Global Perspective on Epilepsy: Improving Access to Epilepsy Care

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Why Epilepsy is a Priority?
I. Epilepsy: The Burden

- More than 50 million people with epilepsy
- Mortality 3-6 times higher than general population
- Epilepsy contributed 17.43 million DALYs in 2010 (0.7% of the global burden) – IHME estimates 2012
- 85% of the burden in poor, underprivileged and vulnerable
- High economic cost - Cost in Europe estimated as 13.8 billion €
Prevalence: How many people have epilepsy?

Plethora of studies (230 studies)
• Wide variations
  • 2.5 - 57/1,000

Number of people with active epilepsy (independent of location):
• 5 - 10/1,000
• Usually higher in rural areas
• Reports that more people have epilepsy in resource-poor countries in selected or isolated populations

GBD review
More people develop epilepsy in resource-poor countries

Higher Incidence: 49 to 215 per 100,000 in LLMIC

Possible reasons:

• Secondary epilepsy
  – CNS infections and parasites (e.g. neurocysticercosis)
  – Head injury, stroke etc
  – Poor perinatal care

• Social factors
  – Poverty
  – poor sanitation
  – inadequate health delivery systems

Duncan et al, Lancet 2006
Role of mortality

- Premature mortality approx 3 time that of general population in developed countries
- Circumstantial evidence of even higher mortality (6x) from developing countries
- Cause of death
  - Accidents
  - Self-harm/Suicide
  - Status epilepticus
  - SUDEP
  - High psychiatric co-morbidity
Key Points - I

- Epilepsy global burden information available

- Higher epilepsy incidence in resource-poor settings due to risk factors – amenable to prevention?

- Prevention of epilepsy deaths – management of psychiatric comorbidity and lifestyle education?

Swedish data: In epilepsy patients with premature mortality due to external causes, 75.2% had comorbid psychiatric disorders (co-occurring depression (13.0, 10.3–16.6) and substance misuse (22.4, 18.3–27.3)), compared with patients with no epilepsy and no psychiatric comorbidity (Fazel et al, Lancet 2013)
Neurocysticercosis – may be responsible for 29% of epilepsy in endemic countries

Ndimubanzi et al, PLoS 2010

Neurocysticercosis prevention projects
- Project in Peru
- Project in Honduras

Decreasing incidence of NCC in Latin America???
Epilepsy prevention programmes

- Decrease in NCC $\rightarrow$ Decrease in epilepsy? (some evidence available from Honduras)

- Decrease in road traffic accidents $\rightarrow$ Decrease in traumatic brain injuries $\rightarrow$ Decrease in epilepsy incidence?

- Malaria control interventions $\rightarrow$ Decrease in cerebral malaria $\rightarrow$ Decrease in epilepsy incidence?

- Improved perinatal care $\rightarrow$ Decreased birth asphyxia $\rightarrow$ Decrease in epilepsy incidence?
II. Epilepsy: The hidden burden (Stigma)

Names
- “being chosen”
- “being possessed”
- “hidden disease”
- “burning or drowning disease”
- “shameful disease”
- “it”
Epilepsy: the impact

- Children not being able to go to school
- Adults with problems obtaining and retaining employment
- Violations of human rights
  - Social ostracism
  - Denial of the right to participate in social activities
  - To marry
Stigma literature review (ILAE)

- Epilepsy stigma well studied (284 studies on factors/frequency/nature of epilepsy stigma)
- 38 studies on stigma tool development
- Only 28 studies on stigma interventions
Key Points - II

- No consensus on measurement of community attitudes/stigma
- Need for well-designed stigma intervention studies
- Role of public awareness/advocacy campaigns
WHAT CAN BE DONE
III. Treatment of epilepsy

- 70% of epilepsy can be successfully treated with antiepileptic medications
- These medications – phenobarbital, phenytoin, carbamazepine, valproic acid are effective, cost-effective and are included in essential medicine list
- Cost of treatment with phenobarbital – as low as 5 USD per person per year
- 23% of burden due to epilepsy is avertable at 50% coverage with standard antiepileptic drugs (Chisholm et al, 2005)
III. Still high treatment gap?

