Improving Seizure Management: Using an Evidence-based Tool for Seizure Management in the IDD Population

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My Story...IDD Nursing and Seizure Management

• Everyone has a story....
• My interest in persons with intellectual and developmental disability and seizure management

Objectives

• Participants will be able to label 5 common seizure types in persons with Intellectual and Developmental Disability and common intervention strategies
• Participants will be able to recognize the complexity and ambiguity of seizure management for persons with Intellectual and Developmental Disability residing within community-based settings
• Participants will be able to identify 3 benefits of using evidence-based tools for seizure management in persons with Intellectual and Developmental Disability
• Participants will be aware of the benefits of participating in research studies in Intellectual and Developmental Disability Nursing
Presentation Outline

• Part One:
  – Overview of Epilepsy
• Part Two:
  – Complexity of Seizure Management in Community-Based Settings
• Part Three:
  – Overview of Research: Implementation of an evidence-based Seizure Algorithm in Intellectual and Developmental Disability Nursing
• Part Four:
  – Recruitment Opportunity!

Part One:
Overview of Epilepsy

Outline

Definition
Prevalence
Physiology
Types/Causes
First Aid
Documentation
Treatment Options
Seizures
Epilepsy

Definition:
- Sudden uncontrolled episodes of excessive electrical discharges of brain cells. These charges can produce changes of behavior, movement or sensation in the person experiencing the seizure.

Prevalence

A Little Physiology

- Action potentials within neurons are initiated by an influx of sodium into the cell.
- Then calcium follows sodium into cells to create an action potential.
- When the cell fires, there is a flood of neurotransmitters into the neuronal synapse.
- The neurotransmitter glutamate produces excitation.
- GABA is a counterbalance to glutamate, preventing hyper-excitation and producing a calming effect.
A Little Physiology

- Seizures may result from either high levels of glutamate or low levels of GABA.
- Partial seizures occur when focus activity is limited to an area of the brain.
- When the focus activity is within both hemispheres, generalized seizure symptoms occur.

Possible Causes of Seizures

- Head injuries
- Strokes
- Brain Tumors
- Problems in infancy
- Infectious Diseases
- Problems during birth
- Problems during brain development
- Degenerative conditions
- Anything that injures a portion of the gray matter (cortex) of the brain

Types of Seizures

- Partial Seizures
  - Simple partial
  - Complex Partial

- Generalized Seizures
  - Tonic Clonic (grand mal)
  - Absence (petit mal)

- Status Epilepticus
Partial Seizures

• Most common type of seizure
• Arise from one part of the brain
• Include simple partial and complex partial

Simple (focal)
- Usually characterized by stiffening or jerking in just one extremity or on just one side of the body.
- The person does not lose consciousness.
- Can be accompanied by a tingling sensation or an aura-smell bright lights

Complex (temporal lobe)
- Often characterized by purposeless activity.
- Differs greatly for each person but is usually consistent for that person
- Often preceded by an aura
- Glassy stare

Generalized Seizures

• Appear to involve the entire brain from the onset.
• Include; generalized, tonic clonic, absence, myoclonic, tonic and atonic seizures
**Generalized Seizures**

**Tonic Clonic:**
- Seizure involves the entire body
- May cry out due to air rushing out of lungs
- May become unconscious
- Body stiffens
- Spasm and jerking
- Loss of urine and stool may occur
- Usually lasts between 3-5 minutes.

**Absence:**
- Brief loss of awareness
- Usually lasts 1-10 seconds
- Staring, eye blinking, mild facial twitching
- Difficult to detect

**Status Epilepticus**

Continuous seizure lasting 30 minutes or longer
Two or more sequential seizures without full recovery of consciousness

**Types:**
- Convulsive: Medical Emergency!!!!!
- Non-convulsive
- Repeated partial seizures without altered consciousness

**Causes of Status Epilepticus**

- Head injury
- Drug withdrawal
- Tumor
- Fever
- Central nervous infection
- Abrupt withdrawal of anticonvulsants
- Sometimes no underlying cause identified
Status Epilepticus
Can Result In:

• Impaired cognition
• Loss of memory
• Loss of motor function
• Other disabilities
• Death

SUDEP
Sudden Unexpected Death from Epilepsy
• The risk for SUDEP is higher in people with uncontrolled seizures. Thus, having as few seizures as possible, or ideally no seizures, is the best way to lessen your risk and prevent SUDEP.
• Make sure family, friends and co-workers know what to do for seizure first aid.

