How to measure and reduce stigma & the experience from other conditions

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Epilepsy

Epilepsy: Facts
One of the most common serious brain disorders affecting > 60 million people worldwide

- no age, racial, national or geographical boundaries
- universal condition
- profound physical, psychological and social consequences
- seizures can cause misunderstanding, fear, secrecy, stigmatisation and social isolation
- misconceptions and prejudice lead to:
  - rejection
  - denial of education
  - isolation
Concept of epilepsy in history

Hammurabi code, dated 1750 BC

- person with epilepsy not to marry
- not to testify in court,
- “if a man buys a male or female slave, and before one month has passed, bennu falls upon him, he (the buyer) will return him to his seller and the buyer will take back the silver that he paid”.
Concept of Epilepsy in history cont.

- **Ancient Indian medicine** (4500-1500 B.C.)
  - Loss of consciousness

- **Mesopotamian civilisation** (3500-1800 B.C)
  - "hand of sin“, god of the moon.

- **Follower Hippocrates** (400 BC), *(On the Sacred Disease)*:
  - “…alleged divine character of epilepsy
  - shelter for ignorance + fraudulent practices
  - gods do not make men's bodies unclean
  - no more divine than other diseases,
  - it’s hereditary, cause lies in brain,
  
Thus: Epilepsy not be treated by magic but by diet + drugs".
Concept of Epilepsy in history cont.

- **Christian world (70 AC)**
  
  "epileptics demoniacs + epilepsy caused by unclean + deaf spirit"
  
  Gospel according to Mark (9:14-29)

- **Ancient China (100 A.C.)**
  
  "epilepsy is the disease of the head"

- **Arab-Persian manuscripts: (600 A.C.)**
  
  Direct reference to epilepsy as sickness caused by de-mons scarce or non-exist
  
  Zoroaster Zarathustra Spitāma
Western world fight against supernatural + occult started with final step progress en-lightened medicine denial demoniac influence.

Leon Eisenberg (20\textsuperscript{th}/21\textsuperscript{st} century):

“Epilepsy ancient disease “explained” for as long as it has been perceived. Its manifestations invite arcane theories of its causes + meanings.

Seizures dramatic, public + frightening. They occur with unpredictable frequency in unexpected places.

Forced cry, loss consciousness, fall, twitching + foaming at mouth, all suggest possession by spirit.”
Epilepsy and Stigma

Stigma and exclusion are common features of epilepsy; a major contributor to the burden associated with the condition.

Quality of life: reducing the stigma of epilepsy is key to improving an individuals’ life opportunities.

Measuring stigma
Methods to measure stigma

**Quantitative**
- Questionnaires
  - Single indicators
  - Scales

**Qualitative**
- Observation
- In-depth interviews
- Focus group discussions
- Media content analysis
- Policy and legislation audits

**Combination of the above**

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Survey the Stigma of Epilepsy in Europe
- Data collected from > 5,000 patients
- Living in 15 countries

Results
- 51% reported feeling stigmatised,
- 18% of these reported feeling highly stigmatised

Stigma Survey at school globally

- Kentucky: parents - epilepsy in classroom: negative
- Germany: 15% parents - children not to play with child with epilepsy
- Taiwan, China: 72% parents - child not to play with child with epilepsy
- Liberia: children with epilepsy not allowed to go to school
- Nigeria: 47% teachers - children with epilepsy insane
  32% epilepsy contagious
  27% not to play with other children
  20% not to attend normal schools
- Tanzania: heads of households - child with epilepsy not to go to school
- Ecuador: child with epilepsy does not have right to study
Stigma Surveys re employment

- Indonesia: problems in employment
- Ecuador: people with epilepsy do not have right to live full life
- India: rural: help in family trade
  urban: unemployment problem
- Nepal: 24% people with epilepsy (PWE): not able to work
- China: discrimination at the work place
- China, Taiwan: 31% PWE not to be employed like others
- Germany, Italy, USA: 40-60% unemployed
  15-20% unemployed
  20% retire early
- Germany + Netherlands: 15%: epileptic personality exists
  32%: epilepsy affects intellectual performance
Stigma in epilepsy

Combatting stigma essential in order to improve quality of life of people with epilepsy

How?

Raising awareness – Public Education

How?
Epilepsy and Stigma

• Learning from each other:

National IBE members \[\leftrightarrow\] National ILAE chapters

Regional/International IBE/ILAE structures

• Learn from others \[\leftrightarrow\]

Alzheimer
HIV
Migraine
Leprosy
Asthma
Diabetes
Etc.
Raising awareness

Public Education

Special Target groups: teachers, police, politicians, health care providers, religious leaders, people with epilepsy, their relatives and friends, etc.
Brazil: Raising awareness – Paula Fernandez

Take into account:

• Magnitude stigma different within different segments society.