- Systematic review (2009) – 74 studies

- Treatment gap
  - over 75% in low-income countries
  - over 50% in most lower middle- and upper middle-income countries
  - many high-income countries had gaps of less than 10%

- Treatment gap significantly higher in rural areas (RR: 2.01; 95% CI: 1.40–2.89) and countries with lower World Bank income classification (RR: 1.55; 95% CI: 1.32–1.82)

Meyer et al, Bull WHO, 2010
Global disparities in the epilepsy treatment gap: a systematic review

Ana-Claire Meyer, Tarun Dua, Juliana Ma, Shekhar Saxena & Gretchen Birbeck

Studies in All Languages

Bull World Health Organ 2010;88:260–266
High treatment gap

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Bull World Health Organ 2010;88:260–266
Why such a high treatment gap?
Supply side - Delivery of Health

- Health economics
  - absence of health insurance

- Priorities
  - epilepsy usually not a priority

- Infra-structure
  - shortage of trained health personnel
  - lack of facilities

- Access to medicines
  - High cost and unavailability
Median number of neurologists per 100,000 population in each WHO region and the world

N=106

4.84

0.89

0.32

0.03

Africa

Americas

Eastern Mediterranean

Europe

South-East Asia

Western Pacific

World

7.4
Neurologists and population in Africa: projected trends

Currently

- 425 neurologists
- 1 per 3 million people

In 10 years time (current trends)

- 600 neurologists
- 1 per 3 million people

(capacity doubled)

- 1,200 neurologists
- 1 per 1.5 million people

Better training for primary care providers essential
National Essential Medicine Lists and AEDs

- Comparative analysis of 109 NEML of countries (2012)

- AED presence on NEML
  - Phenobarbital included in 96% of the responding countries
  - Carbamazepine in 95%
  - Phenytoin in 83%
  - Valproic acid in 92%

- All strengths and formulations of AEDs included as recommended by the WHO EML
  - Phenobarbital in 12%, Carbamazepine in 5%, Phenytoin in 3%, and Valproic acid in 11%. 

Draft publication being prepared
Availability, price and affordability of antiepileptic medicines in 46 countries

- **Availability**
  - Generic essential AEDs in the public sector less than 50%

- **Price for generic carbamazepine and phenytoin**
  - Public sector patient prices were 4.95 and 17.50 times higher than international reference prices
  - Private sector patient prices were 11.27 and 24.77 times higher
  - Originator brand prices were about 30 times higher.
  - Highest prices observed in the lowest income countries.

- **Affordability**
  - The lowest-paid government worker would need 1-2.6 days wages to purchase a month's supply of phenytoin, while carbamazepine would cost 2.7-16.2 days wages

Cameron et al, Epilepsia 2012
Demand side - Health Seeking Behaviour

- Patient’s beliefs
  - Cause of illness
  - Role of biomedical treatment
  - Traditional/faith healers

- Logistics
  - Expense
  - Distance from facilities
What should be done?
Increase access to epilepsy treatment worldwide - III

- Raise epilepsy priority in the national health agendas
- Involve non-specialist providers in delivering epilepsy care and services
- Integrate epilepsy management in primary health care system
- Increase availability of essential antiepileptic medications
- Promote public awareness and education about epilepsy
“OUT OF THE SHADOWS”
A Global Campaign against Epilepsy

The Partners:

The International League Against Epilepsy (ILAE)

The International Bureau for Epilepsy (IBE)

World Health Organization (WHO)
Awareness and advocacy

- Regional Conferences
- Regional Reports
- Atlas: epilepsy care in the world
Care Models

- ICEBERG
  - Kenya, Pakistan, Ecuador

- Country specific examples
  - Tanzania, Malawi, Ethiopia, Kenya, India, Senegal

- SANCHAR-AROD
  - 24 Parganas

- Global Campaign Demo Projects
  - E.g. China, Senegal, Brazil, Georgia
Project

- To test the feasibility of diagnosis and treatment of epilepsy at the primary health care level

- The long-term goal: To integrate epilepsy management into the existing primary health delivery system of the People’s Republic of China

- 6 provinces and 4 million population
Trained town clinic physicians and rural doctors can diagnose and treat people with epilepsy.

Reduction in treatment gap by 13% (statistical significant)

The methods and the experiences obtained are suitable to extend in rural areas of China, as well as in some other developing countries.
Scaling up: China National Epilepsy Project

- Government Support
- Free Medical Care
- Public Education

Ministry of Health, China
China Association Against Epilepsy
2005~2009
The results of the National Epilepsy Project

- Established administration and professional epilepsy teams in 15 provinces (79 counties)

- Popularization of knowledge of epilepsy in project areas (over 44 million population)
Other initiatives

- In rural Kenya, sensitisation of the community and setting up an epilepsy clinic reduced the treatment gap over a 5-year period from 74% to 62%.

- In India, 70% of enrolled patients were still attending the clinics 12 months after initiation of training programmes of volunteer health-care workers, traditional practitioners and clinicians; awareness campaign programmes; and diagnosis, treatment, and monthly follow-up with free AEDs.
Integration into Mental Health or Non-Communicable Diseases?
Mental Health?

