

Quality of Epilepsy Care & What It Means To You

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WHAT IS QUALITY OF EPILEPSY CARE

QUALITY MEASURES | WHY IT MATTERS | YOUR RIGHTS

QUIET-VA: Quality Indicators in Epilepsy Treatment in the VA

- We developed quality of care measures (indicators) for People/Veterans with epilepsy in primary care and general neurology clinics.

- <http://www.biomedcentral.com/1472-6963/11/1/>

- QUIET indicators are based on

- Scientific evidence
 - Expert opinion
 - Patient perceptions

- Find more information on Quality at Epilepsy.Com
http://professionals.epilepsy.com/page/care_quality_measures.html

Pugh et al. BMC Health Services Research 2011, 11:1
<http://www.biomedcentral.com/1472-6963/11/1>



RESEARCH ARTICLE

Open Access

The quality of care for adults with epilepsy: an initial glimpse using the QUIET measure

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Abstract

Background: We examined the quality of adult epilepsy care using the Quality Indicators in Epilepsy Treatment (QUIET) measure, and variations in quality based on the source of epilepsy care.

Methods: We identified 311 individuals with epilepsy diagnosis between 2004 and 2007 in a tertiary medical center in New England. We abstracted medical charts to identify the extent to which participants received quality indicator (QI) concordant care for individual QIs and the proportion of recommended care processes completed for different aspects of epilepsy care over a two year period. Finally, we compared the proportion of recommended care processes completed for those receiving care only in primary care, neurology clinics, or care shared between primary care and neurology providers.

Results: The mean proportion of concordant care by indicator was 55.6 (standard deviation = 31.5). Of the 1985 possible care processes, 877 (44.2%) were performed; care specific to women had the lowest concordance (3.7% vs. 4.2% [first seizure evaluation], 4.4% [initial epilepsy treatment], 4.5% [chronic care]). Individuals receiving shared care had more aspects of QI concordant care performed than did those receiving neurology care for initial treatment (5.9% vs. 4.3%; $\chi^2 = 9.0$; $p = .001$) and chronic epilepsy care (5.9% vs. 4.2%; $\chi^2 = 30.2$; $p < .0001$).

Conclusions: Similar to most other chronic diseases, less than half of recommended care processes were performed. Further investigation is needed to understand whether a shared-care model enhances quality of care, and if so, how it leads to improvements in quality.

Background

While existing quality indicators have focused on a number of highly prevalent chronic conditions (e.g., diabetes, hypertension) they do not address the quality of care for less prevalent, but serious conditions, such as epilepsy. Epilepsy care presents complexity in the sense that providers must balance seizure control, adverse drug effects, and complicated issues associated with epilepsy itself (e.g., mood disorders [1-3]) while also being mindful of consequences related to long-term treatment with antiepileptic drugs (e.g., bone health [4-6]). Thus, it is important to begin examining the quality of care provided to patients with epilepsy using quality measures and identifying gaps in quality of care. The United Kingdom has begun this process [7] due to

the availability of not only clinical guidelines for care for patients with epilepsy [8,9], but also quality indicators from the Quality and Outcomes Framework [7]. While no comprehensive national guidelines for care of patients with epilepsy exist in the United States, the development of the Quality Indicators for Epilepsy Treatment in adults (QUIET) allows us to begin to examine the quality of epilepsy care in the United States.

The purpose of this study is to describe the quality of care received by adults with epilepsy in a major medical center in a Northeastern US city using the QUIET indicators-quality indicators developed as part of a larger study funded by the Centers for Disease Control and Prevention (CDC; Additional file 1)-and to assess the quality of epilepsy care in primary care and general neurology settings. Similar to other countries, in the US a substantial number of patients continue to receive their epilepsy care solely within the context of primary care

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Quality of Care Measures—Why are they important to you

- Definition:
 - The degree to which health services increase the likelihood of desired health outcomes of individuals and populations and which are consistent with current professional knowledge—*Institute of Medicine (IOM)*
- Quality measures:
 - maximize your welfare
 - Improves the quality and length of your life
 - Produces better health outcomes for you



Veterans deserve the highest quality of care

Dimensions of Quality...