Preventing SUDEP

• Keep your Seizure Response Plan up-to-date and make sure people close to you know where it is and how to use it.
• Be seizure safe! Take extra precautions around water, including swimming and bathing.
• Since SUDEP occurs most often during sleep, consider a seizure alert monitor if you have seizures at night.
• People who have frequent seizures at night may want to share a room so help is available if needed.
• Talk about how you can still have privacy and make sure that everyone still gets a good nights sleep!

• http://www.epilepsy.com/learn/impact/mortality/sudep/preventing-sudep
Myths and Misconceptions About Epilepsy

- You can swallow your tongue
- Force something into the mouth
- Restrain during seizures
- Epilepsy is contagious

First Aid for Seizures

**Tonic-Clonic**
- Lying position with something soft under head
- Loosen tight clothing
- Clear area of hard objects
- DO NOT force anything into mouth
- Turn body on side and support

**Complex Partial**
- DO NOT restrain
- Remove harmful objects
- Guide gently away from danger

**Absence Seizure**
- Re-introduce what the person might have missed during the seizure

General Guidelines

- Follow Protocol for each individual person
- Complete Seizure Observation Tracking Form
- Document a Narrative if possible
- Communicate the Seizure Activity
- Send copy of the Seizure Observation Form to each Neurology appointment
Unusual Circumstances

First time seizure
911
Seizure in water
Support the head so it is tilted so face/head above water
Remove from water as soon as possible
CPR as appropriate
ER for assessment of heart/lung damage
Seizure in car/plane
Assist to lying position on side
Pillows under head

When to Call for HELP!

- If seizure lasts over 5 minutes unless otherwise specified by your physician
- If not breathing or having difficulty breathing after seizure
- If skin remains bluish-grey after seizure
- If does not regain consciousness after seizure
- If has 2 or more seizures without regaining consciousness in between
- If sustained serious injury
- If pregnant
- If seizure happened in water
- New Onset of Seizures

Treatment Options:
A Personal Clinical History in Seizure Management

- Marissa’s Story
  - Group Home Setting
  - Location
  - Seizure Types and Frequency
  - Treatment Options at the beginning
  - Newer Treatment Options
    - Better Management...but...
Seizure Management

- Anti-epileptic medications
- DIATSAT
- Surgery (for intractable seizures)
- Vagal Nerve Stimulation
  - New VNS without magnet!

Protocols

How Many Anti-epileptic Medications Work

- The three main ways that antiepileptic drugs work are by:
  - Decreasing the rate at which sodium flows into the cell
  - Inhibiting calcium flow rate into the cell through specific channels
  - Increasing the effect of the inhibitory neurotransmitter gamma-aminobutyric acid (GABA)

Medication Choices

<table>
<thead>
<tr>
<th>Drug</th>
<th>Starting Dose</th>
<th>Target Dose*</th>
<th>Side Effects</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valproate (Depakote)</td>
<td>10-15 mg/kg</td>
<td>750-2,000 mg</td>
<td>Sedation, ataxia, nausea, thrombocytopenia</td>
<td>Hepatic failure or pancreatitis rare</td>
</tr>
<tr>
<td>Levetiracetam (Keppra)</td>
<td>250-500 mg</td>
<td>1000-2,000 mg</td>
<td>Fatigue, dizziness, asthenia</td>
<td>Available in intravenous form</td>
</tr>
<tr>
<td>Lamotrigine (Lamictal)</td>
<td>25 mg</td>
<td>100-200 mg</td>
<td>Dizziness, blurry vision, headache</td>
<td>Stevens-Johnson syndrome in 1-3 of 1,000 patients</td>
</tr>
<tr>
<td>Topiramate (Topamax)</td>
<td>25-50 mg</td>
<td>100-200 mg</td>
<td>Sedation, ataxia, slow speech, word-finding difficulties</td>
<td>Nephrolithiasis in 1.5%, metabolic acidosis in 3%</td>
</tr>
<tr>
<td>Zonisamide (Zonegran)</td>
<td>50 mg</td>
<td>100-200 mg</td>
<td>Sedation, ataxia, anorexia</td>
<td>Nephrolithiasis in up to 4%, small risk of aplastic anemia</td>
</tr>
</tbody>
</table>
General Considerations for Anti-epileptic Medications

