Psychosocial Impacts of Epilepsy

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Questions

+ How common is epilepsy?
+ Aside from seizures, how else does epilepsy affect quality of life?
+ What resources are available?
How common is epilepsy?

- Epilepsy is NOT rare.
- United States: 3.4 million people are affected (Zack 2017)
  - 150,000 new cases per year
  - 1/3 of people with epilepsy have uncontrollable seizures
- World: 65 million people (Moshe 2015)
  - More than 80% live in developing countries (Meinardi 2001)
  - World Health Organization (WHO) study in 2007
    - 9 out of 10 people in Africa with epilepsy are untreated
How else does epilepsy impact lives?

- As you can see, MANY people all over the world are affected.
- However, seizures themselves are NOT the only problem.
- 1 in 4 patients report social and/or economic problems (Fisher 2000)
  - Average income for general public: $32,000
  - Average income for people with epilepsy: $18,750
- Psychosocial issues are often underreported and underappreciated (Zack 2017)
- These factors cumulatively influence your Quality of Life.
Quality of Life (QoL)

+ WHO: individual perception
+ Multiple factors into a “good” QoL
+ Affects all ages
  + Different life experiences
  + Different priorities

QoL in Childhood/Adolescence

+ Children are learning to be independent
  + Parents may be extra cautious
  + Difficult to balance

+ Adolescents are more likely to be bullied
  + Emotional/physical competence is developing

+ Driving is important developmental task, which can become limited
QoL in Adults

+ 2012 Institute of Medicine (IOM) report: Epilepsy Across the Spectrum
  + #1 concern: Driving a motor vehicle
  + Others: employment, recreational activities
QoL in Adults

- Driving
- Employment
- Recreational activities
- Financial burden
- Psychosocial well-being
But first...RISK

+ Always think about risks of desired activity against potential benefits
  + Applies to people without epilepsy also
  + Will vary from person to person
But first...RISK

+ In epilepsy where consciousness can be lost, extra considerations have to be made
  + Risk of seizure will determine safety

+ Factors determining risk:
  + Seizure type(s)
  + Cause of seizure
  + Medication compliance
  + Safety equipment involved/supervision of activity
  + Seizure triggers
Driving

- State governments restrict driving for a person with epilepsy
- Seizure-free intervals prior to reinstatement vary from state to state
- No objective data available to provide “optimum seizure-free intervals”
- Six states require health care providers to report persons with epilepsy to motor vehicle departments

http://content.time.com/time/specials/packages/article/0,28804,1843821_1843820_1843808,00.html
Driving – Arizona

+ Arizona: minimum of 3 seizure-free months
  + Any seizure that occurred must be due to medication change, and seizures are under control after the change
  + Any seizure that occurred must be a single event that will not recur
  + Seizures that do occur only happen during sleep
  + There is a pattern of an established aura of sufficient duration to allow driver to pull over
Recreational Activities

+ Sports, outdoor activities, etc

+ Activities involving driving follow the same rules
  + Sports car racing has individual rules sanctioned by the governing body (i.e. Indy Car Series)

+ Piloting a private plane (noncommercial aviation) is partially regulated by the FAA
  + Third class license considered if only one unprovoked seizure with normal EEG, normal imaging, no additional risk factors, and no AEDs for past 4 years
  + Hang gliding not regulated by FAA...hang at your own risk
Recreational Activities - Athletics

+ There are no official restrictions on athletics, but (figuratively) use your head!

+ Again, weigh the potential benefits of satisfaction and safety

| TABLE 94.4 |
| SPORTING ACTIVITIES CLASSIFIED ACCORDING TO POSSIBLE RISK FOR THE PERSON WITH EPILEPSY |
| Low risk Track |
| Cross-country skiing |
| Golf |
| Bowling |
| Ping-Pong |
| Baseball |
| Weight training (machines) |
| Moderate risk football |
| Biking |
| Soccer |
| Gymnastics |
| Horseback riding |
| Basketball |
| Boating/sailing |
| High risk |
| Scuba diving |
| Hang gliding |
| Motor sports |
| Boxing |
| Downhill skiing/ski flying |
| Long-distance swimming |
| Hockey |
| Boxing |

