Cultural and Associated Barriers to Epilepsy Care
Professionals in Epilepsy Care Symposium:
Access to Epilepsy Care Across the Spectrum
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Disclosure: None

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Learning Objectives

• To recognize and address cultural barriers to managing care for persons with epilepsy
• To better understand approaches to working cross-culturally with persons with epilepsy
• To review lessons learned from cultural psychiatry in working with underserved and marginalized populations with chronic illness
Lia Lee Dies; Life Went On Around Her, Redefining Care

By MARGALIT FOX
Published: September 14, 2012

In 1988, when Anne Fadiman met Lia Lee, then 5, for the first time, she wrote down her impressions in four spare lines that now read like found poetry:

barefoot mother gently rocking silent child
diaper, sweater, strings around wrist
like a baby, but she’s so big
mother kisses and strokes her

The story of Lia, the severely brain-damaged daughter of Hmong refugees who had resettled in California, became the subject of Ms. Fadiman’s first book, “The Spirit Catches
“...the social consequences of epilepsy are often more difficult to overcome than the seizures themselves”

World Health Organization, 2001
Social and Cultural Aspects of Epilepsy

1) Epidemiological surveys by neurologists and MD’s, looking at knowledge, attitudes, perceptions, towards epilepsy
2) Community studies looking at KAP (knowledge, attitudes and practice) towards epilepsy in a non-patient population
3) Ethnographic studies of individual, family and social experiences of epilepsy
4) Studies of traditional and alternative healing
5) International health projects with focus on ‘treatment gap’
6) Health disparities, economics and determinants of health
7) Epilepsy in the Arts and Humanities
8) Patient Narratives eg. Brainstorms Series – lived experience

BIOPSYCHOSOCIAL MODEL OF EPILEPSY

Adapted from Engel, 1980; Carpenter, 1987
What is culture?

• Meanings, values and behavioural norms
• Learned and transmitted within social groups
• Influences cognitions, feelings and self-concept

» NIMH Culture and Diagnosis Group, 1993
D. Iceberg Analogy

This tool can assist in discussing the immediately apparent and not so immediately apparent characteristics of one's culture.

![Iceberg Analogy Diagram]

http://www.hphnet.org/attachments/article/50/US%20HRSA.pdf
Cultural Competence: Definition

A set of congruent behaviors, attitudes and policies that come together as a system, agency or among professionals and enable that system, agency or those professionals to work effectively in cross-cultural situations. The word "culture" is used because it implies the integrated pattern of human thoughts, communications, actions, customs, beliefs, values and institutions of a racial, ethnic, religious or social group. The word competence is used because it implies having a capacity to function effectively.

Generic vs Specific Cultural Competence

**GENERIC**
- Culture – broadly defined
- All cultural interface
- For all clinicians
- Integrated
- Process - CF
- Consultation

**SPECIFIC**
- Culture – ethnoracial
- Specific populations
- Interested clinicians
- Subspecialty
- Stand-alone course
- Content - CBS
- Ethnospecific service
Levels of Cultural Competence

Organizational cultural competence consultation to a mental health institution
Kenneth Fung, Hung-Tat (Ted) Lo, Rani Srivastava and Lisa Andermann
The Social Course of Epilepsy

- **Stigma of chronic illness**
  - Sociosomatic rather than individualistic nature of Chinese society
  - Impact of illness goes beyond individual to involve family
  - Described as ‘moral blame’
  - Can lead to poor marriage prospects, downwards social spiral for entire family
Stigma as an ongoing problem

Daily Life in Epilepsy, (Raty 2007)

- Young adults with epilepsy (Sweden)
- Expression of positive vs. negative emotions in daily life
- Self-appraisal: Healthy vs. Handicapped

- Focus on issues of stigma, exclusion, marginalization
- Literature on psychological adaptations to epilepsy as a chronic illness with impact on self-perception, mood, and self-esteem

Public Knowledge, Private Grief, (Jacoby et al, 2004)

- 1600 surveys, general public (UK)
- Generally knowledgeable
- 90% agreed that people with epilepsy are:
  - As intelligent as everyone else
  - Children with epilepsy should be allowed to play with other children
  - People with epilepsy can be successful in careers
  - People with epilepsy can lead a normal life
- Despite this, 50% felt people with epilepsy treated differently by society
- 25% believed that people with epilepsy have more ‘personality problems’ than others (even those with direct contact - hypothesized to reduce stigma)
Brainstorms: Epilepsy in our World

• Japan (age 36)

“We call this illness Tennkann in Japanese. In writing, it is referred to with a combination of two characters. The first character means madness, mad man or getting mad, and the second character means that someone has a convulsion according to the Japanese dictionary... Thus, the Japanese words for epilepsy bring on contempt and discrimination. That is why I feel that the term Tennkann is not appropriate ethically and morally for the name of the disease in Japan”

Tanzania (24 y.o. mother)

“We went to the clinic. I was astonished to see the very small white tablets and and just could not believe that they would be able to control [epilepsy]. But my parents who had come along...insisted that I give medicine a try. My mother made sure I took the medicine regularly every day...I never forget to take my tablets. I have been free of seizures for several years now, I am well accepted and the villagers are no longer afraid of me”.

