Module Four: Patient/Family Education and Self-Management

At the end of this module, the participant will be able to:

- Describe three learning needs of patients and families pertaining to care of seizures
- Identify self-management strategies to improve health management of epilepsy
The way epilepsy is manifested and the manner in which it affects a person’s life can vary for many reasons. The experience of having epilepsy is different from one person to the next. In about 60% of the people who develop seizures, the seizures will be easily controlled or go away on their own. The seizures don’t affect a person’s daily life or can be easily managed. For the remaining 40% of people who develop epilepsy, their lives can be compromised by having seizures, the effects of seizures on the brain or possibly underlying neurological problems that have caused the seizures as well as other neurological deficits or comorbidities. A stroke or head injury are typical examples of this. For some people, side effects of medications, injuries or other ways that medications or seizures affect a person are the most bothersome parts of living with epilepsy. It’s important to realize that having epilepsy is a spectrum disorder – no two people have the same experiences. Treatment, education and self-management strategies need to be targeted to the experiences of the individual and their family.

References:


A review of educational and self-management needs for people with epilepsy in the IOM Report of 2012 recognized the diversity of educational needs that varies with both seizures and comorbidities. Children and adults with uncompromised or mildly compromised epilepsy and only mild comorbidities may only need epilepsy specific information and self-management strategies. Children and adults with persistent or uncontrolled seizures and moderate to severe comorbidities will require epilepsy specific information and self-management as well as more indepth chronic care self-management that addresses broader chronic care and independent living needs.

Reference:

IOM (Institute of Medicine), 2012. Epilepsy across the spectrum: Promoting health and understanding. Washington DC: The National Academies Press. Figure 7-2.
Seizures and epilepsy- Many misbeliefs and learning needs about seizures and epilepsy are critical to address early in the course of the epilepsy. Fear of seizures, of dying and of being different are some of the more common initial reactions and can influence how people perceive themselves and their confidence and ability to manage their epilepsy.

Treatment options and side effects - Medications can also affect a person’s health by giving rise to side effects. Earlier, side effects of medicines were discussed as they related to selection of AEDs. It is also important for the nurse to assess for the development of side effects while a person is on a medicine, know what effects may be treated, what may require changes in doses, or what may require stopping a medication. Additionally, the nurse needs to consider the impact of AED side effects on a patient’s personal health, safety, and quality of life.

For example, seizure medicines that involve hepatic metabolism can lead to liver problems in some people, whereas some that are metabolized through the kidneys can increase the risk of kidney stones, for example topiramate or zonisamide. Many different side effects can affect safety, resulting in impaired gait, balance, falls, fractures and other injuries.

Safety risks and mortality – Seizures can result in injuries immediately from falls, head lacerations, bruises, or fractures. Injuries and adverse events can also be delayed by hours or days, resulting in aspiration pneumonia, head trauma, and even death.

Patients and families must also learn about the importance of maintaining a healthy lifestyle to help minimize the impact of potential seizure triggers as well as address safety concerns in one’s daily life.

Comorbidities - Medications and seizures can affect a person’s thinking behavior and mood in many ways. The way these problems are manifested may be different among children, adults and older adults. A few examples include: slowed thinking and processing, attention deficits, ADD/ADHD, memory and learning problems, other functions specific to seizure localization or effects of medications, impulse dyscontrol, agitation, anxiety, depression, psychosis, suicidal ideation.
Epilepsy 101: Getting Started

What is Epilepsy Self-Management?

- **A process** – involves learning information, building skills, accessing support
- **A set of behaviors** - what people actually do to manage seizures and their consequences*
  - Does not imply person treats themselves without medical professionals
  - People with epilepsy/families work as ‘co-managers’
  - Implics ‘patient-centered care’ and outcomes


Epilepsy self-management is a process that involves patients and families having the information, skills and resources needed to manage the epilepsy and the impact on their daily lives. It doesn’t mean that the person takes care of themselves, but offers a way that people with epilepsy, families, other caregivers can work together with their health care providers to manage their health and care.

Reference:
Self-management, Nursing and Epilepsy

- By merging and using principles of self-management in care of people with epilepsy, regardless of settings, the nurse can -
  - Look at the total person, beyond seizures and side effects
  - Address factors that promote or are barriers to health behavior and self-management
  - Educate/promote strategies to change health behaviors
  - Focus on patient/provider communication, control and partnerships

The self-management approach offers the nurse a way to look at the total patient and family, and realize that seizures are only part of the problem. This approach encourages the nurse to look at problems that may be barriers to obtaining care or being a good manager and target patient and family education to help them promote healthy behaviors and ways to manage their epilepsy.
There are many different ways that self-management has been conceptualized in epilepsy. This offers a view of different self-management areas that can be easily addressed as part of nursing care.