- Technical quality:
 - Your epilepsy care team has the technical skills to make the right decisions for you and perform care target for you.
- Interpersonal quality:
 - Your epilepsy care team can communicate with you, gained your trust, interacts with you with empathy, honesty, and sensitivity to your concerns.
- Amenities of care:
 - Veterans Health Administration (VA) integrated care offers convenience and coordination of your health care and pharmacy benefits.



Epilepsy Center of Excellence at San Francisco VA Medical Center.
Photo courtesy of Epilepsy Center of Excellence

Your Epilepsy Care Team may feature Epileptologist/Neurologist, Nurse Practitioner & Nurses, EEG Technicians, Pharmacist, Social Worker/Mental Health Provider, and others.

Definitions of Seizures & Epilepsy

- Seizures: sudden discharge of excessive electrical activity in the brain that cause
 - a change in behavior
 - Alterations in movement, awareness, consciousness, experience
- Epilepsy: a neurological condition that affects the nervous system.
 - Epilepsy is diagnosed after two or more unprovoked seizures.
 - A doctor should conduct physical and neurological examinations to determine the possible cause.
- http://www.epilepsy.com/treatment/when_diagnosed



Checking My Care for Epilepsy–

An easy to use checklist available to Epilepsy.Com

epilepsy.com **Quality of Care Checklist**

Checking My Care for Epilepsy

If you or a loved one are being treated for a seizure disorder or epilepsy, use this checklist to see if you're getting some of the basic care and information that you should have. This list was made from a research study that developed "quality indicators" for epilepsy. These indicators are a way to tell if doctors or other health care providers are providing basic quality care to people with epilepsy and seizures. This list does not include everything that people with epilepsy need, but offers a starting point for general care of their epilepsy. Please keep in mind that the word quality can be subjective and may vary from person to person. We hope this checklist will help you start looking at your epilepsy care and help you talk with your doctor.

When a person is first diagnosed with seizures or epilepsy

When you were first evaluated for seizures, did you have...

- ☐ A detailed discussion of your seizure history
- ☐ A review of other conditions that could cause or affect seizures
- ☐ A physical examination to rule out other cause of symptoms or medical problems that could affect seizures
- ☐ A detailed neurological examination to look for other neurological problems or findings that may help tell more about the type or location of seizure
- ☐ Blood and urine tests to look for medical problems that may affect seizures or occur as a result of a seizure

When you were first evaluated for seizures, if there was no obvious cause found, were you given...

- ☐ An EEG (also called an electroencephalogram) to look at the brain waves for possible seizure activity or markers of seizures
- ☐ A brain scan, usually an MRI (magnetic resonance imaging) that looks at the structure of the brain for problems that may cause seizures or tell where they come from.
- ☐ A referral to an epilepsy center or specialist

When you were first evaluated for seizures or diagnosed with epilepsy, were you given information on...

- ☐ Driving restrictions
- ☐ Safety including what to do if a seizure occurred and general safety instructions
- ☐ How to prevent injury, such as any equipment or aids that may help you stay safe