Employment

- Rate of unemployment for persons with epilepsy in US is between 25% and 69% (Fisher 2000) (Salgado 2002)

- Factors identified with higher rate of unemployment:
  - Poorly controlled epilepsy
  - Earlier age of onset

- Strict rules for specific jobs
  - Commercial airline pilot
  - Commercial truck driver
Employment Discrimination

+ Studies in Ireland, Australia showed that people with epilepsy felt they were discriminated against

+ Employer reasons for discrimination:
  + Difficulty getting to work
  + Concerns about safety at work and the liability of the company
  + Seizures may scare off customers

+ In the US, there have been improvements in mindset of companies willing to hire people with epilepsy (Hicks 1991)
Financial

- Lower household incomes
- Direct yearly health care costs per person with epilepsy: $10,192 - $47,862 (Begley 2015)
- Seizures can result in traumatic injuries, which secondarily causes hospitalization
- Newer anti-epileptic medications (AEDs) can be very expensive
Psychosocial

+ Stigma
+ Locus of control
+ Living in fear
+ Self-image
+ Psychiatric disorders
Psychosocial – Stigma

- First mention of epilepsy in negative perception: Bible as a “madness”
  - Also as demonic possession, consequence of negative karma (Austin 2001)
  - Etymology of epilepsy: Taken, or seized...originally thought of by supernatural forces

- Lack of knowledge/education
  - People with epilepsy feel that others are uncomfortable with them

- Epilepsy is kept as family secret
  - As high as 50% of families have kept it as a secret
Psychosocial – Locus of Control

+ How the experience of living and dealing with a disorder may affect a person’s view of the world.
  + The “controllability” of events in life

+ External locus of control = little personal control over life, tends to be more passive and “depressogenic”.

+ Some studies report that people with epilepsy tend to have a more external locus of control
Some types/causes of epilepsy have somewhat predictable patterns, and some do not.

In a study which surveyed many patients, most important subjective disability was fear (Chaplin 1992).

Linked with loss of control, but constant fear adds to difficulty of properly living life → decreased QoL
Psychosocial – Self-image

- Many people with epilepsy report having poor self-esteem
  - Some view themselves as impaired (Wagner 1996)
  - Especially difficult during adolescence

- Public perception, as stated before about stigma, contributes to self-image
Psychosocial – Psychiatric co-morbidities

<table>
<thead>
<tr>
<th></th>
<th>Patients with epilepsy</th>
<th>General population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>11–60%</td>
<td>Dysthymia 3.3% Major depression 4.9–17%</td>
</tr>
<tr>
<td>Psychosis</td>
<td>2–9%</td>
<td>Schizophrenia 1% Schizophreniform disorder 0.2%</td>
</tr>
<tr>
<td>ADHD</td>
<td>12–37%</td>
<td>4–12%</td>
</tr>
<tr>
<td>Generalized anxiety disorders</td>
<td>15–25%</td>
<td>5–7%</td>
</tr>
<tr>
<td>Social phobia</td>
<td>15–20%</td>
<td>10–12%</td>
</tr>
<tr>
<td>Panic disorder</td>
<td>5–21%</td>
<td>0.5–3%</td>
</tr>
</tbody>
</table>
Depression

- Most common co-morbid psychiatric disorder in patients with epilepsy (Kanner 2003)
- Approximately 1 out of 3 patients with epilepsy suffer from depression (Kanner 2012)
- It is underdiagnosed and undertreated (Kanner 2000)
- Uncontrolled depression = harder to control seizures
- Bigger effect on quality of life than memory, seizure frequency, cognitive processing speed
Depression

Risk factors for depression in people with epilepsy
+ More than 1 seizure/month
+ Younger age
+ Psychosocial difficulties

Be aware of:
+ Depressed mood
+ Inability to find pleasure in activities
+ Feelings of worthlessness and/or guilt
+ Decreased ability to concentrate
+ Sleeping too much/too little
+ Fatigue
+ Weight loss or gain
Depression

