

Demographics

Study ID _____

Data Collection Period

- 2008 (Oct 1, 2007 - Sept 30, 2008)
- 2012 (Oct 1, 2011 - Sept 30, 2012)
- 2014 (Oct 1, 2013 - Sep 30, 2014)

Epilepsy Status

- New Diagnosis (within VA)
- Chronic Diagnosis (new to VA)

Does the patient have a diagnosis of PNES (Psychogenic non-epileptic seizures)?

- Yes
- No

When did the patient receive the PNES diagnosis?
(month/year) _____

When was the first seizure/symptom diagnosed?
(month/year) _____

Does the patient remain on any AEDs?

- Yes
- No

Has the patient been referred to Mental Health?

- Yes
- No
- Not reported

Is there evidence that the patient is being seen by Mental Health?

- Yes
- No

DEMOGRAPHIC INFORMATION

Gender

- Female
- Male

Race

- Asian
- Native American/Pacific Islanders
- Black/African American
- White
- Hispanic
- Unknown/Not Reported

If you answered YES to whether the patient has a diagnosis of PNES, the abstraction is finished. Do not continue if the patient has a diagnosis of PNES.

Initial Diagnosis And Treatment

INITIAL DIAGNOSIS AND TREATMENT

Instructions for chart abstractor: Click the "Chart" tab (located on top most row, second from left) then "Documents" (5th row, far right) then "All" or "Visits" then view problems list, Physician/RN's notes and "hospital documents", ER reports, transcripts.

Prior to diagnosis, was a history of TBI reported?
(Please check in problem list)

- Yes
- No
- Not reported

Prior to diagnosis, was a family history of epilepsy reported?

- Yes
- No
- Not reported

New Diagnosis

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If patient is thought to have diagnosis of epilepsy, is there a best estimation of seizure type?
(see dx code)

- Yes
- No

Date of Diagnosis (month/year) _____

Diagnosis or Diagnosis code (Petit mal, Grand mal, Atonic, Myoclonic, Simple partial, Complex partial, other) _____

Chronic Diagnosis

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If chronic or new to VA, check which of the following tests were found to have been performed (outside of the VA).

- EEG
- MRI/CT scan

How old was patient at diagnosis? _____

Date of Diagnosis (month/year) _____

Diagnosis or Diagnosis code (Petit mal, Grand mal, Atonic, Myoclonic, Simple partial, Complex partial, other) _____

General Questions

Does patient meet criteria for epilepsy diagnosis (two unprovoked seizures)? This pertains to any prior "unprovoked" occurrences as well.

(May be difficult to find for chronic - don't spend time searching if chronic.)

- Yes
 No

Was AED treatment discussed with and offered to the patient and caregivers? Look at record when diagnosis was made or the first time AED appeared in patient's record.

(May be difficult to find for chronic - don't spend time searching if chronic.)

- Yes
 No
 Not reported

When diagnosed with seizure disorder/epilepsy, was monotherapy started? (single drug therapy or treatment) Look at record when diagnosis was made or the first time AED appeared in patient's record.

(May be difficult to find for chronic - don't spend time searching if chronic.)

- Yes
 No

Is the patient a woman of childbearing potential (12-44 years old)?

- Yes
 No

Was she referred to a neurologist or an epilepsy specialist?

- Yes
 No
 Not reported

If prescribed valproate or topiramate, did she receive information about the teratogenicity associated with these medications?

- Yes
 No
 Not reported

Did she accept those risks prior to treatment?

- Yes
 No
 Not reported

When initial diagnosis is made, was information given to the patient regarding:
(check all that apply)

- Driving instructions
 Safety and injury prevention
 Diagnosis
 Treatment options
 Importance of taking AEDs as directed
 The affect of triggers or lifestyle factors
 Contraception and family planning

Is patient currently on the medication Warfarin (Coumadin)?
(May view medication list or Physician/RN notes.)

- Yes
- No

Was the INR monitored within a week of any change in AED therapy?
(Click "Chart" tab, then "Documents", then "labs" - check for current date. May view "Physician/RN notes".)

- Yes
- No
- Not reported

Is the INR monitored every 4 weeks?

- Yes
- No
- Not reported

Chronic Epilepsy Care

CHRONIC EPILEPSY CARE

Instructions for chart abstractor: Click the "Chart" tab (located on top most row, second from left) then "Documents" (5th row, far right) then "All" or "Visits" then view problems list, Physician/RN's notes and "hospital documents", transcripts.

During follow-up care, please check if there was documentation regarding:
(check all that apply)

- the estimation of the number of seizures since last visit
- the estimation of the types of seizures since last visit
- the assessment of drug side-effects

Please list the number of visits that address "the estimated # of seizures" _____

Please list the number of visits that address "the estimated types of seizures" _____

Please list the number of visits that address "the assessment of drug side-effects" _____

If patient continues to have seizures after initial treatment, please check if the following interventions were addressed?

(check all that apply)

- Compliance assessment/enhancement
- Monitor AED blood levels
- Increase AED dose
- Change AED dose
- Patient education RE: lifestyle modification
- Referral to higher level of epilepsy care

Does the patient continue to have seizures after three months of care?

