Socio-Economic consequences of Epilepsy

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Epilepsy is often a life-long problem

Seizures are not the only problem, and treatment of seizures is not the only help patients need.

The social and economic problems caused by epilepsy are often under-appreciated (by physicians)

Physicians often don’t address these issues, because we don’t have any specific training regarding these problems.
Social and economic problems with epilepsy:

1. Have been known to be a problem for a long time

A Study of the Socio-economic Effects of Epilepsy

W. P. WILSON, L. F. STEWART AND J. B. PARKER

Department of Psychiatry, Duke University School of Medicine and Psychiatric Service of the Veterans Administration Hospital, Durham, N. C. (U.S.A.)

2. Occur throughout the world

The social and economic impact of epilepsy in Zambia: a cross-sectional study

Gretchen Bierbeck, Elwyn Chomba, Masharip Atadzhanov, Edward Mbewe, Alan Haworth

Summary

Background Among the 40 million people with epilepsy worldwide, 80% reside in low-income regions where human
The most important things for me are:

- To let you know that you are not alone.
- To review the problems that you face *(please tell me!)*
- To review possible solutions
- To reassure you that a full, happy life is possible
1. **You are not alone**

1. Epilepsy affects 0.5 to 1% of the population. **70% of people experience remission during their lifetime**
2. How many people have epilepsy in the US?
3. In the World?
4. What proportion of these have social and economic problems?
1. You are not alone

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   3 million!

3. In the World?

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1. Epilepsy affects 0.5 to 1% Percent of the population.
   
   70% of people experience remission during their lifetime.

2. How many people have epilepsy in the US?

   3 million!

3. In the World?

   50 million!

4. What proportion of these have social and economic problems?
4. How many people with epilepsy have social and economic problems?

- Not a simple question to answer!
- Differs over time, from country to country, and state to state
- Probably, all patients.
- Let's look at some studies...
4. **How many people with epilepsy have social and economic problems?**

- **1/4 of all patients** report that social stigma, fear of other people’s reactions, shame, and loneliness are major concerns\(^1\)

- Germany, Italy, USA – **15 to 20%** unemployed\(^2\)

- PWE had an average income of **$18,750** compared with **$32,000** for the general public. \(^3\)

- **46% (almost half)** of PWE reported poor quality of life compared with **19%** without epilepsy\(^4\)
1. You are not alone

2. WHO fact sheet on Epilepsy
4. CDC 2001 report on Texas Behavioral Risk Factor Surveillance System (BRFSS)
Conclusion Number 1.

“I am not alone.”
2. Problems: Economic – Jobs

- It's even tougher for people with epilepsy.
- They are much more likely to be unemployed.
- They are much more likely to be discriminated against.
2. Problems: Economic – Jobs

- **204 companies in the UK**
- 1/5\(^{th}\) - hiring people with epilepsy would be a “major issue”
- 1/5\(^{th}\) - there were “no jobs for people in the company for people with epilepsy”
2. Problems: Economic – Jobs

Thankfully, things are a bit better in USA:

The number of companies who would willingly hire PWE:

- In 1956 – 20%
- In 1986 – 95% (Why not 100% ???)
2. Problems: Economic – Jobs

Employers give many different reasons:

• Getting to work, especially if not driving
• Concerns about your safety if you have a seizure at work
• Worry about the company's liability
• belief that you have psychological problems or trouble thinking
• Fear that a seizure will scare off customers

- Adapted from Epilepsy.com. Dr. Steven Schachter, M.D.
2. Problems: Economic – Treatment costs

- Having epilepsy is expensive: - 4,523 $/year more expensive!
- Antiepileptics can be expensive!
- Injuries can be costly to treat
- It can be a vicious cycle, especially if you need expensive meds to control your epilepsy!
3. Problems: Social – Attitudes of others → self-image

- Epilepsy was (rather stupidly) considered an act of possession in the distant past.
- Public knowledge (and hence public perception) has improved.
- Has it improved as much as it should?
- Many patients are stigmatized by their diagnosis.
3. Problems: Social

- Attitudes of others → self-image

- Public perception: My informal study - Images posted on google
3. Problems: Social – Attitudes of others → self-image

Has public knowledge/perception improved as much as it should?

- Many people (22%) don’t know whether epilepsy is contagious.

- Many people think that all patients with PWE have severe seizures and are incapacitated by it. *(Jacobs et al 2006)*

- Disability is defined as something that substantially limits one or more (not all) of the major life activities of such individual.

- Just because you are disabled does not mean you are incapacitated !!!
Many patients are stigmatized by their diagnosis.