1 A service of the **epilepsy.com** International League Against Epilepsy

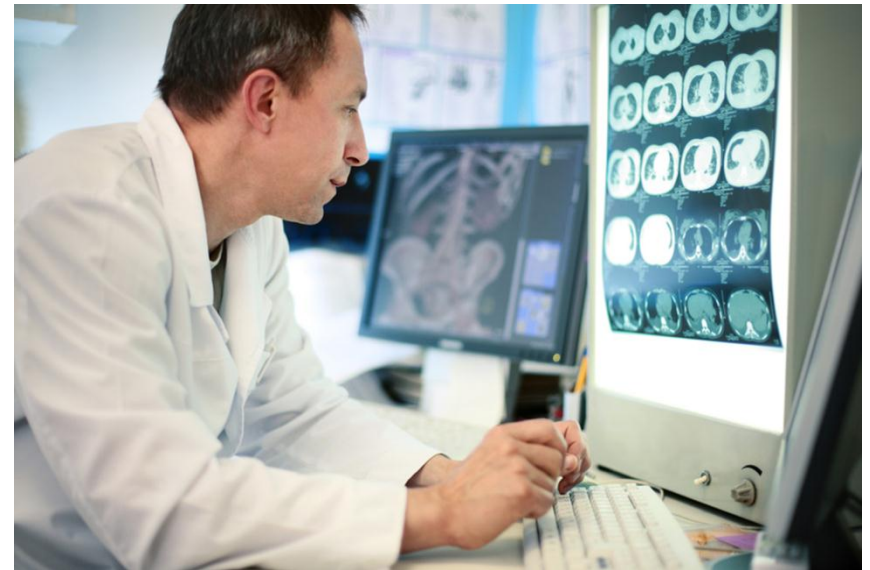


http://www.epilepsy.com/pdfs/my_care_checklist.pdf

Download & print out
“Checking My Care for Epilepsy”

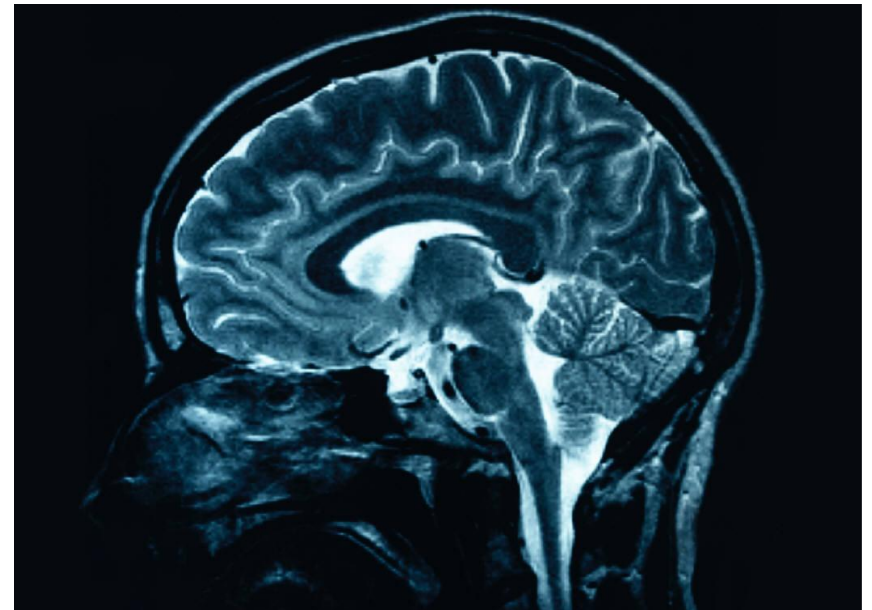
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If your first seizure didn't have any obvious cause,

but other tests were of concern* or if you or your caregivers or family felt the risk of more seizures was worth trying a medicine for seizures, did your doctor...

- ☐ Talk about how seizure medicines may help
- ☐ Talk about side effects or other risks of taking seizure medicine
- ☐ Offer or suggest that you take seizure medicine
- ☐ Describe if seizure medicine wasn't needed and why



After you were diagnosed with epilepsy, did your doctor...

- ☐ Talk about the type of seizures you have
- ☐ Talk about what the diagnosis of epilepsy means
- ☐ Talk about how seizure medicines may help
- ☐ Explain possible side effects of seizure medicine
- ☐ Offer or suggest that you take seizure medicine
- ☐ Stress the importance of taking seizure medicine as prescribed and how to take them



After you were diagnosed with epilepsy, did your doctor...(2)

- ☐ Explain how lifestyle or other factors may affect seizure control and what to do
- ☐ Ask whether you use contraception
- ☐ Explain how seizure medicines may affect some forms of contraception & what to do
- ☐ Ask if you were planning on having children
- ☐ Talk about how seizures and seizure medicines may or may not affect having children



If you are over age 60 and started having seizures, did your doctor...

