233,881</td>
<td>762</td>
<td>699</td>
<td>3.0 (2.8-3.2)</td>
<td>3.8 (3.5-4.0)</td>
<td>525</td>
</tr>
<tr>
<td>Agincourt</td>
<td>82,917</td>
<td>232</td>
<td>191</td>
<td>2.3 (2.0-2.6)</td>
<td>2.7 (2.3-3.0)</td>
<td>286</td>
</tr>
<tr>
<td>Iganga</td>
<td>68,808</td>
<td>278</td>
<td>134</td>
<td>2.4 (2.0-2.8)</td>
<td>5.5 (4.5-6.4)</td>
<td>247</td>
</tr>
<tr>
<td>Ifakara</td>
<td>99,375</td>
<td>442</td>
<td>353</td>
<td>3.6 (3.2-3.9)</td>
<td>6.5 (5.9-7.0)</td>
<td>567</td>
</tr>
<tr>
<td>Kintampo</td>
<td>135,172</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>620,151</strong></td>
<td><strong>1,714</strong></td>
<td><strong>1,377</strong></td>
<td><strong>1,625</strong></td>
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</tbody>
</table>
Problems encountered

Sites differed with regards:
• terminology for convulsions/seizures
  — Depends upon the perceived cause of epilepsy
• methods of census
• data handling
  — single entry
  — data brought on a weekly rather than daily
  — delay in entering the census data
• population mobile
  — Any delays between the stages resulted in lost to follow-up
Future SEEDS studies

- Verbal Autopsy data on epilepsy
  - Mathew Alexander, Ifakara, Tanzania
- Cost effectiveness study
  - Ryan Wagner, Agincourt, South Africa
- Psychiatric co-morbidity
  - Kintampo
- Funding for survey in other sites
  - Pune, Hanif Shaikh
- Genetic studies
  - Definition of the phenotype
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  – Eddie Chengo
  – Rachael Odhiambo
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  – Evasius Bauni
  – Tom Williams
  – Anthony Scott

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  – Mathew Alexander
  – Honorati Masanja

• Kintampo, Ghana
  – Bright Akpalu
  – Ken Ae-Ngebise
  – Albert Akpalu
  – Seth Owusu-Agyei

• Agincourt, South Africa
  – Ryan Wagner
  – Mark Collison
  – Rhian Twine
  – Xavier Gomes
  – Kathy Kahn
  – Steve Tollman

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  – Brian Neville
  – Ley Sander
  – Tim Cox
  – Steve White

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  – Martin Prince
  – Victor Doku

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  – Christian Bottomley
  – Immo Kleinschmidt
  – Andy Hall

• Iganga/Muyage, Uganda
  – Angelina Kakooza
  – Donald Ndyomughenyi
  – Stephan Petersen
  – Georges Pariyo
Future Neurological studies

• Stroke
  – Myles Connor: mconnor@staffmail.ed.ac.uk

• Parkinson’s disease
  – Richard Walker: richard.walker@nhct.nhs.uk