- Blood levels
- Liver function and kidney function tests
  - LFTs, BUN, CREAT
- Single agent best but multiple classes may be needed
- Takes time for medications to reach therapeutic level
- Can be many interactions between anticonvulsants and with other medications
- Sedation, ataxia usually transient side-effects
- Careful monitoring by a neurologist is imperative
- Goal of therapy: Control of seizure activity with minimal side-effects
- Drugs may be used in conjunction with VNS Therapy

DIASTAT

- Diastat is a Valium/diazepam gel that is administered rectally
- Diastat is for Prolonged or Serial seizures
- Diastat has prevented many visits to the ER
- Always check MAR before giving
- Monitor for sedation and respiratory issues after giving

Vagal Nerve Stimulation

Vagal Nerve Stimulator (VNS)
- Implantable device
- Small incision on the side of the neck for lead wire
- Usually out patient or overnight stay
- May include “magnetic device” for control
- Common side effect is hoarseness, cough tickling of throat during stimulation
Group Activity: Clinical Discussion

- Discuss your most challenging individuals with IDD and Epilepsy
- What were your obstacles for providing quality care?
- What was useful in providing care?
- What tools or other resources do you feel would have been beneficial

— Let’s Share Our Experiences and Thoughts

Part Two:
Complexity of Seizure Management in Community-Based Settings

A Complex System
A Collaborative Effort

- Health Care Practitioners
- Direct Support Staff
- Nursing Personnel
- Regulations
- Communication
- Documentation
- The Seizure Plan

Variety of Community Settings
HealthCare Practitioners

- Lack of knowledge related to persons with IDD and how it interfaces with epilepsy
- Lack of knowledge related to community based living and the complex systems of care in place
- Lack of knowledge regarding the regulations in place that nurses and DSPs must follow

Direct Support Staff

- An essential part of the care puzzle
- Turnover
- Training
  - Simulation and DSPs

Nurses

- Varied experience in the field of Nursing
- Varied background in the field of IDD Nursing
- Varied formal education in Epilepsy
- Varied formal education in nursing care for persons with IDD-especially chronic disease management
- Limited evidence-based tools available to use in the IDD field
- Nurses reluctance to use evidence-based tools in the IDD field
Housing

- Family Living
- Community-Based Living
- Group Living
- Institutional Living

Oh….the Regulations and Paperwork

- **Points to Consider**
  - The Individual’s Needs
  - Availability of Neurologist/other Healthcare Professionals
  - Your Nurse Practice Act
  - The Regulations in Place
  - Experience of Staff
  - Turnover of Staff
  - Communication

Communication

- How do you communicate....
- Healthcare Providers
- Direct Support Staff
- Pharmacy
- Other Agency/Organization Key Personnel
- **How Does It Flow?**
- **What are the Issues?**
Documentation

• Getting it Right

Detailed information
  • What happened right before seizure?
  • What happened during seizure?
  • How long was seizure?
  • How long to return to baseline?
  • What is the pattern?

The Seizure Plan

• Development
  – Specific to the person
• Training
• Revising
  – What Evidence-Based Information is Used?

Part Three

Overview of Research: Implementation of an evidence-based Seizure Algorithm in Intellectual and Developmental Disability Nursing
Research

• Research is a careful and organized study or gathering of information about a specific topic.
• Research is defined as to track down information or gain knowledge about a specific subject. Read more at
• Often we start with a question…or questions...

The Questions

• Would the use of an Evidence-Based Seizure Algorithm increase the Confidence of IDD Nurses when guiding care during telephone triage?
  – Confidence is essential to clinical decision-making
• AND...
  – Improve how we manage seizure care?

Out with the Old and in with the New

• Opinion, tradition, authority, personal experience, trial and error often guide current IDD Nursing Practice
• We must begin to recognize and use evidence-based practice in the field of IDD in order to support clinical decision-making
What is Evidence-Based Practice?