- ☐ Talk to you about the benefits and risks of starting seizure medicine after the first seizure or describe why seizure medicine may not be needed
- ☐ Talk about which seizure medicines may be most helpful for you
- ☐ Tell you which seizure medicines may affect other medicines taken for other reasons
- ☐ First recommend that you try a medicine that doesn't interfere with other medicines



If you were started on seizure medicine after being diagnosed with seizures/epilepsy, did the doctor...

- ☐ Begin you on one medicine
- ☐ Talk to you about other medicines you take
- ☐ Talk about ways to lessen the chance that the drugs would affect each other



At follow-up appointments, did the doctor...

- ☐ Ask how often you had seizures and what kind
- ☐ Ask about side effects of medicines



If the first treatment did not work to stop seizures ...

Were you referred to a Neurologist to clarify the diagnosis or type of seizures

☐ Yes

☐ No



If you continued to have seizures for a year after being evaluated by a neurologist...

Were you referred to an epilepsy center or epilepsy specialist to clarify the diagnosis or type of seizures

☐ Yes

☐ No



IF SEIZURES DON'T STOP OR IF MEDICATIONS CAUSED SIDE EFFECTS

If you continued to have bothersome side effects on one medicine, did the doctor plan to change you from one seizure medicine to another

☐ Yes

☐ No



If you have been on seizure medicines...

If you have been on seizure medicines for at least two or more years, has your doctor or other health care professional recommend a test to check the health of your bones

☐ Yes

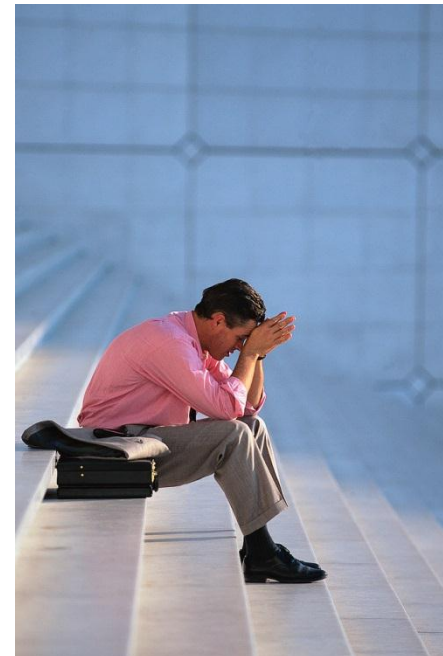
☐ No



If you have problems with mood...

If you have had symptoms or problems with your mood (for examples, problems with depression, anxiety or other changes in mood or behavior), have you been...

- ☐ Referred to a specialist in mental health
- ☐ Given a medication or other treatment for your mood



If you continued to have seizures, did anyone talk to you about...

- ☐ Compliance or how to take the medicine as prescribed
- ☐ How to take medicine more easily
- ☐ If you need to get blood levels of medicine checked and how to do this
- ☐ If the dose of seizure medicine could be changed
- ☐ If a different seizure medicine could be tried
- ☐ How to modify your lifestyle to help lessen seizures and increase safety
- ☐ When a referral to an epilepsy specialist or center may be helpful



Does anyone talk to you on a regular basis (at least once a year) about the following areas...

- ☐ How epilepsy may affect you over time
- ☐ How seizure medicines may affect you over time
- ☐ Contraception, family planning and how pregnancy and menopause may affect seizures
- ☐ Mood or behavior problems
- ☐ Factors that may trigger or affect your seizures
- ☐ Lifestyle modifications
- ☐ How epilepsy may affect other health conditions you may have
- ☐ Driving
- ☐ Safety



Depression...

Does anyone check you for signs or symptoms of depression at least once a year

☐ Yes

☐ No



If you are a woman with epilepsy of child-bearing age

Has the doctor or other health care professional discussed the following...

- ☐ The use of folic acid or folate
- ☐ Possible interactions between oral contraceptives and some seizure medicines and ways to prevent unintended pregnancy
- ☐ The type of prenatal care that is recommended during pregnancy
- ☐ The need for treatment by a neurologist and obstetrician with experience in high risk pregnancy



If you have well-controlled seizures

Has the doctor or other health care professional reviewed the following with you at least once a year...