Health Disparities, Economics and Determinants of Health

• Impact on national economies and individual level in developed world (Yoon et al, 2009) and also developing countries such as China (Hong 2009)

• Direct costs (medication, hospitalization, doctor visits) vs. indirect costs (unemployment, sick leave)
Migration and Epilepsy

- Impact of globalization and migration leading to more newcomers with epilepsy
- Pakistani immigrants with epilepsy in the UK (Rhodes, 2008)
- Hmong in USA (Fadiman, 1997)
- Social deprivation in UK (Overcrowding, poor nutrition, infections, reduced access to health care) shown to lead to increased risk of status epilepticus in childhood (Chin 2009) and similar disparities found in epilepsy care in US (Begley 2009)
Ethnicity

- A sense of belonging to a group of people sharing a common origin and history, along with similar cultural and social beliefs
- Shared descent and aspirations
- National and geographical origin
- Religious beliefs
  - Incorrect assumptions about ethnicity, based on language or appearance alone, can lead to misunderstanding and misdiagnosis
  » Lu, 1995
## Berry Model of Acculturation

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<th>Acculturation Attitudes</th>
<th>- Is it considered to be of value to maintain cultural identity and characteristics?</th>
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<td>Yes</td>
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<td>- Is it considered to be of value to maintain relationships with other groups?</td>
<td>Yes Integrated</td>
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Lessons from Cultural Psychiatry: Approaches that can Inform Epilepsy Care

• Use of cultural consultants as well as interpreters
• Use of cultural formulation and explanatory models
• Use of illness narrative and lived experience perspectives
• Generic and specific cultural competence
• Awareness of power differentials and disparities between client and provider in addition to ASK model (attitudes, knowledge and skills)
L-E-A-R-N Model of Cross Cultural Encounter Guidelines for Health Practitioners

- **Listen** with sympathy and understanding to the patient's perception of the problem
- **Explain** your perceptions of the problem
- **Acknowledge** and discuss the differences and similarities
- **Recommend** treatment
- **Negotiate** agreement

Explanatory Models
(Kleinman’s 8 Questions)

• 1. What do you think caused your problem?
• 2. Why do you think it started when it did?
• 3. What does your sickness do to you? How does it work?
• 4. How severe is your sickness? How long do you expect it to last?
• 5. What problems has your sickness caused you?
• 6. What do you fear about your sickness?
• 7. What kind of treatment do you think you should receive?
• 8. What are the most important results you hope to receive from this treatment?
DSM-IV-TR Cultural Formulation

• I. Cultural identity: Ethnicity, Language, Involvement with culture of origin and host culture
• II. Explanatory Model- Cultural explanations of the illness; Help seeking experiences and plans
• III. Cultural factors in the psychosocial environment: Stressors and supports
• IV. Cultural elements of the clinician-patient relationship
• V. Overall Cultural Assessment
ACT Team vignettes

• Tamil man, 30’s, schizophrenia, who left for Sri Lanka just a few weeks after temporal lobe epilepsy surgery, in order to marry on ‘auspicious’ date according to horoscope, did not tell family about his illness. Marriage took place, but immigration problems ensued.

• Tamil man, 30’s, with dual diagnosis (schizophrenia and developmental delay), whose seizures recurred because mother stopped his medications in favour of expensive herbal treatment;

Plan: Home visit, education for mother, phone consultation with herbalist, and accompanying patient to GP and neurologist appts helped to resolve the situation
Impact on Clinical Care and Practice

Conclusions:

• Keep in mind principles of cultural competence working at micro, meso and macro levels in daily practice:
  • Work with interpreters as well as cultural consultants
  • LEARN model, explanatory model and cultural formulation
  • Look at social determinants of health
  • Advocate for underserved and marginalized patients

• Technology, new media, internet, and increased confidence of patient voices and advocates able to link around the world allow for improved support, sharing of resources and communication between practitioners and those with lived experience, including minority populations
Thank You