The CREST Study
Collaborative Research on Epilepsy Stigma Project
Developing Approaches to Reducing Stigma of Epilepsy

Why is this project important?

- Epilepsy is the world’s most common brain disorder, affecting 50 million people worldwide
- 4/5ths of those affected by epilepsy live in developing countries
- Common features of epilepsy are stigma and exclusion in both developed and developing countries
- Stigma is a major contributor to the burden associated with epilepsy
- Reducing the stigma of epilepsy is therefore key to reducing its impact and improving quality of life
- Effective health policy initiatives need to be developed and implemented to reduce the stigma of epilepsy

Study Aims and Objectives:

- To inform development of culturally appropriate approaches to reducing stigma & discrimination associated with epilepsy in the developing world
- To develop a cross-culturally relevant theoretical model of stigma
- To develop culturally appropriate measures of stigma and discrimination, for use as outcome measures in future intervention programmes
- To enhance social science research capacity in China and Vietnam and develop strong collaborations for future research

Methodology Includes:

- Comprehensive literature reviews
- Rapid Appraisal studies:
  - China
  - Vietnam
- Detailed ethnographic studies
- Development of a conceptual framework
- Identification of assessment methods and outcomes for future educational campaigns

The Global Campaign Against Epilepsy
out of the shadows

“To improve acceptability, treatment, services and prevention of epilepsy worldwide”

The three leading organisations working in epilepsy have joined forces to make this happen:

- World Health Organisation
- International Bureau for Epilepsy
- International League Against Epilepsy

The Campaign aims to:

- Raise general awareness and understanding of epilepsy
- Support Departments of Health in identifying needs and promoting education, training, treatment, services, research and prevention in their countries
- Generating Regional Declarations on Epilepsy
- Producing information on epilepsy for policy-makers
- Incorporating epilepsy care into National Health Plans
- Facilitating the establishment of national organisations of professionals and lay persons dedicated to promoting the well-being of people with epilepsy
- To help organise Demonstration Projects that illustrate good practice in the provision of epilepsy care

What Have We Achieved So Far?

- Established Institutional Review Board approval – Ethical approval now granted in China, Vietnam & UK, where data collection/analysis is being undertaken
- Ensured Compliance with Human Participants Protection – All team members have completed certified Human Participants Protection education
- Conducted an extensive review of the literature on stigma
- Established Project Advisory Group – Professor J Engel (ILAE) & other international researchers
- Planned & conducted Rapid Appraisals of the position of people with epilepsy
- Held regular team meetings and site visits to:
  - Review work to date
  - Agree key methodological aspects
  - Identify team training & communication needs
  - Establish publication policy (commissioned review Sept ’04)
  - Finalise study protocols

The next step...

Ethnographic studies exploring the prevailing beliefs and attitudes to epilepsy in China and Vietnam will commence late 2004. Using in-depth interviews and focus groups data will be gathered from people with epilepsy, their family members, their local communities and their general and specialised health care workers. It is anticipated that study findings will provide insights into the dimensions of epilepsy stigma identifiable in these two countries, and highlight the similarities & differences in order to gain an understanding of:

- Ideas held about epilepsy (explanatory models of causation, treatment, prevention)
- The impact of these ideas on attitudes towards having epilepsy
- Ideas and practices relating to its management as a health condition
- Ideas and practices relating to its management as a potential source of stigma

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Acknowledgement: Research supported by NIH & funded by a Fogarty International Centre Planning & Development Grant
China In Brief...

- Prevalence of Epilepsy
  71,000 (Global Campaign Against Epilepsy Demonstration Project)
- Management
  3 tier public healthcare system
  Government funded free healthcare
  Western Antiepileptic Drugs
  Traditional Chinese Medicine
  Acupuncture, complementary medicine
- Treatment Gap
  40-60%, high economic burden
- Epilepsy Characterised as Mental Disorder
  ‘Not a normal medical condition, it is often equated to insanity’

Living with Epilepsy in China...

- Terminology Associated with Epilepsy
  Most people familiar with the terms ‘epilepsy’ & ‘convulsion’
  Most commonly used terms to denote epilepsy:
  da fua ‘big seizure’
  yang jiao feng ‘making the noise of a sheep’
- Beliefs Re: Seizure Causes
  Anger, possession by spirits, fright/anxiety, bad luck, poverty, overwork.
- Clear Sense of Stigma
  Secretory, sense of being different
  Withdrawn from society
  Frequently denied schooling
  Shunned by peers
  Meet active discrimination when seeking employment.
- Marked Impact on Family Relationships
  Marriage, relationships, fertility, education, employment
- Negative Attitudes Noted in Lay Informants
  About half the population believe people with epilepsy should not be employed
- People with Epilepsy & Family Members Hesitant to Reveal Condition
  Feel isolated and are either over-protected or neglected.
  Many people appear to object to their children marrying or even playing with a person with epilepsy
- Condition Interferes with
  Riding a bicycle, sport, housework, travel, making friends

Vietnam In Brief...

- Prevalence of Epilepsy
  21,011,000
- Management
  Active Management at commune level
  People in the North often go to higher referral institutions after contacting primary health care staff
  People in the South often go to private doctor clinics
  Confirmation & treatment at specialised hospitals only
  Specialist care through Mental Health Programme
  Free treatment with Phenobarbital
  Có bính thi vâi to phương ‘having an illness, pray in all four directions’ seems to be the most typical response.
  Beliefs about Western/Oriental medicines efficacy affect choice of treatment options, however use of Western antiepileptic drugs common & preferred
- Treatment Gap
  280,000-488,000 PWE untreated

Living with Epilepsy in Vietnam...

- Terminology Associated with Epilepsy
  Most terms are combinations of kinh ‘nerve’ (system) & phong ‘wind’.
  In traditional medicine theory there are two kinds of wind: external & internal. The internal wind in association with excessive heat can cause seizures & unconsciousness.
  Most commonly used term is: Đợi kinh, ‘unstable nerve/epilepsy’
- Beliefs Re: Seizure Causes
  ‘Weak nerves’, high fever, overwork, tension
- Stigma Rarely Expressed
  PWE talk about having a normal life but...
  They do not want to join public gatherings and become withdrawn
  Are prevented from doing important tasks e.g. working in the rice field, helping with household chores, cooking
  Young patients tend to keep their illness a secret & try to hide their seizures from their peers
- Community & Family Members Express Sympathy
  Chiũ ‘treat more gently’ is a common strategy to epilepsy
  People with epilepsy are expected to do less homework & other physical activities
- Limitations on different Levels of Functioning
  Mobility – people with epilepsy often confine themselves to their villages.
  Travel is restricted as PWE unable to have a driving license
  Private transport (monocycle) is usually the only available means of transport most parts of Vietnam
- Education
  The belief that psychological tension exaggerates ‘weak nerves’ & increases frequency of seizures, people with epilepsy often drop out of school at an early age
  Employment & job opportunities – Reduced due to limited education & professional training undertaken & also because of risks associated with employment e.g. risk of drowning in the rice fields