- Yes
- No

Was there a further assessment by a neurologist?

- Yes
- No

Does the patient continue to have seizures after 12 months of care by a general neurologist?

- Yes
- No

Was there a referral to an epilepsy specialist?

- Yes
- No

Is there evidence that the patient is seen for epilepsy by providers outside of VA?

- Yes
 No
 Not reported

For patients with chronic epilepsy, check any of the following if they receive an annual review of information regarding:
 (check all that apply)

- Chronic effects of epilepsy
 Treatment and drug side-effects
 drug-drug interactions
 effect on bone health
 contraception and family planning
 How pregnancy and menopause may affect seizures
 screening for mood disorders
 triggers and lifestyle issues that may affect seizures
 impact of epilepsy on other chronic/acute diseases
 other patient self-management issues

DRUG LIST

Carbamazepine (Tegretol, Tegretol XR, Carbatrol, Eptol, Equetro)
Clobazam (Frisium, Onfi, Urbanol)
Clonazepam (Klonopin)
Diazepam (Valium, Diastat)
Ethosuximide (Zarontin, Emeside)
Ezogabine (Potiga, Retigabine)
Felbamate (Felbatol)
Fosphenytoin Sodium (Cerebyx)
Gabapentin (Neurontin)
Lacosamide (Vimpat)
Lamotrigine (Lamictal)
Levetiracetam (Keppra, Keppra IV)
Lorazepam (Ativan)
Oxcarbazepine (Trileptal, Oxtellar XR)
Perampanel (Fycompa)
Phenobarbital (Luminal)
Phenytoin (Dilantin, Phenytek)
Pregabalin (Lyrica)
Primidone (Mysoline)
Rufinamide (Banzel, Inovelon)
Tiagabine (Gabitril)
Topiramate (Topamax)
Valproic Acid (Depakene, Depacon, Depakote, Depakote ER)
Vigabatrin (Sabril)
Zonisamide (Zonegran)

Has patient been on AEDs for more than 2 years?
(Refer to drug list)

- Yes
- No

Has bone health been assessed?

- Yes
- No

Which of the following were done:

- DEXA scan
 - Vitamin D levels
 - Other
-

If receiving AEDs, when has patient been screened for depression/suicide related behaviors (PHQ-9)
(Check all that apply)

- initially
- 4-6 weeks after AED initiation (or next clinic visit)
- yearly

Is there documentation that patient is found to have evidence of a mood disorder?
(Physician notes. Also look for diagnosis of anxiety, depression, or mood disorder.)

- Yes
- No

Is there documentation that patient received treatment for mood disorder?
(Look for any drugs or psychosocial therapy, deoression or mood disorder.)

- Yes
- No

Is there documentation that the patient was referred for mental health care?

- Yes
- No

Is there evidence that the patient is seeing a psychiatrist/counselor/social worker/psychologist outside of VA?

- Yes
- No
- Not reported

Chronic Epilepsy Care For Women

CHRONIC EPILEPSY CARE FOR WOMEN

Instructions for chart abstractor: Click the "Chart" tab (located on top most row, second from left) then "Documents" (5th row, far right) then "All" or "Visits" then view problems list, Physician/RN's notes and "hospital documents", ER reports, transcripts.

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Is patient a woman of childbearing potential (12-44 years old)?

- Yes
- No

Is she taking supplemental folate (at least 400 mcg)? Mark yes if on multivitamins

- Yes
- No
- Not reported

Is patient on oral contraceptives in conjunction with an enzyme inducing AED? (Carbamazepine, Oxcarbazepine, Phenytoin, Phenybarbital, Primidone)

- Yes
- No
- Not reported

Was decreased effectiveness of oral contraception addressed?

- Yes
- No
- Not reported

Please indicate what change was made.

- Higher doses of oral contraceptives
- Alternative birth control method
- Change AED
- Not reported

Prenatal care is co-managed by a neurologist and a high-risk obstetrician.

- Yes
- No
- Not reported

Patient Generated Quality Indicator Statements

PATIENT GENERATED QUALITY INDICATOR STATEMENTS

The following are NOT physician, nurses or other's statements.

These are ONLY from the patient.

(eg. The patient states that they looked up their medication online on the epilepsy website)

Is there any indication that the PATIENT has stated the following: (or that the provider has made note that the PATIENT has stated)

The patient was referred to local support groups or other resources for psychosocial support.
(From patient's perspective ONLY)

- Yes
- No
- Not reported

Name of group or resource _____

The patient was encouraged by a provider to become educated about epilepsy. (examples: written material, epilepsy foundation, or epilepsy websites)
(From patient's perspective ONLY)

- Yes
- No
- Not reported

The patient was referred to social services to assist with: -employment -negotiating through SSDI (Social Security Disability) -insurance -alternative transportation for patients who cannot drive check the following if any or all are yes.
(From patient's perspective ONLY)

- employment
- SSDI
- insurance
- Alternate transportation

The patient was communicated to about the complexity of epilepsy treatment.
(From patient's perspective ONLY)

- Yes
- No
- Not reported

The patient was told that each patient responds to medications differently and that they may need to try different medications before they find out what works best for them.
(From patient's perspective ONLY)

- Yes
- No
- Not reported