- This is partly (but not completely) because of public reactions to it.
- Talking about their epilepsy is a problem for a majority (>50%) of patients, especially adolescents.
- Greater stigma is associated with lower health-related quality of life, socioeconomic status, and need for special education.

(Westbrook 1996, Devinsky 1999)
3. Problems: Social – Driving and others

Some other problems you may face.

- People with epilepsy cannot drive unless their seizures are under control.
- In California – 3 to 6 months
- Both epilepsy and the medications for it can cause thinking problems in some people.
- Partly because of this reason, sometimes it's difficult to pursue higher education.
3. Problems: Summary

- **Economic**
  - Jobs
  - Treatment cost

- **Social**
  - Attitudes of others
  - Self-image
  - Education
  - Driving
  - Other concerns
Conclusion Number 2.

“I am not alone.”

“Many of the problems that I face are known”

How can I deal with these problems?
4. Solutions: RESOURCES

- You may not remember all of the resources available to you, and every person may require different kinds of help.

- Your three most important resources:
  - Your physician
  - A social worker (your physician can refer you to one)
  - A representative of the Epilepsy foundation (EF)
    - [www.epilepsyfoundation.com](http://www.epilepsyfoundation.com)
    - [www.epilepsynorcal.com](http://www.epilepsynorcal.com)
4. Solutions: RESOURCES

- Ask your physician for a referral
- Talk to the Social worker
- Counselor
  Or
- psychiatrist
- Other resources
4. Solutions: RESOURCES

- **Other resources:**
  - A lawyer
  - Patient support groups
  - **State human rights commission**
    25 Van Ness Avenue, Suite 800
    San Francisco, CA 94102-6033
    Maravie Bamba, Director
    Tel: (415) 252-2500
  - **Equal opportunities commission**
    California Department of Justice, Equal Employment Rights & Resolution, (EER&R)
    Office
    1300 I Street
    Sacramento, CA 95814
    (916) 324-5482

*It is best to seek guidance from a social worker, and the EF representative initially.*
4. Solutions: RESOURCES

Ms. Jeannette Hilgert
MSW
SF VA Medical Center

American Disabilities Act (1990)

Not all patients with epilepsy qualify for disability.

- Substantially limits one or more of a person's major life activities
- Substantially limiting some time in the past
- Employer treats the individual as if it does.

During an interview, an employer **cannot** ask:

- whether she has epilepsy or seizures;
- whether she uses any prescription drugs; or
- whether she ever has filed for workers' compensation/was injured

After making a job offer, an employer may ask questions about an applicant's health and may require a medical examination.

- They need to make adjustments to the job requirements
- They may need to make other accommodations e.g. timed breaks

Job applicants with disabilities must first:

- Satisfy the required skill, experience, and education levels required for the position.
- Be able to perform the "essential job functions" with or without "reasonable accommodations".

Complaints to be filed within 180 days with the ECOE (U. S. Equal Employment Opportunity Commission)
4. Solutions: Economic – Treatment cost

- “Service connected” – All treatment costs are covered.
  - Trauma while in service
  - Exposure to agent orange
  - Secondary side-effects of epilepsy medication e.g. osteoporosis

- If not service connected:
  - Talk to your social worker about SSI and other avenues.
3. Solutions – Social – Public perception and self-image

Public perception:
- Epilepsy awareness months
- Newspapers
- Epilepsy foundation
  - Changing public perception is a long and difficult process!
  - YOU CAN HELP!! Contact the epilepsy foundation.
Self-Image:

- Counseling
  - We have an especially good counsellor at the SF VAMC: Gilbert Woo

- Participate in support groups
  - Identifying with other people with the same issues can be very helpful
  - In many ways, other people with epilepsy understand your problems the best
  - They may be able to suggest solutions others have not thought of.

- Bring depression and other mental health issues to the attention of your physician/counselor. Don’t hide them.
4. Famous people with epilepsy

- People who overcame the “Social” issues:
  - Pope Pius IX
  - Danny Glover

- People who overcame the “Economic” issues
  - Ronde Barber
  - Jonty Rhodes

- People who overcame both!
  - Julius Ceasar
  - Napoleon Bonaparte (likely)
My favorite cricket player, happens to have epilepsy
Jonty Rhodes

http://www.youtube.com/watch?v=UADfny6YCjQ
Conclusion: What I hope you’re thinking

1. I am not alone

2. Many of the problems that I face are known

3. There is help. I will talk to my physician, social worker, and the epilepsy foundation and find such resources.

4. I deserve, and will have, a full, complete life.