• “A problem-solving approach to clinical decision making within a health-care organization that integrates the best available scientific evidence with the best experiential (patient and practitioner) evidence.”

  (Johns Hopkins Nursing Evidence-Based Practice Model and Guidelines, 2007)

  • Using what we KNOW from RESEARCH and Moving it into PRACTICE
  • Knowing what works and what does not for the best possible outcome for our Individuals with IDD.

The Goals of Evidence-Based Practice

• Provide practicing nurses with the best evidence-based data
• Resolve problems in the clinical setting
• Achieve excellence in care delivery
• Reduce variations in nursing care
• Promote effective nursing interventions
• Assist with efficient and effective decision-making

Clinical Decision-Making

• Decisions about care are based on:
  • A. Research evidence.
  • B. Clinical expertise, judicious use.
  • C. Patient values and circumstances.

  – (Institute of Medicine, 2003)
Searching and Using Evidence-Based Interventions

Question

Search

Plan and Implement

Evaluate

Revise

Searching For Evidence-Based Tools for Seizure Management

• Would the use of an Evidence-Based Seizure Algorithm increase the Confidence of IDD Nurses when guiding care during telephone triage?

• AND...
  – Improve how we manage seizure care in the field of IDD?

The Evidence from the Research
Findings from the Research

• **Findings:** While no tools specific to IDD nursing epilepsy seizure management via telephone triage was discovered during this review; research did support the use of telephone triage tools, and epilepsy protocols and algorithms to support nurses when guiding care, including in the field of intellectual and developmental disability.

• The American Association of Neuroscience Nurses Seizure Assessment Algorithm!

• Surrogate Decision-Making Self Efficacy Scale! (SDM-SES)

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Evidence-Based Seizure Assessment Algorithm
Adapted with Permission from: American Association of Neuroscience Nurses

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Next Question—Measuring Confidence: The Tool

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I am confident that I know what kind of interventions to make during telephone triage for an individual with intellectual/developmental disability experiencing seizure activity.</td>
<td>x</td>
<td>x</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>2. I am confident that I can obtain the information I need to make informed decisions during telephone triage for individuals who are experiencing seizure activity.</td>
<td>4</td>
<td>x</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3. I am confident that I can adjust the side effects of various treatment options during telephone triage for the individual with intellectual/developmental disability experiencing seizure activity.</td>
<td>4</td>
<td>x</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>4. I can provide the most effective care to the individual with intellectual/developmental disability experiencing seizure activity.</td>
<td>4</td>
<td>x</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5. I am confident that I know what treatment options the individual with intellectual/developmental disability experiencing seizure activity would choose during telephone triage if he/she was able to express his/her preference</td>
<td>4</td>
<td>x</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
Results

Implications for Practice

- Use of evidence-based protocols may increase the confidence of IDD nurses when guiding seizure care through telephone triage
- IDD Nurses may use evidence-based protocols to guide practice when they are made available
- IDD Nurses provide seizure guidance via telephone triage to direct support professionals (DSPs) at a significant level
- There may be a significant need for seizure training management for IDD Nurses who provide telephone triage to DSPs

Part Four:

Recruitment Opportunity!
Participation is Easy!

- Complete a general information sheet
- Complete a pre-test questionnaire related to your confidence in guiding seizure care during telephone triage
- Receive directions on how to use the evidence-based seizure algorithm
- Use the evidence-based seizure algorithm for 3 months
- Track how many times you used the evidence-based seizure algorithm
- Complete a post-test questionnaire related to your confidence in guiding seizure care

The Road to Change and Success

!*SALE*!!

Recruitment Opportunity

- Please join me the next phase of using evidence-based tools for seizure management.
- Sign Up Available Now!!!!!!

• Thank you!
Resources

Academy of Medical-Surgical Nurses. (2013). Strategic plan: independent short study course.
Diastat www.diastat.com

Resources

Epilepsy Foundation – www.epilepsyfoundation.org
Johns Hopkins Nursing Evidence-Based Practice Model and Guidelines, 2007
http://www.yourdictionary.com/research

Resources

MGH Institute of Health Professions, 36 First Avenue, Charlestown Navy Yard, Boston, MA 02129-4557; e-mail: mghihp.edu.