- Atypical expressions of depression in epilepsy
  - Interictal depression

- Depression symptoms can also occur:
  - Several hours to days before a seizure
  - Following a seizure, lasting several days
  - 1-5 days AFTER a seizure
Depression

- There is a bi-directional relationship
  - History of depression has a 4-7x higher risk of developing epilepsy (Hesdorffer 2000)

- Cause is uncertain, several theories exist

- Those with history of psychiatric disorders were more than 3x less likely to be seizure-free with AEDs

- Five studies found that depression is a powerful predictor of reduction in QoL

- Note: Antidepressants do NOT cause more seizures
Summary

- Quality of life
- Driving
- Recreational activities
- Employment
- Psychosocial
What are some solutions to all this?
Things To Know/Solutions

- What is available to help improve QoL?
- Driving
  - Uber, Lyft
  - Self-driving cars?
Things To Know/Solutions

+ Employment
  + Americans with Disabilities Act (ADA)
    + Helps prevent discrimination in the workforce
    + “Reasonable accommodations” must be made for you to remain in a specific job
    + There are no blanket accommodations - they must be tailored to the job
    + Employee must be able to perform “essential” tasks of job
    + Vague?
  + ADA Restoration Act of 2008

**TABLE 94.2**

LIFE ACTIVITIES THAT MUST BE IMPAIRED TO BE CONSIDERED DISABLED BY SEIZURE AS DEFINED BY THE AMERICANS WITH DISABILITIES ACT AMENDMENTS ACT OF 2008

- Walking
- Seeing
- Speaking
- Breathing
- Thinking
- Performing manual tasks
- Concentrating
- Learning
- Social interaction
- Reproduction
- Sleeping

Limitations on one or more of the above life activities due to seizures or side effects of medications used to treat epilepsy must be present to be considered disabled.

Things To Know/Solutions

+ Job applicant must satisfy the required skill, experience, and education levels for the job

+ What an employer cannot ask during an interview:
  + Whether you have epilepsy or seizures
  + Severity of illness

+ Once job begins, employer can:
  + Ask questions about health conditions
  + Require a medical examination
Not all patients with epilepsy qualify for Social Security Administration disability benefits.

Specific evidence and medical records are required.

If epilepsy is causing disability, must prove:
- History of good medication compliance
- Difficult to control seizures
- More than 4 partial seizures per month
- More than 1 “major motor seizure” per month
- EEG abnormalities
- Detailed description of events
- If nocturnal seizures, the post-ictal effects last into the day, affecting activities
Things To Know/Solutions

+ Psychosocial – stigma, self-image
  + Help educate the public!
  + Raise awareness at various events, such as the National Walk for Epilepsy
  + For children/adolescents, the epilepsy camps are a great environment for getting to know others with epilepsy
Psychosocial – Depression

Talk to your doctor if you feel any of the symptoms mentioned before

Good seizure control will help

Be aware some anti-seizures medications can worsen depression

More and more neurologists are aware of the relationship, and often use written scales as a screen

Vagal nerve stimulator: FDA approved for bipolar depression
We are aware.

Please, please talk to us.
Resources: Epilepsy Foundation

+ [http://www.epilepsy.com](http://www.epilepsy.com)
+ Job accommodation network: [http://www.jan.wvu.edu/media/epilepsy](http://www.jan.wvu.edu/media/epilepsy)
+ This is an amazing, extensive, comprehensive, foundation with lots of information

November is Epilepsy Awareness Month

Anyone Can Have Epilepsy
Everyone Should Know

Learn the First Aid. Take Action.

[www.efepa.org](http://www.efepa.org)
Resources

- American Epilepsy Society
  https://www.aesnet.org/for_patients
- Equal Employment Opportunity Commission (EEOC)
- Legal support via Epilepsy Foundation
- Support groups via local Epilepsy Foundation Chapters
- Talk to your doctor/social worker
- If you have feelings of depression, talk to your doctor or SEEK HELP


Salgado PC, Souza EA. [Impact of epilepsy at work: evaluation of quality of life]. Arq Neuropsiquiatr. 2002;60(2-B):442-445


References (cont)


Thank you!