

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*

Who's in the CREST team?

- **UK** Profs Ann Jacoby, Gus Baker, David Chadwick, Ms Dee Snape
- **China** Profs Wenzhi Wang, Jian-zhong Wu
- **Vietnam** Dr Dan Vu Trung, Ms Thanh Nguyen Huong
- **Amsterdam** Dr Ria Reis
- **US** Prof Charles Begley
- **GCAE** Mrs Hanneke de Boer
- **WHO** Dr Leonid Pripilko



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:

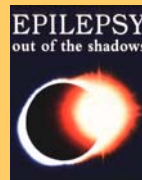
- World Health Organisation
- International Bureau for Epilepsy
- International League Against Epilepsy

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

By:

- 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



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 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*

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

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Poster prepared by: Dee Snape Research Associate The University of Liverpool



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China In Brief...

- **Prevalence of Epilepsy**
7/1,000 (Global Campaign Against Epilepsy Demonstration Project)
- **Management**
3 tier rural Medicare system
Government funded free health care
Western Antiepileptic Drugs
Traditional Chinese Medicine
Acupuncture and folk medicines
- **Treatment Gap**
40-60%, high economic burden
- **Epilepsy Characterised as Mental Disorder**
Not a 'normal' medical disease often equated to insanity

I have not a child, because I worry about anti-epileptic drugs influence foetus. I am very sorry to my father-in-law and mother-in-law. I make my husband family without offspring.

I want to have a child, but my condition admits of no pregnancy. Furthermore, seizures interfere with some of my plans such as I can't do something as other people.

Living with Epilepsy in China...

- **Terminology Associated with Epilepsy**
Most people familiar with the terms 'epilepsy' & 'convulsion'
Most families talked about the phenomenon of convulsions & thought all convulsions were epilepsy
Most commonly used terms to denote epilepsy:
da fa zuo '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**
Secrecy, 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

Research Team
Wenzhi Wang, MD.
Jianzhong Wu, MD.

Conclusion...

People with epilepsy & family members bear a huge spiritual & economic burden. They try to conceal the condition whenever possible as they feel they are treated differently as a consequence of having a family member with epilepsy. People with epilepsy, their families & the general public lack basic knowledge & understanding about the condition

I never told anyone my daughter with epilepsy. I did not tell my son-in-law and his relatives about it before they married.

Prior to commencing the main study, a Rapid Appraisal on the position of PWE was conducted in China & Vietnam. This involved interviewing key informants with the intention of grasping 'insider perspectives'. Findings informed the ethnographic stage of the project by contextualising the issues of epilepsy stigma, lay attitudes towards epilepsy and the current terminology used for discussing epilepsy within communities.

Vietnam In Brief...

- **Prevalence of Epilepsy**
3-10/1,000
- **Management**
Active ID/notification 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 Phenobarbitone
Có bệnh thì vái tứ 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**
380,000-488,000 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 and unconsciousness. Most commonly used term is:
Động 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**
Chiếu 'treat more gentle' is a common strategy to epilepsy
People with epilepsy are expected to do less homework & other physical activities
To 'reduce tensions', family members try to respond to every demand from people with epilepsy
- **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 in 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 and 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

...brothers and sister love her; provide help and assistance as needed. If she needs health care, we help her to get health care. Because of her illness, family does not request any task from her.

I am not enjoying public gathering very much. At the meeting, people often started talking about family. I don't like that talk. I come only to sit and listen to what people were saying.

Research Team
Dang Vu Trung, MD., MA.
Nguyen Thanh Huong, MPH.

Conclusion...

The stigma related to epilepsy is unstated, yet expressed in different dimensions of stigma: withdrawal from social activity, hiding the fact of having a diagnosis of epilepsy, concern about the disruptiveness of seizures. These important dimensions need further investigation

...even if you want her to work, she cannot... she cannot work in the rice field. It is too dangerous for her to stay alone in the rice field, she can get seizure at any moment and fall down into water. She can die. Thus, we never request her to work. We also cannot ask her to cook. It also is too dangerous



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