- In many countries, epilepsy included as part of mental health programme
- Epilepsy managed by community psychiatric nurses – e.g. Ghana
- Many more psychiatrists than neurologists – e.g. Panama (only 12 neurologists for 3 million population)
- Neurologists often not interested in public health aspects of neurological disorders
- Stigma and treatment gap causes similar
- Substantial psychiatric co-morbidity
- Adoption of Comprehensive Mental Health Action Plan
- PAHO – Regional Strategy on Epilepsy
NCDs?

- NCDs high on political agenda – UN high level political resolution
- Issues of access to medicines similar
- Similar strategies being applied for improving care of NCDs
Delivery of Care for Mental, Neurological and Substance use Disorders in Non-specialized Settings:

WHO's Mental Health Gap Action Programme (mhGAP)
Scaling up Care: mhGAP

mental health Gap Action Programme

Scaling up care for mental, neurological and substance use disorders
Setting priorities

Priority conditions:

- Depression
- Suicide prevention
- Psychoses
- Child and adolescent mental disorders
- Epilepsy
- Dementia
- Disorders due to use of alcohol
- Disorders due to illicit drug use
The underlying logic of mhGAP

- Human rights abuses are to be stopped
- Mental health services to be organized rationally – improvement in coverage
- Burden/budget gap to be reduced
Burden/budget gap to be reduced

- Burden: 13%
- Budget: 3%

Budget/burden gap to be reduced
mhGAP Intervention Guide: Evidence based interventions for priority conditions in non-specialized health care settings
Guide d’intervention mhGAP
pour lutter contre les troubles mentaux, neurologiques et liés à l’utilisation de substances psychoactives dans les structures de soins non spécialisées

Guía de Intervención mhGAP
para los trastornos mentales, neurológicos y por uso de sustancias en el nivel de atención de la salud no especializada
Evidence based
3. Has the person had at least 2 convulsive seizures in the last year on 2 different days?

If no acute cause

**NO**
If there is no clear cause and the person had a single convulsive seizure

- Not epilepsy
  - Maintenance of antiepileptic drugs is not required.
  - Follow up after 3 months. If there are additional abnormal movements suggestive of a seizure, assess for possible epilepsy.

**YES**
If yes, consider epilepsy

- Initiate antiepileptic drug
- Educate about condition, lifestyle and safety issues, and importance of adherence and regular follow-up.
- Follow up regularly.

Ask about:
- Severity:
  - How often do they occur?
  - How many did they have in the last year?
  - When was the last episode?
- Possible etiology of the epilepsy (any history of birth asphyxia or trauma, head injury, infection of the brain, family history of seizures)
mhGAP Country Implementation

- Ethiopia, Nigeria, Uganda
- Jordan
- Panama, Belize
- Implementation by PAHO in other countries in the region
- Implementation by national or international partners in many countries (e.g. CBM)
- Research funding for multiple countries
- Epilepsy projects in Ghana, Viet Nam, Myanmar and Mozambique
Target beneficiaries

- Ministry of Health
  - Policy Makers

- National stakeholders
  - NGOs, National experts, Academic universities

- People and their families

- International stakeholders
  - Organizations
  - Foundations
  - Private
  - World Health Organization

- Non-specialists (doctors, nurses)
- Specialists
- Health planners
- Traditional healers
mhGAP strategy

- Non-specialist health personnel within first and second level care
- Involvement of nurses and community health workers, as applicable
- Under supervision and support and educative role of specialists (mental health professionals, neurologists, paediatricians)
- Strengthening of health systems
  - Referral
  - Supervision
  - Supply of medicines
  - Traditional healers/faith healers where applicable
- Involvement of self help/user groups, NGOs
- Attention to undergraduate and postgraduate curriculum
**Evaluation framework**

- **OUTPUTS**
  - Trained health workers
  - Knowledge gains
  - Development of tools
  - Increased priority

- **OUTCOMES**
  - Improved capacity
  - Raised public awareness
  - Sustained partnerships

- **IMPACT**
  - Reduced treatment gap
  - More children with epilepsy going to school
  - More adults employed
  - Social and economic impact
EPILEPSY
OUT OF THE SHADOWS

• EPILEPSY is the commonest serious brain disorder in every country.

• It is misunderstood, feared, hidden, stigmatised.

• 60-90% of people with EPILEPSY in developing countries do not receive appropriate treatment.

• There are 50 million people with EPILEPSY in the world and 85% of them are living in developing countries.

• EPILEPSY is a treatable brain disorder.

• It is not a supernatural, mental or psychological disorder.

• 70-80% of people with EPILEPSY could lead normal lives if properly treated.

• Please help bring EPILEPSY "Out of the Shadows".