Self-management areas can incorporate those that are general healthy lifestyle behaviors, and those that are epilepsy specific. For example, education and interventions for seizures and treatments will be epilepsy specific, whereas lifestyle, general health needs, and even some aspects of independent living may be relevant to many people with chronic illness.

Types of interventions that may be recommended will depend on the severity of the person’s epilepsy, how it is affecting them, their motivation and readiness for education and health behavior changes, and other factors.

References:


Developing Self-Management Plans

- Assess seizure history, functional status and psychosocial function, learning needs
- Uncover hidden problems, identify risks and barriers.
- Assess patient/family motivation and readiness for learning.
- Assess patient and family self-efficacy.

Nurses develop care plans for patients and families routinely. Using a self-management approach, nurses can develop plans together with people with epilepsy to help them coordinate what they must do to manage their seizures. These plans may be tailored to the individual patient by incorporating information from their seizure history, impact on their daily functioning and learning needs. Developing seizure plans also helps patients identify hidden problems or risks that they weren’t aware of previously.
Self-management outcomes can be very varied. Using a patient-centered approach, the outcomes will depend on what is most important to the individual patient and family. In most instances, the nurse would consider outcomes pertaining to seizure control and treatment, enhancing the patient’s confidence in their ability to manage their health and seizures, and their ability to manage how the epilepsy affects the quality of their life.
There are many different behaviors that we all do to manage our health or a specific problem. This slide suggests some behaviors that patients must do to manage their symptoms (seizures, side effects or other problems), provide appropriate seizure first aid, assess safety risks and take appropriate precautions, identify and manage triggers to seizures, and work together with others to make appropriate treatment decision, adhere to treatment recommendations and respond appropriately to seizures and be able to adhere to and manage treatment plans.
For example a person who is learning how to manage their seizures must learn how to identify seizure triggers if appropriate and other high risk situations, know what to tell others to do during a seizure, use seizure diaries to record and monitor their seizures and develop a plan to know what to do and how to communicate important information to their health care team and others. Some areas critical for treatment are also listed here.
Tailoring/individualizing safety precautions is one of the most necessary areas but one that is hard to do. While there are some clear safety guidelines, for example when people can drive, other safety concerns must be tailored to the individual.

Much has been written about the psychosocial impact of living with epilepsy. This lists just a few areas that are commonly reported as problems for people with epilepsy. When taking a patient’s epilepsy history, ask 2 simple questions – how has your epilepsy affected your daily life and how does your daily life affect your seizures? Answers to these questions will offer you a glimpse of the challenges they face and help the nurse tailor her/his interventions, education, and referrals to other professionals and community agencies to address specific problem areas.
When patients are first diagnosed with seizures /epilepsy, many questions and concerns will arise. Health care providers should provide information and resources to help patients understand their diagnosis and follow treatment recommendations, but learning needs will also extend to many other areas, particularly for patients who may have comorbidities in addition to seizures. Nurses should be aware of the types of resources and services for epilepsy that are available to people with epilepsy outside of health care settings. Education and support is also available from epilepsy organizations, such as the Epilepsy Foundation affiliates found in many regions of the United States. Support is critical, and can be obtained through individual counseling or support groups in health care settings or community settings. Specific area and management for comorbidities may be needed, such as supports for other neurological and health problems, learning disabilities and other cognitive problems, mental health problems, or other concerns. Both seizures and comorbid conditions affect educational and employment opportunities and performance thus referring people to appropriate resources to address these needs is critical. Some people with epilepsy may need additional supports for independent living or alternative living supports to maximize their independence and quality of life. Unfortunately, epilepsy specific resources for independent living are hard to find and will require connecting families to community, state and federal disability and chronic care supports.
Additional resources for nurses who care for people with epilepsy frequently are available and others are being developed.

For nurses referring patients to an epilepsy center or who work on an inpatient epilepsy monitoring unit, please visit www.emucaring.org. Here you will find modules addressing patient safety from a variety of perspectives and care approaches.

The American Epilepsy Society is also developing more indepth modules addressing nursing care in epilepsy. Stay tuned for Epilepsy 102 coming soon!

Another resource for nurses to learn more about epilepsy – www.epilepsy.com and www.epilepsy.com/professionals – websites of the Epilepsy Foundation.
Summary

- Nurses are often the ‘front line’ of health care providers, the people that patients may see first or most often. Regardless of the setting, nurses provide a role in the assessment, care and education of people with epilepsy and their families. A self-management perspective will facilitate patient-centered care which is crucial for successful management of epilepsy.