• Demographical + socio-cultural factors important predictors epilepsy stigma.

• Mass media campaigns to target these social segments

Important: correct information with emphasis on attitudes and behaviour
Learning from each other

“Epileptic” or “Person with epilepsy”

Epileptic → Person with epilepsy

Group 1:
- 105 students
- mean age = 16
- 23.8% men

Group 2:
- 109 students
- mean age =16
- 33.9% men
Learning from each other

Do you think that people with epilepsy/epileptics are rejected by society?

- Yes: 87.2% EPILEPTICS, 41.0% PEOPLE WITH EPILEPSY
- No: 12.8% EPILEPTICS, 59.0% PEOPLE WITH EPILEPSY

p < 0.001

Do you have negative feelings about people with epilepsy/epileptics?

- Yes: 2.8% EPILEPTICS, 0% PEOPLE WITH EPILEPSY
- No: 97.2% EPILEPTICS, 100% PEOPLE WITH EPILEPSY

p = 0.08
Learning from each other

Do you think that people with epilepsy / epileptics have more difficulties to get employed?

- EPILEPTICS: 93.6%
- PEOPLE WITH EPILEPSY: 61.9%
- Yes: 93.6%
- No: 61.9%
- p<0.001

Do you think that people with epilepsy / epileptics have more difficulties at school?

- EPILEPTICS: 69.7%
- PEOPLE WITH EPILEPSY: 37.1%
- Yes: 69.7%
- No: 37.1%
- p<0.001

EPILEPTICS  PEOPLE WITH EPILEPSY
Learning from each other

Language can influence imaginary perception

social stigma

Using “inadequate social labels”

Contributes to increase psycho-social difficulties + stigma
Learning from each other

Epilepsy → Alzheimer, HIV, Mental illness
Migraine → Epilepsy

All groups mention legislation issue to be investigated:

**EPILEPSY**
- Laws impacting PWE’s lives outdated
- Laws fail to promote + protect human rights
- Laws sometimes actively violating rights
- In many countries no legislation
- Legislation based on ages of stigmatisation

**ILAE/IBE/WHO** within the framework of the Global Campaign conducted Project on "epilepsy and legislation"

Aim:
“to collect information on existing legislation + regulations related to epilepsy in areas civil rights, education, employment, residential + community services + provision of appropriate health care”
Epilepsy, Stigma and Legislation

Right to equal treatment described in international law:

* United Nations Declaration of Human Rights
* Convention of the Rights of People with Disabilities
* African Charter on Human and Peoples’ Rights
* Treaty of Amsterdam

therefore:

– People with epilepsy should not be treated less favourable than others
– Blanket restrictions in response to epilepsy should be prohibited
– People should be entitled to individual assessment of abilities and risks
Epilepsy and Stigma

Convention for the rights of Persons with Disabilities (CRPD)


Purpose:
- To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity

UN Secretary General, Kofi Annan,

"Today promises to be the dawn of a new era – an era in which disabled people will no longer have to endure the discriminatory practices and attitudes that have been permitted to prevail for all too long. This Convention is a remarkable and forward-looking document."
CRPD and Optional Protocol Signatures and Ratifications

- Not Signed
- Signed Convention
- Signed Convention & Protocol
- Ratified Convention
- Ratified Convention & Protocol

As of 23 March 2013

155 signatories to the Convention
91 signatories to the Optional Protocol
130 ratifications and accessions to the Convention
76 ratifications and accessions to the Optional Protocol

Notes:
The European Union, a regional integration organization, is a State party to the Convention. The Cook Islands, a non-member State of the United Nations, is a State party to the Convention.
Treaty of Amsterdam

Combating discrimination in European Union

Treaty of Amsterdam, equipped European Union to take measures against discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.

- **02 October 1997**: Treaty of Amsterdam signed
- **19 November 1997**: Formally signed and approved by European Parliament
- **01 May 1999**: Treaty came into force
Epilepsy and legislation

Result Epilepsy and Legislation Project under Global Campaign Against Epilepsy:

Development

- **Basic Principles for Epilepsy Legislation** (setting out basic principles and rights that should be considered when drafting legislation related to epilepsy)

  and

- **Guidance Instrument for developing, adopting and implementing epilepsy legislation**
How to measure and reduce stigma &
the experience from other conditions

Stigma and exclusion are common features of epilepsy

To reduce stigma + improve quality of life

Raising awareness

Legislation

Learning from each other

Check legislation

Change legislation

Develop legislation

Measuring results: awareness raising efforts
How to measure and reduce stigma & the experience from other conditions

Go raibh maith agat
Thank you
Merci beaucoup
Danke vielmals
Muchas Gracias
Dank u
Grazie molte
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Спасибо
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