- ☐ Side effects of seizure medicines
- ☐ How you manage epilepsy



Have you been given information on the following areas...

- ☐ Resources to learn about epilepsy
- ☐ How complex epilepsy treatment can be and the need to individualize treatment
- ☐ How to advocate for yourself in the healthcare system and with health care providers
- ☐ Possible side effects of medicine, including problems with thinking or memory, physical and sexual function
- ☐ Social services for help with jobs, Social Security Disability Insurance (SSDI), insurance, and transportation
- ☐ Local support groups or other resources for emotional support



Items for this checklist were adapted from:

- Pugh MJ, Berlowitz DR, Montouris G, et al. What constitutes high quality of care for adults with epilepsy Neurology 2007;69:2020-2027.
- http://my.epilepsy.com/treatment/receiving_quality_care
- http://professionals.epilepsy.com/page/care_quality_measures.html



Your Rights

- Whether you receive care as outpatient, inpatient or long-term care in a VA Medical Center or community-based outpatient clinics (CBOC), you deserve
 - Timely Care
 - Compassionate Care
 - And the most out of your experience.
- You also have the right to a Patient Advocate
<http://www.va.gov/HEALTH/patientadvocate/>



Helpful Websites & Apps

**TAKE CONTROL.
OF YOUR EPILEPSY
AND SEIZURES.**

**REGISTER AND START
My Epilepsy Diary Today**

Seizure management has never been easier. Take control today with
My Epilepsy Diary!
Manage your epilepsy using the same technology you use to simplify the rest of your

myepilepsydiary
powered by epilepsy

Now available on
iPhone and iPod touch
Visit the App Store to get it NOW.
More information in Downloads & Extras

6 months

Epilepsy Foundation app available for iPhone and iPod Touch. Web version accessible at <http://www.epilepsy.com/seizurediary>

FREE

★★★★★ (39)

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Epilepsy Society

10,000 - 50,000 downloads

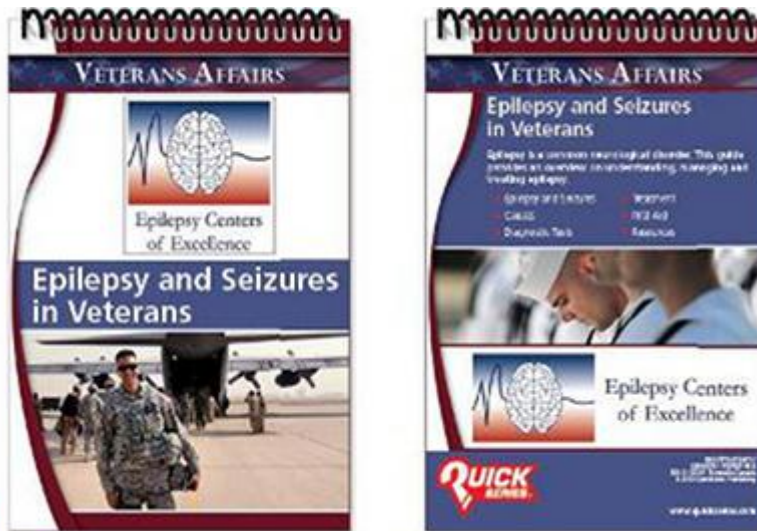
American Epilepsy Society app available for iPhone, iPad, Android, Blackberry Storm and Touch.

More Helpful Websites & Apps

- **Patients Like Me** offers community, information, seizure tracker, and news
 - <http://www.patientslikeme.com/>
- **Seizure Tracker** logs seizures, meds, appointments; interfaces with mobile phones
 - <https://www.seizuretracker.com/>
- **WebEase** helps you manage meds, stress, & sleep
 - <https://www.webease.org/>



Learn More! Epilepsy Centers of Excellence Patient Education Video & Audio Presentations



Patient Education

The ECoEs have created several educational presentations about epilepsy.

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http://www.epilepsy.va.gov/Patient_Education.asp